

Adults with multiple long-term conditions in Brighton & Hove

November 2018

Part of the Joint Strategic Needs Assessment programme

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1. Introduction

1.1 The reason for this needs assessment

The number of people living with multiple long-term conditions (MLTCs) is considered to be on the rise, in part because more people are living longer than ever before with accumulated health risks, but also due to unhealthy lifestyle and other factors. Some clusters of medical conditions are more common than others and multiple long-term conditions have been shown to be more predictive of hospital use than single specific conditions or age. There is evidence that people who have both a mental and physical health condition do worse than those who just have physical health problems and that the likelihood of a mental health condition increases as the number of physical health conditions increase.

There is a need to better understand this situation in Brighton and Hove in order to commission and deliver services to improve outcomes for people with MLTCs. The purpose of this needs assessment is to understand and inform the priorities for developing and integrating the health and care system in Brighton and Hove. The focus of the needs assessment is on adults with multiple long-term conditions, both physical and mental health conditions.

This needs assessment is conducted as part of the programme of Joint Strategic Needs Assessments overseen by Brighton & Hove Health & Wellbeing Board. Adults with multiple long-term conditions was identified as a priority by the City Needs Assessment Steering Group and agreed by the Health & Wellbeing Board in March 2018.

1.2 Definition and scope

The overall aim is to assess the health and wellbeing needs and assets of adults with, and at risk of, developing multiple long-term conditions (MLTCs) and their carers' in Brighton and Hove and to make recommendations for future commissioning and provision of health and care services.

Objectives are as follows:

1. To assess the size, impact and characteristics of the population with MLTC
2. To conduct an evidence review for prevention of developing MLTCs and for care, treatment and support for patients with MLTCs
3. To assess how different parts of the local system respond to patients with MLTCs and their carers
4. To make recommendations for: prevention of developing MLTCs; and the care; treatment and; support for patients with MLTCs and their carers

This needs assessment focuses on adults who have two or more LTCs.

1.3 Methodology

There were the following elements within the needs assessment (see Appendix for more detail):

- Literature reviews of who has multiple long-term conditions and effective interventions and services for those at risk of, or with, MLTCs
- Analysis of local data from primary, secondary and adult social care
- Qualitative analysis of local surveys and interviews
- Collation of information on key services supporting those with MLTCs in the city.

2. National context

There is increasing recognition of the growing impact of multiple long-term conditions (MLTCs) on the health and wellbeing of individuals, as well as the burden and cost to health and care systems.

The prevalence of MLTCs (also referred to as multimorbidity in many studies) has risen due to the ageing population, development of chronic diseases at younger ages, as well as better diagnoses and improved survival.¹ In England in 2015, over half of the population (54%) aged 65 or over had two or more long-term conditions.²

Multi-morbidity has been found to be more common among women and those living in socio-economically deprived areas.³ The presence in three or more conditions has been associated with greater reduction in Health Related Quality of Life (HRQoL) than the sum or the impact of individual conditions; the decline in quality of life associated with an additional condition in those with two or more physical conditions was less for older people than for younger people.⁴ Diabetes has been shown to reduce quality of life more than other conditions and a having a comorbid mental health problem (aside from neurological conditions) has more of an adverse effect on HRQoL, than any single comorbid physical condition.

People with MLTCs are more likely to die early, have poor quality of life, loss of physical functioning, physical disability and be unable to work.^{5,6,7} They are at increased risk of admission to hospital, longer hospital stays, and adverse drug events.^{8,9}

The number of long-term conditions an individual has can better predict their use of health services than looking at the single specific conditions which they have,¹⁰ with 78% of GP consultations for people with MLTCs.¹¹

More people needing complex care means that health and social care services, designed around treatment of individual conditions, are struggling to keep pace and ensure consistently high standards of care; people with MLTCs are less satisfied with their care.¹² As the number of long-term conditions increases, so does the number of healthcare professionals involved and transitions across specialties and healthcare boundaries.^{13,14} This can result in fragmented, duplicative, inefficient or unsafe care, unnecessary emergency admissions and delayed discharge^{15,16,17,18}; patients attending four or more doctors experience problems such as conflicting medical advice, unavailable test results and duplication of tests.¹⁹ Poor communication, care coordination and integration can be compounded by specialists who may not feel able to provide care outside their area of expertise or take overall responsibility for patients' care.^{20,21,22,19}

The clinical care for multimorbid patients is complex, however the evidence base for managing chronic conditions and the resulting clinical guidelines are largely created for individual diseases and rarely account for multi-morbidity.^{23,24,25} As a result, patients can experience conflicting care plans and drug management, while mixed signs and symptoms from MLTCs can make diagnosis challenging. Patients with MLTCs are more likely to experience polypharmacy (the use of multiple medicines), resulting in increased

drug burden, reduced likelihood of adherence and increased risk of adverse events.^{5,6,8,9,24,14}

Multiple long-term conditions are also associated with disproportionately high healthcare costs; increased use of ambulatory care, unscheduled or unnecessary hospital admissions which cost more and can result in increased length of stay, delayed transfers of care and long-term institutionalisation.^{26,27,28,29,30,31}

Public satisfaction with the NHS overall has dropped sharply in the past year and dissatisfaction is at its highest level since 2007.³²

2.1 Physical and mental health conditions

Around one third (30%) of people with a physical long-term condition also has a mental health condition, while almost half (46%) of people with a mental health condition has a long-term physical illness.³³ Coexisting physical and mental health conditions occur most commonly in deprived areas³⁴; those from the most deprived decile (10%) are more than twice as likely to have a mental health condition as those from the least deprived, and prevalence of a psychiatric condition increased significantly with the degree of deprivation.²⁰ The contribution of mental ill-health to the morbidity burden also rises with the number of long-term conditions a person has.^{2,35,36} Coexisting physical and mental conditions are more common in women than men.³⁷ It has been found that real world psychiatric care is more accurately approached from a multi-morbidity perspective than principal or dual diagnoses.³⁸

2.2 Policy and strategy

The NHS Five Year Forward View (FYFV),³⁹ emphasised that the NHS needed to dissolve traditional boundaries between primary care, community services and hospitals, recognising that this divide was increasingly a barrier to personalised and coordinated healthcare. Different models were part of the FYFV. The multispecialty community provider (MCP) model aimed to integrate and redesign care around the health of the population and included a new system of care delivery, backed up by new financial and business ways of working.⁴⁰ The MCP model was about being the focal point for a wider range of care needed by registered patients and to offer federations and super-practices the potential to combine with community services and create a broader, more holistic and resilient form of general practice. The MCP model, over time, should help with managing demand for general practice, by building community networks, connecting with the voluntary sector, and supporting patient activation and self-care. An MCP combines the delivery of primary care and community-based health and care services – not just planning and budgets. The building blocks of an MCP are the ‘care hubs’ of integrated teams, serving a community of around 30-50,000 people; they are the practical, operational level of any model of accountable care provision. Other bigger models are the primary and acute care systems (PACS) model, under which all hospital services are also included under a single form of integrated provision. Both are place-based models of care, serving the whole population within a geographical area.

NHS England planning guidance 2018/19 and Next Steps Five Year Forward View (2017) has a focus on integration and the voluntary roll-out of Integrated Care Systems. Integrated Care Systems are those in which commissioners and NHS providers, working closely with GP networks, local authorities and other partners and agree to take shared responsibility for how they operate their collective resources for the benefit of local populations.⁴¹

NHS England considers Integrated Care Systems as key to sustainable improvements in health and care by:

- creating more robust cross-organisational arrangements to tackle the systemic challenges facing the NHS;
- supporting population health management approaches that facilitate the integration of services focused on populations that are at risk of developing acute illness and hospitalisation;
- delivering more care through re-designed community-based and homebased services, including in partnership with social care, the voluntary and community sector; and
- allowing systems to take collective responsibility for financial and operational performance and health outcomes.

National surveys tell us that over 40% of people want to be more involved in decisions about their care and similarly 40% of people living with long-term conditions want more support to manage their health and wellbeing on a day to day basis. This is backed up by the Five Year Forward View which states that more could be done to involve people in their own health and care, to involve communities and the voluntary sector in improving health and wellbeing and to coordinate and personalise care and support including through personal health budgets.⁴²

3. Who's at risk and why?

3.1 How are multiple long-term conditions defined?

Multiple long-term conditions are generally defined as the co-occurrence of two or more long-term medical conditions, including physical and mental health conditions. However, there is no standardised method for measuring them, with variation in the number (from 4 to 102), type of condition and weighting of the importance of each condition, making comparisons of prevalence and impact across different studies difficult.⁴³ The use of different definitions and measures of multiple long-term conditions leads to widely different estimates of prevalence in populations with similar demographics.⁴⁴

Different approaches to measuring, defining or prioritising multiple long-term conditions can be taken.⁴⁵ The most common is to count diseases that patients have, using indices such as the Charlson Comorbidities Index,¹ or to identify common disease combinations.⁴⁶ However this approach fails to consider the severity of each disease or associated pain or impact on daily functioning; the extent to which certain disease combinations are expected due to shared pathology (such as chronic heart disease being causally linked to hypertension); complexity with regard to prevention and treatment⁴⁴; how concordant or discordant disease combinations are with regard to their management⁴⁷; or which combinations of disease are most relevant to each subgroup (such as age or gender).

A limited number of studies have considered which disease combinations are associated with worst clinical outcomes, higher healthcare utilisation or greatest economic costs.^{48,47,27,49,50,51,52} However, differences in how studies categorise correlation and causal relationships between diseases has a substantial effect on estimates of utilisation and cost,^{1,53} although all studies found distinct variations in utilisation depending on the disease combination. Ruiz (2015)⁵³ found that in elderly patients (70 years or above), worse outcomes were associated with combinations of heart disease, cerebrovascular disease, renal failure, hypertension and diabetes. Kadam (2013)⁴⁷ found that for all ages, combinations such as chronic heart failure/disease plus chronic kidney disease/COPD cost more and result in higher healthcare impact, while hypertension and diabetes proportionally cost less. Diederichs et al⁴³ who conducted a systematic review of selection methods for MLTCs, recommend including at a minimum 11 of the most frequently listed diagnoses (in the ICD-10) for people aged over 65: cancer, diabetes mellitus, depression, hypertension, myocardial infarction, chronic ischemic heart disease, heart arrhythmias, heart insufficiency, stroke, COPD and arthritis. Different approaches prioritise different combinations of disease; for example a focus on healthcare use may result in increased focus on heart disease, renal failure and COPD,^{53,47} analysis of the most prevalent disease combinations may result in a focus on cardiovascular disease, anxiety, depression and pain, or neuropsychiatric disorders.⁵⁴

While it is important for commissioners and providers is to understand which combinations of disease are most common and result in the highest impact and are thus

best to target limited resources for greatest effect, the approach is usually determined by what data is available.

This needs assessment definition is based upon conditions identified by two studies: Barnett et al (2012)²⁰ and N’Goran et al (2016)⁵⁵ (more details are provided in Section 4). Barnett et al estimated prevalence of multimorbidity in Scotland using a list of 40 conditions recorded in GP read codes, by including morbidities recommended as core for any study of multimorbidity measured by a systematic review, diseases in the quality and outcomes framework of the UK general practice contract, and long-term disorders identified as important by NHS Scotland. N’Goran, a Swedish study, used a four step process to identify relevant conditions, involving experts to reach consensus on chronic conditions and those conditions most relevant in terms of MLTCs; they narrowed the 686 items included in the ICPC-2^a down to 75 chronic conditions identified as relevant for multimorbidity.

3.2 Mental and physical health conditions

Many people with long-term physical health conditions also have mental health problems. These can lead to significantly poorer health outcomes and reduced quality of life. Costs to the health care system are also significant – by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem.⁵⁶ Evidence suggests that between 12% and 18% of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing – between £8billion and £13billion in England each year. The more conservative of these figures equates to around £1 in every £8 spent on long-term conditions. There are significant inequalities in outcomes for people with serious mental illness including psychosis and other long-term conditions. However, nationally almost 40% of mental health trusts do not have a specific policy or strategy for supporting comorbidities.⁵⁷

A another large study of patients in England found that, with the exception of neurological conditions, the presence of a comorbid mental health problem had a more adverse effect on Health related Quality of Life (HRQoL) than any single comorbid physical condition.⁵⁸ Multiple studies have shown that people with long-term health conditions require integrated mental and physical healthcare services.⁵⁹

In terms of suicidal ideation, although it is associated with multi-morbidity, it does not appear to elevate risk beyond the independent effects of common mental illness or physical health problems.⁶⁰

Depression decreases an older person’s quality of life, sense of wellness and increases functional impairment. Patients with comorbid depression and physical health problems have poorer outcomes compared with those with single or multiple LTCs without depression⁶¹ and are significantly more likely to use unscheduled hospital care than

^a The International Classification of Primary Care (ICPC) is an international classification system for capturing and ordering clinical information in primary care. It was developed and updated by the World Organisation of Family Doctors’ (WONCA) International Classification Committee (WICC).

individuals with a LTC or multiple LTCs without depression.⁶² Individuals with depression are more likely than those without it to have multiple physical conditions and this is associated with social deprivation.⁶³ The extent of this association between depression and a very wide range of physical health comorbidities has important implications for the integrated management of depression and physical health problems.

Depression is up to seven times more likely to be seen in people with MLTCs, it is more likely to occur as the number of conditions increases^{64,65} and is more common amongst women with MLTCs.³⁷ Whilst a person may develop certain mental health conditions, such as depression, as a result of living with a long-term physical illness, mental health conditions can also reduce a person's ability to manage their physical health conditions.

In a large study mixed physical and mental morbidity was the most common type of multimorbidity in those aged under 55 years and was two to three times more common in the most deprived compared to the least deprived communities. Physical only morbidity was the most common type of multimorbidity in those aged more than 55 years.⁶⁶ Ten conditions (seven physical and three mental) accounted for the top five most common conditions in people with multimorbidity in all age groups. Depression and pain featured in the top five across all age groups. Deprivation was associated with higher prevalence of depression, drugs misuse, anxiety, dyspepsia, pain, coronary heart disease and diabetes.

Taking the example of epilepsy, people with epilepsy have higher rates of both physical and mental health comorbidity than people without after adjusting for age, gender and levels of deprivation. Depression is more common than in the general population but prevalence is similar to that of other physical health conditions, and is strongly associated with the total burden of physical conditions.⁶⁷

For survivors of stroke, the prevalence of disability increased with time and survivors reported greater loss of physical than mental quality of life. One in five people live at least 15 years after a stroke and poor functional, cognitive and psychological outcomes affect a substantial proportion of these long-term survivors.⁶⁸ Increasing focus is required on preventing and managing the long-term consequences of stroke.

3.3 Learning disabilities

For adults with learning disabilities the multi-morbidity burden is greater, occurs at much earlier age, and the profile of health conditions differs. Co-morbidity increases with age but is highly prevalent at all ages, being similar at age 20-25 to 50-54 year olds in the general population.⁶⁹

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability. It is estimated that nationally for every 1,000 people, 20 will have a learning disability.⁷⁰ This is likely to increase as people with learning disabilities are living longer.

Adults with learning disabilities have higher morbidity, earlier mortality and substantially more unidentified health needs than the general population.⁷¹ Access to primary health care is lower, despite a higher prevalence of many long-term conditions.⁷² A systematic

review published in 2018 found that adults with learning disabilities are less likely than the general population to receive screening and health promotion interventions that may improve identification of health needs, and management of long-term conditions. Although health checks have been implemented in various primary care contexts, the long-term impact on outcomes has not been investigated. The review also found there to be issues relating to primary care access, communication, and disease management. Accounts of experiences of adults with learning disabilities reveal a dilemma between promoting self-care and ensuring access to services, while avoiding paternalistic care. The review concluded that longer-term evaluation is required to improve access and management of LTCs for adults with learning disabilities.

In one large study⁷³ adults with learning disabilities received significantly poorer management of all long-term conditions on 38/57 (66.7%) indicators. Achievement was high (75%–100%) for only 19.6% of adults with learning disabilities, compared with 77% of the general population. Adults with learning disabilities had higher rates of epilepsy, psychosis, hypothyroidism, asthma, diabetes and heart failure. This large study shows that adults with learning disabilities receive poorer care, despite conditions being more prevalent.

People with Down syndrome died about 28 years younger than the general population. Congenital heart anomalies, comorbidities, low birthweight, and Black and minority ethnicity influences earlier age of death, as does younger maternal age and poorer parental education.⁷⁴ Congenital heart anomalies and respiratory conditions were the leading causes of death, and more common than in the general population. Survival rates have improved over time, particularly for those with congenital heart anomalies.

3.4 Dementia

The relationship between dementia and comorbidities can be complex and variable: high blood pressure and diabetes can increase someone's risk of dementia; having a stroke can cause dementia; and depression can be a consequence of it. Other comorbidities that may be present are coincidental, e.g. arthritis. The severity of someone's dementia can have consequences on their ability to manage their other conditions.⁷⁵ For example, someone managing diabetes has to carry out self-testing and administer insulin at certain times of the day, poor management of which can result in an emergency admission to hospital.

Seven in ten people living with dementia are also living with another medical condition.⁷⁵ There are 850,000 people in the UK living with dementia, 42,000 of whom are under the age of 65 years. Many people with dementia also live with one or more other health conditions. Studies have shown that:

- 41% have high blood pressure
- 32% have depression
- 27% have heart disease
- 18% have had a stroke or transient ischemic attack (mini stroke)
- 13% have diabetes.⁷⁵

Those aged 65 plus in city with a diagnosis of dementia have on average 4.7 long-term conditions (including dementia), whereas those aged 65 without dementia have 2.4 on average. Only 5.9% of those registered with dementia (aged 65 and over) have this condition in isolation. Only 11.8% of those registered with dementia (of all ages) have this condition in isolation.

NHS England⁷⁶ estimate that there 2,782 people aged 65 plus living with dementia in Brighton & Hove. However there are only 1,887 people aged over 65 with a recorded diagnosis on GP registers.

This equates to a Dementia Diagnosis Rate (DDR)^[6] of 68%, against the national ambition of 67%. The gap between actual and expected prevalence also exists for those with early onset dementia – whilst there are 54 people aged below 65 with a recorded diagnosis, available data suggests the city should have between 66 and 76 people formally diagnosed.

3.5 Age

Multiple long-term conditions become progressively more common with age.^{77,78,27} In England (2015) 54% of the population aged 65 or over has two or more MLTCs (rising to 69% of those aged 85 or over), with a projected increase to 64% in 2025 and 68% in 2035 as a result of people living longer, in more ill-health due to multiple lifestyle and environmental factors.² However is also worth noting that currently, in absolute terms, there are more people aged under 65 with MLTCs, than over; it is this younger cohort which must be the focus of preventive interventions to stop the onset or escalation of MLTCs.

Unscheduled and avoidable hospital admissions are up to ninety times more common in older people (aged 65+) with multiple long-term conditions, and can result in delayed transfers of care and long-term institutionalisation.^{79,80,31} Multi-morbidity among the elderly is associated with decreased quality of life, psychological distress, poor hospital outcomes and longer stays, more postoperative complications, higher cost of care and higher mortality.^{53,81}

Between 2002 and 2012 the number of people aged 75 or over admitted to NHS hospitals in England rose by almost two thirds, with 63% of elderly hospital patients diagnosed with two or more conditions.⁵³ The prevalence of co-existing physical and mental health conditions is substantially higher in older people²⁰ and hospitalised older patients often present with mental, psychological or other social difficulties requiring coordinated care from different health specialties and services.^{53,82}

Comorbidity in the elderly is clustered around diseases such as cardiac arrhythmias, hypertension, diabetes, heart disease, cerebrovascular disease, renal failure, congestive heart failure,⁵³ anxiety/depression/pain and neuropsychiatric disorders.⁵⁴ However, the ageing population also means more people are living with dementia, which can make management of a physical condition especially challenging due to

^[6] <https://digital.nhs.uk/data-and-information/national-indicator-library/dementia-65-estimated-diagnosis-rate>

forgetfulness or confusion, and if medication is not taken a patient's physical condition may decline.¹⁹⁶

3.6 Gender

Women have more multiple long-term conditions than men at all ages,^{83,77,84} although the size of the difference varies between studies.³⁷

Women are affected by different conditions compared to men, and are more likely to experience pain, reproductive cancers and depression, whereas men are more likely to experience cardiovascular disease, diabetes and alcohol or substance misuse.^{85,37}

3.7 Deprivation

Socio-economic deprivation has a clear association with the onset of multiple long-term conditions; there is higher prevalence of multiple long-term conditions amongst deprived populations across all age groups,^{25,86,15,16,17,87} with mental illness one of the first characteristics of multi-morbidity to appear.^{20,88} Young-middle-aged adults living in the most deprived areas have rates of multiple long-term conditions equivalent to those aged 10-15 years older in the most affluent areas.²⁰ Patients who are socioeconomically disadvantaged often have poorer health and higher health care needs, while also experiencing poorer provision of services.⁸⁹ A lack of social and personal resources, coupled with multiple stresses, can make coping difficult for these patients⁹⁰ and the multiplicity of physical, psychological and social problems means that family physicians sometimes struggle to support patients with multimorbidity in deprived settings.⁹¹

3.8 Frailty

Frailty is a common clinical syndrome in older adults, characterised by increased vulnerability resulting from ageing-associated decline in reserve and function across multiple physiological systems; the ability to cope with every day or acute stressors is reduced, and the risk of poor health outcomes including disability, hospitalisation, care home admission, and mortality is increased.^{92,93} Frailty and multiple long-term conditions commonly coexist in older populations, can mutually contribute to each other, and are both predictors of disability.⁷⁹ A fall, new medications or minor infections can result in disproportionate deterioration in physical, functional and mental health in frail people.⁹⁴ As frailty frequently deteriorates once it has developed, emphasis should be placed on prevention of frailty to reduce care home admissions.⁷⁹

Women have double the risk of developing frailty (10%) compared to men (5%) which, coupled with a loss of mobility, make women particularly vulnerable to the effects of both frailty and disability.^{79,95}

Frail and multi-morbid individuals often have difficulty eating and absorbing nutrients, and can develop unrecognised malnutrition,⁹⁶ which prolongs recovery and increases the risk of complications. They are also at greater risk of falls, adverse effects, long-term dependence and death.^{6,7,97} Older people with frailty can often present to hospital with atypical symptoms and complex needs, so that assessment in emergency departments can often exceed four hours, and awareness of symptoms associated with frailty, such as delirium, is very variable amongst acute hospital staff.⁹⁸

Frail patients can easily lose their independence in hospital,⁹⁸ and hospital admissions can be a key trigger to frailty amongst non-frail people and can seriously impede recovery and discharge in frail individuals,^{79,99} with frailty the biggest predictor of death and institutionalisation in the elderly.¹⁰⁰ Comprehensive Geriatric Assessment (CGA) by a multi-disciplinary team (MDT), and follow-on care planning, reduces the number of people who are unexpectedly readmitted to hospital better enables people to live in their own home after a hospital admission.⁹⁸

3.9 LGBTQ

There is significant evidence that lesbian, gay, bisexual, other women who have sex with women, men who have sex with men and trans people experience significant health inequalities, and specific barriers to services and support.

The relationship between sexual orientation, gender identity and health has often been overlooked by the healthcare system, and there is a lack of sexual orientation and gender identity monitoring in service provision and population level research.¹⁰¹

LGBT people experience higher levels of health risk behaviours, such as smoking and drug and alcohol use, as well as higher levels of self-harm including suicide attempts. LGBT people are less likely to engage with health interventions and screening programmes, and gender-specific screening can present particular challenges for trans and non-gendered individuals. LGBT communities therefore have higher levels of need for intervention and targeted support related to these indicators.

Regarding lesbian, bisexual and other women who have sex with women (LBWSW) the international and UK evidence suggests¹⁰² that they experience inequalities across a range of areas but especially in relation to mental health, reproductive health issues, domestic violence and health risk behaviours such as smoking and alcohol misuse. There was also evidence from a bespoke analysis of the England GP Patient Survey of higher rates of musculoskeletal health issues, asthma and respiratory conditions and some types of cancer among LB women compared to heterosexual women.

Research indicates that gay and bisexual men are less likely than men in general to have diabetes, which is consistent with a population that is less likely to be overweight or obese. As lesbian and bisexual women may be more likely to be overweight or obese than heterosexual women this would indicate that they may be at greater risk of diabetes. The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document¹⁰¹ provides additional detail across a range of health indicators.

Although there is a lack of data specific to multiple long-term conditions for trans and Q people evidence shows that trans people attending transgender health-care services appear to have a higher risk of psychiatric morbidity (that improves following treatment), and thus confirms the vulnerability of this population¹⁰³ with some evidence of 'pathologisation' (i.e. attributing mental health problems to their transgender status).¹⁰⁴

3.10 Ethnicity

There is a lack of evidence relating to ethnicity and MLTCs, therefore this section focuses on single conditions and rates of limiting long-term illness. Most ethnic minority

groups have poorer health than the White British group, although ethnic health inequalities vary by gender and there is a complex picture of ethnic differences across different health indicators,¹⁰⁵ some groups, notably individuals identifying as Gypsy or Irish Traveller, and to a lesser extent those identifying as Bangladeshi, Pakistani or Irish, stand out as having poor health across a range of indicators.

Both men and women who identified as White Gypsy or Irish Traveller have twice the White British rates of limiting long-term illness, and at each age they are the group most likely to be ill. Over 70% of Pakistani, Bangladeshi and White Gypsy or Irish Traveller women at this age reported a limiting long-term illness. Arab and Indian older women also reported high percentages of limiting long-term illness (66% and 68% respectively). 50% of all men aged 65 or over reported a limiting long-term illness, but 69% of Bangladeshi and White Gypsy or Irish Traveller older men. Chinese individuals reported persistently better health, with half (or less) the White rates for men and women.¹⁰⁶

Evidence on ethnic differences in common mental disorders is patchy and inconsistent, though those identifying as Gypsy or Irish Traveller appear to have much higher rates of anxiety and depression than other groups; Black or Black British men have higher reported rates of psychotic disorder than men in other ethnic groups; available data suggest lower levels of reported 'wellbeing' among most minority ethnic groups than the White population and cancer burden by site of the cancer varies between ethnic groups (e.g. prostate cancer makes up over 40% of Black or Black British men's cancer compared with around 15% among Chinese men and 25% among all men).¹⁰⁵

There is evidence to show inequity in access to cardiovascular care relating to ethnicity, showing that South Asian populations have higher access and black populations lower.¹⁰⁷ Evidence of inequality increases with stage on the care pathway for cardiovascular disease, which may indicate that barriers to access arise from the way in which health professionals are adjudicating health needs rather than a failure to seek help in the first place.

3.11 Pregnancy

Chronic diseases, in particular asthma and arterial hypertension can have a significant impact during pregnancy, causing complications at the fetal and maternal level.¹⁰⁸ For pregnant women with epilepsy although most will have an uneventful pregnancy, pregnancy carries additional risks to a women's wellbeing and that of their developing foetus and their infant. For some women, these risks include worsening symptoms of epilepsy, increased mortality risks and less effective treatment of other conditions and comorbidities like depression.¹⁰⁹

Maternal obesity is also associated with increased maternal and foetal risks during pregnancy. One study¹¹⁰ showed there to be differences between pregnant women with at least one chronic disease and pregnant women without any. Prenatal complications were more frequent in women without chronic disease however women with chronic diseases deliver by Caesarean section more frequently than others and are at higher risk of giving birth to a premature infant.

3.12 Behavioural risk factors

A number of unhealthy lifestyle factors, including smoking, obesity, lack of physical activity, fruit and vegetable consumption and excessive consumption of alcohol, are key factors in the development of long-term conditions and multiple long-term conditions.^{111,112}

Behavioural factors can influence how individuals manage their long-term conditions after onset, with barriers to optimal management including poor self-care behaviour and non-adherence to medication.^{113,114} However, education, counselling, advocacy and support to people with multiple long-term conditions and their caregivers, to make sense of complex risk–benefit information in order to elicit treatment preferences, can help to overcome these barriers.¹¹³

4. The level of need in Brighton & Hove

4.1 General health

There are currently no national data on multiple long-term conditions to be able to compare and monitor trends in Brighton & Hove.

The percentage of GP registered patients with a long-standing health condition is 52% in Brighton & Hove¹¹⁵ which is significantly lower than England at 54%. However, Brighton & Hove has a younger age profile than other CCGs. Compared to England, the city has a younger profile with a higher percentage of its male and female population aged 20 to 54 years (Figure 1). In contrast, Brighton & Hove has a higher percentage of patients reporting a long-term mental health problem at 9%, significantly higher than England at 6%, and the South East at 5%.¹¹⁵

Brighton & Hove is one of the most deprived parts of the South East. Smoking, alcohol and drug misuse in particular are significant health issues in the city. In contrast the city has more residents who are physically active and fewer obese and overweight adults compared to England. More than two in five older residents live alone which is more than the national average of 31%. The Brighton & Hove JSNA Executive Summary 2017 gives a more complete profile of the city's population.¹¹⁶

Figure 1: Age Profile (population pyramid) of the GP registered population by gender and quinary age band, NHS Brighton and Hove CCG, 2017



Source: National General Practice Profiles, Fingertips Public Health England

4.2 Life expectancy and healthy life expectancy

Between 2001-03 and 2014-16 life expectancy increased from 75.1 years to 79.5 years for males and from 80.8 years to 83.4 years for females in the city. However healthy life expectancy (the number of years of self-assessed good health) has actually fallen in recent years – from 63.9 years to 61.6 years for males between 2009-11 and 2014-16 and from 64.1 years to 62.2 years for females.¹¹⁷ People are therefore living longer in ill-health. This, alongside the rising retirement age, means that increasing numbers of people of working age are in ill-health.

4.3 Multiple long-term conditions

The literature review showed there was no clear consensus on a definition of multiple long-term conditions (MLTCs). Existing definitions either focus on addressing specific needs or mainly focus on the most prevalent chronic conditions. Barnett et al. (2012)²⁰ provides some basis for the analysis of MLTCs. It identified morbidities as core for any multimorbidity measure through a systematic review, diseases in the Quality and Outcomes Framework (QOF) of the UK general practice contract and long-term disorders identified as important by NHS Scotland. It defined 40 morbidities by Read codes and prescription data.

Other studies of definitions of multiple long-term conditions were considered and a rigorous and comprehensive study identified was N’Goran et al (2016).⁵⁵ This Swedish study, with criteria relevant to the UK context, used a four step process involving family medicine experts to reach consensus on chronic conditions, of which 75 were considered most relevant in terms of MLTCs. Key criteria to determine these conditions were duration of condition, sequelae, recurrence/pattern and diagnosis itself.

A comparative list of chronic conditions was compiled from these two papers and matched, as far as possible, to the available data in the GP patient level dataset^b. Conditions were agreed by a specific meeting of the clinicians from the needs assessment steering group (see Appendix for full detail). The final list of 41 conditions is shown in Table 1. The data is a snapshot of the patient record for the previous year, and as such details all conditions the patient has on their GP record during that time. However, for cancer and depression, to avoid capturing excessive/irrelevant data, the definition was restricted to whether the individual had the condition in the past five years only.

Some conditions have lower prevalence than might be expected as completeness is dependent on effective recording by GP practices, as well as full disclosure from the patient to the GP of their health conditions. Chronic pain and HIV/AIDs are two examples of conditions which have lower prevalence than we might expect. The prevalence of moderate-severely disabling chronic pain is estimated to be at least 10% in the UK population¹¹⁸ compared to the less than 1% found here. There were 1,849

^b Long-term conditions in the GP level data are based on EDC codes determined via the John Hopkins model. Expanded Diagnosis Cluster (EDC) codes have been used to categorise similar diseases or conditions. The EDC methodology assigns ICD codes found on medical notes to one of 264 EDCs. Essentially the EDC codes are broad groupings of diagnosis codes to remove differences in coding behaviour between medical practitioners.

residents who received HIV-related care from Brighton & Hove in 2016,¹¹⁹ much higher than the 219 recorded in the GP dataset. The full breakdown of the number of people with each condition is provided in the Appendix.

Table 1: The 41 long-term conditions included in the definition of MLTCs

| Condition group | Condition in GP patient records |
|---|---|
| Cancer | Cancer (in past five years) |
| Blood, blood forming organs and immune mechanism | HIV/AIDs Sickle cell disease |
| Digestive | Inflammatory bowel disease Chronic liver disease |
| Endocrine/ metabolic and nutritional | Obesity Diabetes Hypothyroidism Gout |
| Neurological | Multiple sclerosis Parkinson's disease Muscular dystrophy Peripheral neuropathy Paralytic syndromes Cerebrovascular disease |
| Skin | Chronic skin ulcer |
| Musculoskeletal | Osteoporosis Rheumatoid arthritis Degenerative joint disease |
| Urological | Chronic renal failure |
| Respiratory | Asthma COPD (including Emphysema, Chronic bronchitis, COPD) |
| Eye | Blindness and/or Age-related macular degeneration |
| Ear | Deafness, hearing loss |
| Cardiovascular | Hypertension Congestive heart failure Atrial fibrillation Ischemic Heart Disease and/or generalised atherosclerosis and/or cardiovascular disorders Peripheral vascular disease |
| Psychological | Substance misuse (incl. alcohol dependence) Moderate/severe depression Learning disability Anxiety Schizophrenia and affective psychosis and/or bipolar disorder Seizure disorders Dementia |
| General and unspecified | Chronic pain Immunosuppression Cerebral Palsy Urinary incontinence Autoimmune diseases |

Source: GP patient data (Sollis)

4.4 Who has multiple long-term conditions in Brighton & Hove

There are 51,379 adults aged 20 years or over in Brighton & Hove recorded as having multiple long-term conditions (two or more) in March 2017, just under a quarter of the population (22%) (Table 2). Just over 19,000 people have both mental and physical health long-term conditions (8%).

Table 2: Prevalence of long-term health conditions in adults aged 20+, Brighton & Hove, March 2017

| | Prevalence of health conditions | Number of adults (aged 20+) |
|--|---------------------------------|-----------------------------|
| No health conditions | 54% | 126,826 |
| 1 or more conditions | 46% | 106,590 |
| 2 or more conditions | 22% | 51,379 |
| 3 or more conditions | 12% | 26,984 |
| 4 or more conditions | 6% | 14,700 |
| 5 or more conditions | 3% | 8,084 |
| 6 or more conditions | 2% | 4,431 |
| Physical and mental health co-morbidity | 8% | 19,060 |
| All registered patients (20+) | | 253,652 |

***Mental health includes severe or moderate depression, anxiety, schizophrenia and/or bipolar disorder

Source: GP patient data (Sollis)

These figures can be compared to the Public Health England (PHE) estimates for each local authority, based upon the Barnett study age, sex and deprivation specific rates, using 2011 population data.¹²⁰ The prevalence of two or more (21%) and three or more (12%) long-term conditions are very similar and for physical and mental health co-morbidity, the prevalence is 8% in both the local data and in application of estimates from the Barnett study. Our findings also chime with those from the November 2018 Health Foundation report Understanding the health care needs of people with multiple health conditions.¹²¹

The local authority estimates provided by Public Health England show that, given our population characteristics, we would be expected to have significantly higher prevalence of multiple long-term conditions than the South East for both males and females in all age groups, with the exception of those aged 85 years or over where there was no significant difference in prevalence across local authorities. However, because we have a younger population, and having multiple long-term conditions is highly age-related, the estimate of our overall prevalence (21%) is lower than the South East and England (both 23%).

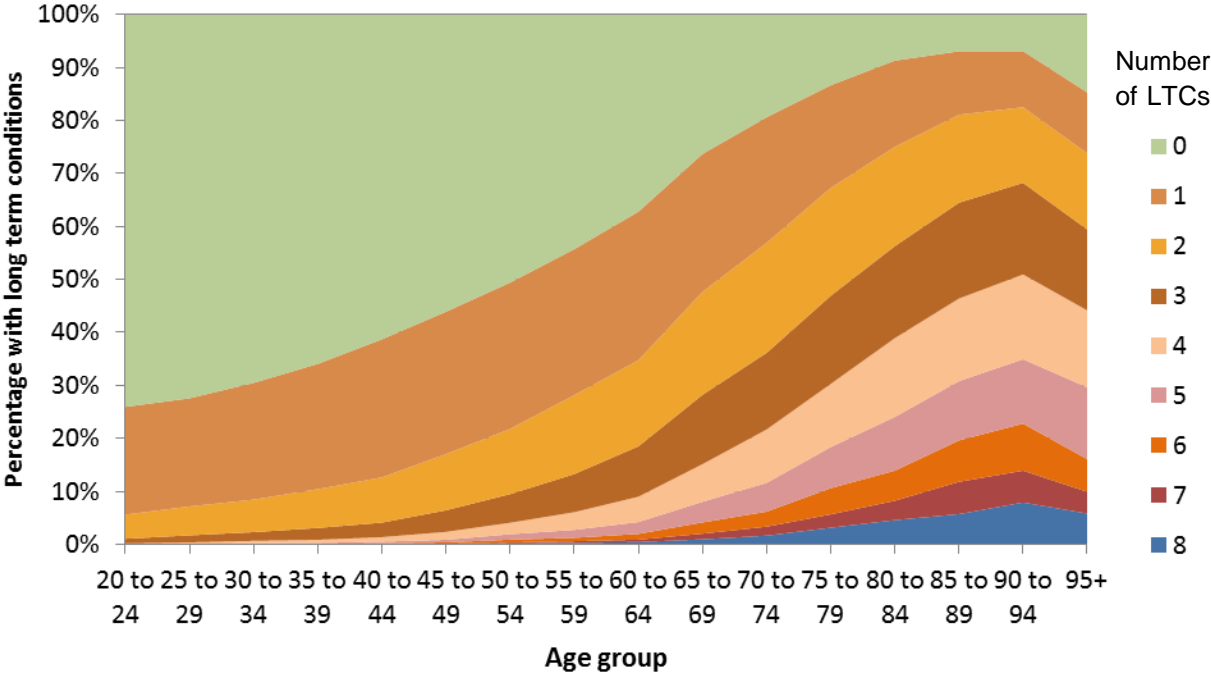
We are limited by the data available as to which demographic characteristics we can consider. For example, ethnicity is poorly recorded across primary care and data is not available on sexual orientation, non-binary gender or demographic characteristics other than age, gender or deprivation.

4.4.1 Age and gender

The percentage of people living with long-term conditions increases exponentially with age (Figure 2). In 20-24 year olds 74% have no long-term conditions and up to the age of 50 years the majority of people in Brighton & Hove still have no long-term conditions. At 50-54 years, 22% have multiple long-term conditions, rising to 48% of those aged 65-69 years and 81% of those aged 85-89 years. However, those who reach 95 years or over have fewer conditions than those aged 80-94 years. This may be due to the increased mortality rates of those with higher numbers of long-term conditions aged over 80, resulting in a lower prevalence in the surviving population over this age.

This is similar to the Public Health England estimates applied to the Brighton & Hove population, which showed that while gender and deprivation are strongly associated with morbidity, age has the most influence in number of morbidities. This picture was similar for both males and females.

Figure 2: Percentage of people with specified number of long-term conditions, by age group, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

In terms of numbers, there are more adults with multiple long-term conditions in Brighton & Hove aged under 65 years (27,923) than there are aged 65 years or over (23,456). There are also more females (27,239) with MLTCs than males (24,140).

4.4.2 Deprivation

Prevalence of MLTCs is greater in the most deprived areas of the city compared to the least deprived (Figure 3) and this is most noticeable between the ages of around 40-44 years up to 60-64 years. Under age 30 and at around age 80-84 years, prevalence is similar for the most and least deprived areas.

Prevalence of five or more LTCs has an even more marked difference between the most and least deprived areas. Not only this, but people having five or more LTCs

appears around 15 years earlier in the most deprived areas, at 35-39 years compared to 50-54 years in the least deprived areas (Figure 4).

Prevalence of five or more LTCs is increased most in deprived areas at 45-49 years; it is almost eight times as prevalent in the most compared to in the least deprived quintile (Figure 5). Prevalence of two or more LTCs is also most increased at 45-49 years, with more than twice the prevalence. This is similar to the Barnett study which showed age and deprivation interact together: young adults living in the most deprived areas had rates equivalent to those aged 10-15 years older in the least deprived areas.

Figure 3: Proportion of adults with 2+ LTCs by age group in the most and least deprived quintiles, Brighton & Hove, March 2017

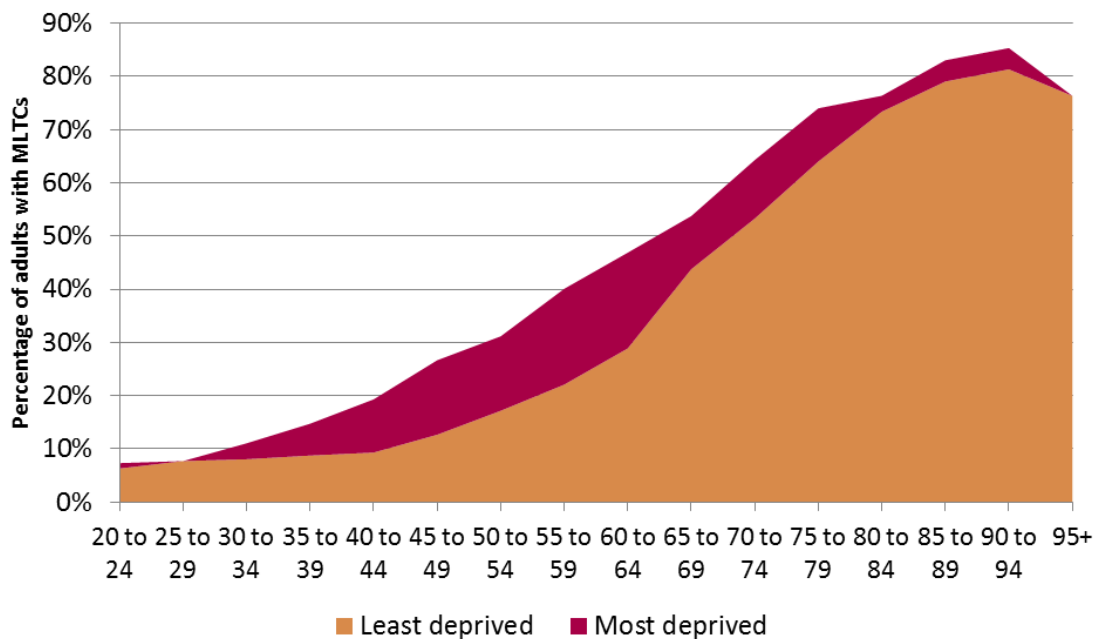
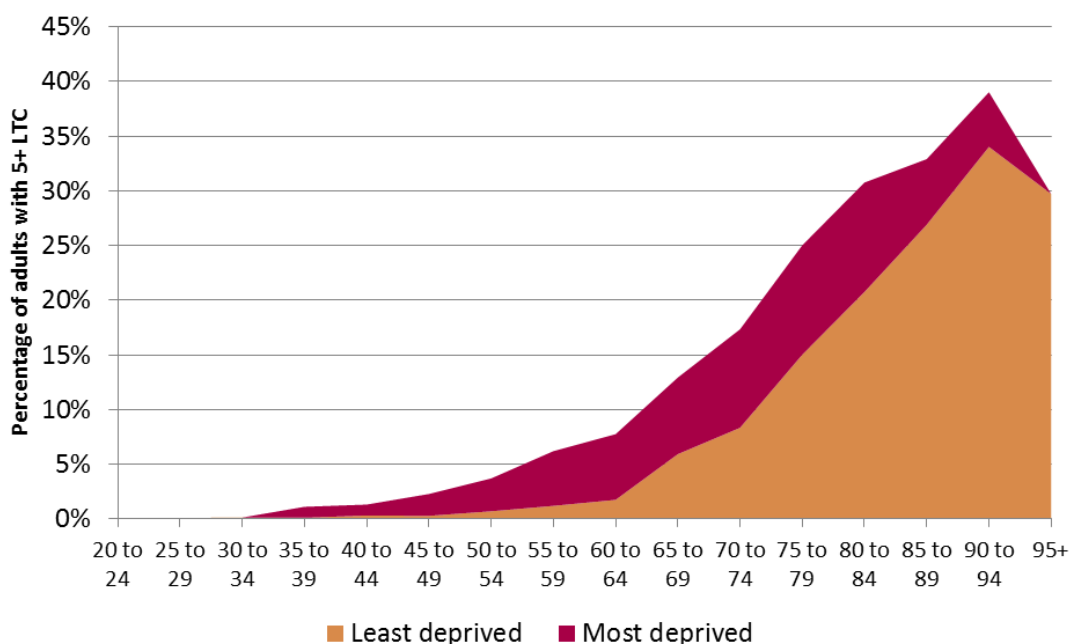
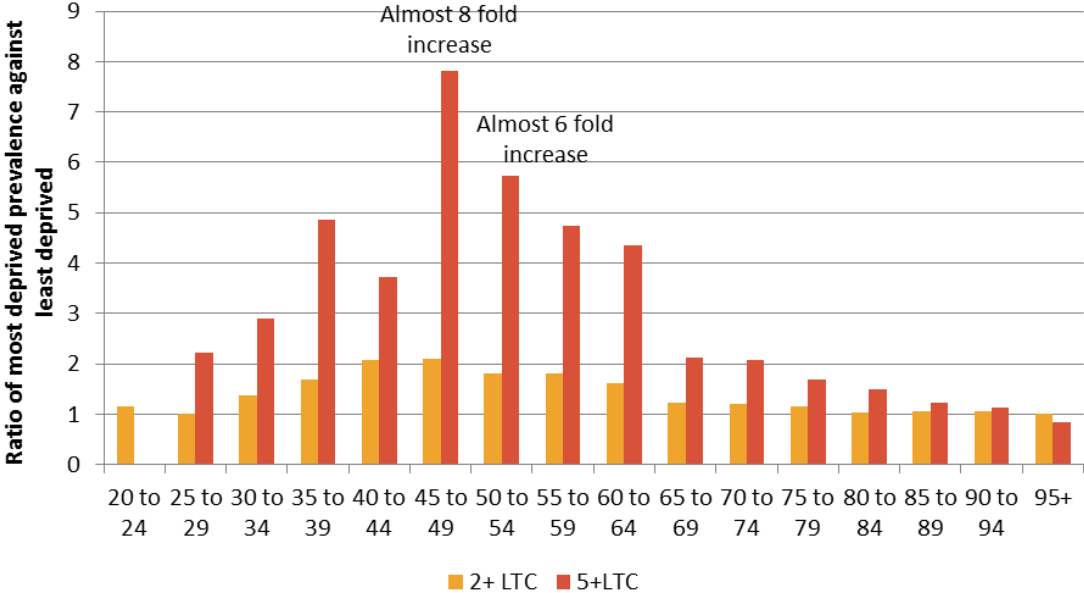


Figure 4: Proportion of adults with 5+ LTCs by age group in the most and least deprived quintiles, Brighton and Hove, March 2017



Source: GP patient data (Sollis)

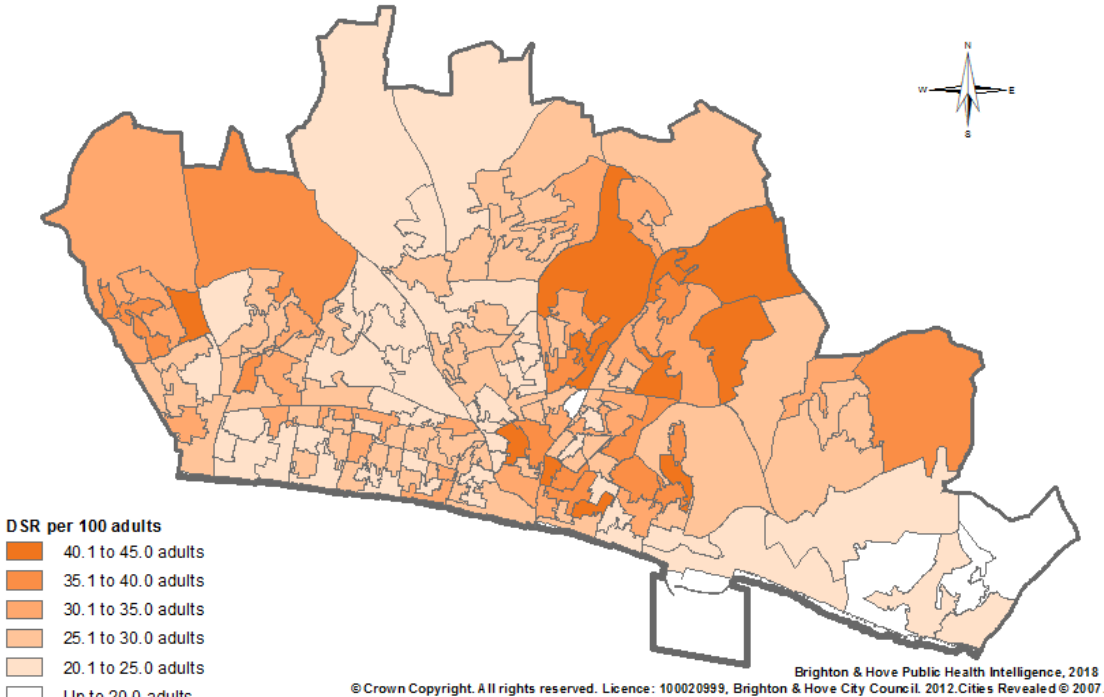
Figure 5: Ratio of the percentage of adults with 2+ and 5+ LTCs by age group in most deprived against least deprived (IMD 2015), Brighton & Hove, March 2017



Source: GP patient data (Sollis)

In those aged under 65, adults with multiple long-term conditions are concentrated in more deprived areas particularly central Brighton and around Portslade. In those aged 65 years or over, where adults with MLTCs live doesn't appear to relate to deprivation and is far more linked to where older people live, in the outer areas of the city. Once age-standardised, to take account of age structures of different areas of the city, the highest rates of people with MLTCs are around the Moulsecoomb and Bevendean and East Brighton wards and areas of North Portslade and Woodingdean (Figure 6).

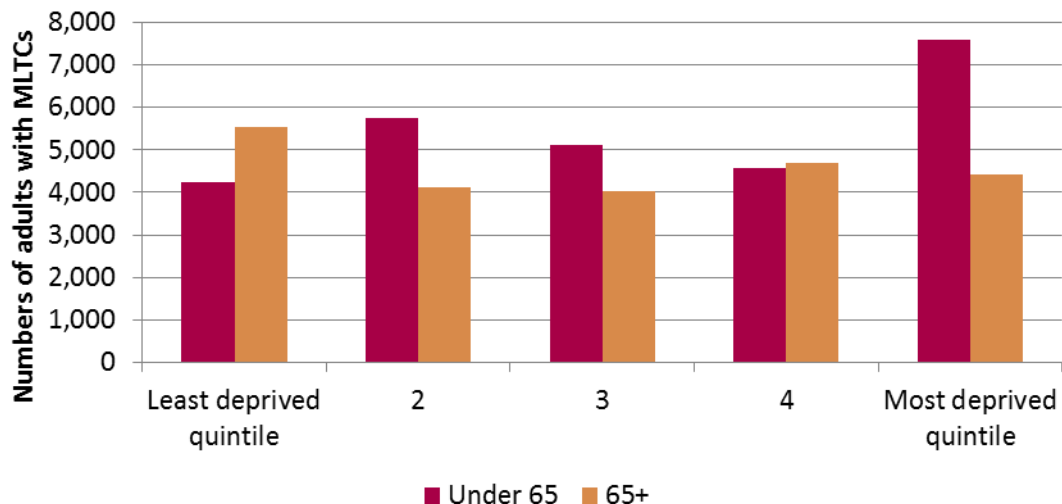
Figure 6: Percentage of adults with 2+ long-term conditions (directly age standardised), LSOAs in Brighton & Hove, March 2017



Source: GP patient data (Sollis)

In terms of numbers, there are almost twice as many adults aged under 65 with multiple long-term conditions living in the most deprived quintile than in the least deprived quintile. For those aged 65 years or over, there are more adults with multiple long-term conditions living in the least deprived quintile than in the most deprived (Figure 7).

Figure 7: Numbers of adults with MLTCs by deprivation quintile, for under 65s and 65+; Brighton & Hove, March 2017



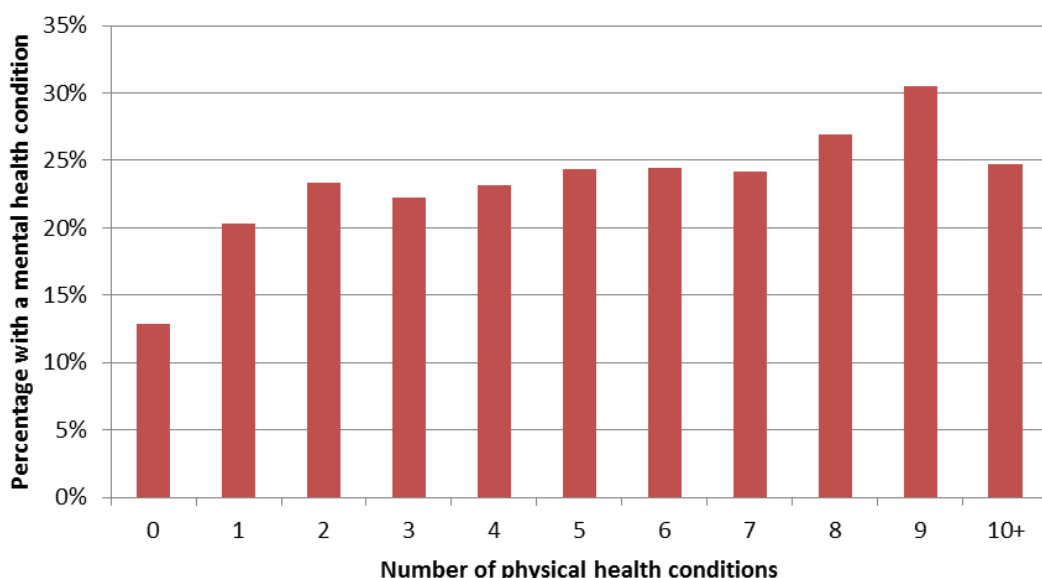
Source: GP patient data (Sollis)

4.5 Co-occurring mental and physical long-term conditions

Just over 19,000 people have both mental and physical health long-term conditions (8%). This rises to around 35,000 people (15%) if mild depression is included rather than limiting to moderate or severe depression).

The percentage of adults with a mental health condition increases as the number of physical health conditions increase – from 13% of those with no conditions to 23% of those with two conditions and to 31% of those with nine physical conditions (Figure 8).

Figure 8: Percentage of adults with a mental health condition, by number of physical health conditions they have, Brighton & Hove, March 2017

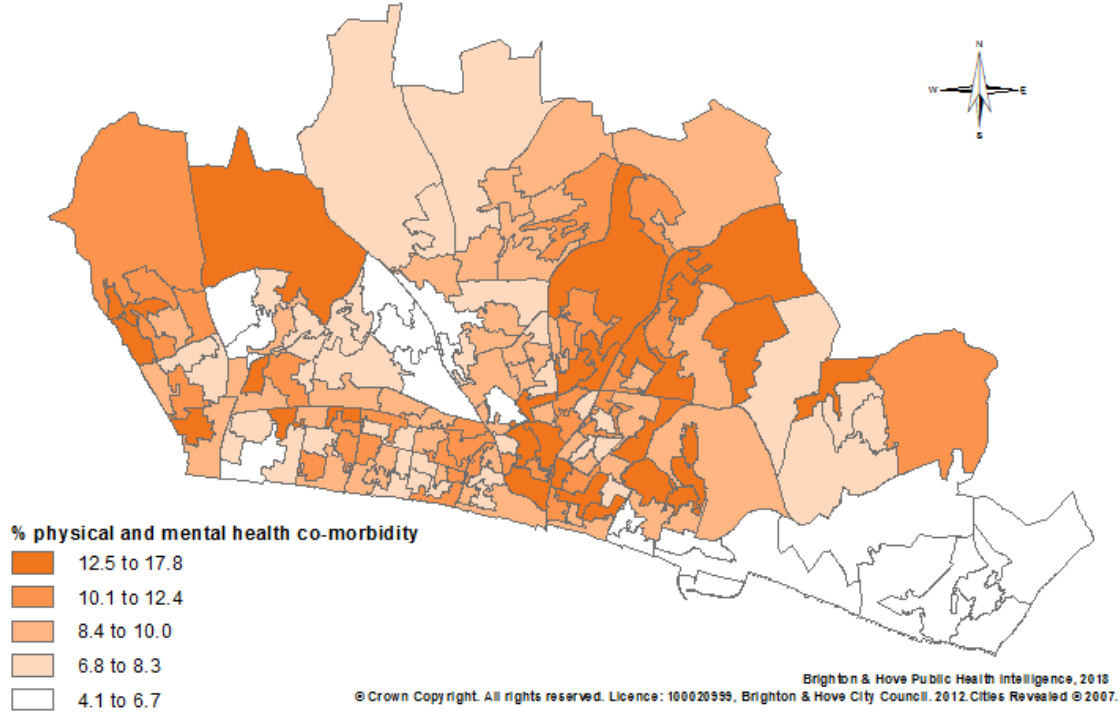


Source: GP patient data (Sollis)

In Brighton & Hove, the highest percentages of adults with mental health conditions (moderate or severe depression and/or anxiety and/or schizophrenia/bipolar disorder) are concentrated around the more deprived areas of the city (Figure 9). This corresponds with the findings from the Barnett study. In Brighton & Hove, physical and mental health comorbidity tends to be higher in females than males (Figure 10), which agrees with the findings of the Barnett study.

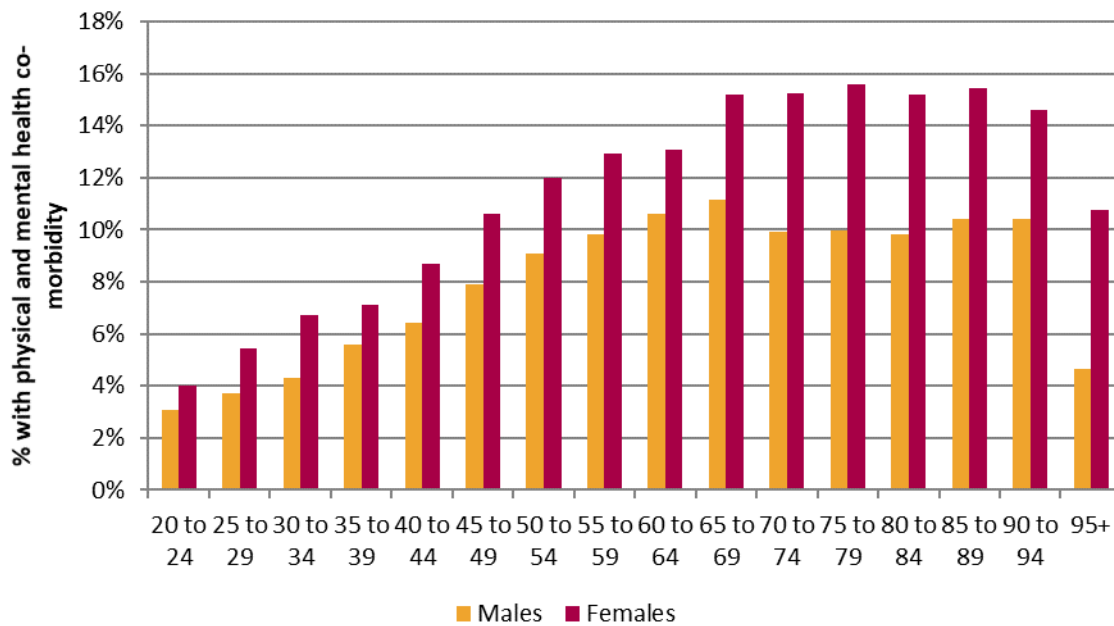
For females in Brighton & Hove, physical and mental health co-morbidities are disproportionately high in the most deprived areas among those aged 45 to 64 years (Figure 11). For males, physical and mental health co-morbidity is disproportionately high among those in the most deprived areas in those aged 40 to 59 years (Figure 12). PHE estimates (based upon the Barnett study),²⁰ and national evidence on common patterns of morbidity and multi-morbidity,³ concur with this finding with the greatest variance for those in the most deprived areas among those in their mid-40s. However the PHE estimates showed physical and mental health co-morbidity to be more pronounced in men whereas in our observed data this does not appear to be the case.

Figure 9: Age-standardised percentage of adults with physical and mental health co-morbidity, by LSOA in Brighton & Hove, March 2017



Source: GP patient data (Sollis)

Figure 10: Physical and mental health co-morbidity by gender, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

Figure 11: Females: Physical and mental health co-morbidity by age group in the most and least deprived quintiles, Brighton & Hove, March 2017

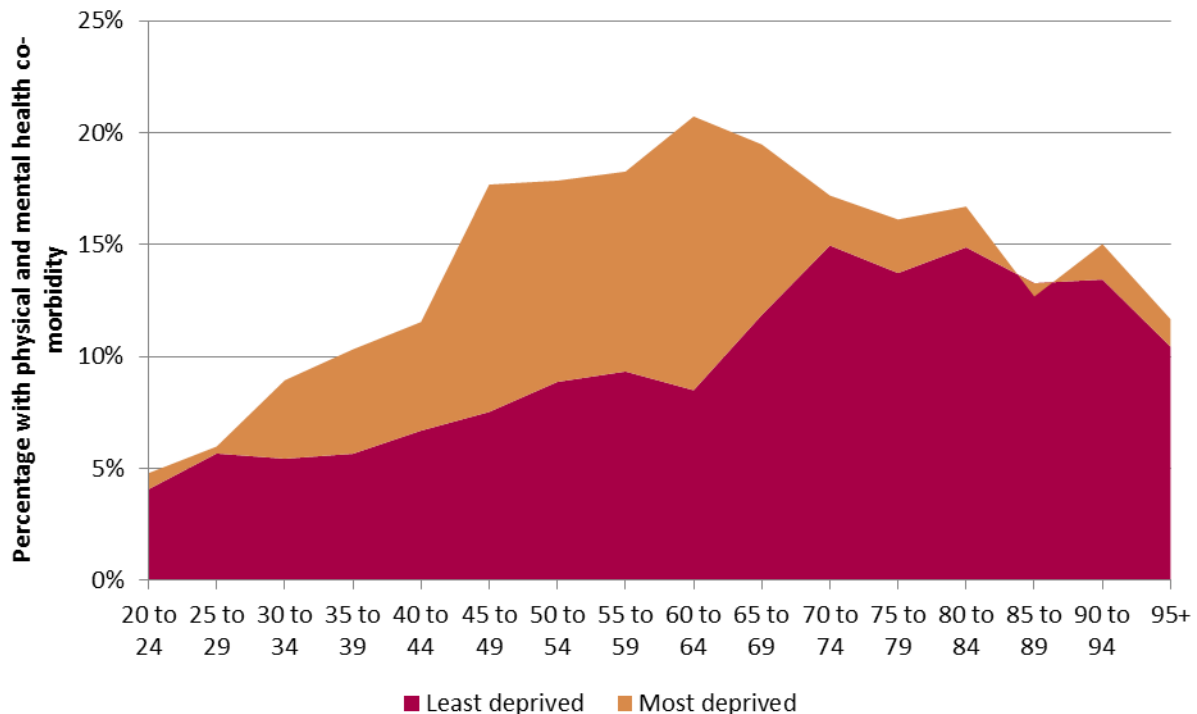
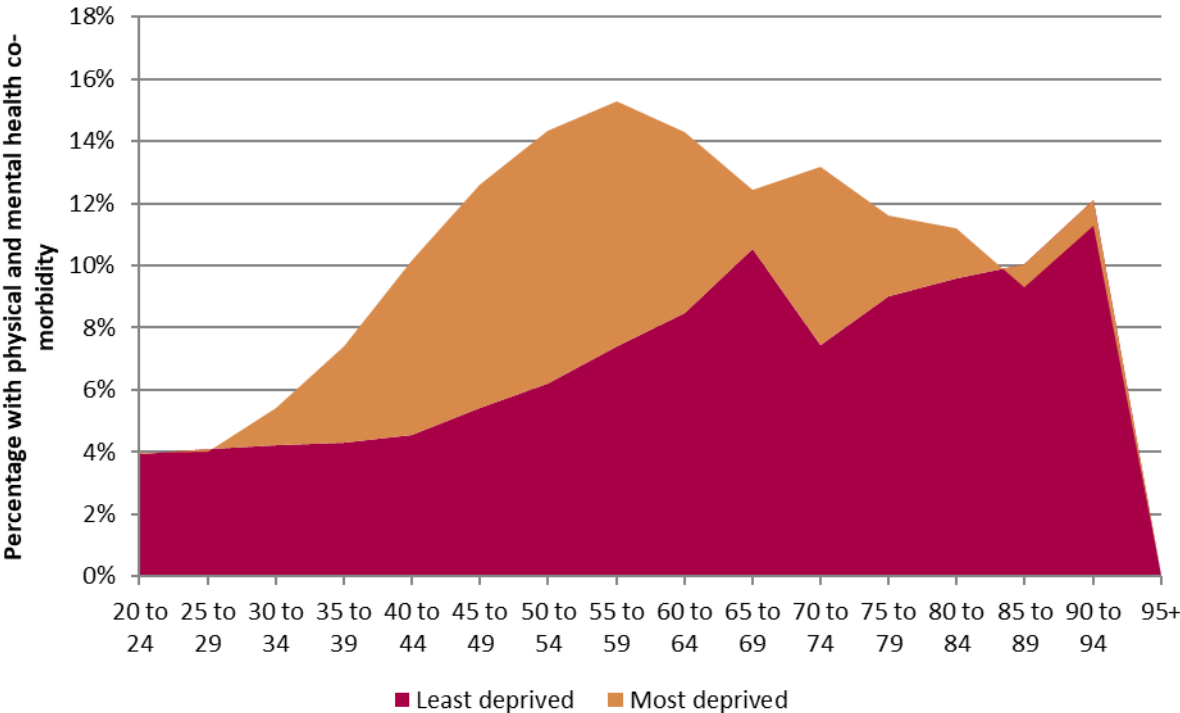


Figure 12: Males: Physical and mental health co-morbidity by age group in the most and least deprived quintiles, Brighton & Hove, March 2017

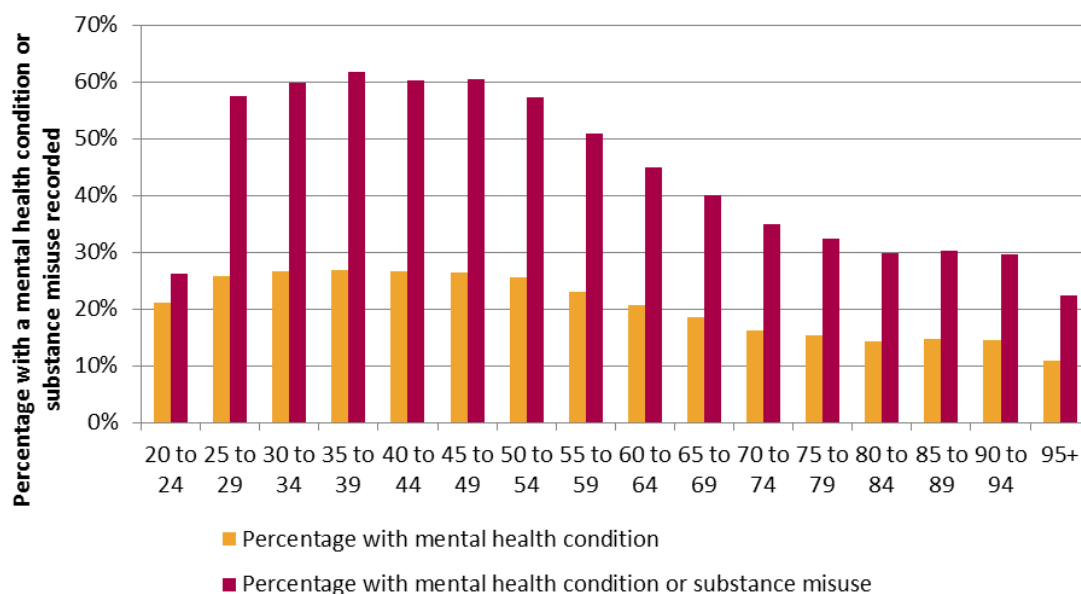


*** At least one physical health condition and at least one mental health condition

Source: GP patient data (Sollis)

The majority (63%) of adults with multiple long-term conditions under 65 **have** a recorded mental health condition and/or recorded substance misuse (alcohol or drugs misuse) (Figure 13). This applies to both males and females aged under 65. However, in those adults with multiple long-term conditions aged 65 or over, the majority (77%) **do not have** a recorded mental health condition and/or substance misuse. A quarter (25%) of those aged under 65 with a physical health condition, also have a mental health condition, but this drops to around 15% in those aged 65 or over (Figure 13).

Figure 13: Percentage of adults with at least one physical health condition who also have a recorded mental health condition and/or substance misuse by age, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

4.6 Risk factors for having multiple long-term conditions

Obesity, substance misuse and being a current or ex-smoker are all highly significant risk factors for having multiple long-term conditions (Table 3).

Obesity has the largest association with having multiple long-term conditions, more so than substance misuse (includes alcohol dependence) and being a smoker. Of those adults who are obese, 56% have multiple long-term conditions compared with only 10% of adults who are not obese. Of current or ex-smokers, 31% have multiple long-term conditions compared with 17% of those who have never smoked and 43% of those with recorded alcohol or substance misuse issues have multiple long-term conditions compared with 10% of those with no record of this.

In the rest of the analysis, these factors are in themselves long-term conditions. Therefore, in order to assess their association with having multiple long-term conditions, here they are excluded from the multiple long-term conditions condition list.

Table 3: Risk factors and long-term conditions, Brighton & Hove, March 2017

| Risk factor | No health conditions | | |
|---------------------|---|---|--|
| Never-smoked | 61% of never-smokers have no health conditions* | 42% of current or ex-smokers have no health conditions* | Current or ex-smoker |
| Non-current smoker | 56%* | 48%* | Current smoker |
| Not obese | 80%* | 20%* | Obese |
| No substance misuse | 80%* | 26%* | Substance misuse (Inc. alcohol dependence) |
| Risk factor | 2+ long-term conditions | | |
| Never-smoked | 17% of never-smokers have | 31% of current or ex-smokers have | Current or ex-smoker |

| | MLTCs* | MLTCs* | |
|---------------------|--------|--------|---|
| Non-current smoker | 21%* | 26%* | Current smoker |
| Not obese | 10%* | 56%* | Obese |
| No substance misuse | 10%* | 43%* | Substance misuse (Inc. alcohol dependence) |

*Having risk factor is significantly different to not having risk factor (statistical test of proportions)

***Risk factor excluded as a long-term condition within this table

Source: GP patient data (Sollis)

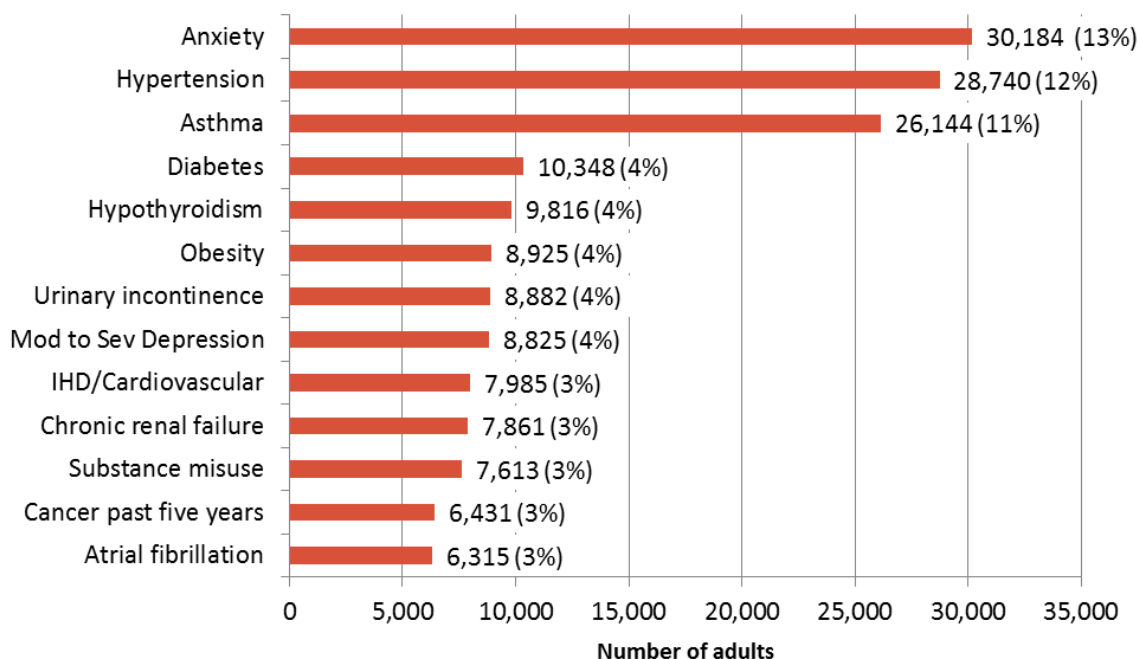
4.7 Most common conditions

The most common long-term condition in adults in the city is anxiety, with over 30,000 adults (13% of adults), followed by hypertension (28,740 adults or 12%) and asthma (26,144 adults or 11%) (Figure 14). Prevalence is dependent on effective GP recording and patient disclosure of health conditions. It should be noted that all recorded depression has a prevalence of 17% (40,177 adults), but the analysis was restricted to moderate/severe depression which has a prevalence of 4% (nearly 9,000 adults). This was based upon the advice of a clinical meeting of the steering group.

Prevalence of long-term conditions approximately triples in adults with multiple long-term conditions compared to in all adults. For example, hypertension has a prevalence of 12% in all adults but 45% in adults with MLTCs. Diabetes has a prevalence of 4% in all adults and 17% in adults with MLTCs (Figure 15).

Patients with heart disease and COPD both have on average three other long-term conditions. This contrasts with patients with asthma, who tend to be younger, and have on average one other long-term condition (Figure 16).

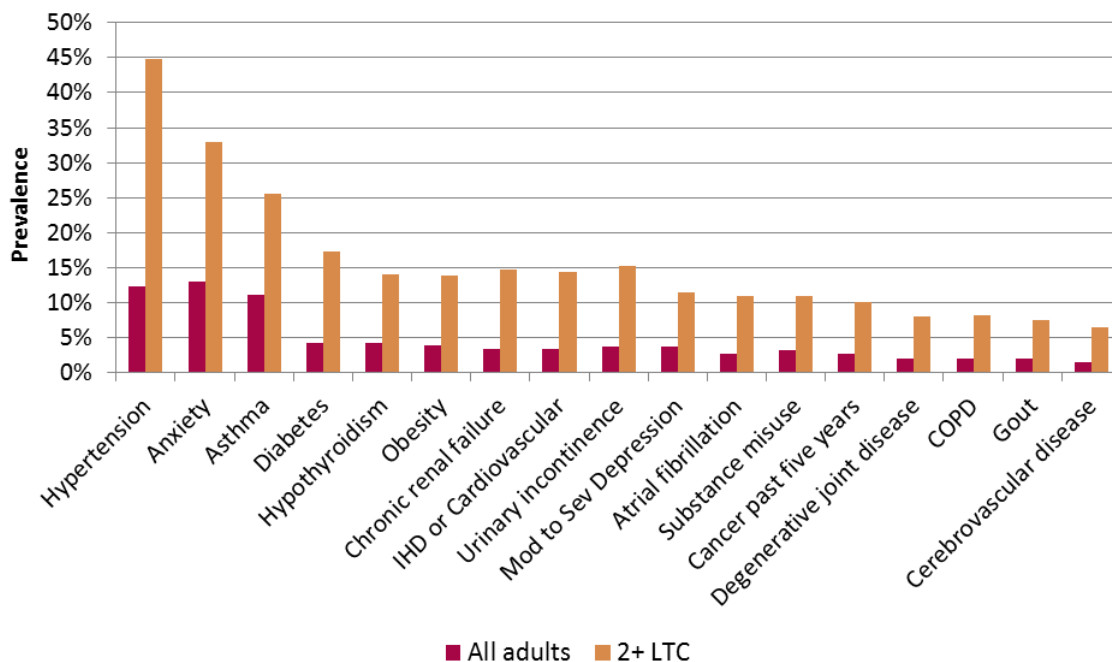
Figure 14: Number (and percentage) of adults with various long-term conditions, Brighton & Hove, March 2017



***Long-term conditions with fewer than 5,000 adults were omitted from the above graph.

*** Substance misuse includes alcohol dependence

Figure 15: Prevalence (%) of long-term conditions in all adults compared to in adults with MLTCs, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

Figure 16: Average number of additional long-term conditions (mean number) for adults with specified long-term conditions, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

4.7.1 Most common conditions by age, sex and deprivation

The most common conditions adults have in Brighton & Hove vary with age, sex and deprivation (Table 4):

- In adults aged under 50 depression, anxiety and asthma are the most common conditions in adults with multiple long-term conditions.
- In adults with multiple long-term conditions aged under 35 living in the least deprived areas, anxiety is more common than all recorded depression and more common than moderate/severe depression.
- In the most deprived areas, substance misuse (alcohol dependence or drugs misuse) is a common condition for males 20-49 years with multiple long-term conditions.

- Gender is an important factor in type of condition. Obesity is one of the most common conditions in females aged under 50. Hypothyroidism is common in females aged 35 or over. However, in males aged 35-64, hypertension is one of most common conditions, and diabetes appears as one of the most common conditions between 50-64 years.
- Amongst adults aged 80 years or over with multiple long-term conditions, the same set of conditions is most common across all groups: hypertension, chronic renal failure, atrial fibrillation (AF), IHD/heart conditions, urinary incontinence.
- In adults aged 65-79 years hypertension is most common. Urinary incontinence also appears as a very common condition in this age group. In males aged 65-79 years IHD/heart conditions and diabetes are among the most common conditions in those with MLTCs. In females aged 65-79 years depression and anxiety are among the most common conditions in those with multiple long-term conditions.

In summary, the combinations of conditions adults with multiple long-term conditions have tend to vary by whether male or female in those aged under 65 years and this is consistent with the findings of the literature review. In those aged 65 years or over, the same set of conditions appear to be most common whether male or female.

Table 4: Five most common conditions (under 65s) by age-band, sex, deprivation, Brighton & Hove, March 2017

| | Females, most deprived (n = 6,220) | Females, least deprived (n = 5,246) | Males, most deprived (n = 5,777) | Males, least deprived (n = 4,523) |
|----------------------------|---|---|---|---|
| 20 to 34 (n = 2,223) | (n = 928) Anxiety 64% Asthma 51% Depression 32% Obesity 21% Substance misuse 19% | (n = 329) Anxiety 70% Asthma 47% Depression 27% Obesity 14% Hypothyroidism 10% | (n = 676) Anxiety 56% Asthma 48% Substance misuse 32% Depression 26% Schizophr/bipolar 12% | (n = 290) Anxiety 59% Asthma 57% Depression 19% Substance misuse 17% Learning difficulties 15% |
| 35 to 49 (n = 3,792) | (n = 1,274) Anxiety 53% Asthma 40% Depression 25% Obesity 25% Substance misuse 19% | (n = 695) Anxiety 59% Asthma 38% Depression 23% Hypothyroidism 18% Obesity 16% | (n = 1,270) Anxiety 45% Substance misuse 39% Asthma 35% Hypertension 20% Depression 20% | (n = 553) Anxiety 45% Asthma 36% Hypertension 24% Depression 18% Substance misuse 16% |
| 50 to 64 (n = 5,822) | (n = 1,649) Hypertension 40% Anxiety 39% Asthma 32% Obesity 28% Hypothyroidism 23% | (n = 1,178) Anxiety 36% Hypertension 35% Asthma 28% Hypothyroidism 25% Obesity 18% | (n = 1,793) Hypertension 46% Anxiety 32% Diabetes 27% Substance misuse 25% Asthma 23% | (n = 1,202) Hypertension 52% Anxiety 30% Asthma 22% Diabetes 21% Gout 16% |
| 65 to 79 (n = 6,369) | (n = 1,452) Hypertension 65% Urinary incontinence 27% Chronic renal failure 26% Diabetes 23% Anxiety 23% | (n = 1,736) Hypertension 61% Urinary incontinence 33% Anxiety 23% Hypothyroidism 22% Chronic renal failure 21% | (n = 1,513) Hypertension 66% Diabetes 32% IHD/heart 31% Urinary incontinence 29% COPD 21% | (n = 1,668) Hypertension 62% Urinary incontinence 26% IHD/heart 26% Diabetes 22% Atrial fibrillation 18% |
| 80 and over (n = 3,560) | (n = 917) Hypertension 80% Chronic renal failure 49% Urinary incontinence 28% AF 28% IHD/heart 27% | (n = 1,308) Hypertension 74% Chronic renal failure 38% Urinary incontinence 34% AF 24% IHD/heart 22% | (n = 525) Hypertension 68% Chronic renal failure 40% IHD/heart 38% Urinary incontinence 34% AF 31% | (n = 810) Hypertension 69% Urinary incontinence 47% Chronic renal failure 35% IHD/heart 32% AF 32% |

Source: GP patient data (Sollis)

4.8 Clustering of conditions

Clustering of the common conditions an adult might have gives a picture of which groups of conditions patients most commonly have together, and allows further analysis of healthcare costs and activity without just considering the 41 conditions independently. A global health report released by the Academy of Medical Sciences in April 2018 “Multimorbidity a priority for global health research”¹²² stated “clustering is useful as more clarity is needed on which combinations of conditions are commonly seen together, but such descriptive work would also benefit from a great understanding of the mechanistic basis underlying such clustering”.

Clustering, in this needs assessment, is based upon the presence or absence of a condition, given the presence or absence of another condition i.e. if an adult has moderate/severe depression as a long-term condition, what is the likelihood they also have anxiety? The methodology for obtaining the disease clusters was based on Deruaz-Luyet et al. (2017)¹²³ and looks at the odds ratios between every pair of conditions in Brighton & Hove. The premise is that if an adult has a condition in a particular disease cluster, they are more likely to have other conditions in that cluster (see Appendix for further details).

Nine clusters were identified (Table 5):

- There is a very strong association of 4 conditions in Cluster 1: substance misuse, schizophrenia/bipolar disorder, depression and anxiety.
- Cluster 2 shows seizure disorders and learning disabilities to be a common combination for adults with multiple long-term conditions which may be explained by problems in the same area of the brain.
- Adults with multiple long-term conditions who have asthma (cluster 3) or IBD (cluster 4) typically have a range of other conditions, but no association with any condition in particular.
- Cluster 5 shows various neurological conditions to be common combinations which may have the same pathophysiological origins. However, also in this cluster was chronic pain and HIV/AIDs.
- Cluster 6 includes blindness, urinary incontinence, heart conditions, chronic renal failure and hypertension whose commonality appeared to be older age.
- Cluster 7 shows clusters of adults with multiple long-term conditions who have combinations of dementia, paralytic syndromes, and cerebrovascular disease alongside chronic skin ulcer. A link between dementia and chronic skin ulcer is not surprising given that pressure ulcers are a particular risk for people with dementia due to the nature of the disease.
- Cluster 8 shows arthritis alongside osteoporosis, and autoimmune disorders and cancer to be a common combination of conditions for adults with multiple long-term conditions. Hearing loss, COPD and hypothyroidism are also included in this cluster (although these conditions could fit in several other clusters).
- Cluster 9 shows chronic liver disease, obesity, diabetes and peripheral neuropathy to be a common combination of conditions for adults with MLTCs.
- Clusters 1,2,3 and 4 are overarching, meaning that adults with any of these clusters of conditions also commonly have in addition conditions in disease clusters 5 to 9. In

other words, adults with multiple long-term conditions who have mental health conditions or learning disabilities might also typically have neurological conditions or perhaps conditions of older age, metabolic disorders or immune conditions (any of the diseases in clusters 5 to 9).

- Clusters with particularly high prevalence in adults with MLTCs are cluster 6 (older age), 8 (immune incl. arthritis) and 1 (mental health and substance misuse).

Table 5: Disease clusters for adults with MLTCs, Brighton & Hove, March 2017*

| Disease cluster** | Long-term conditions | Number of adults with 1+ conditions in cluster*** |
|---------------------------------------|--|---|
| 1. Mental health and substance misuse | 1a. Substance misuse (alc/drugs), schizophrenia/bipolar disorder 1b. Depression, anxiety | 22,933 |
| 2. Learning disabilities | 2a. Seizure disorders, learning disabilities | 2,505 |
| 3. Asthma | 3. Asthma | 13,090 |
| 4. IBD | 4. Inflammatory Bowel Disease (IBD) | 1,030 |
| 5. Neurological | 5. Muscular dystrophy, immunosuppression, pain in past five years, cerebral palsy, Parkinson's, sickle cell disease, HIV/AIDS, peripheral vascular disease, M.S. | 1,831 |
| 6. Age-related | 6a. Blindness, urinary incontinence 6b. Atrial fibrillation, congestive heart failure, IHD/G.A./Cardiovascular 6c. Chronic renal failure, hypertension | 30,481 |
| 7. Brain | 7a. Chronic ulcer skin, dementia 7b. Paralytic syndromes, cerebrovascular disease | 5,876 |
| 8. Immune incl. arthritis | 8a. Osteoarthritis, osteoporosis 8b. Autoimmune disorders, rheumatoid arthritis 8c. Gout, Cancer in past five years, hearing loss, COPD, Hypothyroidism | 23,297 |
| 9. Metabolic/ endocrine | 9a. Chronic liver disease, obesity, diabetes 9b. Peripheral neuropathy | 16,528 |

Source: GP patient data (Sollis)

* Subclusters are referenced a, b, c and indicate conditions which are more strongly related to each other within the cluster as a whole. Cluster 6 is often linked with cluster 7.

** Cluster names are a best fit to the conditions in the cluster, but it is important to refer to the list of conditions when interpreting any analysis presented here (for example chronic ulcer of the skin within the cluster of predominantly brain conditions).

*** Adults may have conditions in more than one cluster

The clustering gives interesting new insight for patients with multiple long-term conditions, but in the main it reflects that some conditions is due to common pathophysiological pathways, for example an association between atrial fibrillation, hypertension and IHD/generalised atherosclerosis/other

cardiovascular diseases would be expected. Similarly, an association between diabetes and obesity would be expected as obesity is a known risk factor for diabetes. Other clusters are age-related. Therefore they do not on the whole inform commissioning intentions

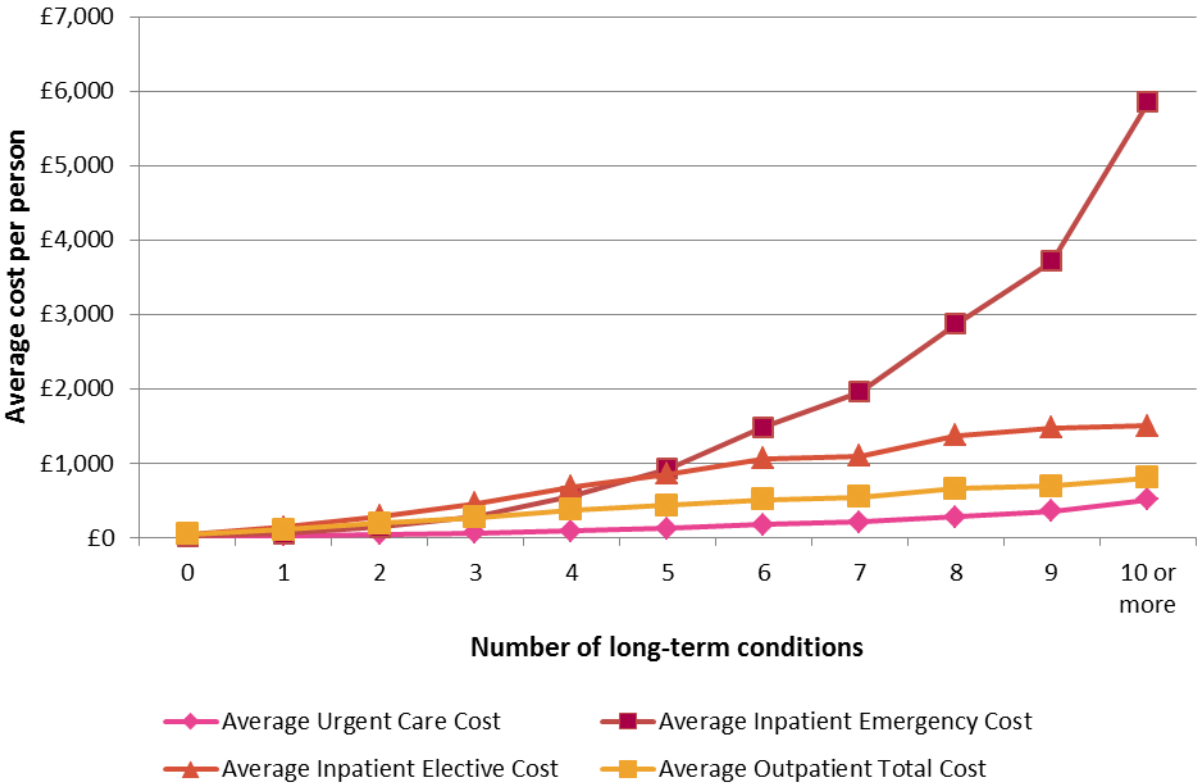
However, Cluster 1, with mental health and substance misuse is particularly seen in younger adults and a significant cluster within the city which wasn't found elsewhere.

4.9 Healthcare activity and costs

As similar patterns can be seen for hospital activity and costs, we focus mainly on costs.

On average, individuals with no long-term conditions cost £116 in the last year in terms of A&E attendances, outpatient appointments, elective and emergency admissions (Table 7). This increases to £662 for those with two conditions and £1,081 for those with three conditions. The average cost for individuals with eight conditions is £5,187 and £8,668 for ten or more conditions. The costs increase most in relation to emergency hospital admissions, up to £5,852 for those with 10 or more conditions.

Figure 17: Average cost per person of various acute care in the last year, by number of conditions; Brighton & Hove, March 2017



Source: GP patient level data (Sollis)

The average number of hospital inpatient admissions, A&E attendances, outpatient appointments, prescribed medications and GP practice contacts are all highly related with the number of long-term conditions an individual has.

Table 6: Average number of hospital admissions and attendances, GP practice contacts^c and prescribed medications by number of long-term conditions

| | Average outpatient appointments | Average emergency inpatient admissions | Average elective inpatient admissions | Average A&E attendances | Average GP practice contacts ¹ | Average distinct prescribed medication count |
|-------------------------|---------------------------------|--|---------------------------------------|-------------------------|---|--|
| <2 conditions | 0.9 | 0.0 | 0.1 | 0.2 | 2.3 | 2.0 |
| 2+ long-term conditions | 3.7 | 0.2 | 0.4 | 0.6 | 11.1 | 10.0 |
| 5+long-term conditions | 6.6 | 0.7 | 0.7 | 1.3 | 19.2 | 18.2 |

Source: GP patient level data (Sollis)

4.9.1 Total costs by age-group

In adults aged under 65, those with fewer (two or three) long-term conditions living in the most deprived quintile had the highest total costs in the past year (Figure 18). In adults aged 65 or over, those with greater numbers (five or six) of conditions had the highest total costs (Figure 19), with little difference by deprivation quintile.

In the year previous to March 2017, comparing adults with multiple long-term conditions to adults with single conditions, it is emergency admissions costs which show the largest increase with a cost of £1,440 per admission in adults with single conditions compared to a cost of £2,017 per admission in adults with multiple long-term conditions (Table 7). It should be noted however that these are average emergency costs for adults with those conditions and not costs specific to treating those conditions.

Just over half (56%) of emergency admission costs in the past year can be attributed to adults aged 65 or over, whilst two thirds (66%) of emergency admission costs in adults with multiple long-term conditions can be attributed to adults aged 65 or over. It is not surprising then that of all adults with multiple long-term conditions who had an emergency admission in the past year, 80% of these adults have a condition in disease cluster 6 which are mainly conditions of old age. Furthermore 66% of adults with multiple long-term conditions who had an emergency admission in the past year have a condition in disease cluster 8 (immune incl. arthritis).

In addition, in the under 65s, two thirds of adults with multiple long-term conditions who have had an emergency admission in the past year, have conditions in disease cluster 1 (mental health and substance misuse).

^c Note: GP contacts do not equate to appointments (they are an overestimate as include administrative changes to records)

Figure 18: Total emergency admission costs in past year by number of LTCs (aged under 65), Brighton & Hove, March 2017

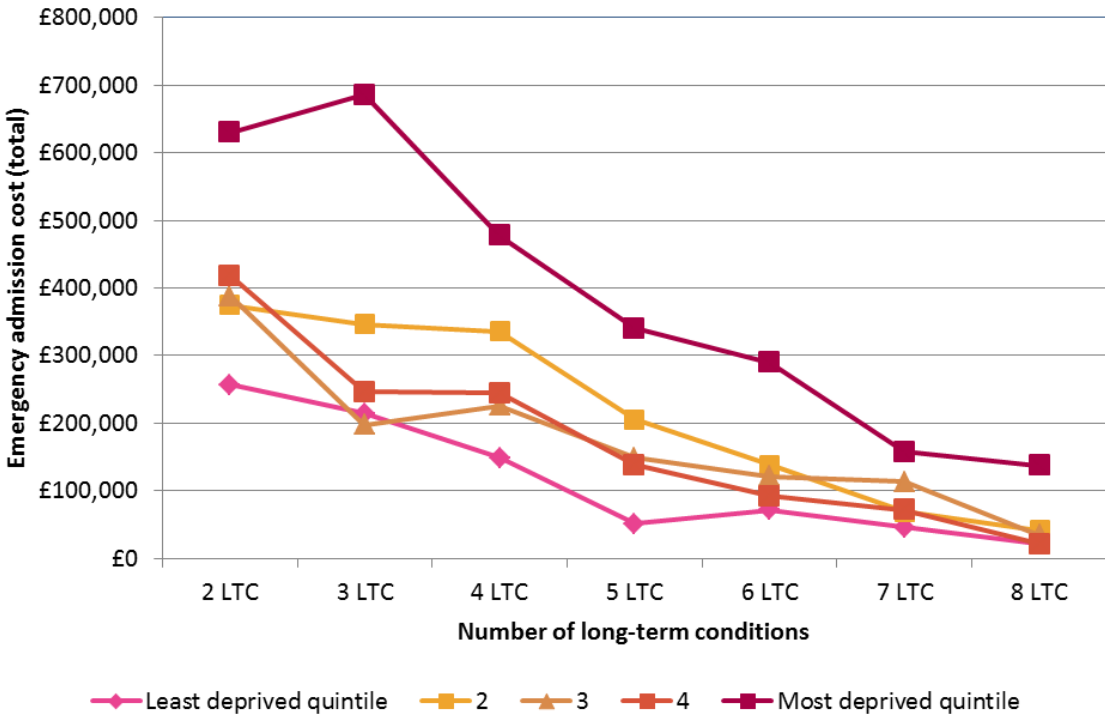
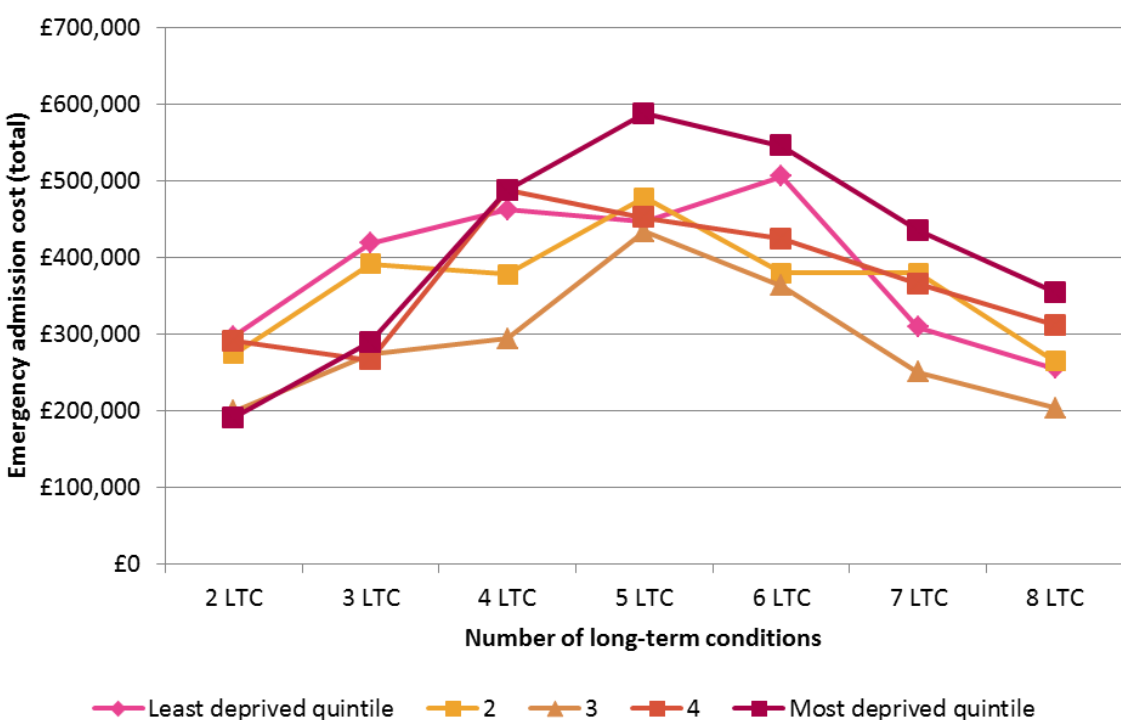


Figure 19: 65+



Source: GP patient data (Sollis)

Table 7: Total costs and number of admissions comparing adults with single conditions to adults with MLTCs, Brighton & Hove, March 2017

| | Elective admissions | Emergency admissions | Outpatients | A&E |
|--|---------------------|----------------------|-------------|-------------|
| Total cost for adults with single conditions | £7,598,523 | £3,179,959 | £5,895,596 | £1,552,523 |
| Number of admissions for adults with single conditions | 7,135 | 2,208 | 80,480 | 13,995 |
| Cost per admission (single conditions) | £1,065 | £1,440 | £73 | £111 |
| Total cost for adults with MLTCs | £25,479,145 | £23,901,913 | £14,529,940 | £4,022,752 |
| Number of admissions for adults with MLTCs | 19,729 | 11,850 | 188,261 | 31,303 |
| Cost per admission (MLTCs) | £1,291 | £2,017 | £77 | £129 |

Source: GP patient level data (Sollis)

4.9.2 Costs by specific condition

Adults with hypertension (60%), chronic renal failure (29%) and heart conditions (IHD 34% and AF 32%) make up the greatest contribution to total emergency costs in adults with multiple long-term conditions. However peripheral vascular disease, urinary incontinence, chronic skin ulcer, gout, chronic renal failure, arthritis (both OA and RA) and congestive heart failure all represent the highest **increased average** cost per person in adults with multiple long-term conditions compared to adults with these as single conditions.

In summary, emergency admissions costs show the largest increase in adults with multiple long-term conditions compared to adults with single conditions and it is those aged 65 or over that make up the majority of emergency admissions. As the number of long-term conditions they have increases, the cost begins to escalate exponentially. These adults tend to have conditions in disease clusters 6 (blindness/age-related macular degeneration, urinary incontinence, heart conditions, chronic renal failure, hypertension) and 8 (arthritis, osteoporosis, autoimmune disorders, cancer, COPD, hearing loss, hypothyroidism).

In emergency admissions in those aged under 65, the same conditions tend to be most prevalent (disease clusters 6 and 8) and this may be related to earlier onset. These younger adults tend to have fewer conditions overall (two or three conditions) with one

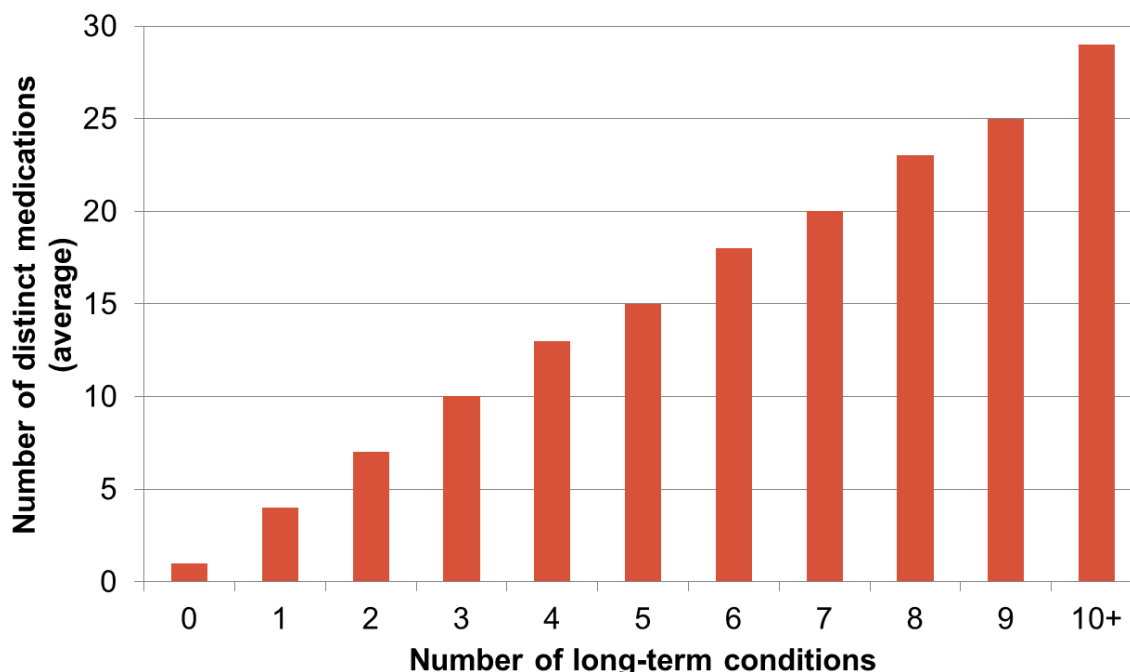
of these typically being a mental health condition / substance misuse. This is unlike adults aged 65 or over, who typically do not have a recorded mental health condition / substance misuse.

4.10 Prescribing

On average patients with no long-term conditions had 1.3 distinct medications prescribed by their GP in the last year, this increases to 3.6 for those with one condition to 6.5 distinct medications for those with two long-term conditions and reaches over 20 distinct medications for those with seven long-term conditions.

Around three-quarters (73%) in total prescribing costs was attributable to those with multiple long-term conditions (22% of adults), with 27% attributable to those with five or more conditions (3% of adults).

Figure 20: Average number of distinct medications in the past year, and average pharmacy cost, by number of long-term conditions, Brighton & Hove, March 2017



Source: GP patient level data (Sollis)

4.11 Frailty and multiple long-term conditions

Frailty, in the GP patient dataset, is measured using the Electronic Frailty Index (eFI) which uses data routinely available in the GP electronic health record to identify and grade frailty by severity. It is based on over 2,000 Read codes^d. There are 36 “deficits” that make up the eFI to give a frailty score for each adult (Figure 21). There is some cross-over between the conditions within our multiple long-term conditions definition and the eFI deficits. **The eFI only applies to adults aged 65 or over** to whom frailty is considered most relevant. These adults are scored into one of four categories:

^d Read codes are the standard clinical terminology system used in General Practice in the United Kingdom.

- **Fit (eFIscore 0 -0.12):** People who have no/few LTCs that are usually well controlled. This group would mainly be independent in day to day living activities.
- **Mild frailty (eFIscore 0.13 –0.24):** People who are slowing up in older age and may need help with personal activities of daily living such as finance, shopping, transport.
- **Moderate frailty (eFIscore 0.25 –0.36):** People who have difficulties with outdoor activities and may have mobility problems or require help with activities such as washing and dressing.
- **Severe frailty (eFIscore > 0.36):** People who are often dependent for personal cares and have a range of long-term conditions/multi-morbidity. Some may be medically stable but others can be unstable and at risk of dying within 6 -12 months.

Figure 21: The Electronic Frailty Index (eFI) and its 36 deficits; Brighton & Hove, March 2017

| 20 disease states | 8 symptoms and signs | 1 abnormal laboratory value | 7 disabilities |
|---|--|---|--|
| <ul style="list-style-type: none"> • Arthritis • COPD • Atrial fibrillation • CVD • CKD • Diabetes • Foot problems • Fragility fracture • Heart failure • Hypertension • Hypotension • IHD • Osteoporosis • Parkinsonism • Peptic ulcer • PVD • Respiratory disease • Skin ulcer • Thyroid disease • Urinary system disease | <ul style="list-style-type: none"> • Dizziness • Falls • Dyspnoea • Memory • Polypharmacy • Sleep disturbance • Urinary incontinence • Weight loss | <ul style="list-style-type: none"> • Anaemia and haematinic deficiency | <ul style="list-style-type: none"> • Activity limitation • Housebound • Hearing impairment • Mobility • Requirement for care • Social vulnerability • Visual impairment |

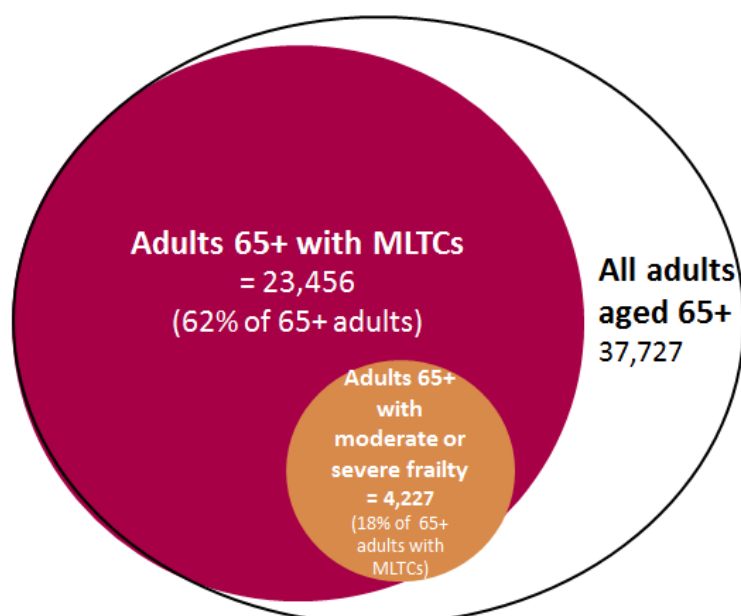
Source: NHS England

Most adults aged 65 or over in Brighton & Hove have some degree of frailty (88%) and 11% are classed as having moderate or severe frailty (9% moderate and 2% severe) (Table 8). Only 2% of adults with moderate or severe frailty do not have multiple long-term conditions (Figure 22), which is to be expected given that multi-morbidity is part of the definition. Effectively, moderate or severe frailty is a subset of having multiple long-term conditions.

Table 8: Frailty in those aged 65+, by age group, Brighton & Hove, March 2017

| Age group | Population count | Have some degree of frailty (a non-zero eFI score) | Moderate frailty | Severe frailty | Moderate or severe frailty |
|--------------|------------------|--|-------------------|-----------------|----------------------------|
| 65 to 69 | 11,091 | 8,918 (80%) | 338 (3%) | 29 (0%) | 367 (3%) |
| 70 to 74 | 9,083 | 7,852 (86%) | 486 (5%) | 62 (1%) | 548 (6%) |
| 75 to 79 | 6,506 | 5,971 (92%) | 630 (10%) | 88 (1%) | 718 (11%) |
| 80 to 84 | 5,149 | 4,911 (95%) | 758 (15%) | 147 (3%) | 905 (18%) |
| 85 to 89 | 3,519 | 3,384 (96%) | 718 (20%) | 166 (5%) | 884 (25%) |
| 90 to 94 | 1,745 | 1,683 (96%) | 466 (27%) | 132 (8%) | 598 (34%) |
| 95+ | 634 | 569 (90%) | 154 (24%) | 53 (8%) | 207 (33%) |
| Total | 37,727 | 33,288 (88%) | 3,550 (9%) | 677 (2%) | 4,227 (11%) |

Figure 22: Adults aged 65+ with MLTCs, who also have moderate or severe frailty; Brighton & Hove, March 2017



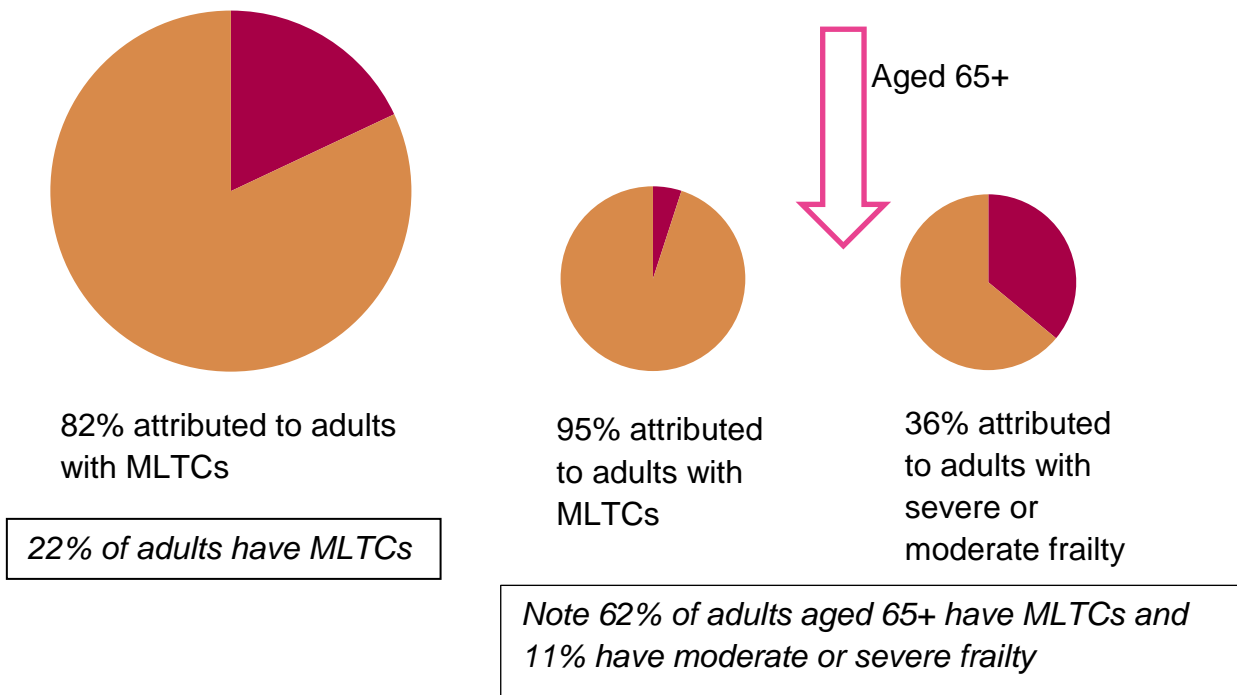
Source: GP patient data (Sollis)

4.11.1 Frailty in relation to hospital costs

Whilst only 22% of adults have multiple long-term conditions, they account for 82% of all emergency admission costs in the year prior to March 2017 (Figure 23).

In adults aged 65 or over, 95% of all emergency admission costs could be attributed to the 62% of adults with multiple long-term conditions (Figure 23). Whereas, around a third (36%) of all emergency admission costs in the past year in adults aged 65 and over can be attributed to the 11% of adults with moderate or severe frailty (Figure 23).

Figure 23: Total emergency admission costs in past year, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

The patterns were similar for elective admissions and A&E, although the extent is less than for emergency admissions (Table 8).

Adults who are moderately / severely frail had a higher average number of hospital outpatient appointments than all adults with MLTCs. Adults with severe frailty had on average seven outpatient appointments in the year previous compared to only three or four for all adults with multiple long-term conditions (Table 10).

The difference is less marked for the numbers of emergency admissions, elective admissions and A&E. However, adults with severe frailty only account for a small number of total outpatients appointments a year compared to adults aged 65 or over with multiple long-term conditions (Table 11). Adults aged under 65 with multiple long-term conditions have a higher number of total A&E attendances compared to adults aged 65 and over with multiple long-term conditions.

Table 9: Hospital costs attributed to adults with MLTCs, and frailty, Brighton & Hove, March 2017

| | All adults | Aged 65 and over | | |
|----------------------|---|--|---|---|
| | with MLTCs | with MLTCs | with moderate frailty | with severe frailty |
| Emergency admissions | 82% (of emergency admission costs attributed to adults with MLTCs) | 95% (of emergency admission costs in age 65+ attributed to adults with MLTCs) | 26% (of emergency admission costs in age 65+ attributed to adults with moderate frailty) | 10% (of emergency admission costs in age 65+ attributed to adults with severe frailty) |
| Elective admissions | 66% | 87% | 15% | 3% |
| Outpatients | 56% | 82% | 13% | 3% |
| A&E | 54% | 88% | 22% | 7% |

Source: GP patient data (Sollis)

Table 10: Average hospital activity for various groups of patients, Brighton & Hove, March 2017

| | Emergency admissions | Elective admissions | Outpatients | A&E |
|------------------------------------|----------------------|---------------------|-------------|-----|
| All adults | 0.1 | 0.1 | 1.5 | 0.3 |
| Adults with MLTCs aged under 65 | 0.2 | 0.3 | 3.1 | 0.6 |
| Adults with MLTCs aged 65 and over | 0.3 | 0.4 | 4.3 | 0.6 |
| Adults with moderate frailty | 0.5 | 0.5 | 5.6 | 0.9 |
| Adults with severe frailty | 1.0 | 0.6 | 7.2 | 1.6 |

Source: GP patient data (Sollis)

Table 11: Total hospital activity for various groups of patients; Brighton & Hove, March 2017

| | Emergency admissions | Elective admissions | Outpatients | A&E |
|------------------------------------|----------------------|---------------------|-------------|--------|
| All adults | 15,669 | 32,644 | 352,686 | 63,700 |
| Adults with MLTCs aged under 65 | 4,999 | 9,291 | 86,529 | 17,273 |
| Adults with MLTCs aged 65 and over | 6,851 | 10,438 | 101,732 | 14,030 |
| Adults with moderate frailty | 1,867 | 1,767 | 19,811 | 3,324 |
| Adults with severe frailty | 659 | 377 | 4,859 | 1,070 |

Source: GP patient data (Sollis)

In summary, in adults aged 65 or over emergency hospital costs, in particular, are driven by adults with multiple conditions. Adults with moderate and severe frailty explain up to a third of all hospital costs in those aged 65 or over, but focusing only on this group will have less impact than on those with multiple long-term conditions.

The average cost of emergency admissions per person increases more in relation to the number of conditions a patient has than due to frailty (Table 12). Adults who are moderately or severely frail, but have lower numbers of long-term conditions (0.6% of adults) have emergency admissions costs of £0.5million in the last year, but those who are **not** moderately or severely frail, but have five or more long-term conditions (2.3% of adults) have emergency admissions costs of £8million per year (Table 13). It is this group which requires more intensive support and proactive management.

Table 12: Emergency admission costs in the past year by frailty and number of long-term conditions, Brighton & Hove, March 2017

| | | Number of long-term conditions | | | | |
|--|------------|--------------------------------|--------|--------|---------------|---------------|
| | | 0 | 1 | 2-4 | 5-7 | 8+ |
| Fit / null (includes all adults under 65 years) | No. | 126,710 | 54,419 | 35,409 | 2,192 | 184 |
| | % of pop | 54.3% | 23.3% | 15.2% | 0.9% | 0.1% |
| | Ave cost | £17 | £57 | £223 | £1,348 | £4,699 |
| | TOTAL COST | £2.1m | £3.1m | £7.9m | £3.0m | £0.9m |
| Mild | No. | 108 | 732 | 6,557 | 2,627 | 251 |
| | % of pop | 0.1% | 0.3% | 2.8% | 1.1% | 0.1% |
| | Ave cost | £58 | £74 | £323 | £1,253 | £3,706 |
| | TOTAL COST | £0.01m | £0.05m | £2.1m | £3.3m | £0.9m |
| Moderate | No. | 8 | 59 | 1,258 | 1,722 | 503 |
| | % of pop | 0.0% | 0.0% | 0.5% | 0.7% | 0.2% |
| | Ave cost | £0 | £144 | £397 | £1,204 | £3,359 |
| | TOTAL COST | - | £0.01m | £0.5m | £2.1m | £1.7m |
| Severe | No. | 0 | 1 | 71 | 305 | 300 |
| | % of pop | - | - | 0.0% | 0.1% | 0.1% |
| | Ave cost | - | - | £280 | £1,061 | £4,168 |
| | TOTAL COST | - | - | £0.02m | £0.3m | £1.3m |

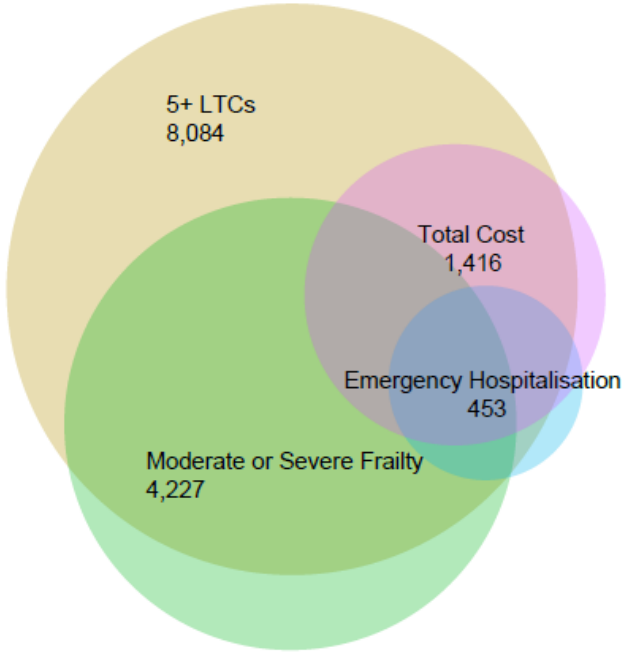
Source: GP patient data (Sollis)

Table 13: Emergency admission costs in the past year by frailty and number of long-term conditions summary table, Brighton & Hove, March 2017

| Frailty | Number of long-term conditions | | | | |
|---|---|---|-----|---|----|
| | 0 | 1 | 2-4 | 5-7 | 8+ |
| Fit / null (includes all adults under 65 years) | Very large numbers of people (96%, 223,935 people) with fewer conditions and less frail. Total emergency admissions costs of £15.3m | | | 2.3% (5,254) who are not frail but who have 5+ LTCs. Require intensive support and proactive management. Total emergency admission costs of £8.0m | |
| Mild | | | | | |
| Moderate | Small number (0.6%, 1,397 people) of people who have fewer conditions but a high degree of frailty. Total emergency admissions costs of £0.5m | | | 1.2% (2,830 people) who have 5+ LTCs and frail who require intensive support. Total emergency admission costs of £5.3m | |
| Severe | | | | | |

Source: GP patient data (Sollis)

Figure 24: Venn diagram of the number of people with 5+ LTCs, moderate/severe frailty, high risk of high total cost of admission and high risk of emergency admission in the next year with the overlaps, Brighton & Hove, March 2017



Source: GP patient data (Sollis)

If you only focus on moderate or severe frailty, you miss out on 62% of patients who are most at risk of having high total costs or most at risk of an emergency admission in the

next year and 87% of those patients you do intervene with are not people who are most at risk of high cost or emergency admission (Figure 24).

We also looked at the number of GP contacts by frailty and number of long-term conditions. It should be noted that GP contacts do not equate to appointments. They are an overestimate as include administrative changes to records, however are likely to reflect higher GP practice activity for patients with MLTCs. However they are still useful to indicate higher resource use in GP practices.

Those patients who have higher number of MLTCs and are identified as moderately or severely frail according to the eFI only make up 1.2% of patients but have 20% of all GP contacts. Adults who are moderately or severely frail, but have lower numbers of long-term conditions (0.6% of adults) make up 8% of GP contacts and those who are **not** identified as being moderately or severely frail, but have five or more long-term conditions (2.3% of adults) make up 12% of GP contacts (Table 14). It is this group who are having many more emergency admissions and so requires more intensive support and proactive management from primary, community and social care.

Table 14: GP contacts* in the past year by frailty and number of long-term conditions summary table, Brighton & Hove, March 2017

| Frailty | Number of long-term conditions | | | | |
|--|---|---|-----|---|----|
| | 0 | 1 | 2-4 | 5-7 | 8+ |
| Fit / null (includes all adults under 65 years) | <p>Very large numbers of people (96%, 223,935 people) with fewer conditions and less frail. Total GP contacts of 230,572 (60%)</p> | | | <p>2.3% (5,254) who are not frail but who have 5+ LTCs. Require intensive support and proactive management. Total GP contacts of 44,901 (12%)</p> | |
| Mild | | | | | |
| Moderate | <p>Small number (0.6%, 1,397 people) of people who have fewer conditions but a high degree of frailty. Total GP contacts of 31,422 (8%)</p> | | | <p>1.2% (2,830 people) who have 5+ LTCs and frail who require intensive support. Total GP contacts of 74,880 (20%)</p> | |
| Severe | | | | | |

Source: GP patient data (Sollis)

* GP contacts do not equate to appointments. They are an overestimate as include administrative changes to records, however are likely to reflect higher GP practice activity for patients with MLTCs

4.12 Adult Social Care

Without integrated data systems, we have been unable to look at people's pathways through health and social care within this needs assessment. Here we provide an overview of the long-term conditions of adults in receipt of care from Adult Social Care.

Over 1,000 people in the city live in Council funded residential and nursing care, representing 67% of overall Community Care budget spend (additionally some care is organised by the council but is fully paid by the individual). Rates of admission to long-term care in Brighton & Hove are increasing and currently much higher than England.

Table 15: Admission for long-term care for adults aged 65+, per 100,000 people, Brighton & Hove and England, 2014/15 to 2016/17

| Year | Brighton & Hove | England |
|---------|-----------------|---------|
| 2014/15 | 835.1 | 658.5 |
| 2015/16 | 835.2 | 628.2 |
| 2016/17 | 841.2 | 610.7 |

Source: NHS Digital Analytical Hub

As of the financial year 2017/18, there were 4,288 clients in receipt of care, this covers residential care, nursing care and community care (that is home based care or direct payment to the client to purchase care in the community). Of these, 2,658 adults (62%) are recorded as having multiple long-term conditions.

4.12.1 Defining multiple long-term conditions in the social care data

The recorded health conditions are not identified in the same way as the 41 long-term conditions in the GP data. Conditions in the GP data are based on Read codes^e, whereas health conditions in adult social care data are based on disclosure to the social worker and are recorded using a defined list from the NHS Digital Equalities and Classifications framework (see list in Appendix). Social workers do not have direct access to GP patient records.

The information on health conditions is completed by social workers as part of the client care pathway and is only as reliable as what has been recorded. In practice, this may mean that only conditions relevant to social care are recorded. Some conditions such as asthma may be under-recorded, but others such as arthritis which directly impact on social care needs are more likely to be well recorded. There are various caveats around the data; however it is still possible to draw broad conclusions. It is reassuring to note that there were similar findings to the GP patient data.

Social Care data shows that around a third of adults aged 18 years or over who are in receipt of care have only one recorded health condition (31%), with 62% having two or more recorded health conditions.

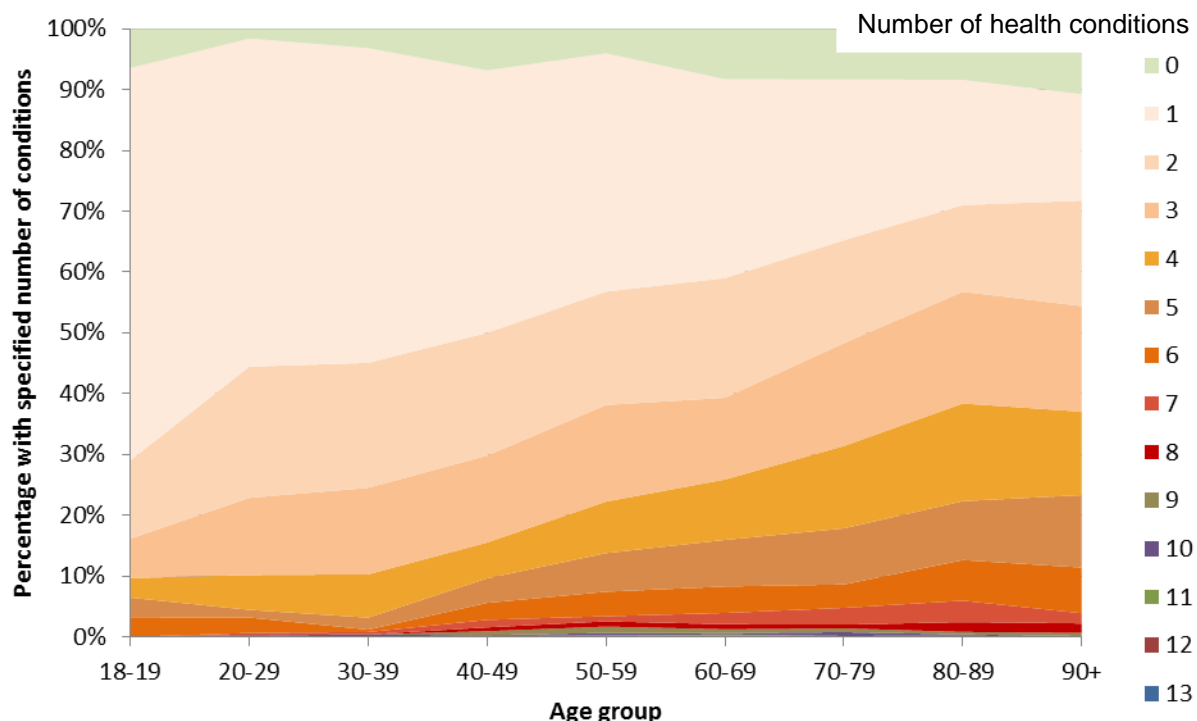
4.12.2 Demographics of adults with MLTCs in receipt of care

The likelihood of having multiple long-term conditions increases with age. The steepest rise with age appears to be in having two or more conditions (Figure 25). At age 18-19, under a third of adults in receipt of care have multiple long-term conditions, compared to around half of 40-49 year olds to around 60-70% of adults aged 70 or over. At age 70 years or over, the rates of females with multiple long-term conditions in receipt of care are greater than males.

^e Read codes are the standard clinical terminology system used in General Practice in the United Kingdom.

The vast majority (over 90%) of all adults in receipt of care, and of those with multiple long-term conditions, are White British particularly in the older age-bands, but numbers are too small to compare rates of individuals by ethnic group.

Figure 25: Percentage of all adults receiving social care by number of health conditions recorded and age group, Brighton & Hove, 2017/18



Source: Adult Social Care

4.12.3 Condition type

Anyone starting to receive social care is classified (in line with NHS Digital statutory requirements) with a primary support reason which indicates the main area of need e.g. mental health, learning disability, physical support. The majority of clients with multiple long-term conditions (66%) are in receipt of physical support for personal care, which is known to be a proxy for frailty. This is higher than in all adults in receipt of care (57%). A further 14% of adults with multiple long-term conditions have memory and cognition as their primary support reason, this usually refers to dementia.

There has been an increase in new long-term care placements for younger adults aged 18-64 years, with the biggest increases seen in mental health and physical support placements. The majority of new long-term care placements for older adults aged 65 years or over were for people with a primary support reason of physical support for personal care, with many also relating to memory and cognition.

This high-level primary support reason coding structure belies the complexity of individuals and the extent of people living with multiple long-term conditions in the city. It is not currently possible to link social care data with wider health data due to the lack of an integrated data system. Further work is therefore needed to explore the relationship between multiple long-term conditions and demand for residential/nursing care. However, social work services are reporting increasing complexity and acuity of cases. This is borne out by an increase in the proportion of nursing care placements as

opposed to residential care placements; in 2015, 39% of older clients were in nursing care compared to 46% in 2018.

4.12.4 Specific health conditions

Other physical condition/impairment is the most commonly specified health condition for adults with multiple long-term conditions requiring long-term care (32%) Arthritis is the second most common, at 28%, compared with 10% of adults with multiple long-term conditions in primary care having arthritis. Dementia is also a commonly specified health condition for adults with multiple long-term conditions in receipt of care, 27%, compared to only 4% amongst adults with multiple long-term conditions in primary care. Depression and anxiety (recorded together in adult social care), hypertension, diabetes and heart conditions all feature in the most commonly specified conditions – similar to primary care. The prevalence of visual impairment in adults with multiple long-term conditions in receipt of care was 4%, similar to in primary care at 3%.

However, other conditions are either under-recorded or not as prevalent in adults with multiple long-term conditions in receipt of social care: asthma (8% adult social care, 25% primary care), chronic kidney disease (7% adult social care, 15% primary care): chronic renal failure and cancer (both 6% adult social care, 10% primary care). As stated previously, the under-recording of certain conditions is likely due to the lesser impact of these conditions on people's social care needs.

Adults aged 80 years or over have the same top three conditions, whether male or female (similar to in primary care): arthritis, dementia and physical impairments (Table 16). Dementia is a significant issue in the city with a shortage of specialist residential / nursing provision. In 2017/18, 43% of delayed transfers of care related to people awaiting dementia placement.^f In the youngest age group (20-39 years), learning disability and autism are by far the most common health condition specified, with 74% of females having learning disability recorded and 92% of males. Depression / anxiety are also common conditions for this age group.

The vast majority of adults with multiple long-term conditions in receipt of long-term care (88%) live in Brighton & Hove with 12% living out of area (mostly within surroundings of the city i.e. Shoreham, Peacehaven, Worthing). The highest rates of adults with multiple long-term conditions in receipt of care are in Westbourne and Queen's Park wards, central areas of the city, followed by the east of the city. This does not appear to match deprivation or where older adults live, but may be more to do with locations of residential and nursing care and / or supported accommodation.

^f 2017/18 SPFT non-acute delays attributable to social care

Table 16: Three most common conditions for adults with MLTCs in receipt of care, by age and sex; Brighton & Hove, 2017/18

| FEMALES | | | |
|---|---|---|---|
| 20 to 39 years | 40 to 59 years | 60 to 79 years | 80 years and over |
| Learning Disability (Inc. Autism (74%)) | Depression/anxiety (48%) | Arthritis (48%) | Arthritis (54%) |
| Other Physical Condition / Impairment (34%) | Other Physical Condition / Impairment (43%) | Other Physical Condition / Impairment (47%) | Dementia (Inc. Alzheimer's) (49%) |
| Depression/anxiety (29%) | Learning Disability (Inc. Autism (42%)) | Depression/anxiety (41%) | Other Physical Condition / Impairment (42%) |
| MALES | | | |
| 20 to 39 years | 40 to 59 years | 60 to 79 years | 80 years and over |
| Learning Disability (Inc. Autism (92%)) | Learning Disability (Inc. Autism (55%)) | Other Physical Condition / Impairment (45%) | Dementia (Inc. Alzheimer's) (52%) |
| Epilepsy (25%) | Other Physical Condition / Impairment (39%) | Depression/anxiety (42%) | Other Physical Condition / Impairment (48%) |
| Other Physical Condition / Impairment (25%) | Depression/anxiety (38%) | Dementia (Inc. Alzheimer's) (41%) | Arthritis (39%) |

Source: Adult Social Care

4.12.5 Costs for adults with MLTCs in receipt of care

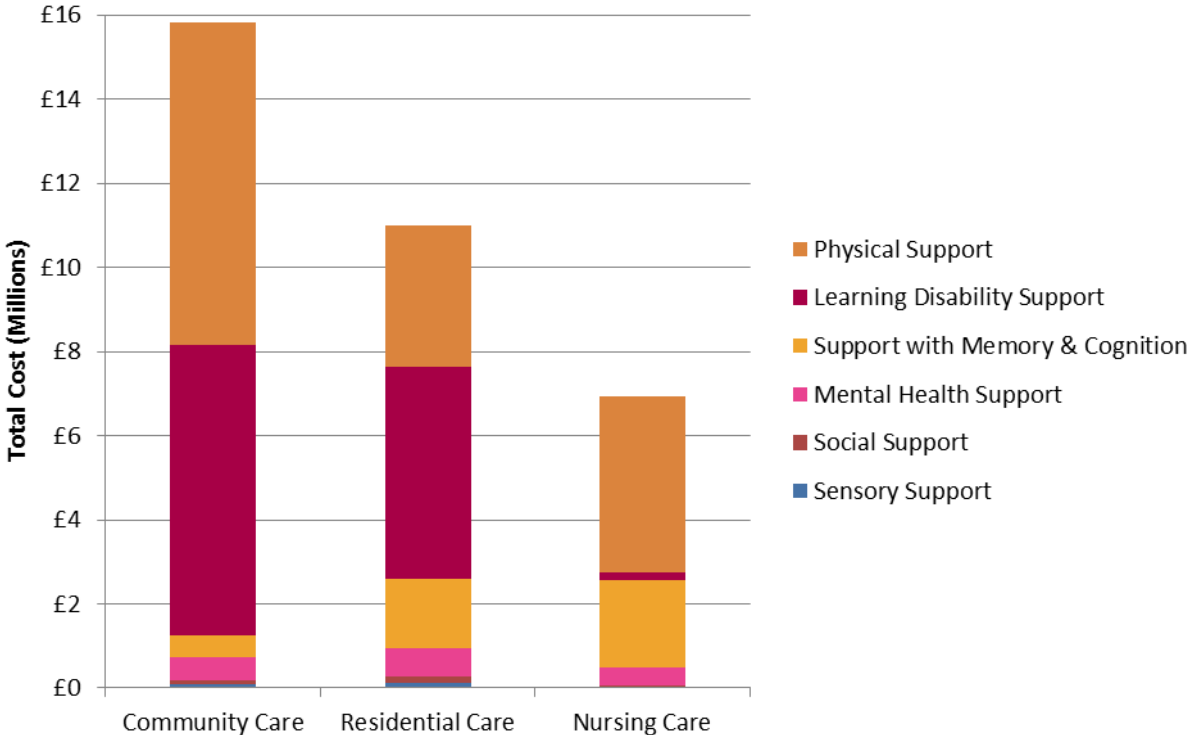
Community care represents the highest costs to adult social care, followed by residential then nursing care (Figure 26). The cost is calculated as total cost minus client contribution and is summed over all the client's costs for the year. The bulk of costs are for Physical Support and Learning Disability.

Adults in nursing care receive NHS Funded Nursing Care contributions towards placement costs. Therefore the council fund a lower proportion of whole cost for nursing placements than of residential placements.

In terms of primary support reason, physical support costs the most, forming a high proportion of all costs. More adults in nursing care need support with memory and cognition. More adults in residential care need learning disability support.

The median length of stay in residential care is particularly long for adults aged 18 to 30 years. These adults predominately need support for learning disabilities and often remain in high cost residential placements for many years.

Figure 26: Sum of costs in past year by Primary Support Reason, for all adults with MLTCs in receipt of care, Brighton & Hove, 2017/18



Source: Adult Social Care

Many adults with multiple long-term conditions become eligible for Continuing Health Care (CHC) funding⁹ meaning that their ongoing care costs are met through health (Clinical Commissioning Group) funding. There is no detailed data available on CHC and multiple long-term conditions. However due to these contributions, costs to the council via adult social care can often be lower for adults with MLTCs than for adults with single conditions.

⁹ **What is NHS continuing healthcare?** NHS continuing healthcare is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing health care needs. You can receive NHS continuing healthcare in any setting, including your own home or in a care home. NHS continuing healthcare is free, unlike support provided by local authorities for which a financial charge may be made depending on your income and savings. **Who is eligible?** Anyone over 18 years assessed as having a certain level of care needs may be entitled. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If the overall assessment of care needs shows a 'primary health need' the person should be eligible for NHS continuing healthcare. Whether someone has a 'primary health need' is assessed by looking at all of their care needs and relating them to four key indicators: nature, complexity, intensity and unpredictability.

5. Future trends

Whilst we have a snapshot of valuable information on multiple long-term conditions in our local population, we do not have trend data and so cannot make robust projections of how this might change in the future. The lack of an integrated data system also means at present that we cannot monitor trends following this 2017 snapshot.

Population increases alone suggest we will have nearly 8,000 more people with multiple long-term conditions in the city by 2030 (Table 17), with the majority of the increase being in those aged 65 years or over. The greater percentage increase in this age group is due to the greater population rises in older age groups, more likely to have MLTCs.

Table 17: Current (2017) and projected (2028) number of adults with multiple long-term conditions, Brighton & Hove based on population change alone

| | Current population 2017 | Projected population in 2030 | Adults with MLTCs in 2017 | Adults with MLTCs in 2030 (projected) |
|------------------|-------------------------|------------------------------|---------------------------|---------------------------------------|
| Aged 20-64 | 195,689 | 199,900 (2% increase) | 27,923 | 28,524 (2% increase) |
| Aged 65 and over | 37,727 | 49,100 (30% increase) | 23,456 | 30,527 (30% increase) |
| Total aged 20+ | 233,416 | 249,000 (15% increase) | 51,379 | 59,051 (15% increase) |

Source: GP patient data (Sollis) and ONS subnational population projections by persons, 2016-based

***Projections calculated by applying percentage of adults with MLTCs in 2017 to ONS 2016-based population estimates for Brighton & Hove in 2030.

Evidence from elsewhere also tells us that the rates of multiple long-term conditions are increasing and so these figures are likely to be underestimates. Two-thirds of adults aged 65 years or over are expected to be living with multiple conditions by 2035 according to recent research.² This would equate to a 7% increase in the prevalence of adults aged 65 years or over in Brighton & Hove between 2017 and 2035, and an increase of approximately 5% by 2030. There is not such evidence around expected prevalence of adults under the age of 65 years.

Combing this increase in prevalence with the increases due to population projections, we have conducted a sensitivity analysis. As there are no estimates of prevalence for those aged under 65 years, we have applied the same 5% increase to this age group. This analysis provides an indication of what could happen to the numbers of adults with multiple long-term conditions, their emergency admissions (if they follow current patterns) and healthcare costs in 2030 if the prevalence of all adults with multiple long-term conditions were to increase by 5%, or if rates increase at a greater rate by 10%.

We also present what could happen if prevention measures can be put in place and the prevalence of adults with multiple long-term conditions could be decreased by 1%, or by 5%, by 2030.

These figures are only meant to illustrate what could happen based on these increases or reductions; more detailed modelling would take into account age-specific prevalence rates for each long-term condition. However, we do not have sound evidence of expected changes in prevalence of all conditions by age group in order to do this.

Without upscaling prevention, the numbers of people with multiple long-term conditions in the city could increase by over 10,500 people to over 62,000 by 2030, with almost 2,900 more emergency admissions to hospital and £16.7million more in acute healthcare costs per year, based upon expected population growth and an increase in prevalence of 5%, similar to that within a national study.

We would need to see a decrease in prevalence of over 13% for there to be any reduction in the number of people with multiple long-term conditions in the city by 2030, because of our growing population.

If the prevalence of people with MLTCs increases by 5% between 2017 and 2030^h:



There would be 62,003 adults with MLTCs (up from the current 51,379 adults in 2017) (10,624 more adults)



An increase in emergency admissions to an estimated 14,724 admissions a year (up from the current 11,850 total emergency admissions in 2017) (2,874 more admissions)



A resulting increase in all acute healthcare costs (emergency, elective, outpatients and A&E) to an estimated cost of £84.6million a year (up from the current £67.9 million a year in 2017) (an increase of £16.7million)

If the prevalence of people with MLTCs increases by 10% by 2030:



There would be 64,956 adults with MLTCs (an increase of 13,577)



An increase in emergency admissions to an estimated 15,425 admissions a year (an increase of 3,575 admissions)



A resulting increase in acute healthcare costs (emergency, elective, outpatients and A&E) to an estimated cost of £88.6million a year

In contrast:

If the prevalence of people with MLTCs decreases by 1% by 2030:



There would be 58,460 adults with MLTCs or 7,081 more adults with MLTCs.



An increase in emergency admissions to an estimated 13,883 admissions a year



An increase in acute healthcare costs (emergency, elective, outpatients and A&E) to an estimated cost of £79.7 million a year

If the prevalence of people with MLTCs decreases by 5% by 2030:



There would be 56,098 adults with MLTCs or 4,719 more adults with MLTCs.



An increase in emergency admissions to an estimated 13,322 admissions a year



An increase fall in acute healthcare costs (emergency, elective, outpatients and A&E) to an estimated cost of £76.5 million a year

^h Assumes emergency admissions and all healthcare costs rise in direct proportion to the increase in prevalence of adults with MLTCs

6. Professional voice

In order to gain understanding of what is working well, and the challenges, for adults with multiple long-term conditions in the city from the perspectives of professionals providing care and support between July and September 2018 an online survey and semi-structured interviews were conducted across the city.

6.1 Online survey

An online survey was widely circulated and open from the 30th July to the 2nd Sept 2018. There were 160 responses to the survey and the breakdown of respondents is shown in Table 18. The number of respondents working in mental health (3) and healthy lifestyles (3) are too low to be shown separately (included in the other category).

Table 18: Respondents' area of work (%): professionals' online survey for MLTC needs assessment, 2018

| <i>Area of work</i> | <i>Number of respondents</i> | <i>%**</i> |
|--------------------------------------|------------------------------|------------|
| Primary care | 19 | 12% |
| Secondary care | 8 | 5% |
| Community care | 17 | 11% |
| Pharmacy | 12 | 8% |
| Social care | 36 | 23% |
| Community and voluntary sector (CVS) | 34 | 21% |
| Housing / housing support | 14 | 9% |
| Other* | 20 | 13% |
| All respondents | 160 | |

Source: Brighton & Hove Public Health team

*(includes mental health and healthy lifestyles as numbers too low to show separately)

**%s do not sum due to rounding

6.1.1 Care of those with multiple long-term conditions in Brighton & Hove

Almost two-thirds of respondents strongly or tended to agree that the care of people with MLTCs in Brighton & Hove works well (62%, 93/151 respondents to the question). This was highest for those working in housing / housing support (93%), followed by secondary care (75%) and lowest for those working in the community and voluntary sector (46%), pharmacy (50%) and other (50%).

6.1.2 What works well

When asked about what works well for people with MLTCs, support for staying healthy, shared-decision making between patients and health professionals and support for self-management of conditions were most commonly cited (all above a third of respondents). Sharing of patient records (17%), referrals between health services (23%) and links between mental and physical health services (24%) were least commonly selected as working well (Figure 27).

6.1.3 Challenges

From the same list, when asked about what are the challenges for people with MLTCs the most commonly cited were links between mental and physical health services (51%), sharing information between services (51%), referral between health and social

care (42%) and referrals between health services (41%). Whilst support for staying healthy was cited least often as a challenge, still 24% of respondents said it was a challenge (Figure 28).

Figure 27: What’s working well for people with MLTCs in Brighton & Hove (%), professionals’ online survey for needs assessment, 2018

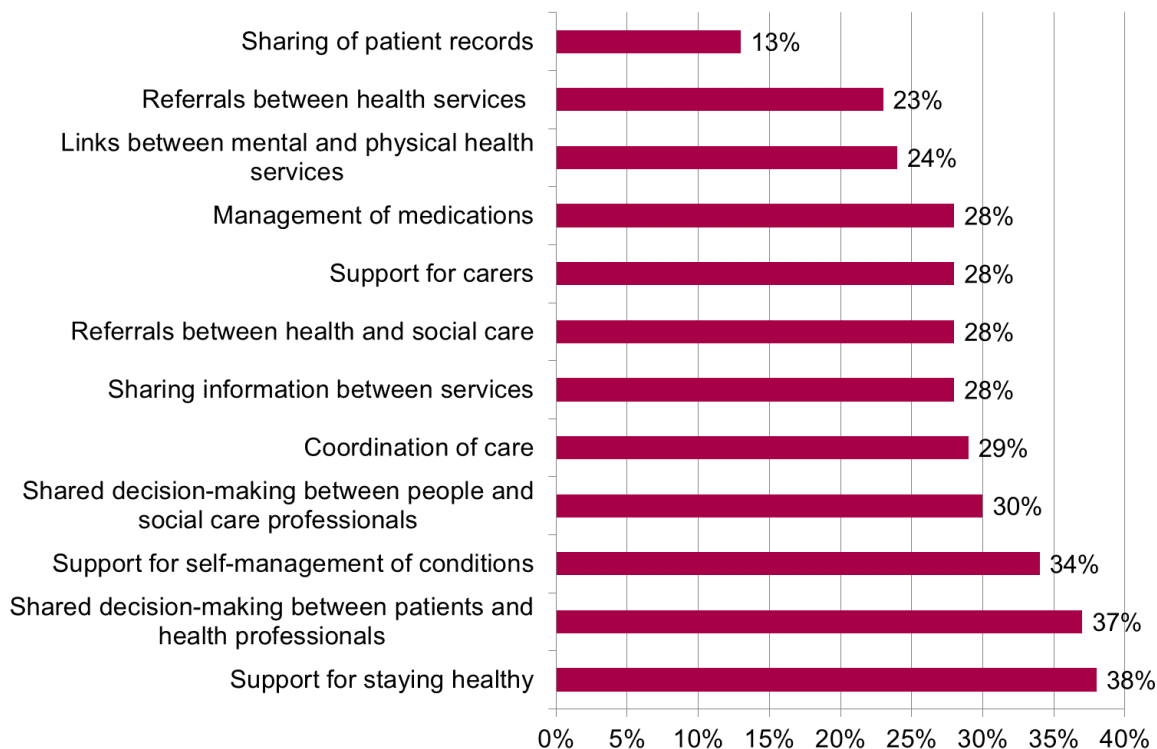
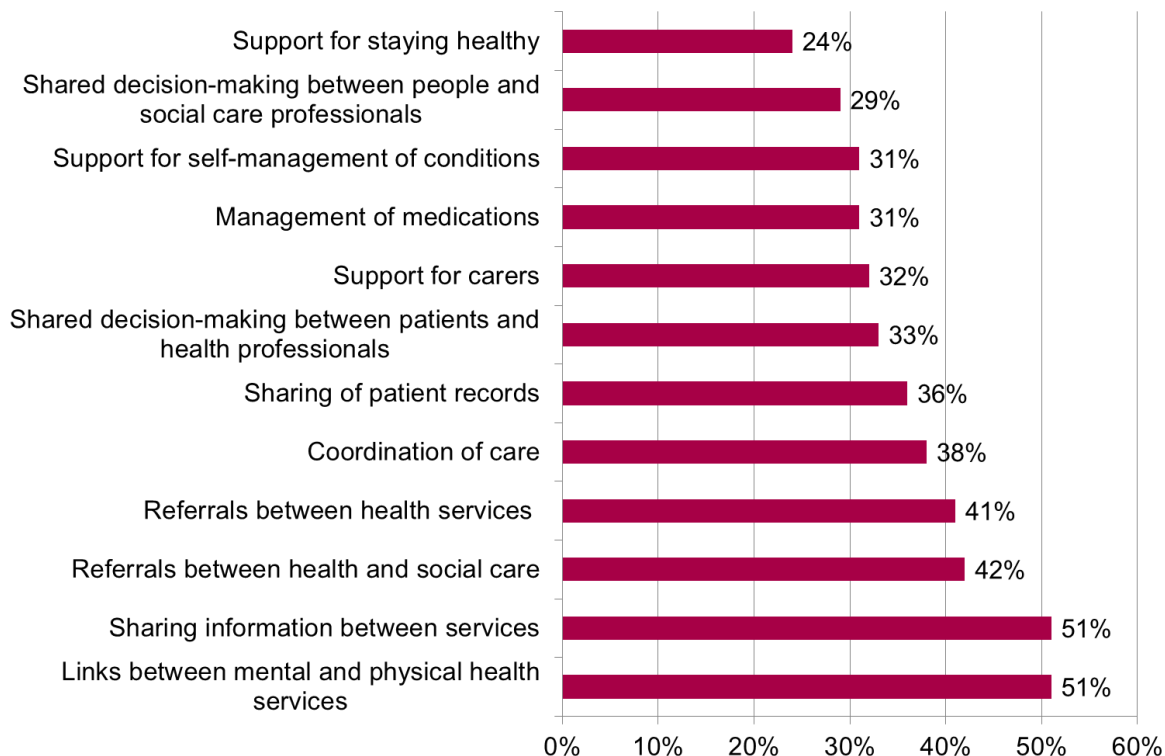


Figure 28: What’s are the challenges for care for people with MLTCs in Brighton & Hove (%), professionals’ online survey for needs assessment, 2018



Source: Brighton & Hove Public Health team

6.1.4 Themes from the free text responses

There were the following recurring themes from the professionals when asked about how they felt care for people with multiple long-term conditions could be improved:

- **Better communication between services, and with patients**
- **Stop looking at individual conditions, but all the conditions an individual has. The Quality and Outcomes Framework (QOF) drives primary care to look at conditions separately.**

“new QOF domain? QOF only considers single diseases” GP

- **Integrated information systems for sharing necessary information between services**

“Talking to the clients I work with the thing that infuriates them more than anything is having to repeat everything each time they visit a GP/health professional. They often suffer with extreme fatigue and anxiety and this puts them off seeking the help they need on many occasions. If the communication between services could be properly managed and streamlined then this needless anxiety could be reduced.” CVS

- **Shared care plans and multidisciplinary teams around the individual, agreed with them**

“Health and Social Care needs to be genuinely integrated. Joint commissioning, joint decision-making, shared information and resources.....We are not making joint strategic decisions which impacts on the quality of care people in care receive” Social Care

“A coherent strategy leading to identification, risk stratification, individual problem solving, therapy and ongoing integrated case management” Secondary care doctor

- **More time for appointments with, and resources dedicated to, these patients to look at needs holistically and provide the support they need to help prevent the escalation of their conditions and the need for acute or long-term care.**

“Longer appointments to assess all needs together, and less fragmented care. Maybe a one stop clinic to address mental, physical and social needs” Pharmacist

- **Increased focus on prevention, on educating individuals and on empowering them to help self-manage their conditions.**

“refocus on the basics of good care planning and empower people to make choices having been provided with the right information early” GP

“More empowering approach – giving people with multiple long-term conditions a choice in the way they are supported” CVS

- **The needs of two groups were particularly highlighted - those with mental and physical health conditions**
- **Housebound patients**

“housebound patients with multiple conditions are particularly missing out....

commission a “Housebound GP service” with a team dedicated to this group.” GP

“much more outreach as people with multiple issues often find it difficult or impossible to attend appointments away from their homes” Housing support

6.2 Semi-structured interviews

This section summarises key themes from the semi-structured interviews with health, care, voluntary and community sector representatives. It gives valuable insight, but should be read acknowledging the limitations of this approach, as not all professionals and services experience issues in the same way.

6.2.1 Overview

As there is no systematic way of approaching care for people with MLTCs, and no clear definition, professionals may not have a clear picture of what 'multiple long-terms conditions' are, i.e. how many and which conditions would be included.

It is difficult for professionals to know when mental health problems are classified as a long-term condition, rather than a single episode of an illness such as depression or personality disorder. These are particularly difficult to classify.

Management of people with MLTCs as a whole, with all of their conditions considered, does not happen with any one professional or organisation taking the lead. Health services are set up to manage individual health conditions, social care to look at the person's needs from the perspective of how are they managing and the links between these two systems are not always clear to either professionals or individuals.

Professionals say services need to be more empowering, rather than presumptive about what people and carers want or need. Carers too experience significant changes to their lives as a result of being a carer and their changing perspectives of having to adjust may not be as apparent as with people with MLTCs.

6.2.2 Prevention

It is reported that social care sees people only once they have hit crisis point. Although a social worker may pick up the person in hospital and refer them to community social workers for a review on discharge, as there are such a high number of referrals relating to safeguarding it might be unlikely for the community social work team to pick it up.

6.2.3 Person-centred care

The community and voluntary sector interviews frequently highlight a lack of person-centred care experienced by those they support. They describe a failure to put the person and their needs at the centre of decision making, to address personalised care, or to think holistically. Siloed, short-term, and target-focused care is described as the norm; they describe the need and value of a holistic approach that includes individuals' goals and values. This is linked to the inability of vulnerable or very ill patients to advocate for their own needs and communicate the details of their conditions, reducing access to appropriate or timely care for the people who need it most. This is a particular problem in a system with limited capacity to follow-up or reach out proactively.

6.2.4 Primary care

GPs currently have no easy to use, systematic way of identifying people at risk of or with multiple long-term conditions and there is no mechanism within existing systems to flag patients with MLTCs. GP practices are under increasing pressure, the context of the below needs to be considered within that.

Frailty: The electronic frailty record is used for those aged 65 or over and does not include the complex younger cohort with MLTCs. The record is helpful to highlight volumes of frail patients, but is not considered to be an accurate measure of frailty itself (it is more of a screening tool). Professionals use Rockwood or another score for this – for consistency in use of the Rockwood scale would allow for commonality of language and frailty awareness when patients move across the system. Frailty scores are used mostly by health professionals rather than social care. Some practices have specific ways of managing patients with MLTCs, such as longer appointments.

There is a gap in the care of younger, frail patients with multiple long-term conditions and GP practices don't currently have a plan to deal with this.

Other services such as social services, or long-term condition services, mostly see only people who have MLTCs and so have different ways of framing an individual's needs.

Proactive versus reactive: The community and voluntary sector interviews reflect problems experienced by vulnerable patient groups when interacting with primary care; they describe limited capacity, leading to reactive rather than proactive engagement with people and their needs. Vulnerable people are more likely miss appointments due to problems understanding where to be when, navigating complex contact or referral systems, accessing transport. Feeling safe and accepted during interactions with health services is particularly important.

Complexity for people with MLTCS and professionals: Community interviews also describe a lack of capacity in primary care to communicate clearly with, or understand the behaviour of, particular vulnerable groups such as people with learning disabilities; providing appropriate support is resource intensive and may require two extra people to attend appointments. A lack of appropriate care resulting from GPs not having time to read patient notes, combined with a patient who is unable to accurately describe their condition and needs themselves, is also highlighted. Particular aspects of primary care highlighted as problematic for some individuals, such as those with dementia or learning difficulties, include:

- Complex appointment booking systems, such as automated phone systems or lack of online booking systems
- Appointment letters which are not simply worded or easy to understand
- Long waiting times in the GP practice
- Difficulties using technology, such as self-monitoring systems
- Issues with trust and feeling understood may lead people to miss appointments or withhold information when they do attend
- Lack of continuity of care, with clients seeing different GPs each time they visit.

Professionals describe the following elements within primary care that can be improved to make life easier for people with multiple long-term conditions:

Systems / opportunities in GP practices:

- Longer appointments - to allow time to address multiple / complex needs, allow people to open up and communicate clearly about their needs, or for individuals

who find it difficult to attend multiple short appointments (e.g. those with mobility issues). One practice choose 1% of patients from their registered list to invite for double appointments and find it doesn't increase pressure on the practice overall.

- Combining annual reviews and enabling them to be captured within GP practice systems and reported through QOF. This could include mental health reviews. Training is required to enable professionals to conduct reviews of MLTCs and to incorporate mental health. One practice says that they invite people with MLTCs annually during their month of birth as standard.
- Shadowing of other services e.g. between community nurses and GPs.
- Continuity and frequency of care - in one GP practice the most frequent attenders are assigned a lead clinician and invited in to see the GP once a week. For example, a patient with multiple physical health problems and mental health issues who is not engaging with mental health services and would often call an ambulance. Scheduling the weekly appointment results in regular contact, which reduces impact on other health services.

Quality and Outcomes Framework (QOF): An opportunity would be to relook at how QOF works, as well as locally commissioned services. There are issues with QOF and mental health care, for example Lithium reviews only need to hit 90%, but the 10% missed are probably those we should be most worried about.

6.2.5 Community care

The need for preventive and treatment services which go 'to the client' is mentioned in multiple community and voluntary sector professional interviews; travelling to the service provider to receive care is a particular problem for the vulnerable clients often supported by these groups. They suggest more outreach (e.g. visits to social housing or hostels) by both preventive services, such as health trainers or screening programmes, and service providers such as chiropodists, optometrists, and nurses, would significantly reduce barriers to accessing care. This is particularly recommended in the context of the lack of appropriate city-wide support to patient transport.

Access to specialist advice: Instead of referring the patient and waiting, GPs could speak to the team and pull in specialist advice. For example, this allows the diabetes team to focus on using their specialist skills and not duplicating primary care. This could be applied across many long-term condition clinics.

Supportive and responsive services: If a person who is receiving care visits three times a day becomes unwell, for example with a urine infection, they require much higher levels of care and this provision is unavailable. The only option is then admission to hospital. An alternative might be a 'step up' bed in a care home.

Frailty and diabetes: The community diabetes team are integrating the Electronic Frailty Index (eFI) into their referral documents, which is provided by primary care. It is seen as useful to understand how frail a person is, so that the diabetes management can be tailored to a patient's needs. For those without an eFI, they are building the Rockwood Scale into templates. It is important to balance the harm caused by tight glucose control - a lot of older people are over treated, conversely younger patients may

not be managed tightly enough. This could be supported by relooking at the GP practice QOF criteria to avoid over treatment of older / frail patients.

Palliative / end of life care: Another key issue reported by health and social care professionals is a lack of access to palliative / end of life care for people with MLTCs, as services tend to focus on people with cancer. Recommendations made are to put severely frail people on palliative care / end of life registers which would result in the patients being reviewed and to review palliative / end of life care within nursing homes. A specific example is given of how patients with heart failure need to be seen earlier by the palliative care teams. An example of good practice was the provision of welfare / benefits advice to carers of those in the palliative care pathway.

6.2.6 Social care

Integration with social care was found to be more difficult when professionals used Access Point, the single point of access for adult social care, as opposed to a social worker within their team / service. As there is no shared information system, professionals have no way of knowing what happens to people once they are referred. Primary care professionals also feel that social care is very distant to them, that it is very under resourced, and the thresholds are very high for intervention.

Professionals think it would be helpful to have a named social worker to ask for advice, rather than an Access Point email. GPs may have differing expectations. The realignment of social care with the GP practice clusters is an opportunity and more joint working is needed.

Social workers generally feel that other professionals aren't clear about their roles and find health services difficult to navigate. Also, it is noted that different social workers aren't clear about other social care teams' roles and responsibilities in different settings.

Professionals think that there is still a stigma and barriers around interactions with social care, with people worrying about having to pay for social care or what the social worker may say.

Referrals: Quality of referrals is found to be problematic, with professionals often not providing enough detail, or overstating needs as they believe the person may not hit the threshold, which can result in them being referred to an inappropriate team.

6.2.7 Secondary care

Secondary care is considered good at managing one condition in a multi-disciplinary way. This involves team discussions with different professionals and seeing patients in a joint clinic. Those interviewed say it is not good at managing one person with lots of conditions, with many clinicians involved, in a combined way. There isn't a forum for professionals to manage people with MLTCs. It happens through email referrals and phone calls, often in a disjointed way or a letter copying others in. There is one example of joint forum given; there is a virtual clinic with the HIV and Diabetes Consultants looking at patients who have HIV and endocrine issues.

Discharge: There are multiple discharge pathways out of hospital; this involves large numbers of patients with multiple and varying health and care needs. To keep the flow of patients within the hospital, professionals report that there is pressure to discharge patients rapidly, which can lead to a lack of coordination and errors for people with MLTCs. This can mean that these patients are then picked up by responsive services.

As it is difficult to engage specialists in multidisciplinary team (MDT) meetings, this makes it harder to discharge patients. Benefits of MDTs need to be promoted across all specialisms within hospitals.

Discharge from hospital is considered to present a risk, whereby a person may improve in hospital when care is centred around them with professionals under one roof, but when discharged they may have new medication, carers might not be given all the information and they can be confused about which medications (new and existing) to take. Patient transport is also an issue relating to discharge.

Responsive services: Responsive services are made up of physical and mental health clinicians and social care professionals who work with patients at risk of being admitted to hospital within 24 hours. Professionals report that there can be challenges to quickly put in place professional carers, because of a lack of capacity with care agencies. Responsive services can find that carer capacity has been diverted to cover patients who have been recently discharged.

Role of the geriatrician: Geriatrician input is found to be very helpful for other specialities, particularly surgical such as musculoskeletal surgery; surgeons would not necessarily pick up on how important medication reviews are or falls risk. Geriatrician input can help with length of stay and falls, and expert medication reviews can be undertaken. However, there is reported there is a shortage of geriatricians.

6.2.8 Integrating mental and physical health

Complexity of services, care coordination and navigation: There are multiple pathways that health, social care and voluntary / community sector organisations work with. Interviewees recommend that key to enabling people with MLTCs to manage mental and physical health 'pathways' is for there to be a 'link person' or 'coordinator' to support access to services. Multiple services do not speak the same 'language' and having a dedicated person / professional was considered helpful in terms of building relationships and trust, as well as reducing social isolation.

Lack of a system of healthcare for people with MLTCs: Specialist health services don't often know about what is happening with each other's advice and medication and may give contradictory advice. There is a requirement for rationalisation of outpatient appointments, to understand where people are benefitting the most.

It's difficult for mental health teams to address individuals' physical symptoms and their interactions with mental health. Similarly 'physical' health staff make assumptions about people with mental health problems, and are not confident in addressing issues of mental illness. It is hard to solve this, although there is a lot of will to improve it.

The way that services are structured means that individuals see their own physical and mental health separately, or conversely they assume that all organisations are able to see all of their notes, which isn't the case. When someone is in a crisis, it will often have physical, mental and social aspects to it, and each one of those services will have part of the picture and respond accordingly. This includes social care and the voluntary sector, who cannot necessarily see any records.

A focus on mental health: Professionals recommend that a more holistic approach is needed to address people's mental health needs as well as physical health conditions and issues such as substance misuse. The stigma related to mental health still remains a barrier to accessing services.

Each physical health pathway could have a mental health pathway included; staff could be trained up to talk about mental health and be able to deal with those issues within the team, rather than refer to another organisation. Likewise, physical health could become a normal part of the mental health review. Taking the example of breathlessness, this is multifactorial and can be related to psychological and physical health issues. There are challenges relating to diagnosis and managing symptoms which can be related to anxiety as well as other physical conditions. There is a complexity in relation to managing a person's symptoms. Professionals need to work together more to avoid over medicalising this issue. Although there is a psychological element (cognitive behavioural therapy as part of the COPD pathway), earlier intervention is needed for mental health problems for people with MLTCs.

It is harder for those with mental health problems, to engage with mainstream health promotion activities around exercise and mental wellbeing to improve both their physical and mental health. An example of this is people with diabetes and mental illness. It would be good if people with mental health problems could be supported to access a football team or swimming group, but those clubs would need to have training around mental illness and be able to support people to access the group.

Interviews with community and voluntary sector providers highlight issues relating to support for clients with mental and physical health conditions; these include variations in the way that mental health crises are managed, misunderstandings by social or healthcare staff regarding the cause of an individual's behaviour leading to unnecessary escalation and lack of training on or misunderstanding / misuse of the Mental Capacity Act or legal frameworks related to people's mental capacity.

Training / education: More training and education is required across multiple professional groups relating to mental health, the Mental Health Capacity Act as well as on areas such as side effects of mental health drugs and related health consequences.

Boundaries between secondary mental health care and primary care: There are differences in how services are delivered within secondary mental health care. For example some patients need clinical engagement with the specialist nurses in secondary mental health care, but others could be discharged. If a patient has prostate cancer, they can go to the GP to get the monthly injection but if they have schizophrenia they can't. This is also a missed opportunity for primary care to address any physical

health issues in this group, which could prevent them from developing co-morbid conditions. The locally commissioned service (LCS) for serious mental illness in GP practices is an attempt to overcome this issue, where GP practices are paid to provide the injections and are trained. However, people need to meet the criteria for the LCS, which still excludes a large group of people.

It is hard for non-mental health professionals to understand the thresholds for referring to mental health services. Mental health services have social work teams, however there is little sharing of information between teams. Mental health social workers use a different IT system to other social workers as they are under the mental health trust. This means that they don't necessarily have information about a person and joint packages of care are not standard practice. If a person's referral gets rejected, others don't necessarily know why or what pressures the service is under.

There needs to be better engagement across the system between commissioners as well as providers to ensure better access to services and shared responsibility relating to risk. For example, there is psychology and psychotherapy for patients with diabetes within the community team, but there is a limit to the risk they can hold.

6.2.9 Care coordination and integration

Care coordination is understood differently by different groups of professionals, some professionals view it as a specific 'method' or approach to care, however all agree that there needs to be an identified professional to coordinate care. Such a role could reduce the lack of coordination and communication between multiple specialist providers; and lack of information sharing about the individual's needs / circumstances.

Roles of GPs: Most interviewees think that the GP would be best placed to be the 'care coordinator' as they hold the most information about the person within records (not the care navigator which helps a person find their way through the complex health and care system). However, GPs are described as being isolated or disconnected from other services, as they do not work within a team. Models to solve this include case management involving multi-disciplinary team working, whereby one professional takes the lead for acting at the 'care coordinator'.

Health and social care professionals think there are opportunities to maximise the role of GPs, in terms of being able to be responsible for ensuring the person accesses care and support, so that they are able to pull in information, advice and support from other services. An example of this could be for the GP to directly access a social worker for advice. However, there is very little capacity in primary care to undertake care coordination. GPs' expertise lies in generalist work and using GPs may be too expensive a model. An alternative care coordinator role for complex patients with MLTCs could be fulfilled by community matrons.

Administration of medical appointments can be very challenging for people with MLTCs, GPs sometimes ask their support staff to, or themselves try to help, find out what has happened with referrals and appointments but this takes a great deal of time. Without this help, people could fall through the gaps in care.

Co-location of multi-disciplinary professionals and sharing responsibilities:

Health and social care professionals work really well together when people are assigned to one area and work with one practice / team, when people know names and faces and can ask for advice and support. Co-location of teams is considered to be effective by many professionals across health, social care and voluntary sector. This was evident in the community provider e.g. community heart failure, diabetes and Integrated Primary Care Teams and within Brighton & Sussex University Hospital Trust in particular e.g. Home First, and social workers based at the hospital, occupational therapists and psychiatric liaison.

One suggestion from the interviewees is that professionals, such as community nurses, could have more general roles and following communication with other professionals, could ask questions and feedback, and there could be an electronic diary and notes system where everyone can see the notes. Case workers could also be a model that would work in primary care but it would be very difficult to design, as the case workers would need to have appropriate training and supervision and other professionals would need to understand what case load they could handle including size and complexity. Although this model might be cheaper than a clinician, funding would still be needed.

It is easy to get lost in the breadth of medical conditions and teams that are involved with people with MLTCs. The system doesn't take into consideration that a person may be seen by multiple professionals, for example a social worker assessing for a package of care, a community nurse changing a dressing, carers coming in four times a day (but could be three different people), a nurse comes in from a different team to check the catheter, and later on a community nurse to take blood and give an injection. For vulnerable people, they might not know who is coming into their home, which can be frightening. Interviewees say this could be rationalised with less visits, although it's acknowledged that the use of expert teams is helpful. For example professionals other than community nurses could be trained to administer insulin.

It is also considered that the community and voluntary sector should be more integrated with statutory services as an equal partner. One example of this could be providing information and advice on geriatric wards to support access to benefits / support.

As social work teams are being aligned to GP practice clusters, it's considered it will be easier to build relationships going forwards.

Care plans: Care plans carried out by GPs are not considered holistic reviews, but are mainly for contingency planning. Advanced nurse practitioners conduct holistic care plans with housebound patients. However GP practice care plans can be uploaded to data systems that other providers can see such as the Spine, IBIS and Summary Care Record with Additional Information (SCRAI). One GP offered to print care plans for patients, but these offers were declined by some.

Professionals find it difficult to keep care plans up to date for complex patients; they need to know it is up to date and all the information is there. It might be useful to have something held by the person, but this presents other challenges as patients may not

like, or understand, what's referred to in the notes and it may make it harder for professionals to communicate. This issue also relates to sharing patient records.

Advanced care plans: There is a need for more robust advanced care plans for palliative care, which are accessible across the health and care system for contingency purposes, including future wishes for priorities and care. Without this in place, a person can be more likely to be admitted to hospital. This is particularly pertinent for those in a residential or nursing home.

One professional suggests that advanced care planning should be automatically done with those with moderate to severe frailty and those who are admitted to a residential or nursing home. Another recommendation is for organisations to conduct an audit of the number of people from a nursing home that die within 24 hours of admission to hospital. For most, advanced care plans aren't in place and there is no decision for future care. Earlier, and more explicit, decision making would improve individuals' and families' experiences significantly.

Trusted Assessor model: A number of professionals consider that the trusted assessor model is an opportunity as it enables one professional to conduct an assessment and for others to act upon it as appropriate. This involves sharing risk between organisations and different professionals taking responsibility and holding the risk for a given role e.g. a home care provider providing information and reducing a package of care and for all to trust this is appropriate. Shadowing is also recommended so that professionals can better understand different job roles.

6.2.10 Information sharing and lack of shared records

Overall, different services do not understand how best to communicate with each other and do not understand each other's systems.

Every professional mentions information sharing, particularly difficulty in getting relevant information about people from other health professionals and issues with not having a shared IT system that every health and social care professional can see. GPs and community pharmacists were unaware when their patients had been admitted to hospital, or discharged, until much later. The community and voluntary sector also reflect the negative impact of the lack of shared information about individuals across sectors, and highlight the particular impact on people who are not able to communicate clearly about their own condition, needs or support and treatment they are receiving.

Where different providers deliver services such as mental wellbeing and substance misuse, professionals cannot see a person's notes if they are admitted to hospital, which is particularly challenging out of hours.

There can be a long wait to see community services, for example the diabetes service. When seen, they 'start from scratch' as they don't have access to primary care notes.

Relationships between primary care and community nurses are developing; however it is evident that there is a lot of duplication in activity. By understanding each other's practice and sharing information and records, this duplication could be reduced.

Housebound patients: Patients who are housebound are a good example of where services could work better together. These patients are likely to have multiple professionals going in over a week, some from the same and some from different services, and it is felt that these patients would benefit from a smaller number of 'different faces'. Professionals often ask the same questions, don't know what other professionals are going in and when and they don't know what has been done with a patient. There might be a paper record within a yellow folder but not everyone records their notes in it, some professionals e.g. community nurses have hand held electronic devices to record notes, others still use paper. Another example is heart failure nurses who record notes on laptops, note in the folder this has been done and send a letter. The use of letters or fax is challenging as community nurses can be asked by the GP via a letter or fax (the main way to refer to community nurses) to administer insulin if their carer is away for example, however letters and faxes can get lost.

Referrals: Referrals between services are often viewed as problematic, with each service having its own referral form which takes time to complete (particularly problematic for GPs). Communications regarding referrals, to any part of the system, is almost always noted as poor, with referrers receiving little information whether the patient was accepted or what the outcome was. Time is often wasted referring to services and being bounced back. This is noted as a particular problem for younger adults, where there is no general acute medicine doctor or equivalent to a geriatrician who can deal with multiple issues.

Linking patient records: There are examples where services are trying to link patient records. The community dermatology service have started linking into primary care notes, so this can be seen by GPs. The community trust diabetes team would like to share patient records with primary care in order to reduce duplication; they plan to include frailty scores so that records can be coded and audited and it be possible to search for patients that are being over-treated in order for this to be addressed within primary care. However there are challenges with information governance, as it's technically harder to share parts of patient records rather than the whole record.

Patient access to records: Patient access to notes can be really positive experience, with patients feeling more in control of their health. It's acknowledged that this is large topic and there wasn't time in the interviews to explore this adequately.

6.2.11 Medicines management

Within primary care patients on polypharmacy are often searched for and reviewed; however there is no coding or flagging system used. Medicines are reviewed annually in GP practices, although the community and voluntary sector interviews highlighted that not all GPs keep up to date with reviews, or proactively identify patients and initiate a medicines review.

For pharmacists that are based in GP practices, or within clusters, there are many ways of identifying patients for medication reviews e.g. over 75s, taking 25+ or 5+ medicines, number of hospital admissions, severely frail patients through electronic frailty record.

There is no defined methodology or specific form for a medicines review and different healthcare professionals interpret a review in different ways. Pharmacists report that they will look holistically at all medicines and what is happening with the patient, taking into consideration social needs and health preferences and look at all medicines together. Others consider the review to be about whether the medicines are still appropriate for a specific condition.

There needs to be better communication between pharmacists, GPs, consultants and others to maximise the value of each medicines reviews and any changes to medications.

There are issues with communication about medicines when patients move between providers and home. For example, pharmacists still dispensing medicines to patients in hospital as they don't know about admissions, so patients have multiple sources of medicines on discharge which presents risk and waste. Discharge summaries don't always have enough information to make appropriate changes in medication and IT systems are not in place to easily share information.

The management of patients in nursing homes is very complex due to the number of GPs and pharmacists working with the home and communication required.

Professionals considered that it was difficult to have an impact with severely frail patients and wondered if it would be better to target those who are less severely frail.

Mental health medications: There is a risk around mental health drugs when a patient is admitted to hospital. For example, summary care records may only include prescriptions that had been administered by primary care in the last year, therefore a mental health drug like Clozapine may not show up on the system as it is only prescribed by secondary care. When someone is admitted to hospital they then won't know about the drug and it might not be prescribed, meaning that the patients might become mentally unwell and be required to start all over again with a two week titration and weekly monitoring for 18 weeks, after being stable and on a monthly monitoring regime.

6.2.12 Community pharmacy

In Brighton & Hove, community pharmacists work within community mental health teams and this works well. Now 95% of patients are looked after in the community, however most mental health pharmacy resources are focused on inpatients. There has been investment in four mental health pharmacists across Sussex who are working in the community. These pharmacists need to work more with 'general' community pharmacists and with people following discharge from hospital.

6.2.13 Carers

Key points raised in relation to carers highlight that carers assessments could be completed online by the carers themselves, which could free up social care resource and that professionals need to make more use of the carers' hub and refer to them. People don't always identify themselves as carers or see the importance of identifying themselves as such. There are a huge number of carers that haven't been identified,

including young carers. Carers should be flagged in GP practice systems but the numbers identified currently are low. GP receptionists are being trained to make referrals and could refer to the Carer's Hub.

Professionals highlight how many carers have MLTCs themselves and that they are aware of carers being at increased risk of mental or physical health issues as a result of their caring role, particularly if they are elderly. They find keeping carers safe and well is a big challenge. Carers can find themselves with huge responsibility liaising between organisations regarding medications / treatment and there is no formal training for this.

Specialist health professionals highlight the lack of time in a consultation to consider the needs of the carers.

A few professionals report how, at the start of treatment, professionals should look at the support system around the person. This can start with work in diagnostic services who could email the Carers Hub. If the person doesn't need help at that moment, they can call back in a few weeks. There are a range of services for carers that can be wrapped around a family. In addition, when someone is diagnosed, professionals need to check whether they are in a caring role, as this will have implications for rest and recovery, or how they manage their own health conditions.

The Carers Hub is considered very good. It has carer support workers who are able to do joint visits. The support should be promoted more widely so that when a person is 'self-funded', they are aware they can still be supported through the hub even though they are not eligible for social care support.

There is a financial impact of caring, people can get into a lot of debt; the benefits system does not recognise the extent of caring. If people are referred, money management services can really help.

Young carers: For many years, organisations have just looked at the needs of the person presented to them, rather than consider the wider family around them. This is especially problematic for young carers, as many professionals do not recognise that children are in a caring role. There is a reluctance to ask further questions about how a child / young person might be caring for an adult, and perhaps reluctance from the person to answer. Young carers are very vulnerable to having their own health needs, through early risky behaviours.

6.2.14 Cross sector systems – making change happen

Strategic join up: Professionals highlight issues with organisations having different budgets and the challenges regarding reductions in budgets that happen without considering the person's overall care. Having separate budgets doesn't encourage working together and integration. Communication at the top of organisations is required to facilitate change, with a clear vision for the future, so that all organisations can be part of it. Time needs to be made to make those strategic decisions, to reflect and to plan for the future.

Health and social care professionals want to see clear measurement frameworks for impact of initiatives for this complex area of care / support and assurance that new services will be evidence based and developed with a medium to long-term view.

Professionals agree that there needs to be a shift in commissioning and provider organisation behaviour to focus on improving outcomes.

A weakness of all services and therefore system integration, according to one health professional, is the lack of seven day working.

Relationships, permission and flexibility: Relationships at different levels are considered the most important issue in order to make change happen across different organisational silos. Future re-design of service needs to come from front line workers across different agencies and involving people with MLTCs, re-organisation of structures was considered to delay progress. Professionals need the freedom to try new things, and use a Plan Do Study Act cycle to see if the change is worth doing.

Specific service gaps: bariatric care. Bariatric care was reported as being an issue, as it continues to increase and there aren't specialised services to address this. People requiring bariatric care require the same access to rehabilitation as others.

7. Patient and carer voice

7.1 Sources

Within the timescale of the needs assessment there was limited time to conduct new qualitative data collection on local people’s experience with the management of their conditions. The following were used for to gather evidence:

- NHS England provided extra tables from the 2018 NHS GP patient survey for Brighton & Hove splitting results by those with 0, 1, 2 and 3+ long-term physical or mental health conditions.
- An online survey, open from 30th July to the 2nd Sept with 111 responses from adults with MLTCs and 36 responses from carers.
- Older people were invited to focus groups arranged by Age UK Brighton & Hove. However, there were unfortunately not enough participants registered. Those participants registered were sent the details of the online survey to complete, with an offer of telephone support to complete the survey.
- A call for evidence was sent to voluntary and community sector organisations to gather additional evidence of people with MLTC’s views, assets and needs.

7.2 National GP Patient Survey

NHS England provided us with additional tables from the 2018 National GP Patient Survey¹²⁴ for respondents from Brighton & Hove by the number of long-term conditions they have (0, 1, 2 or 3+ conditions). There were 3,633 respondents to the survey, a response rate of 30%. Survey results are weighted to match population characteristics.

The survey asked people about their experience of primary care and for those with long-term conditions about the management of those conditions. These are based upon self-report. The list of long-term conditions asked about is given in Table 19.

Table 19: Long-term conditions included in the National GP Patient Survey, 2018

| Conditions: | |
|--|--|
| Alzheimer’s disease or other cause of dementia | A hear conditions, such as angina or atrial fibrillation |
| Arthritis or ongoing problem with back or joints | High blood pressure |
| Blindness or partial sight | Kidney or liver disease |
| A breathing condition such as asthma or COPD | A learning disability |
| Cancer (diagnosis or treatment in the last five years) | A mental health condition |
| Deafness or hearing loss | A neurological condition, such as epilepsy |
| A developmental disability, such as autism or ADHD | A stroke (which affects your day-to-day life) |
| Diabetes | Another long-term condition or disability |

Source: NHS England GP Patient Survey 2018 (Additional tables provided by NHS England)

Over half (53%) of respondents in Brighton & Hove had one or more long-term condition, 21% had two or more long-term conditions (the definition of multiple long-term

conditions used in this needs assessment) and 10% had three or more long-term conditions. This is very similar to the results of our local analysis, with 22% of adults having two or more long-term conditions and 12% having three or more conditions.

7.2.1 Demographic characteristics of respondents

Respondents with MLTCs were:

- **Older:** only 13% of respondents with MLTCs were aged 16-34 compared with 36% of those with 0 or 1 condition and 44% of respondents with MLTCs were aged 65+ compared with 9% of those with 0 or 1 condition
- **Much more likely to be retired or permanently sick or disabled:** 40% of those with MLTCs are fully retired compared with 10% of those with 0 or 1 condition; in addition 15% of those with MLTCs are permanently sick or disabled compared with 2% with 0 or 1 condition; so rates of full or part-time work were lower for those with MLTCs at 33% compared with 69% of those with 0 or 1 condition.
- **More likely to be unpaid carers:** 23% of those with MLTCs are unpaid carers compared with 13% of those with 0 or 1 condition. 6% of those with MLTCs are caring for 50 or more hours per week (1% with 0 or 1 condition).
- **More likely to be a current or former smoker:** 59% of those with MLTCs are current or former smokers (9% regular smokers) compared with 46% of those with 0 or 1 condition (6% regular smokers) (Table 20). Though it is worth noting that the overall current smoking rates (occasional plus regular) are similar (16%).

Table 20: Smoking status (%), National GP Patient Survey Brighton & Hove, 2018

| Smoking status | 0-1 long-term condition | 2+ long-term conditions |
|--------------------------------------|--------------------------------|--------------------------------|
| Never smoked | 54% | 41% |
| Former smoker | 30% | 42% |
| Occasional smoker | 10% | 7% |
| Regular smoker | 6% | 9% |
| Total respondents (Weighted)* | 3,031 | 812 |

Source: NHS England GP Patient Survey 2018 (Additional tables provided by NHS England)

*Results to the national survey are weighted to match population characteristics

These demographic differences need to be considered when interpreting the results – in particular the older age profile of respondents with multiple long-term conditions.

7.2.2 Preferred GP

Respondents with MLTCs were significantly more likely to prefer to see or speak to a particular GP at their practice for some or all appointments (72% compared to 46% of those with 0 or 1 condition). Of those with MLTCs with a preferred GP, 61% got to see this GP always or a lot of the time (similar to those with 0 or 1 condition at 57%).

7.2.3 Making an appointment

Patients with MLTCs were significantly more likely to have tried to make a general practice appointment within the last six months (88% compared to 74% of those with 0 or 1 condition). They were also significantly more likely to have been very or fairly concerned about their health at the time of making this appointment (74% compared to

65% of those with 0 or 1 condition). They were more likely NOT to have tried to get other information or advice prior to this appointment (39% vs 26%).

7.2.4 Last general practice appointment

Patients with MLTCs were significantly more likely to have had an appointment within the last six months (87% compared to 69% of those with 0 or 1 condition). At this appointment they were as likely to:

- Rate their healthcare professional as very good or good in: giving enough time (87% vs 88%); listening to you (89% vs 90%); treating you with care and concern (88% vs 87%).
- Feel that their healthcare professional recognised/understood any mental health needs (91% vs 92%); Be involved as much as they wanted in decisions about their care and treatment (93% vs 94%); Have confidence and trust in the healthcare professional they saw or spoke to (95% vs 96%); Feel that their needs were met (94% vs 95%).

7.2.5 Health

Patients with MLTCs were significantly more likely to have experienced the following in the last 12 months: Problems with physical mobility, for example, difficulty getting about your home (35% vs 6%); Two or more falls that needed medical attention (7% vs 1%); Feeling isolated from others (21% vs 7%).

Half of those with MLTCs take 5+ medications on a regular basis (51%), ten times higher than those with 0 or 1 condition (5%). Those with MLTCs were significantly more likely to say that their long-term conditions reduced their ability to carry out day-to-day activities (76%) compared with those with one long-term condition (51%).

7.2.6 Managing their health conditions

There isn't a significant difference between those with MLTCs and those with one condition in confidence in managing any issues arising from their condition(s) – 79% of those with MLTCs vs 84% of those with one condition were very / fairly confident. Those with MLTCs and those with one condition were similarly likely to feel that they have had enough support from local services or organisations to help manage their condition(s) (81% vs 83%). Significantly more respondents with MLTCs had had any unexpected stays in hospital due to their condition(s) than those with one condition (15% vs 4%).

7.2.7 Care plans

Of those with MLTCs, 42% had had a conversation with a healthcare professional from their GP practice to discuss what is important for them when managing their condition (compared to 39% of those with one condition). Of these (311 weighted patients) 55% had agreed a plan to manage their condition (compared with 64% of those with one LTC – no significant difference). And of these 94 found this plan helpful (97% of those with one LTC) and 42% of those with MLTCs had been given (or offered) a written or printed copy of this plan (significantly higher than those with one LTC at 29%).

7.2.8 Out of hours care

In the last twelve months, patients with MLTCs were significantly more likely than those with 0 or 1 condition to have contacted an NHS service when they wanted to see a GP

but their GP practice was closed (17% vs 13%). The most common services contacted were NHS service by telephone (74%), followed by A&E (47%) and a call back from a healthcare professional (42%). Patients with MLTCs were significantly more likely than those with 0 or 1 condition to have attended A&E (47% vs 30%), have a healthcare professional call them back (42% vs 29%), have seen a pharmacist (23% vs 11%) and have had a healthcare professional visit them at home (11% vs 4%).

Of those with MLTCs receiving any out of hours care in the past twelve months: 64% thought that how quickly they received care was about right (67% for those with 0 or 1 condition – no significant difference); 90% had confidence and trust in the people they saw or spoke to (94% for those with 0 or 1 condition – no significant difference); and 71% described their overall experience as very or fairly good (72% for those with 0 or 1 condition – no significant difference).

7.3 Patient online survey

In order to get local views of adults with multiple long-term conditions, in addition to their views about primary care, an online survey was widely circulated and open from the 30th July to the 2nd Sept. There were 111 responses to the survey from adults with MLTCs.

Around of third of all respondents did not complete the demographic questions and so we have not presented this information here with the exception of the question on type of long-term condition, disability or impairment (Table 21). There were responders which is type of condition/disability/impairment, including mental health conditions.

Table 21: Respondents' long-term conditions (%): individuals with MLTCs online survey for needs assessment, 2018

| <i>Impairment/disability</i> | <i>Number of respondents</i> | <i>%*</i> |
|-----------------------------------|------------------------------|-----------|
| Physical impairment | 36 | 32% |
| Sensory impairment | 17 | 15% |
| Learning disability or difficulty | 9 | 8% |
| Long-standing illness | 35 | 32% |
| Mental health condition | 45 | 41% |
| Autistic Spectrum Condition | 24 | 22% |
| Other developmental condition | 3 | 3% |
| Other | 6 | 5% |
| All respondents | 111 | |

Source: Brighton & Hove Public Health team

*percentages do not sum as individuals can have more than one condition

7.3.1 Care of those with multiple long-term conditions in Brighton & Hove

30% of respondents strongly or tended to agree that the care for people with MLTCs in Brighton & Hove works well (33/110 respondents to the question).

7.3.2 What works well

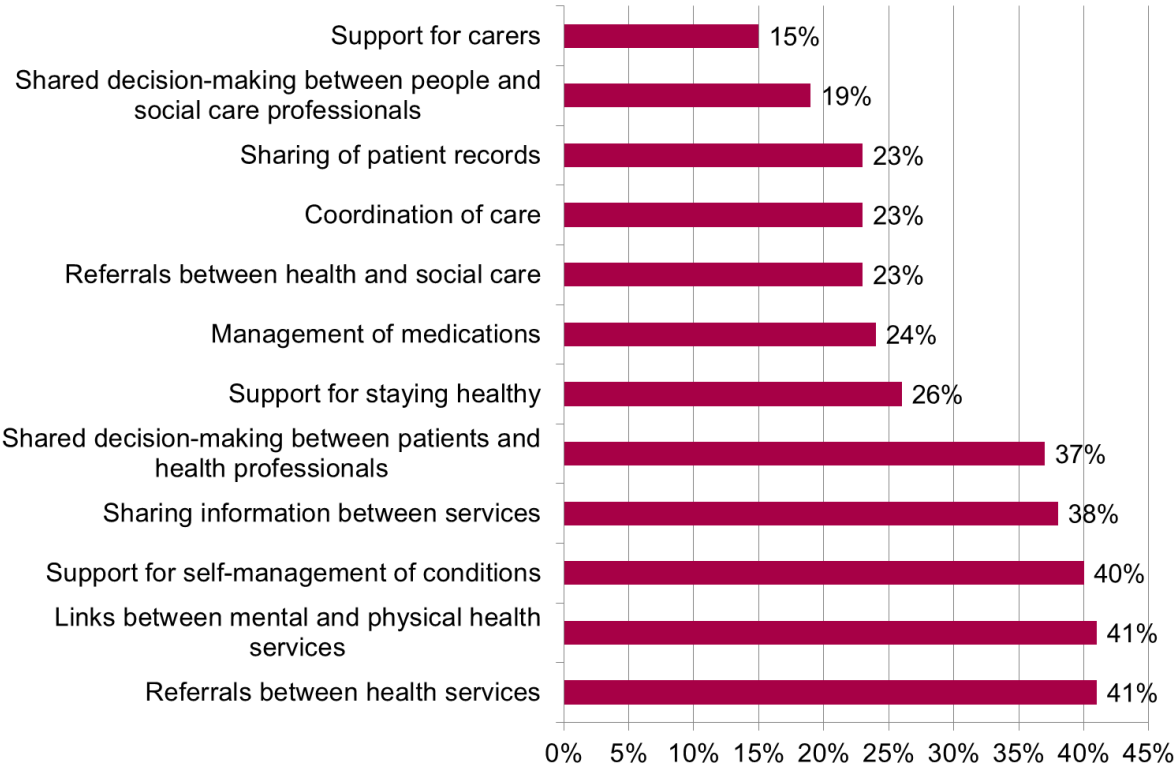
When asked about what works well for people with MLTCs, shared-decision making between patients and health professionals (37%), referrals between health services

(30%), management of medications (24%) and support for self-management of conditions (23%) were most commonly cited. Shared decision-making between people and social care professionals (9%), referrals between health and social care (8%) and support for carers (5%) were least commonly selected as working well.

7.3.3 Challenges

From the same list, when asked about what are the challenges for people with MLTCs the most commonly cited were referrals between health services (41%), links between mental and physical health services (41%), support for self-management of conditions (40%), sharing information between services (38%) and shared decision making between patients and health professionals (37%) (Figure 29).

Figure 29: What’s are the challenges for care for people with MLTCs in Brighton & Hove (%), individuals with MLTCs online survey for needs assessment, 2018



Source: Brighton & Hove Public Health team

7.3.4 Themes from the free text responses

There were the following recurring themes from individuals with multiple long-term conditions when asked about how their care could be improved:

- **More time for appointments (particularly face to face), more support for daily living and a more holistic approach to care, rather than professionals only dealing with one condition**

“I get passed around different services who all think someone else would be a better fit, but I’ve never found a good fit.”

“Getting to see a GP in person, this would massively improve health and wellbeing as things can be missed over the phone.”

- **Better communication with individuals and between services**
- **Professionals working together and sharing necessary, but not unnecessary, information to prevent individuals having to tell different professionals the same thing**

“Joined up care where all parties involved communicate and work as a team. I am not lots of separate body parts, I am a whole person needing holistic care! I’d like more transparency so I could access my records and care plans and for them to be regularly reviewed and updated with input from the whole multidisciplinary team.”

“The care system needs to concentrate on the person, not as is the case at the moment, on just one specific health condition. There is not a joined up approach that includes the care of all ones several chronic health conditions. This is not the case across all of the country and I have found that it is often better to travel to another county/City where this joined-up approach is the norm.”

- **Joined up care was particularly highlighted for those with mental health conditions or learning disabilities in addition to physical health conditions, with a sense that physical health conditions were often not given enough focus**

“Stop hearing the word ‘depression’ and then attributing everything to it.”

- **Greater focus on prevention and activities to keep people well**
- **Trusting individuals with multiple long-term conditions and empowering them to help self-manage their conditions.**
- **More knowledge/reviews of medication interactions by professionals and better information about medications to GP on being discharged from hospital**

“Many times I have been given medication from Dr’s or GP that causes issues or should not be taken with other medication and I then need to discuss in detail with the pharmacist.”

- **More support and involvement of carers**

These are similar to the themes highlighted in the national Our health, our care, our say: a new direction for community services – consultation (responses from people with long-term conditions) that people:

- want to be involved in decisions about their care – they want to be listened to
- want access to information to help them make those decisions
- want support to understand their condition and confidence to manage – support to self-care
- want joined up, seamless services
- want proactive care
- do not want to be in hospital unless it is absolutely necessary and then only as part of a planned approach
- want to be treated as a whole person and for the NHS to act as one team.¹²⁵

7.4 Carer online survey

In order to get local views of carers an online survey was widely circulated and was open from the 30th July to the 2nd September. There were 36 responses to the survey from unpaid carers.

7.4.1 Care of those with multiple long-term conditions in Brighton & Hove

46% of respondents who were unpaid carers strongly or tended to agree that the care for people with MLTCs in Brighton & Hove works well (16/35 respondents to the question). However, a similar percentage (43%) tended or strongly disagreed.

7.4.2 What's working well

When asked about what works well for people with MLTCs, shared-decision making between patients and health professionals (44%), referrals between health services (36%) and support for carers (33%) were most commonly cited. Referrals between health and social care (fewer than five respondents), Sharing of patient records (14%) and links between mental and physical health services (17%) were least commonly selected as working well (Figure 30).

7.4.3 Challenges

From the same list, when asked about what are the challenges for people with MLTCs the most commonly cited were sharing information between services (50%), referrals between health services (47%), support for carers (47%), links between links between mental and physical health services (44%) and coordination of care (42%) (Figure 31). Figure 31: What's are the challenges for care for people with MLTCs in Brighton & Hove (%), carers of individuals with MLTCs online survey for needs assessment, 2018).

7.4.4 Themes from the free text responses

The key themes for carers were the same as those of individuals with multiple long-term conditions when asked about how care could be improved, so this information is not repeated here.

Figure 30: What's working well for people with MLTCs in Brighton & Hove (%), carers of individuals with MLTCs online survey for needs assessment, 2018

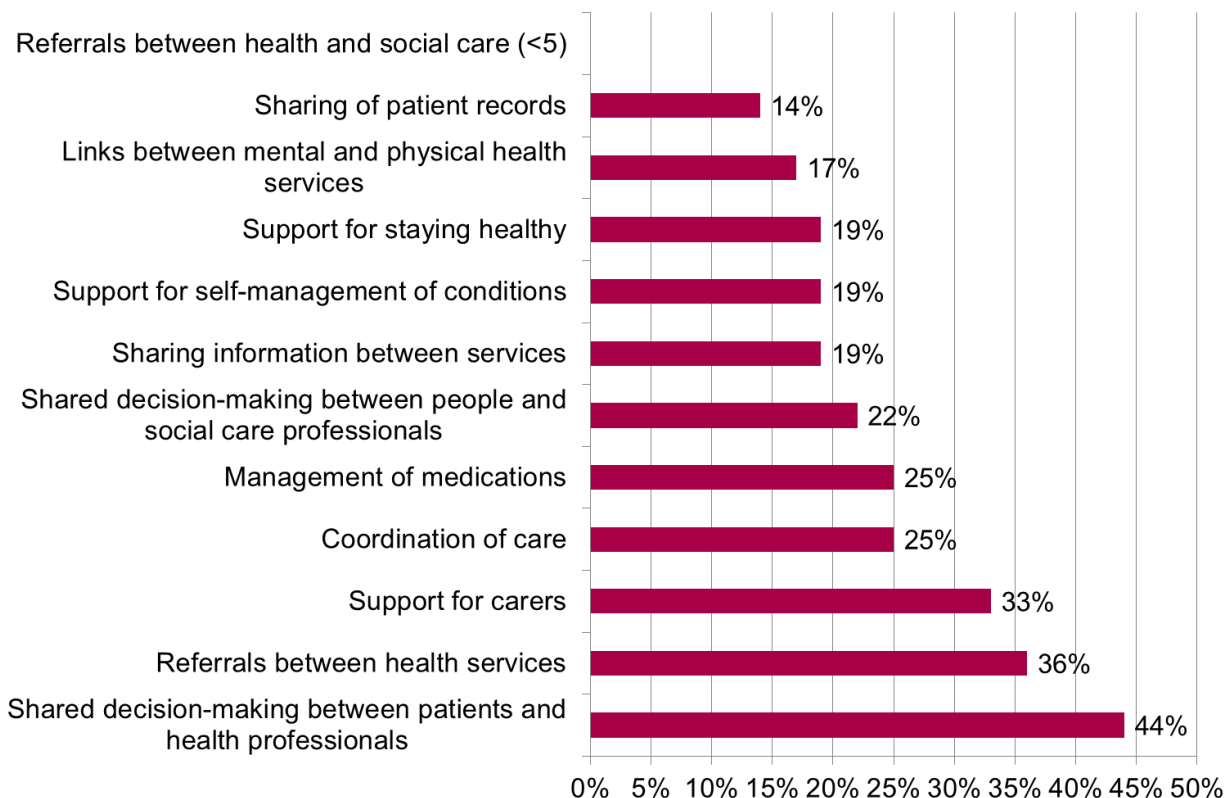


Figure 31: What's are the challenges for care for people with MLTCs in Brighton & Hove (%), carers of individuals with MLTCs online survey for needs assessment, 2018



Source: Brighton & Hove Public Health team

7.5 Call for evidence – voluntary and community sector

Evidence was submitted by six voluntary and community sector organisations as part of a call for evidence put out for the needs assessment. Key issues are detailed below.

7.5.1 Cross cutting evidence

Money Advice Plus highlighted that the most common gap in services for their clients with MLTCs is obtaining supporting information from health professionals for disability benefit claims and appeals and a key issue for a considerable number of clients with MLTCs is in obtaining and maintaining private rented accommodation.

The food partnership submitted evidence regarding healthy eating, highlighting that people with a long-term health conditions need to eat a healthy diet to stay well and that this is true for those with physical and mental health conditions (The ‘food and mood’ connection being well established). However, they report that people with long-term health conditions, especially where these are multiple, are often less able to access a healthy diet due to cost, lower budgets and are at greater risk of malnutrition. One of the key principles from their healthy ageing and food report states:

“Food should be looked at in a holistic way, recognising that meals can be an opportunity to socialise, share and enjoy. Food is vital for good mental health and wellbeing as well as good physical health. Whilst good practice on supplements should be followed (e.g. Vitamin D supplements) and other vitamin intake as recommended by health professionals, in general the vision for a Healthy Ageing City should be that everyone is able to access tasty and nutritious meals.”

7.5.2 LGBTQ

A Mindout, Opening Doors London and Brighton & Hove LGBT Switchboard report¹²⁶ highlights discrimination and prejudice related to LGBTQ older people and the fear of dealing with health and care, including residential care and supported housing services, that are heteronormative and cisgenderist. Individuals report that if they were to need care, recognition of identity would be essential to mental wellbeing.

In addition, Switchboard emphasise the importance of an intersectional approach to understanding MLTCs. That is, how a given individuals’ various characteristics (particularly protected characteristics – including age, ethnicity, marital / civil partnership status, pregnancy) intersect to create distinct needs and experiences. This is considered distinct from an ‘accumulation’ model of understanding the experiences of those who experience marginalisation along more than one characteristic, which sees these experiences as ‘adding up’ without necessarily considering how the different experiences and identities interrelate and interpenetrate in a person’s life, and in response to different contexts and situations, which all adds to complexity.

In relation to MLTCs and LGBTQ+ experience – both broad categories in themselves – this is relevant in terms of understanding how a person’s sexual orientation, gender and/or trans status may intersect with their experience of living with MLTCs. A person’s ethnicity, age, immigration status and other characteristics will also intersect to inform this complexity.

LGBTQ+ communities experience a range of health inequalities that contribute to higher rates of co-morbidity than their cis-heterosexual peers, including higher rates of poor mental health, smoking, problematic alcohol and substance use and poverty. Bisexual and trans communities show particularly poor health outcomes in these areas, attributable to the particularly intense minority stress these groups face, both within and outside of the LGBTQ+ community.

Barriers to care that LGBTQ+ people with MLTCs experience include: low trust and confidence in staff to be LGBTQ+ aware and inclusive; experiences of homo-/bi-/trans-phobia from health and care staff; heteronormativity in patient interactions; and low levels of, or inappropriately asked, sexual orientation, gender and trans monitoring.

Recommendations for service providers include that they should receive LGBTQ affirmative practice training, for an LGBTQ 'kite mark' for older people's services to be developed and intervention to prevent social isolation and loneliness.

7.5.3 People with learning disabilities and MLTCs

Money Advice Plus provided evidence of their clients with learning disabilities and multiple other conditions / issues requiring extra support. Seventy five percent (59 people) of those with learning disabilities that they supported in 2017/18 had been identified as vulnerable to financial abuse and in many cases support with money was part of a protection plan.

7.5.4 Mental health and MLTCs

In 2017/18 support with money was commissioned for 173 individuals with mental ill health in Brighton & Hove via Money Advice Plus. 60% had been identified as vulnerable to financial abuse, and in many cases support with money was also part of a protection plan.

Money Advice Plus highlighted how mental health problems can be a cause and a consequence of financial exclusion and that there is a strong association between debt and poor mental health. It is estimated that one in four people with mental health problems is also in debt. A report by the Royal College of Psychiatrists (RCPsych) found that the more debts people have, the more likely they may be to have mental ill health. The study also found that debt may have indirect effects on household psychological wellbeing over time, as it impacts on feelings of economic pressure, parental depression, conflict based family relationships, and potential mental health problems among children.

Guidance from the RCPsych¹²⁷ for primary care includes:

- Spotting problems
- Talking about it
- Referring to debt advice
- Providing medical evidence
- Prevention is better than a cure.

8. What works – evidence of effectiveness

This section outlines a review of the literature.

8.1 Prevention¹²⁸

Primary prevention aims to prevent people from becoming unwell in the first place through promoting and protecting their health and wellbeing to prevent people from acquiring long-term health conditions. Interventions include population based public health programmes, such as childhood immunisation or healthy weight, or the targeting of individuals at high risk of developing ill health in the future, such as supporting smokers to stop.

Secondary prevention aims to identify and prevent an existing health condition progressing. Cancer screening programmes are population level examples of where the cancer is detected and treated much earlier than it would otherwise have been, frequently resulting in improved health outcomes.

Tertiary prevention aims to help those with existing conditions regain as much autonomy and independence as possible. Examples include cardiac and stroke rehabilitation and supporting people with complex / long-term conditions to look after themselves and to stay in their own homes / the community.

To achieve a real impact on the population's health, and subsequent use of services, primary and secondary prevention interventions should be promoted to and adopted by as many of those who can benefit as possible.

With growing numbers of people being diagnosed with long-term conditions the effectiveness of secondary and tertiary prevention is an increasing priority.

The Director of Public Health Annual Public Health Report Brighton & Hove 2017 covers prevention initiatives across the life-course, providing the evidence for integrating primary, secondary and tertiary evidence across pathways and services.¹²⁸

A large study found that multi-morbidity is independently associated with a history of adverse childhood experiences,¹²⁹ demonstrating the psychosocial complexity associated with multi-morbidity which should be used to inform prevention initiatives as well as health care provision.

Research shows that it could be possible to reduce the number of people with LTCs developing mental health problems through effective approaches including promoting wellbeing in the workplace, providing debt advice and befriending interventions aimed at older people. These interventions can be effective and deliver a financial return on investment by reducing mental health needs.¹³⁰ People with LTCs could be a particular focus for interventions such as debt advice.

The role of community and voluntary sector organisations are significant as they often work at the intersection between individuals' mental, physical and social needs, including through the provision of support groups and peer-delivered services preventing further exacerbations.

Evidence has shown that particularly men and those without a partner with chronic depression may lose emotional and social support over time, becoming socially isolated and requiring professional attention to prevent this from happening and to support preservation of personal social networks.¹³¹

Primary prevention in people younger than 60 will improve the health of successive cohorts, however to reduce disease burden effectively primary, secondary and tertiary prevention is needed¹³² targeted at people across the life course from young to old.

8.2 Integrating mental and physical health

There is a strong body of evidence showing the effectiveness of improving outcomes and reducing health care costs by integrating mental health within chronic disease management programmes.⁵⁶ Referral to psychological therapy was associated with reduced department attendance¹³³ and psychological interventions in hospitals and other settings reduced length of stay by on average 2.5 days and overall health care costs per patient by approximately 20%.¹³⁴

It is not sufficient to treat a co-morbid mental health problem by itself, integrating mental health and physical health needs can result in more significant effects, rather than overlaying mental health interventions on top of existing treatment protocols. Integrated ways of working with collaboration between mental and physical health professionals improve outcomes the most.¹³⁵ There is also evidence that the costs of including psychological or mental health initiatives within disease management or rehabilitation programmes can be more than outweighed by the savings arising from improved physical health and decreased service use.¹³⁶ However research has found that nurses didn't necessarily feel that they could have conversations about depression or mood, or weren't equipped in providing depression care management with older patients.^{137,138}

Evidence shows effectiveness in terms of outcomes and costs for the following integrated approaches⁵⁶:

- Adding psychological component to pulmonary rehabilitation programmes improves completion rates and reduces re-admission. In Hillingdon Hospital this led to 1.17 fewer A&E presentations and 1.93 fewer hospital bed days per person in the six months after intervention. In addition, tailored CBT reduces anxiety in COPD resulting in better self-management, reducing exacerbations and unnecessary admissions.
- A disease management programme to allow people with cardiovascular disease and bipolar disorder to self-manage their psychiatric and medical condition. This was more effective than standard care in slowing the decline in physical health and similarly, psycho-educational interventions have shown to reduce angina frequency and medication use.
- CBT-based interventions to improve treatment adherence, psychosocial adjustment, coping skills and quality of life for people with co-morbid long-term conditions, as well as reducing use of health care services.

Collaborative care arrangements between primary care and mental health specialists can improve outcomes. In addition, liaison psychiatry demonstrates that providing better support for co-morbid mental health needs can reduce physical health care costs in acute hospitals.

Research shows that collaborative care that incorporates low intensity psychological therapy delivered in partnership with practice nurses in GP practices can reduce depression and improve self-management of chronic disease in people with mental and physical multi-morbidity.¹³⁹ A study of a GP practice based collaborative care model found that patients and professionals valued an integrated approach, as it enhanced a coordinated and holistic way of working, but their preference was for there to be spatial and therapeutic separation between mental and physical health. Patients particularly valued space outside of the LTC clinics to discuss their emotional health problems.¹⁴⁰ Care models need to be flexible and patient-centred.

Collaborative care is a form of systematic team-based care that includes: a case manager responsible for the coordination of different components of care; a structured care management plan, shared with the patient; systematic patient management based on protocols and the tracking of outcomes; delivery of care by a multidisciplinary team which includes a psychiatrist; and collaboration between primary and secondary care.¹⁴¹

Care for people with multiple long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.⁵⁶ Active case-finding among people with LTCs may therefore be needed to improve detection, in line with NICE guidelines, e.g. for COPD.¹⁴²

Screening for geriatric depression should be considered in residential care settings using scales most effective for the patient.¹⁴³ In addition a systematic review found that antidepressant medication treatment is less efficacious in treating less severe depression in older adults and therefore minor depression should be treated initially with a non-pharmacologic intervention.¹⁴⁴

8.3 Dementia

Moderate to severe cognitive impairment was found to increase the risk of mortality and was associated with prolonged institutional stays and decreased function in individuals with multiple chronic conditions.¹⁴⁵ However, notably there wasn't a relationship between cognitive impairment and the use of cardiovascular or hypertensive medications for persons with these comorbidities.

People living with dementia and comorbidities are less likely to receive the equivalent level of care for similar conditions than people living without dementia, due to delays in the recognition of new or exacerbating symptoms.¹⁴⁶ One report found six discrepancies in health outcomes for people with dementia and comorbidities¹⁴⁷:

1. Atypical symptoms
2. Communication difficulties and failure by the health system to recognise the individual as a whole
3. A knowledge gap of hospital staff and carers
4. Poor medical management
5. Lack of support to aid self-management
6. Poor monitoring of comorbidities by health professionals

There are significant financial implications of mismanagement of dementia. Mismanagement includes late or no diagnoses of depression, diabetes or urinary tract infections (UTIs) and patients not receiving the same help to manage these comorbidities which means that dementia progresses more quickly. This, in turn, leads to greater estimated health and social care costs for dementia plus depression, diabetes and UTIs to be a net loss of £994.4million annually in the UK.¹⁴⁷

Nationally, it is estimated that a quarter of hospital beds are occupied by people with dementia aged over 65 years at any one time. Dementia is unlikely to be the primary reason for admission for the majority of people and data on it as a secondary condition may not always be recorded.¹⁴⁸

The top five reasons why carers report a person with dementia is admitted to hospital are: following a fall (14%); broken fracture hip or hip replacement (12%); urine infection including urinary tract infection (9%); chest infection (7%); or stroke/minor stroke (7%).

People with dementia tend to do poorly in acute hospital settings and hospital admission can result in adverse outcomes²³²; cognitive impairment results in a reduced threshold for sensory overload and distress which can lead to disruptive behaviour.^{149,150,151}

Dementia can also be a significant barrier for paramedic staff and clinicians in A&E; confusion resulting from dementia can contribute to inaccuracies in the medical or medication history and history of the present illness, and an individual's ability to comprehend or follow discharge instructions; 'Diagnostic shadowing' can also occur, when multimorbid conditions mask symptoms of dementia or vice versa.²³² This can lead to adverse clinical outcomes^{232,152} and if admitted for inpatient hospital care, older people with multimorbidities including dementia have the highest readmission rates and highest rate of long-term care use after discharge.^{232,153,154}

Given the strong association between dementia and other health needs, statutory services should be organised to treat multi-morbidity as the norm rather than as an exception. However, often, services treat illnesses in isolation from one another. This treatment of disease within separate silos of specialisation is a barrier to diagnosis, management and support, including the following key issues:⁷⁵

- commissioners lack the data on people with dementia and comorbidities that would allow them to commission integrated, personalised services
- reviews of care for people with multiple morbidities in general practice often only consider one health condition
- clinicians' lack guidance around how to prescribe medicine to people with multiple morbidities
- the Care Quality Commission, the health and adult social care regulator, inspect individual providers rather than care pathways.¹⁵⁵

8.3.1 Continuity and person-centred care

Studies show there is a lack of continuity in health-care systems for people living with dementia and comorbidity with little integration or communication between different teams and specialities and people living with dementia having poorer access to services.¹⁵⁶ Examples of good practice tend to be about the behaviour of individual

practitioners rather than system-based approaches.¹⁵⁷ More of a focus on improving quality of life, independence and patient and carer priorities is required.¹⁵⁸

People with dementia and comorbidities need to receive better quality, more flexible, holistic care that recognises that a diagnosis of dementia affects the management of other long-term conditions. Action is required in the following areas: to improve risk reduction, holistic annual reviews, new guidance for medication management, better collaboration across specialities and organisations and better joined up commissioning and regulation of care pathways as well as providers.^{159,160}

8.4 Integrated care and care coordination

A robust review (2018)¹⁶¹ reported that a common integrated care model for people with MLTCs in primary care is the Guided Care Model.¹⁶² It aims to be a proactive, comprehensive model of care which improves quality of care, patient's access to care and their capacity for self-care. It includes comprehensive assessment, individual care planning, monitoring, coaching, self-management, education and support for caregivers, coordinated transitions between providers / sites, and access to community services. The review found that the five elements of integrated care most often identified in the literature were person-centred care, holistic assessment, self-management, integration and coordination of services and collaboration.¹⁶¹

The term 'coordinated care', like 'integrated care' does not have a universally recognised definition; the two terms are often used interchangeably.¹⁶³ Both care coordination and integration are relevant to patients with chronic and complex medical conditions who may find it difficult to navigate a fragmented care system.¹⁶³

A large systematic review found that care coordination strategies with older adults significantly improved outcomes, in this case these included: depressive symptoms for patients with depression and COPD plus patients with cardiovascular disease and diabetes; reduced HbA1c levels but not mortality.¹⁶⁴ It improved functional impairment in patients with arthritis and depression, and with diabetes and depression; improved cognitive functioning in patients with diabetes and depression, and heart failure and COPD. It also showed increased use of mental health services in those with diabetes plus either cardiovascular disease or depression.

The Kings Fund published a review of five different coordinated care programmes across the UK; the problems outlined included lack of GP engagement, inability of the wider health system to see innovation as 'core business', a lack of integrated IT systems and problems caring for people in remote rural locations.¹⁶⁵ Factors which facilitate a move towards patient centred care include local leadership and commitment; a clearly defined vision of what better patient care looks like; being able to react flexibly to patients' changing needs; and investment in supporting carers and 'low-level' community support services. The following design features appear to facilitate successful care coordination: a holistic focus which supports patients and carers; building community awareness and trust in care coordination programmes; effective communication based on good working relationships between members of the

multidisciplinary team (MDT); localised design of care coordination programmes; and integrated health and social care commissioning.¹⁶³

Investment and professional support is found to be crucial for the role of the care coordinator and that they have the requisite skills and competencies to act as a care professional to the patient and exert authority among other care professionals to ensure multidisciplinary care plans are implemented successfully.

The House of Care model¹⁶⁶ was developed to try change the way the NHS manages long-term conditions, based on five pillars of empowered patients and person-centred, coordinated care; engaged informed individuals and carers; partnership working and professional collaboration; commissioning; and organisational and clinical processes. It is based on recognition that there has been a failure to provide integrated care around the person. Barriers to effective care for people with long-term conditions include:

- Single condition services
- Lack of care coordination
- Lack of attention to the impact of mental health
- Fragmented care
- Lack of informational continuity
- Reactive, rather than predictive services
- Lack of care planning consultation.

The model differed from others in two important ways: 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.¹⁶⁷

8.4.1 Multidisciplinary working

A strong, appropriately skilled, multi-professional team is one of the most effective ways of delivering holistic, longitudinal care to patients with MLTCs.²⁰ The development of new professional roles, such as a dedicated clinician to take responsibility for care coordination¹⁶⁸ for each patient could improve communication and clarify lines of responsibility. Primary care physicians are well placed to take on this role, although geriatricians may be most appropriate for frail elderly patients with predominantly physical disorders.²⁰ For current care professionals, development of multidisciplinary guidelines for patients with MLTCs, as well as electronic decision support systems to support patient-centred care are needed. Decision support systems should be integrated into information systems to be used by multiple care professionals in order to enhance collaboration and care coordination.

8.5 Self-management

Self-management aims to equip individuals with knowledge, skills and confidence in order to change behaviour to improve their health, thus improving how they manage crises, reducing their need for services and unplanned care. Self-management includes: education for patients and carers tailored to their existing knowledge and beliefs; psychological strategies to support adjusting to life with long-term conditions; practical support tailored to the specific condition(s) or issue; support to self-manage specific

clinical tasks; strategies to improve adherence to medication; social and psychological support; and action planning for conditions where risk of deterioration is high.^{169,170}

Evidence shows that self-management can improve quality of life and reduce healthcare use.^{171,172} This relates to improvements in health outcomes for diabetic, respiratory, cardiovascular and mental health patients with consistent, though small, reductions in hospital use and costs in respiratory and cardiovascular patients.^{173,170}

Self-management programmes may have different aims for different conditions: in respiratory and cardiovascular conditions the aim may be to reduce unplanned admissions, whereas for diabetes it may be to increase engagement with services. The use of self-management to reduce demand may be limited, where use is not patient-led but a result of the way services are delivered (such as requiring attendance at appointments),¹⁷⁴ or where usual clinical practice does not involve utilisation of secondary care (for example in the management of depression).¹⁷¹

Implementation requires a whole-systems approach which intervenes at the level of the individual, the healthcare professional and the organisation. Support for self-management is often provided by specialist nurses, as well as therapists, physicians, pharmacists, and in some cases lay-educators / mentors.¹⁷⁰

NICE Guidelines on Older People with Social Care Needs and MLTCs provides recommendations for supporting self-management.¹⁷⁵ These include: providing individuals with information about services to help them manage their lives; increased focus on medicines management (such as regular medicines review and follow-up, improving information sharing on changes to medication and ensuring social care practitioners report concerns about medicines to the care coordinator and healthcare practitioners); and improved diagnosis, treatment and provision of information about incontinence.¹⁷⁵

Integrating mental health interventions within physical health care can exploit synergies between mental and physical health care regarding self-management approaches for long-term conditions and can avoid the tensions between different treatments.¹⁷⁶

Without this, there is a risk that treatments for one disease may worsen another; for example, use of some psychotropic medications can lead to significant weight gain and further cardio-metabolic complications. Despite this, integrated approaches are currently the exception. The evidence tells us that people with co-morbid mental health problems can gain particularly large benefits from inclusion in self-management support programmes, suggesting that they should be targeted for referral.¹⁷⁷ Peer support is also shown to empower people with multiple morbid mental health conditions.

Effective self-management interventions are multi-faceted, tailored to the individual's culture and beliefs and clinical needs, and underpinned by a collaborative and communicative relationship between the patient and healthcare professional, within a system that actively promotes self-management.¹⁷⁰

eHealth technologies can potentially address some patient-experienced challenges by promoting self-management and access, however as people's needs and preferences

vary, it cannot substitute personal interaction with professionals. Patient assessment and stratification is helpful to ensure appropriate use of eHealth.¹⁷⁸

Barriers to self-management include recruiting and retaining patients, particularly in deprived communities, work schedules, family commitments, lack of transportation, and the cost of medication and dietary changes, or avoided follow-up due to fear of not having achieved goals.¹⁷¹

Care must be taken for self-management approaches to be appropriate and not over burdensome for individuals.^{114,91,179} The approach should be about supporting patients to exert responsibility and autonomy and promote self-determination to lead purposeful lives via improved access to appropriate social and psychological support.¹⁸⁰

8.6 Carers

Much of the day-to-day care for people with MLTCs falls to caregivers as they engage in decision-making, monitor treatment adherence and coordinate care,⁸⁰ although there are few studies which explore their experiences. Existing studies found that most care givers were the primary organisers of care and their experiences reflected the problems faced by those with MLTCs, such as the difficulty of balancing multiple appointments with full-time employment; poor communication from and between multiple care providers, not knowing where to go for information about care and conditions; confusion over the role of different providers; long waiting times for appointments and feedback; and lack of support to make decisions about care, prioritise appointments and medicines, or manage people in their care who do not adhere to treatment.^{181,182} Lack of awareness of, or access to, available home and community support services, and disparities between the perceptions of people with MLTCs and their carers compared to providers in terms of goal setting and care planning are also reported.¹⁸³

As recognised by NICE Guidelines on Older People with Social Care Needs and MLTCs,¹⁷⁴ many carers of older people with MLTCs may have specific social care needs of their own which require referral, or people with MLTCs may also act as carers, but may not see themselves in that way. As such, it is important for local authorities and social care to identify and offer carers individual assessments of their needs, and provide support, such as with budget management or access to support services.

The evidence¹⁸⁴ tells us that:

- Health professionals may be in a unique position to validate carer's roles as carers and to encourage support seeking
- Greater focus on 'hidden carers' who support people to minimise the impact of illness on their lives in order to increase recognition of their role and more support seeking.

8.7 People with MLTCs' experiences, views and perspectives

Mental and physical multi-morbidity is experienced as moments of complexity rather than numbers of illnesses. Successful self-management of physical symptoms was contingent on the use of medicines, whilst emotional health was more commonly managed by engaging in behavioural strategies, albeit social or spiritual ones.¹⁸⁰

People with MLTCs report having worse experiences and more problems with hospital care than those with one or no long-term conditions.¹⁸⁵

A large meta-review of qualitative studies¹⁸⁶ shows that patients with chronic heart failure, COPD and chronic kidney disease and their caregivers' help seeking and decision-making are shaped by their degree of:

- Structural advantage: which includes socioeconomic status, geographic location and health service quality;
- Interactional advantage, including:
 - cognitive advantage: access to educational resources and information and understanding of disease and disease progression
 - affective state: relating to experiences of symptom burden and psychological responses to limitations on everyday activities and relationships that can lead to social isolation, loss of hope and fear of death
 - interaction quality¹⁸⁷: professional–patient relations, timing and type of information given
- Structural resilience: which is about adaptation to adversity, competence in managing care and caregiver responses to demands.

The review shows patients and caregivers value relationships and practices to mitigate the distressing effects and consequences of health status deterioration.¹⁸⁸ Interventions that seek to empower individuals may have limited effectiveness for those most affected by the combined weight of structural, relational and practical disadvantage.

Another qualitative review¹⁸⁹ looking at use of unscheduled care finds that patients with LTCs used unscheduled care when there was a pressing clinical need and in situations when they considered it to be the only option. For socially or economically marginalised patients, unscheduled care offers access to clinical or social care that was otherwise unavailable to them. Key themes from in relation to people's experience include:

- need for holistic care that includes physical and mental health and quality of life
- barriers to care in relation to service availability and delivery
- dealing with complexity regarding conditions and the way care is organised
- importance good professional communication and relationships
- a need to be able to manage their situation, have some control
- the significance that personal issues relating to logistics and financial strain can't be under estimated
- social connectedness
- dealing with lower mental wellbeing
- mobility – it's often ignored until it's a problem, support needs to promote maintenance of mobility particularly in healthy people.^{190,188,191}

Organisations need to ensure they are collecting insight from people beyond individual interactions with services, to collect people's experiences in order to augment routinely collected health and care data^{192,193} helping the system understand patients' views.

8.8 Assessment, management and support

In 2016 and 2017, NICE produced a set of guidelines that set out broad principles for the care of patients living with MLTCs.^{194,195} These cover topics including: the need to develop and deliver a tailored approach to patient care; understanding the significance of frailty in patients who have MLTCs; and the importance of reviewing medication. The guidelines do not attempt to make recommendations for every possible combination of conditions, or to cover the full range of circumstances that clinicians may encounter.¹⁹⁶ They provide overarching recommendations which focus on:

- Identifying patients with MLTCs, opportunistically through routine care and proactively using electronic health records, including identifying patients at risk of adverse events.
- Addressing polypharmacy, by using primary care records and identifying patients at higher risk of adverse events and drug interactions.
- Assessing frailty in community, primary and secondary care settings, using relevant tools. Use of validated tools is an important element of quality care. The Disease Burden Impact Scale questionnaire has been found to be a useful measure for assessing multi-morbidity from a primary care perspective as it's more predictive of health outcomes than simple count of conditions.¹⁹⁷ The Illness Perception questionnaire can also help to measure how people view their conditions and perceived priorities among conditions and their management.¹⁹⁸
- Agreeing an individual management plan with the patient, which: takes account of quality of life and treatment burden; patient needs, treatment preferences, health and lifestyle priorities and goals for future care; reviews medicines and treatments; establishes who is responsible for care coordination and how this will be communicated to all professionals and services; and arranging follow-up coordination and access to urgent care.
- Starting a comprehensive assessment of older people with complex needs at the point of admission, preferably in a specialist unit for older people.

In addition, interventions which target specific risk factors (such as treatment for depression) or interventions that focus on improving patients' daily functioning (such as physiotherapy treatment to improve physical mobility) are considered effective.

8.8.1 Primary and community health care

Evidence regarding the management of people with multi-morbidity located within primary and community care services shows improvements in health outcomes, moderate improvements in patient-reported outcomes, reductions in mortality and potentially improved patient-related behaviour and quality of care.¹⁹⁹

Much of the management of patients with MLTCs is undertaken in GP practices,¹¹ with GPs acting as a first point of contact with the healthcare system. GPs play a pivotal role in care coordination, ensuring patients with MLTCs receive holistic, person-centred care, and facilitating transitions between primary and secondary care.¹⁹⁶ The continuity of the relationship created through ongoing contact between patients and their GP is essential for people living with multi-morbidity.²⁰⁰

However, the increasing prevalence of patients with MLTCs places a large demand on GPs.²⁰¹ A disproportionate number of consultations are spent with multi-morbid patients, who have around 2.5 times as many consultations as patients without MLTCs.^{202,27}

Problems experienced by GPs managing patients with MLTCs include: insufficient consultation time;¹⁷ outcome frameworks and reimbursement focused on specific disease guidelines;²⁰³ difficulties communicating and coordinating with the required range of medical specialists; lack of guidance and training on how to manage polypharmacy;²⁰⁴ lack of clarity regarding who has overall responsibility for patient management. For patients, lack of information from GPs about their condition and treatment options was a significant issue.²⁰⁵ One study finds that patients more likely to report problems in primary care are those with multi-morbidity, symptoms of anxiety and depression, of younger age, in paid employment.²⁰⁵

In England (2013/14) the average consultation length was 9.2 minutes, which is insufficient to meet the needs of patients with multiple health problems.^{196,201} GPs have reported that short appointments can lead to amended or suboptimal care^{200,17,91,206} and needing longer with multimorbid patients to ensure that their care is effective.²⁰⁷

Reducing unplanned admissions necessitates better coordinated generalist care in the community, across both community and primary care.²²⁰ The involvement of multiple medical specialties, each emphasising their respective guidelines, can lead to fragmented care which is not patient-centred^{204,203} and can make communication between specialists, hospitals and GPs more difficult.²⁰⁸ GPs who modify their interpretation of disease specific guidelines may feel anxiety about potential conflicts with best practice or reimbursements linked to guideline adherence.^{91,203}

Reliance on disease specific prescription guidelines can also result in a large number of medications being prescribed to patients with MLTCs.²⁰⁴ It can be difficult for GPs to know how numerous drugs for different diseases will interact, which to prioritise, or who should take responsibility for screening prescriptions.¹⁷ Whilst the importance of eliciting patient preferences is widely acknowledged,²⁰⁰ GPs may find it difficult in practice^{203,209} and discussions of risks and outcomes may cause patients distress or anxiety.²⁰⁶

Care planning: There is evidence to show that personalised care planning improves physical and psychological health status and people's capacity to manage their conditions when compared to usual care and effects are greater when the intervention is more comprehensive, more intensive and better integrated into routine care.²¹⁰

Collaborative care planning²¹¹ includes shared decision making, proactive goal setting reflecting patient priorities and continuity of care with a named professional. Examples include Care Plus in Scotland, and the 3D Study in Collaborative Care. Goal setting should include people's priorities in life as well as clinical and functional goals.²¹² Using a goal-oriented approach including periodic comprehensive needs assessments, can improve the responsiveness of care to the medical needs, personal goals, resources and care preferences of patients.

Advanced care planning (ACP)²¹³: is found to be uncommon and primarily focused on specific documented tasks involving decisions about preferred place of death and cardiopulmonary resuscitation. Professionals find it challenging, it is unwelcomed by a substantial number of patients and it tends to be postponed until death is imminent. Currently, implementation largely ignores the purpose of ACP as a means of extending personal autonomy in the event of lost capacity. Attention needs to be paid to public attitudes to death and dying across culturally and diverse groups.

Action to improve care: Guidance and evidence recommends the following to improve care for people with MLTCs¹⁹⁶:

- **Increased consultation length** (using time freed up by more integrated working)²¹⁴ is associated with higher patient enablement³⁴ and more effective management of LTCs.^{17,206} For example The Deep End, Glasgow.
- **Medication reviews with GPs, pharmacists and patients** conducted as a discrete activity rather than part of the usual GP-consultation, this may prevent hospital admissions.²¹⁵ More complex reviews to be led by a clinical pharmacist.
- **Multidisciplinary teams** to improve integration between primary care, community health services and secondary care, ensuring comprehensive community care for the patient by including physiotherapists, medical assistants and district nurses; sharing information across multiple services e.g. from GP, GP out of hours services, emergency services, and clinicians conducting home visits, lab results, and discharge and outpatient letters.
- **Taking a holistic approach, including social prescribing** has been found to help strengthen people with MLTCs' resilience, resulting in more effective problem solving strategies.²¹⁶ It incorporates physical and mental health and social and economic factors.
- **Health information systems** which ensure access to comprehensive medical records are a prerequisite for effective multi-disciplinary team working, with records shared across GPs, secondary care and out of hours services. Advanced systems could highlight risks of multiple medications,²¹⁷ search for previous changes in medication²¹⁸ or prioritise the most important medications. E.g. Patient Online (an NHS England programme offering online services to patients); and STOPP START Medication Review Tool.
- **Use of Patient Activation Measures (PAM)²¹⁹ and other relevant tools** – PAM is a validated, reliable unidimensional scale that covers 1) the patient role is important, 2) having confidence and knowledge to take action, 3) taking action to maintain and improve health and 4) staying the course even under stress.

8.8.2 Secondary care

Patients with multi-morbidity have more than twice the number of hospitalisations than patients with single conditions.²⁰² Many of these patients are elderly; the majority (65%) of people admitted to hospitals in England are aged over 65 years, accounting for 70% of bed days,⁸² with demand for hospital care by the elderly continuing to rise.

Multi-morbidity in the elderly is highly prevalent, and hospitalised older people often present with multiple conditions,^{53,220,26,221,222} including mental, psychological and / or

social difficulties requiring coordinated care from different specialities.^{82,53} These patients are referred to as the 'complex elderly' or 'older patients with complex needs' and whilst there is no consensus on terms, they are intended to reflect the higher cost of care, need for multiple interventions / referrals and complexity of clinical profile.^{53,223,224}

There is large overlap in elderly patients who have multi-morbidity, those with complex needs, and those with frailty. However, while there are processes in place to identify frail patients, a gap exists in the identification of the non-frail but complex hospitalised elderly patients, often presenting high levels of multi-morbidity.⁵³ Multimorbidity amongst the elderly is associated with poorer outcomes, decreased quality of life, psychological distress, longer hospital stays, more postoperative complications, increased utilisation of hospital resources, higher cost of care and higher mortality.⁵³

Unplanned emergency care and hospital admissions: Unplanned hospital admissions are a particular problem amongst both people with MLTCs and the elderly. The higher levels of multimorbidity amongst elderly patients accounts for many of their unplanned admissions, however frailty and reduced functional status increase risk further.²²⁰ People with high levels of physical multimorbidity, mental illness and those living in deprived areas are also at increased risk of unplanned admissions.²²⁰

Amongst older patients, the main risk factors for presentation to hospital are perceived and actual poor health status, adverse drug reactions, previous hospital or A&E admission and lack of access to primary health care services.^{225,226} Within primary care, low continuity of care and a lack of timely access to services^{225,227,228,229} have also been identified as increasing the risk of emergency care utilisation by older adults.

Despite efforts to reduce emergency admissions in England, over the last 12 years the number has increased by 42% (2006/7 to 2017/18), from 4.25million to 6.02million; A&E attendances have also increased in the same period, though not as rapidly (by 13%).

There has been a particularly sharp rise in the number of emergency admissions for patients aged 85 or older and with multiple health conditions (increasing by 59% since 2006/07 for all people aged 85 or over²³⁰); driven by their increasingly complex needs. Over 60% of patients admitted to hospital in England as an emergency have multiple long-term health conditions; in 2015/16 a third of emergency patients admitted for overnight stay had five or more health conditions, an increase from 10% in 2006/07.

Older people with multimorbidities also frequently access 999 services, resulting in A&E attendance, with increased likelihood that they will then be admitted. The 'conversion rate' (proportion of A&E attendances arriving by ambulance that become a hospital admission) is very high in this patient group²³¹; this is reflected in the increase in the proportion of A&E attendances that are admitted to hospital: 29% in 2017/18 from 22% in 2006/07.²³⁰ When multi-morbidity includes dementia the risk of ambulance use, A&E and hospital admission are all increased, even when the condition is treatable in the community.²³² One study finds that patients most able to manage a mental health condition, as well as any physical health conditions, experienced 49% fewer emergency admissions than those who are least able to do so.²³⁰ This suggests there is potential to

reduce emergency admissions by improving the ability of patients with mental health conditions to manage their wellbeing.

Older patients with MLTCs stay longer in hospital once admitted.²³⁰ Hospitals have attempted to manage these and around a third of all emergency admissions are now zero-day stays (the patient does not stay overnight).²³⁰ Reductions in length of stay have been particularly dramatic for patients with MLTCs; patients with five or more conditions who were admitted overnight spent an average of 10.8 nights in hospital in 2015/16, compared with 15.8 nights in 2006/07; and the number of zero-day stays for these patients increased by 373%.²³⁰

Within secondary care, interventions could include a comprehensive assessment of elderly patients during admission that includes a flagging system to identify a critical level of multimorbidity to deliver a more informed care and discharge plan⁵³ and improved in-patient generalist care from geriatricians.²³³

A key to reducing emergency admissions is better management of conditions at home and via community and primary care services. Minor deteriorations, exacerbations or complications can all be dealt with at home or in the community as long as effective and timely access to responsive health and care services exist.²³²

Patients who were most able to manage their health conditions (measured using Patient Activation Scores) had 38% fewer emergency admissions than the patients who were least able to. They also had 32% fewer attendances at A&E, were 32% less likely to attend A&E with a minor condition that could be better treated elsewhere and had 18% fewer general practice appointments.²³⁰

Interventions to improve management of conditions at home include education (to improve knowledge, skills and confidence) and tailed support for self-management^{230,234}; this includes health coaching, self-management support through apps, social prescribing initiatives and peer support including via online communities.²³⁰ Other interventions found to reduce unplanned hospital admissions include:

- Early review by a senior clinician in emergency departments²³⁵
- Structured discharge planning,²³⁴ communication and continuity of care after discharge²³⁶
- Joined up working between health and social care²³⁷
- Active management of transitions between care to prevent re-admissions, including timely and accurate information, good communication between hospital and primary care physicians and a single point of coordination²³⁷
- Closer integration between general practices and other services²³⁷
- Improved patient experience of GP practices, including ability to see a preferred GP and the proportion of patients who find it 'very easy' to speak to somebody at their surgery on the phone.²³⁸

8.8.3 Social care

NICE have produced guidelines and quality statements regarding social care for older people with multiple long-term conditions.^{175,239} These set out recommendations

focused on identifying and assessing social care needs, and care planning (summarised below), as well as supporting the integration of health and social care planning, delivering care and preventing social isolation. The guidelines also include recommendations regarding supporting self-management and carers, which are explored in the other sections of this needs assessment. The recommendations on assessment of social care needs include:

- Making advice and information available at all times so that people can make informed choices and can access the right kind of support at the right time e.g. low level equipment to remain independent
- Involving the person and their carer when planning and undertaking assessments, and during assessments considering their strengths, needs and preferences, as well as telecare options available
- Recognising the needs of carers and the potential for their own social care needs, and considering referral to the local authority for assessment
- Referring older people with MLTCs to the local authority for a needs assessment; and considering referral or specialist clinical assessment by a geriatrician or old-age psychiatrist to guide social care planning, with a focus on improving wellbeing if admitted to nursing or care homes.

The recommendations on care planning for older individuals with multiple health issues and social care needs include coordinating care and planning care collaboratively by:

- Ensuring a single, named, care coordinator who should play a lead role in the assessment process, coordinate with health and social care services, ensure referrals are made and actioned
- Ensuring the person has the opportunity to be involved in their care and support, prioritise the care they need and have a summary of their life story included in their care plan. Where necessary it may be appropriate to involve an advocate or a more specialist mental health advocate (IMCA)
- Review and update care plans regularly (at least annually) and record the results
- Ensure care plans are tailored to each person and collaboratively created and include: medical, psychological, emotional, social, personal, sexual, spiritual and cultural needs, sight, hearing and communication, accommodation, environmental care, palliative, and end of life needs; health problems such as incontinence, chronic pain, and skin integrity; the help required for self-care and support to manage their own conditions; and leisure and social activities outside / inside the home, mobility and transport needs, and home adaptations.

8.8.4 MLTCs and the community and voluntary sector

Although the community and voluntary sector plays an important role in supporting people living with MLTCs, there is little focus on this sector in either NICE guidelines or academic publications. However, the sector is ideally placed to identify and support people in the community; they can provide a trusted and active presence, embedded within communities, and facilitate the integration and coordination of care.²⁴⁰

8.8.5 Continuity of care

As people with MLTCs transition between primary, community and secondary and social care, information can be lost and professionals may not be aware of the actions and decisions taken by those from other parts of the system. This risk can be reduced if primary, community and secondary care physicians and social care professionals collaborate to assess patients and plan their care. For example, GPs conducting geriatric assessments, and conduct individual discharge planning from the moment a patient is admitted to hospital.¹⁹⁶ Relationship continuity as well as continuity of care overall is important to prevent people with MLTCs from falling through gaps in care²⁴¹

NICE have produced guidelines regarding transitions between inpatient hospital settings and community care homes for adults with social care needs, which cover overarching principles, actions before and during admission and during discharge.²⁴²

Evidence suggests that the following components are critical for transfers of care²⁴³:

- Early discharge planning: For emergency care, robust systems to plan and manage discharge should allow discharge dates to be set within 48 hours
- A system to monitor patient flow to enable teams to identify and manage problems
- Multi-disciplinary / agency discharge teams, including community and voluntary sector: this should include coordinated discharge planning based on joint assessment processes and protocols, on shared agreement and responsibilities
- Discharge to Assess or Home First: Reducing delays in discharge assessments, by providing short-term care and re-ablement in people's home using step-down beds to bridge the gap between hospital and home
- Availability of a 7-day service improves the flow of people through the system and between health and social care
- Trusted assessors, who conduct holistic assessments, avoid duplication and speed up response times
- A focus on choice: early engagement with families and carers, based on a robust protocol
- Enhanced care in Care Homes: joined-up coordinated health and care services, e.g. by aligning community nurse teams and GPs with care homes and reduce unnecessary admissions to hospital and improve discharge.

The Department of Health and Social Care have published guidance on hospital transfer for patients in care homes, called the 'Red Bag' Initiative. The objective is to provide prompt, safe and efficient transfer of clinical care when a resident moves between a care home and other clinical settings, such as hospital or 'step up' or 'step down' beds. When a resident becomes unwell and is assessed as needing hospital care, care home staff prepare a dedicated Red Bag that contains standardised information about their general health, existing medical conditions, medication, and the current health concern, so that ambulance and hospital staff can determine the treatment needed more effectively. This pack stays with the patient throughout their hospital stay, when a copy of their discharge summary is placed in the Red Bag so that care home staff can access this information following discharge.

8.9 Care and nursing homes

Although there are differences in dependency, cognitive function, behaviour, nutrition, medication and use of services between nursing and residential care homes, residents of both are characterised by profound dependency and frailty.²⁴⁴ Thus the section below will present findings from both residential and nursing homes as a single section.

England, like elsewhere, does not have a specialty service for care home medicine, nor are specialised geriatric medical services routinely involved in provision. Instead, primary health care is usually provided by GPs and their teams, and community health services such as community nursing and physiotherapy.²⁴⁴ However, arrangements to provide health care to UK care homes could be improved and the incentive framework for GPs, QOF, does not provide for such a service.²⁴⁵

Multiple studies have found that people with MLTCs have significantly higher risk of becoming dependent on long-term care,^{246,247,248,249,250} with higher risk as the number of conditions increases.²⁴⁶ The presence of neurological conditions increases likelihood of a person becoming care dependent^{246,244}; other studies have also highlighted the role of cerebrovascular disease, arthritic and coronary heart disease^{246,251}; as well as other disorders such as depression, stroke and urinary incontinence.^{246,54,244} Frailty is a particularly common problem amongst care home residents.²⁵² Multi-morbidity is thus a defining feature of the care home population with a requirement for expertise in geriatric medicine that may be beyond that of some GPs.²⁴⁴

Multi-morbidity in nursing home residents is associated with increased hospitalisation and higher likelihood of A&E attendance;²⁵³ it is associated with up to a 79% increased probability of A&E attendance.²⁵³ The presence of physical and mental comorbidity did not increase likelihood of hospitalisation; the presence of mental ill health may be related to reduced communication skills leading to an under-recognition by staff of a condition warranting hospitalisation, or better recognition of mental-health disease related symptoms leading to better care, or the fact that staff may avoid sending people with dementia to the emergency department.²⁵³

Residents of nursing homes are characterised by use of multiple medications^{254,253,255} and an increased use of health care services,²⁵⁶ which increases their risk of adverse care outcomes.²⁵⁷ A review of medicines use in care homes found that residents were taking on average eight medicines; they documented a high proportion of errors (one or more) in medications (70% of patients); these were the result of prescribing, monitoring, administration or dispensing errors.²⁵⁸ Reasons for this included doctors who were not accessible, did not know the residents and lacked information in homes when prescribing; staff's high workload, lack of medicines training and drug round interruptions; lack of team work among homes, GP practices and pharmacies; inefficient ordering systems; inaccurate medicine records and prevalence of verbal communication; and difficult to fill (and check) medication administration.²⁵⁸ High rates of polypharmacy support a role for pharmacist facilitated medication review.²⁵⁹

Patients in care homes are more likely to be prescribed excess medicines, experience poor medicines review and experience a lack of patient centred care.²⁶⁰ NICE recommendations regarding review of medicines in care homes covers:

- sharing information about a resident's medicines, including when they transfer between care settings
- medicines reconciliation when a patient is transferred in
- ensuring that records are accurate and up to date
- identifying, reporting and reviewing medicines-related problems
- keeping residents safe (safeguarding)
- reviewing medicines (medication review)
- prescribing, ordering, receiving, storing and disposing of medicines
- self-administration of medicines
- care home staff administering medicines to residents, including staff training and competence requirements; this covers covert administration and giving non-prescription and over-the-counter products to residents.

Conducting medication reviews in care homes has demonstrated improvement in quality and reduced healthcare costs.²⁶¹ The NICE recommendations around medicines reviews indicate GPs should lead the process of ensuring a medicines review is occurring and identifying a lead. MDTs can include a pharmacist, community matron or specialist nurse, GP, care home staff member, practice nurse and social care practitioner; but the exact composition of the team isn't specified. They recommend what should be covered in the review but that the roles and responsibilities of each member and the frequency should be agreed locally. They found that the highest quality of care was achieved when GPs were present at MDT meetings reviewing medicines, but that the most cost-effective model was when GPs were absent and prescription interventions were made autonomously by clinical pharmacist prescribers.²⁶²

8.10 Polypharmacy and medicines management

Patients with multiple long-term conditions are more likely to experience polypharmacy, which can result in increased drug burden, problems with adherence, and increased likelihood of adverse events.^{5,6,8,9,24}

Reliance on disease specific prescription guidelines can result in a large number of medications being prescribed to patients with MLTCs.^{204,202} The number of medications increases with the number of conditions, with studies reporting a significant proportion of multi-morbid patients (between 20% and 42%) who take more than nine medications daily.^{64,263} Some polypharmacy is necessary, however it can become inappropriate when the medicine combination is hazardous because of interactions, the overall demands of medicines taking (pill burden) are unacceptable to the person, these demands mean the patient is less likely to adhere to treatment, and medicines are no longer indicated (for example prescribed to treat side effects of other medicines when alternative solutions are available to reduce the number of medicines prescribed).^{Error!}
Bookmark not defined.⁷⁹ However, as prescription guidelines are designed for single diseases, and many studies exclude patients with multimorbidity and polypharmacy, the appropriateness of many drug combinations is unclear.²⁶⁴

It can be difficult for GPs to know how numerous drugs for different diseases will interact, which to prioritise, or who should take responsibility for screening prescriptions.¹⁷ De-prescribing medications by GPs, if carried out without very clear communication, can be interpreted as withdrawing care.^{204,203,208} The burden of multiple medications in primary care can be compounded by certain patient characteristics, such as cognitive or memory problems, poor social support and finances, and low levels of motivation,^{200,17,91,265,266,206} which are likely to affect the patient's ability to understand and adhere to treatment.^{91,204,203,208,209}

The more drugs prescribed, the greater the risk of human error or adverse drug reactions.¹⁹⁶ One study found that adverse drug reactions account for 6.5% of hospital admissions, most of which are avoidable,²⁶⁷ with unnecessary money spent on medicines. Another found that the number of drugs prescribed was the best predictor of future outpatient visits and the second-best predictor of mortality.⁵²

Regular and structured medicines reviews are particularly important for multimorbid patients who experience polypharmacy; tools such as STOPP (a Screening Tool of Older Person's Prescription) or START (Screening Tool to Alert the Doctor to Right Treatment) are effective for rationalising medications according to person-centred, rather than guideline-based, priorities⁷⁹; however, how patients are identified for review, when reviews are conducted, which care providers participate in the reviews and how outcomes are communicated to different care providers are all critical detail in ensuring the reviews are effective.

NICE guidelines provide recommendations related to identifying, reporting and learning from medicines-related patient safety incidents: medicines-related communication systems when patients move from one care setting to another; medicines reconciliation and medication reviews; self-management plans; patient decision aids used in consultations involving medicines; clinical decision support; and medicines-related models of organisational and cross-sector working.

NICE Quality Standards on medicines optimisation outline resources and quality standards relevant to management of polypharmacy, including to:

- Give people the opportunity to be involved in decision making about medicines
- Give people who are prescribed medicines an explanation on how to identify and report medicines-related patient safety incidents
- Reconciled list of medicines for inpatients in acute settings within 24 hours of admission
- Ensure people discharged from care settings have a reconciled list of medicines on their GP record within one week of the practice receiving the information and before a prescription or new supply of medicines is issued
- Identify patients who would benefit from a structured medicines review
- Monitor medicines-related patient safety incidents to inform learning in the use of medicines.

NICE recommendations on multimorbidity and polypharmacy include broader recommendations, including:

- Develop and agree an action plan for multimorbidity and polypharmacy to inform local medicines optimisation strategic and operational plans
- Develop an individualised, person-centred approach to reviewing people with multimorbidity and polypharmacy.

8.10.1 Community pharmacy

The use of community pharmacy to support self-care is being not maximised.²⁶⁸ Priority in community pharmacy is given to dispensing activities, which is connected to the pharmacy contact. There is an opportunity to shift cost-effective support in pharmacies to a more patient-centred and proactive approach.²⁶⁹

9. Service provision

This section covers key services in the city in respect to the prevention, care, treatment and support of people with multiple long-term conditions (MLTCs). It is not possible to include all services, but those with a particular focus / interest on MLTCs are included.

9.1 Prevention

Many of the services aimed at preventing MLTCs will not focus on a particular LTC and will address risk factors for multiple conditions. The list highlights key programmes delivered across the city, in communities and with individuals. More information is included on health trainers, the GP practice alcohol service and social prescribing.

- Healthy Child and public health schools programme
- Ageing well
- Dying well
- Falls prevention
- Health trainers
- Weight management
- Physical activity
- Cancer prevention and awareness
- Smoking cessation and tobacco control
- Alcohol and substance misuse prevention, treatment and support
- Sexual health
- Social prescribing – community navigation service
- Healthy living pharmacies.

9.1.1 Health Trainers²⁷⁰

Health Trainers are based within the Healthy Lifestyles Team at Brighton & Hove City Council. They use behaviour change techniques to support, encourage and motivate people to adopt healthier lifestyle behaviours including a healthy diet, stopping smoking, increasing physical activity, drinking less alcohol and accessing other support services in the city. These interventions are delivered in both clinical and community settings. Health Trainers are able to see people on a 1-2-1 basis and the service is free and confidential. The programme is effective in addressing health inequalities and changing behaviour, including effectively targeting clients in the most deprived areas of the city. Most clients access the programme to improve their diet and increase their physical activity. In practice, clients learn lifelong skills that help them tackle multiple risk factors.

9.1.2 Alcohol service in GP practice cluster 1

The Cluster 1 (see section 9.2.1) Locally Commissioned Service (LCS) Alcohol Liaison Nurse Service provides an expanded practice based service to people with alcohol issues, provides advice and support to practice staff, including screening, all of which reduces repeat presentations at A&E. The service works with:

- All the GP practices across Cluster 1 and the A&E nurses at the Royal Sussex County Hospital to take referrals of patients with alcohol issues.
- Pavilions, the local adult substance misuse service provider, to signpost and refer patients and other local and national services if needed.
- Adults, contacted initially mainly by phone, to offer them advice and support and brief or extended interventions as required.

- Practices to ensure adequate screening of those with alcohol issues is conducted
- Practice staff - to update knowledge and understanding around alcohol issues.

The target population for this service is individuals attending A&E with an alcohol related admission. If they are contacted and have a brief intervention delivered, then it is likely that between 10-19% will reduce their drinking to safe levels for up to 48 months, delivering benefits to the individual, society and the NHS.

9.1.3 Social prescribing

Community Navigation GP practice programme: Impetus' Community Navigation Service provides a social prescribing service in conjunction with GP practices. Their workers are volunteers known as Community Navigators (CNs), many of whom have had a previous career in healthcare, social services, teaching or counselling. Volunteer navigators will take referrals from clinicians and practice staff, where there is identification of a social need which is beyond the scope of clinical care. CNs conduct a guided conversation and make supported referrals to (primarily) community and voluntary sector services / organisations. The top reasons for referral are social isolation (24%), low mood (14%) and stress (12%). Feedback shows improved wellbeing, resilience and independence as well as increased choice and reduced isolation.

Social prescribing within secondary care: Possibility People's Link Back Service provides social prescribing within secondary care, working to support people after discharge when they have been home for a minimum of a week. The service works with discharge services to identify those who may benefit; they are then visited at home and a guided conversation is conducted, from which referrals are made and support provided to access appropriate community and voluntary organisations / services and, where appropriate, community activities. The cohort of patients is generally older people (92% of service users aged 56 years or over and 67% of these 76 years or over).

9.2 Primary care

Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacy, dental, and optometry (eye health) services. This section includes services in GP practices and community pharmacy.

9.2.1 GP practices

There are 35 GP practices in Brighton & Hove, working together in six clusters each caring for approximately 30-50,000 people. GP practices provide care under the General Medical Services (GMS) contract and other contracts to provide generalist healthcare to the local population, which involves focusing on preventing illness, diagnosing, treating and managing conditions. GPs act as advocates, make referrals and enable their patients to access required care. The services that fall within the GMS are listed below.

Essential GMS services:

- Illness from conditions from which recovery is generally expected
- Terminal illness
- Chronic disease

- Advice and health promotion
- Referral to other services
- Primary medical services required in core hours
- Immediately necessary treatment of accidents or emergencies
- Consultation and, where appropriate, physical examination
- Making available treatment or further investigations as necessary
- Liaison with other health care professionals.

The Quality and Outcomes Framework (QOF) is the optional annual reward and incentive programme offered to all GP surgeries in England, detailing practice achievement results. It includes management of long-term conditions (<https://www.nice.org.uk/standards-and-indicators/gofindicators> and <https://qof.digital.nhs.uk>)

.GP practices in the city provide the following enhanced services related to adults with MLTCs:

| | |
|---|--|
| <ul style="list-style-type: none"> • Ambulatory Blood Pressure Monitoring • Alcohol screening • Alcohol support (Cluster 1) • Cancer • Chronic Obstructive Pulmonary Disease (COPD) • Community Dermatology • Diabetes • Drug Monitoring in Primary Care • End of Life Care • GP persistent symptoms (Cluster 1 and 6) • HIV • Injectable Medicines | <ul style="list-style-type: none"> • NHS Health Check • Phlebotomy • Serious Mental Illness • Smoking Cessation • Substance Misuse • Supporting Carers • Wound Care • Seasonal influenza and pneumococcal polysaccharide vaccination programme • Meningococcal - freshers vaccination programme • Shingles (catch up) vaccination programme • Learning disabilities |
|---|--|

9.2.2 Community pharmacy

There are 55 pharmacies (including one distance selling online pharmacy) in Brighton & Hove. The Pharmaceutical Needs Assessment (March 2018) concluded that the current number of pharmacies and pharmacists is sufficient to meet the needs of residents in the city. This is due to the proximity of pharmacies in the city and the increasing numbers of pharmacist roles (such as Better Care pharmacists – see section 9.3.3) and the numbers of non-medical prescribers, which supports increased access to pharmaceutical advice and support overall.

Community pharmacies provide services under the national contract which includes:

- **Essential services:** dispensing, repeat dispensing, disposal of unwanted medicines, promotion of healthy lifestyles, signposting, support for self-care and clinical governance
- **Advanced services:** medicine use reviews and prescriptions, new medicines service, stoma appliance customisation service, appliance use review service.

Locally Commissioned Services in pharmacies in the city include:

- Flu vaccination
- Stop smoking
- Sexual health: Emergency Hormonal Contraception, condom provision through the C-Card, Chlamydia screening and treatment
- Substance misuse: needle and syringe exchange and supervised consumption
- Intravenous medications within the community.

There are 28 locally commissioned Healthy Living Pharmacies (HLPs) across the city, providing advice and support to people to make healthy changes to their lifestyle. The health champions within HLPs engage with their local communities, provide opportunistic healthcare advice and brief interventions and signpost to NHS and local authority services. They receive quarterly training to develop their healthcare knowledge and form links with other health and social care providers in the city.

9.3 Medicines management

9.3.1 Pharmacist roles in the city

CCG Medicines Optimisation Pharmacists and Pharmacy Technicians provide:

- **Clinical medication review** - there is one whole time equivalent 'cluster' pharmacist (previously Better Care pharmacist) working within each GP Practice Cluster in Brighton & Hove to provide comprehensive clinical medication reviews (to assess the appropriateness, safety, and efficacy of medication) for patients at risk of hospital admission and to ensure medicines use is optimised. The team also undertake comprehensive medication reviews for nursing home residents with a focus on those who would benefit most - new admissions, recent hospital discharges, inappropriate polypharmacy and those who would benefit from a face-to-face discussion about their medicines to enable shared decision making, reduced pill burden and better outcomes. Appropriate prescribing is an essential part of this service, working closely with residents, GPs, care home nurses and community pharmacy with full read / write access to patient records with patient and GP consent. See also section 9.3.3.
- **Prescribing advice** – The team also assist primary care prescribers in achieving rational prescribing that maximises clinical and cost-effectiveness, minimises risk, and reflects national and local targets. Pharmacists lead on a number of prescribing projects, support the development of prescribing guidelines and provide advice on medication related queries from prescribers. Pharmacy technicians work in GP practices to assist the Medicines Management Team in implementing CCG prescribing initiatives in line with practice and CCG prescribing policies. In addition to: supporting prescribing projects and audits in individual practices; implementing changes and; liaising with GPs, practice staff and patients.
- **Consultant cardiac pharmacist** – This post is divided between primary and secondary care and leads on medicines optimisation for patients with cardiovascular conditions. Work is taking place with GPs and non-medical prescribers to improve the prescribing of anticoagulation to patients with atrial fibrillation, to reduce stroke risk and to improve management of hypertension.

In addition there are rapid response pharmacists and community health services pharmacists and pharmacy technicians in Sussex Community Foundation Trust and

specialist pharmacists and pharmacy technicians in mental health community teams (including dementia) and Sussex Partnership Foundation Trust.

9.3.2 Medicines optimisation in care homes

A medicines optimisation scheme is being launched in England, funded through the Pharmacy Integration Fund. This will be used to deploy pharmacists and pharmacy technicians into care homes, with the aim of targeting those who are prescribed too many medicines and to increase patient involvement in decisions about their medicines.

9.3.3 Cluster pharmacists

Cluster pharmacists identify high risk / frail patients using a number of established searches and criteria. This includes looking at the GP frailty list which uses the electronic frailty index (eFI) and using some polypharmacy indicators based on the SIGN polypharmacy guide. Other searches include:

- Patients on 10 or more medications
- Recent discharge from hospital with one or more changes to medication
- History of falls
- Significant changes to medication in the last three months i.e. \geq two changes including medication stopped / started / dose changed
- Renal or liver impairment
- Chronic illnesses causing recurrent hospital admissions or primary care contacts (e.g. heart failure, epilepsy, asthma, COPD, coronary heart disease, diabetes mellitus, Parkinson's disease, hypertension, rheumatoid arthritis).

Reasons for referrals to Cluster Pharmacists include:

- Struggling to manage medicines or unclear on indication for medicines
- Recent decline in patient daily activity or deterioration in condition
- Specific medication problems e.g. possible side effect(s), interaction(s), taking a drug with no obvious indication.

9.4 Dementia

There is a Dementia steering group chaired by Brighton and Sussex University Hospitals Trust (BSUH) to develop pathways to improve care for people living with dementia.

9.4.1 Memory Assessment Service

The Memory Assessment Service (MAS) is provided by HERE in partnership with the Alzheimer's Society, Carers Centre and Sussex Partnership Foundation Trust (SPFT). The majority of dementia diagnoses in the city are carried out by the MAS; however patients are also diagnosed by SPFT Specialist Older Adults Mental Health Service (SOAMHS) and BSUH.

The MAS provides a single point of access for people for whom there are concerns relating to cognitive impairment, in order to provide timely and accurate diagnosis and intervention for people with dementia. An initial care and treatment plan is delivered to those diagnosed and their carers, with access to support and information provided. This is time limited to one year post diagnosis. However dementia is a progressive long term condition and support is required from diagnosis to end of life for individuals and their carers. After one year patients should be discharged to the care of their GP for ongoing

monitoring and review. However, primary care data for 2016/17 suggests that only 68% of patients with dementia received an annual face to face review of their care plan, which may be due to insufficient resource in or aligned to GPs to provide this support.

The CCG benchmarked the local dementia pathway against NHS England and NICE dementia guidance in quarter 1 2018/19. This identified a number of significant gaps with regards access to referral to treatment for certain groups, care coordination, holistic regular review, advanced care planning and medicines optimisation. Where these elements are in place, availability is, at best, time-limited. Support and care coordination is available largely for those referred via the MAS and not more broadly.

There is no systematic means of diagnosing patients who reside in Care Homes (CH), although plans are being developed for this through the Enhanced Health and Care Home Locally Commissioned Service to be delivered by GP Practices, as it is thought that there is a significant number of people residing in the care home sector who are living with dementia, but who are not formally diagnosed.

9.4.2 Community and voluntary sector services for people living with dementia

There are a number of commissioned community and voluntary sector services for people living with dementia and their carers, which are mainly accessed by those who are newly diagnosed with dementia, but could be of benefit to people at varying stages of disease severity. The psychosocial interventions for people living with dementia currently include: support from the Alzheimer's Society providing Singing for the Brain, Living well with Dementia and Cognitive Stimulation Therapy, Brighton & Hove Food Partnership providing cookery and gardening, Hop 50+ providing dementia specific activities and Open Strings music therapy. A small number of physical exercise activities are micro-commissioned by the Dementia Action Alliance (DAA).

The DAA has ensured that Brighton & Hove is officially recognised as 'Dementia Friendly' and actively promotes Dementia Friends education sessions to health and care professionals and other public and private sector organisations. It has established a number of Dementia Cafes across the city as well as a nationally recognised D-Mob DEEP (Dementia Empowerment Engagement Programme), group which has become a strong independent focal point for people living with dementia.

9.4.3 Specialist Older Adults Mental Health Service (SOAMHS)

The service provided by SPFT is available for those with complex dementia related and, or additional mental health needs are referred. It includes an Enhanced duty team which provides rapid response and intensive support (for up to six weeks) to support a service user and family during periods of crisis.

Dementia Liaison Nurses embedded in the service have a specific focus in providing intensive assessment and support with care homes and Brunswick ward to prevent hospital admissions and assist transfers of complex care from the ward to care homes.

The Care Home In Reach Team works proactively with the whole care home sector to lead and drive improvements in quality of dementia care.

9.4.4 BSUH dementia provision

Dementia specialist nursing and consultants are based within BSUH. There are two specialist dementia wards, Emerald ward with 16 beds and Poynings with 8. The 'small acts of friendship' initiative focused on care of the elderly wards at Brighton provides activities and volunteer support for patients staying in hospital. Training has started in conjunction with the University of Surrey aimed initially at ward managers, nurses and those working in acute to help the initial transition in to hospital for patients with dementia. Sixty dementia champions have been recruited across multiple wards to provide additional support and projects for their ward areas.

9.5 Carers support

The Carers Hub²⁷¹ new model was launched April 2017 for carers of all ages. It is a partnership of three local charities and local authority assessment staff, who have joined together to create a focal point for unpaid carers to get information and support. It aims to improve the quality of life of carers in Brighton & Hove by offering them a wide range of services and comprehensive local resources:

- Information / advice / signposting
- Carers awareness training for professionals
- Carers assessments and support
- Young carers project
- Home-based respite to enable carers to attend health-related appointments
- Supporting carers who are caring for someone at the end of their life, and those who have been bereaved
- Peer support for carers
- Supporting carers of people with dementia
- Improving the well-being of carers through the carers reablement project.

9.6 Mental health

9.6.1 Primary mental health care

Brighton & Hove wellbeing service provides therapeutic support to people through our Increasing Access to Psychological Therapies (IAPT) service. The service provides different types of talking therapies if someone is experiencing mild to moderate mental health issues (depression, general anxiety and worry, panic attacks, social anxiety, traumatic memories and obsessive compulsive disorder). The support includes workshops and courses as well as guided online therapy and one to one support. Primary care mental health practitioners provide short-term support and Mind provides advice and information as well as advocacy services, participation and peer support and wellbeing projects.

9.6.2 Secondary mental health care

Sussex Partnership NHS Foundation Trust (SPFT) offers clinical and social care services to children, young people, adults and older adults, who have emotional and mental health problems or learning disabilities.

The trust supports people with conditions such as psychosis, depression, anxiety disorders, eating disorders, dementia and personality disorder and also provides

community and inpatient care for people with complex health needs that can't be met elsewhere (through the learning disability, neurobehavioural, forensic healthcare and Carehome Plus services).

SPFTs clinical strategy²⁷² covers the below objectives and service areas (there are also objectives relating to being the provider and employer and partner of choice and living within their means):

- **Safe, effective, quality patient care:** SPFT will treat everyone as an individual, focusing on their strengths and helping them with their recovery and wellbeing in a safety focused culture. Services include: Secondary care community and youth services; 24/7 crisis care; Acute inpatient services; Rehabilitation and services for older people and people with dementia.
- **Local, joined up patient care:** SPFT want to understand the needs of communities, work with service users, carers and partners to consistently provide good quality services. Services include: Access to care; Working with our communities; Integrated physical & mental healthcare; Wellbeing, recovery and discovery college and pathways of care.
- **Putting research, innovation and learning into practice:** SPFT learn from their research and innovative practice and ensure that this learning is embedded across the Trust. Services include: digital by design; pathways of care; using data and technology to improve care.

Assessment:

Following a referral to SPFT a person is assessed using the mental health clustering tool (MHCT).²⁷³ In this context a cluster is a global description of a group of people with similar characteristics as identified from a holistic assessment and then rated. As people's needs change over time, and over the course of their treatment, the payment system for mental healthcare must reflect the differing levels of input that are provided throughout changing and unpredictable episodes of care. In order to achieve this, people are not only assessed and clustered at the point of referral, but also re-assessed and re-clustered periodically.

The MHCT incorporates items from the Health of the Nations Outcome Scales (HoNOS), and the Summary of Assessments of Risk and Need (SARN), in order to provide all the information necessary to allocate individuals to clusters. HoNOS is an internationally recognised outcome measure developed to measure health and social functioning outcomes in Mental Health Services. The aim of the HoNOS was to produce a brief measure capable of being completed routinely by clinicians and recorded as part of a minimum mental health dataset. The first twelve items of the MHCT are HoNOS items. The Summary of Assessments of Risk and Need (SARN) was developed to aid in the process of establishing a classification of Service Users based on their needs so that appropriate service responses could be developed both at the individual and service level. It provides a brief description of the needs of people entering into Mental Health Services for the first time or presenting with a possible need for change in their care or treatment. It allows professionals from a range of backgrounds to summarise their assessments in a shared format. Thus it provides a common language for

describing health states and related social conditions and improves communication between different users of the tool including health and social care professionals, Service Users themselves, commissioners and researchers.

The clusters are:

| | |
|----|--|
| 0 | Variance – (unable to assign Adult mental health care cluster code) |
| 01 | Care Cluster 1 - Common Mental Health Problems (Low Severity) |
| 02 | Care Cluster 2 - Common Mental Health Problems (Low Severity with Greater Need) |
| 03 | Care Cluster 3 - Non-Psychotic (Moderate Severity) |
| 04 | Care Cluster 4 - Non-Psychotic (Severe) |
| 05 | Care Cluster 5 - Non-Psychotic Disorders (Very Severe) |
| 06 | Care Cluster 6 - Non-Psychotic Disorder of Over-Valued Ideas |
| 07 | Care Cluster 7 - Enduring Non-Psychotic Disorders (High Disability) |
| 08 | Care Cluster 8 - Non-Psychotic Chaotic and Challenging Disorders |
| 09 | Care Cluster 9 - Cluster Under Review - Note: This CARE CLUSTER is under review and should not be used. |
| 10 | Care Cluster 10 - First Episode Psychosis |
| 11 | Care Cluster 11 - Ongoing Recurrent Psychosis (Low Symptoms) |
| 12 | Care Cluster 12 - Ongoing or Recurrent Psychosis (High Disability) |
| 13 | Care Cluster 13 - Ongoing or Recurrent Psychosis (High Symptoms and Disability) |
| 14 | Care Cluster 14 - Psychotic Crisis |
| 15 | Care Cluster 15 - Severe Psychotic Depression |
| 16 | Care Cluster 16 - Dual Diagnosis |
| 17 | Care Cluster 17 - Psychosis and Affective Disorder (Difficult to Engage) |
| 18 | Care Cluster 18 - Cognitive Impairment (Low Need) |
| 19 | Care Cluster 19 - Cognitive Impairment or Dementia Complicated (Moderate Need) |
| 20 | Care Cluster 20 - Cognitive Impairment or Dementia Complicated (High Need) |
| 21 | Care Cluster 21 - Cognitive Impairment or Dementia Complicated (High Physical or Engagement) |

Health of the Nation Outcome Scales (HoNOS)

Care coordination: Under SPFT everyone is assigned a lead practitioner, depending on their needs they will be seen by a consultant and / or be supported by a multidisciplinary team approach. SPFT uses the data information system Care Notes to record people's treatment and support. Information is shared with the person, their carer and their GP. There is no formal data sharing system between the BSUH Royal Sussex County hospital and SPFT. On referral, medications for physical LTCs are included.

Physical health checks with those with mental illness: Health checks are carried out and part of a person's care plan and risk assessment. The care plans will include a carer's input and how a person's LTC is being managed and any support / treatment they are receiving their physical health conditions as well as mental health. All in-patients have a falls risk assessment, as well as physical health, transport and home environment assessments. Relevant assessments are shared with social care to inform support given.

Triangle of Care: The Triangle of Care is a therapeutic alliance between a service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing. SPFT works with the Carers' Trust to achieve better collaboration and partnership with carers as a service user and carer journeys through mental health services. Each team within SPFT assesses themselves using the Triangle of Care self-assessment tool. The six key standards for this are:

- Carers and the essential role they play are identified at first contact or as soon as possible thereafter
- Staff are 'carer aware' and trained in carer engagement strategies
- Policy and practice protocols re: confidentiality and sharing information are in place
- Defined post(s) responsible for carers are in place
- A carer introduction to the service and staff is available, with a relevant range of information across the care pathway
- A range of carer support services is available.

9.7 Integrated care

9.7.1 Integrated patient records

There are some local elements of integrated patient records for GP practices which use the clinical system TPP SystemOne. These practices can enable a sharing mechanism which combines the record with other services that use TPP such as SCFT and MSK.

9.7.2 Information sharing / IT infrastructure

All of the GP practices are part of the Sussex COIN network. This is an enabler to moving the practices onto the same domain / file environment which has the following benefits.

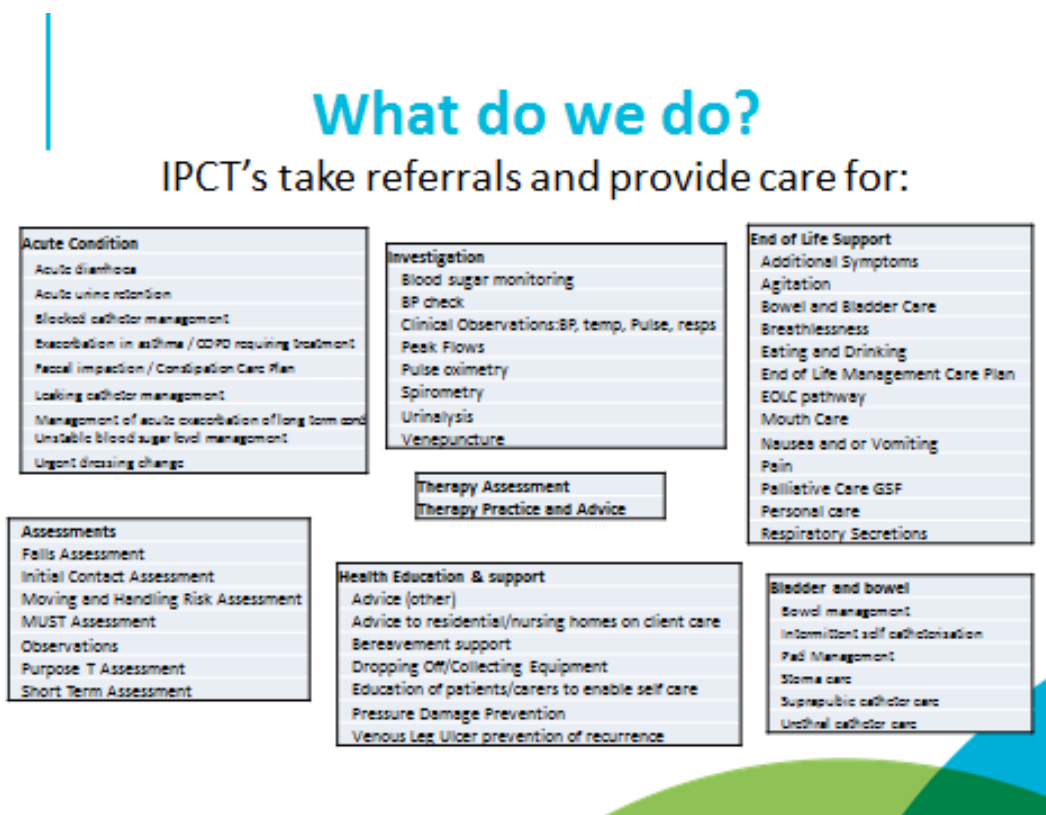
- Enables cross site working as one network account for all sites
- Improves business continuity
- Moving servers off site allowing better disaster recovery options as backups are done off site
- More first line fixes
- Access to password self-serve
- Ease of using Sussex Wifi
- Ease of using VPN.

9.7.3 Integrated Primary Care Teams (IPCTs)

The overall aim of the service is to provide care and support to housebound (either temporarily or permanently) patients with a Long Term Condition (LTC). IPCT's aim to facilitate proactive care, improve patient experience, deliver better health outcomes, reduce health inequalities and make better use of health resources. The teams aim to focus on predicting events and preventative measures for this cohort of patients. The teams provide care coordination for those patients identified with complex needs, in close partnership with existing services and other providers/agencies etc. as appropriate. The teams operate between the hours of 8am and 8pm; 7 days per week; 365/6 days a year.

The IPCTs are multidisciplinary teams working across the community and staffed with a skill mix to effectively manage people with long-term conditions. The teams are made up of: Operational Leads –Band 7, Clinical Nurse Leads -Band 7, District Nurses and Community Charge Nurses -Band 6, Staff nurses -Band 5, Band 3 and 4 unqualified therapy and nursing support staff, Occupational Therapists, Physiotherapists, Admiral nurses (In partnership with Dementia UK), Community Phlebotomists, End of Life coordinator and Continuing Healthcare Assessor.

The teams are also partnered with the Sussex Partnership Foundation Trust who provide two registered mental health nurses and with Brighton and Hove City Council Adult Social Care with social workers identified for each locality. IPCT's are based in five sites within Brighton & Hove. The below pictures illustrate the work of IPTCs:



Highlights- Activity

- Over 88,000 care plans completed over the last 12 months.
- Important to recognise that patients have multiple care plans.

| Category | Total Care Plans | Total Patients |
|------------------|------------------|----------------|
| Wound Management | 31609 | 1939 |

| Category | Total Care Plans | Total Patients |
|---------------------------|------------------|----------------|
| Medication Administration | 29636 | 1049 |

| | | |
|---|-------|-----|
| Pressure Damage Care | 5502 | 608 |
| Trauma Wound Care | 5126 | 523 |
| Leaking Leg | 1957 | 199 |
| Administration of injection - Insulin | 22132 | 191 |
| Administration of Injection Anticoagulant | 2088 | 64 |
| Administration of vaccination - Flu | 454 | 408 |

What do we do?

| Specialist Assessment |
|---|
| Advanced Nursing Physical Assessment |
| Anxiety Depression Assessment |
| Chronic Disease Review |
| Continence Assessment |
| Continuing healthcare assessment |
| Diabetic annual review |
| Equipment Assessment and Provision |
| Fast track assessment for continuing healthcare |
| Initial Therapy Assessment |
| Leg ulceration wound assessment |
| Mental Health and Wellbeing assessment |
| Mini Mental State Examination |
| Pain Assessment |
| Pressure relieving equip assessment and provision |
| Safeguarding Adults |
| Specialist Assessment COPD |
| Wound Assessment |

| Wound Management |
|-----------------------------------|
| Fungating Wound Care |
| General Wound Care |
| Leaking Leg |
| Leg Ulcer Care - Arterial |
| Leg Ulcer Care - Mixed Aetiology |
| Leg Ulcer Care - Venous |
| Moisture Lesion Care |
| Peritoneal Drainage |
| Pilonidal Sinus Care |
| Pleural Drainage |
| Pressure Damage Care |
| Surgical Wound Care |
| Topical Negative Pressure Therapy |
| Trauma Wound Care |
| Varicose Eczema Care |

| Medication, Treatment & Nutrition |
|---|
| Administration of Eye Medication |
| Administration of injection - Anticoagulant |
| Administration of injection - B12 |
| Administration of injection - Insulin |
| Administration of injection - Zoledex |
| Administration of injection GCSF |
| Administration of medication via syringe driver |
| Administration of PR medication |
| Administration of Topical medication |
| Administration of TPN |
| Administration of vaccination - Flu |
| Ear Care |
| Enteral Feeding (P.E.G.) Management |
| Medication Review |

Discharge from hospital

There are early supported discharge pathways aligned to the Community Neuro Rehab Team (CNRT) Stroke. However numbers remain very low. Red Cross supported discharge from BSUH across Brighton & Hove CCG and High Weald, Lewes and Haven CCG integrated pilot is currently in development for implementation this winter.

Home First pathway is available on 10 wards at Royal Sussex County Hospital, with the remaining wards having a mix of Discharge to Assess, Responsive Services, Community Nursing, Independence at Home and Hospital@ Home discharge pathways. There continues to be an increase of patients being discharged back home under both home first and discharge to assess principles. However patients are also discharged into the community beds and the Home First principles are applied on discharge home.

There have been on-going initiatives to roll Home First out across all wards across both Royal Sussex County Hospital and Princess Royal Hospital; however challenges remain relating to finances and home care hours. There are currently proposals and recommendations on the future of Home First.

There are 'step down' beds for people who are not yet ready to return home from hospital. Managing the capacity of the system to make these beds available is a challenge however professionals consider if it is done well, it could prevent readmissions to hospital. Consideration is required in terms of the types of service available as well including facilities that include for example hoists for lifting, addressing mental health needs, management of medications.

There is also a Community Navigation, Link Back service run by the voluntary and community sector to support frail older people when they leave hospital.

9.7.4 Interface between acute sector and primary care in/out reach

Primary Care streaming at the front door of the Emergency Department is in place at both Royal Sussex County Hospital and Princess Royal Hospital. Hospital Rapid Discharge Team includes social worker presence and Royal Sussex County Hospital has access to the Rapid Access Clinic for Older People (RACOP).

9.7.5 Hospital at home

Hospital at home is a joint partnership between Brighton and Sussex University Hospitals NHS Trust and Sussex Community NHS Foundation Trust which provides complex care in people's own homes. The services aim to get people out of hospital quicker and avoid further admissions to hospital. The service includes providing intravenous (IV) therapy and vacuum wound treatment.

9.7.6 Evaluations of services integrating care

This section provides an opportunity to share the learning from three evaluations of programmes that support people with MLTCs.

Proactive Care Pilot:

Proactive Care (PAC) was a model of care aimed at improving the identification and management of patients at risk of deterioration in independence and an avoidable hospital admission or care home placement. It was designed to improve the health outcomes for patients based on holistic and personalised care planning, case management, with a focus on self-management, early intervention and health and wellbeing. PAC was launched in NHS Brighton and Hove Clinical Commissioning Group (CCG) in April 2015 and ended July 2017. The evaluation reported April 2017. Key learning from the PAC pilot evaluation concluded that there were many successful elements of the PAC model that contributed towards better integrating care but that the cost and the lack of reduction of hospital utilisation meant the services needed to be commissioned in a different way. Key elements were that:

- Joint working with other professions was very beneficial
- Targeting of the top 1% wasn't necessarily cost effective
- The development of clusters had been very successful

- Goal planning using a de-medicalised Whole Person Assessment was an efficient way of supporting care planning
- A number of people had received good quality PAC support from a variety of professionals
- Contingency planning was very beneficial although some services weren't using them despite plans being available.
- Better Care Pharmacists had had a significant impact on patient's quality of life.
- Extended appointments with GPs was a very helpful option for some patients
- The risk stratification tool was found useful by some and not by others and the opportunity for informing more system wide provision was not realised
- Involvement of the voluntary sector was an important part of the model
- The care coach role didn't work for all
- Social prescribing was considered beneficial
- It wasn't feasible to implement Patient reported outcome measures.

Home First Pathway:

The aim of the Home First pathway is to enable the safe discharge to home of frail and elderly patients as soon as they are medically fit to leave hospital. The Home First scheme in Brighton & Hove was instigated by providers of services, who were keen to streamline the process so that patients could be discharged home in a timely way. These providers were Brighton and Sussex University Hospitals NHS Trust (BSUH), Sussex Community NHS Foundation Trust (SCFT) and Brighton & Hove Health and Adult Social Care Team (HASC). It was anticipated that the scheme would free up capacity on acute wards and enable people to resume their usual day to day activities at home, with the necessary support, as quickly as possible.

The Home First scheme was piloted by providers in Brighton & Hove on one ward at the Royal Sussex County Hospital (RSCH) from May 2016 and from January 2017, it was rolled out across seven wards until the end of June 2017 and by October 2018 was available in ten wards. The evaluation reported September 2017.

Areas identified as constraints to the current and future expansion of the Home First discharge pathway covered: identification for discharge, discharge process, patient information, transport, equipment, putting care in place, management, network, data collection, audit and expansion to all wards.

Good practice as part of the Home First pathway:

| Topic | Good practice |
|--|---|
| Identifying people eligible for Home first | Daily MDTs have been put in place on the acute ward and are a forum where patients eligible for the Home First pathway can be identified. A hospital HASC social worker attends most of the meetings. SCFT in-reach nurse supports acute ward staff to identify people eligible for the Home first pathway. |
| Discharge | A 'ready to transfer' form was developed by the Home First (DIG) in consultation with acute ward staff. This is part of the referral from the acute ward and contains information important to community services to assess support required. It was developed to be as short and as easy as possible for acute ward staff to complete. It has been |

| | |
|--|---|
| | referenced in the NHS England Quick Guide ⁵ to Discharge to Assess as good practice. |
| Transport | Use of the Red Cross transport service has worked very well for mobile patients. The Red Cross driver will settle the person at home and stay with them for 90 minutes making them a meal or drink if required. |
| Putting care in place | The Coastal Homecare ring fenced funding has brought some stability to the carers employed by the provider. Teams of two carers work 4 days on and 4 days off duty which means the person is likely to only see one or two carers during the time they are supported. This helps the carer build a relationship with the person and understand their situation and change in functioning. The daily virtual MDTs to discuss all people with an open Home First referral enables rapid action and decision making in response to changes in a person's functioning. |
| Management | The weekly Home First (DIG) meeting ensures that there is constant review of processes and an understanding of the pathway and how it is working. It enables rapid problem solving of issues as they arise. |
| Networking | There is a strong networking ethos amongst the providers of the Home First pathway and the Home first (DIG) proactively link with other teams and pathways in order to streamline the discharge process. Teams within provider organisations support each other across organisational boundaries when required. |
| Expand Home First to all RSCH wards and more complex patients | The Home First (DIG) are engaged and committed to widening the offer of the Home First pathway to more wards and more complex patients. |

Social prescribing and community navigation:

At the time of writing, an evaluation of the social prescribing model in the city and an evidence review is being completed. Key issues coming out of the evaluation is for the overall aims and objectives of the model to be clear; for the model to reflect and have capacity to respond to the needs and assets of people; the importance of cost effectiveness; refining the model in relation to other services; and balancing complexity, prevention and early intervention.

9.8 Mental and physical health

This section includes examples of services and interventions that integrate mental and physical health.

9.8.1 Serious Mental Illness (SMI) service in GP practices

All GP Practices in the city offer this Locally Commissioned Service (LCS) to adults. It is designed to give ongoing support and treatment in primary care, to those who no longer require the level of intervention previously provided by secondary care.

Participating practices provide: prescribing; monitoring and administration of medication; regular reviews; proactive follow-up; risk assessments and collaborative care planning.

The LCS is managed through a lead GP and Practice Nurse in each cluster and a lead practitioner in each practice. GP Practice staff are required to have ongoing training covering: serious mental illness; giving medication; physical health issues for SMI patients; prescribing; recovery care planning and having effective recall and follow –up systems.

The LCS has two levels. Level one patients are on the GPs’ SMI QOF register and can be managed in primary care, with an annual care plan and medical review. Level 2 SMI patients are very stable but still have recovery and support needs that require involvement of the SPFT Mental Health Liaison Nurse or are receiving depot injections from the GP in primary care settings. These patients receive biannual reviews

9.8.2 Pilot GP persistent symptom (GPS) service

The GPS is a two year pilot provided by the CCG and SPFT. It provides consultation, assessment and treatment pathways in primary care for patients with complex Medically Unexplained Symptoms (MUS). These are persistent physical symptoms where no clear medical cause has been found. The GPS provides an integrated team of 1.2 WTE psychiatrists and psychologists who are embedded in primary care and work closely with GPs.

The service is based at a GP Practice in Hove and provides a service to cluster 6 and one GP Practice in cluster 1. It currently has 18 patients on its caseload. Patients are only eligible for GPS if they are not being seen by another service. Patients are offered assessments over three sessions and are involved with the collaborative report that is given to their GP. “Check -in” sessions are also available three months after their final appointment.

So far the pilot has developed an integrated mental health and primary care team; made savings of £2,223 per patient; received excellent feedback from GPs and patients; developed links with secondary care specialists that want to introduce the bio-psychosocial model into their practice and provided a proactive and systemic response to a gap in service.

9.9 Secondary care

Secondary / acute care clinical services are focused on single conditions with exception of the department of Elderly Medicine. Much of the care for MLTCs happens through out-patient cardiology, respiratory, endocrine, orthopaedics, and ear, nose and throat departments. Below is a full list of secondary care clinical services relevant to adults with MLTCs:

| | | |
|--|--|---|
| <ul style="list-style-type: none"> • A&E • Acute Medicine Unit • Anaesthetics • Audiology • Bowel screening • Breast care • Cancer services | <ul style="list-style-type: none"> • Emergency ambulatory care • Endoscopy • Gynaecology • Gynaecology Assessment Unit • Haematology • Hepatology • HIV | <ul style="list-style-type: none"> • Ophthalmology • Oral and maxillofacial • Pain management • Palliative care • Pharmacy • Physiotherapy • Renal services • Respiratory |
|--|--|---|

| | | |
|--|---|--|
| <ul style="list-style-type: none"> • Cardiac services • Clinical Media centre • Day surgery • Dermatology • Diabetes and endocrinology • Dietetics • Digestive diseases • Ear, nose and throat • Elderly medicine | <ul style="list-style-type: none"> • Imaging (radiology) • Intensive care unit • Medical physics • Neurological • Rehabilitation • Neurology • Neuropsychology • Neurosurgery | <ul style="list-style-type: none"> • Rheumatology • Sexual health • Speech and Language therapy • Stroke • Trauma and orthopaedics • Urogynaecology • Urology • Vascular |
|--|---|--|

9.9.1 Rapid Access Clinic for Older People (RACOP)

The Rapid Access Clinic for Older People (RACOP) is to provide a person with a more comprehensive assessment during one longer visit to the hospital, rather than asking them to return to the hospital many times for multiple short assessments and investigations. The approach enables clinicians to look at all of a person's needs together and take them all into account when deciding the best course of treatment and care. This may involve a review of mobility and / or social needs, for example alongside a medical condition. People are seen order of priority according to need, following a referral. GPs, community nurses or hospital consultants make referrals to RACOP.

9.9.2 Admission avoidance

Admission avoidance pathways and initiatives are being developed in a joint initiative with multiple partners, BSUH, CCG, BHCC, South East Coast Ambulance Trust and SCFT. At the time of writing the work is focusing on:

- Homeless / No-fixed abode population
- Drug / alcohol related presentations (this may conflate with the homeless/ NFA group)
- Frail population who have multiple ED attendances and admissions (number to be determined)
- Patients with chronic respiratory disease – who may or may not be linked in with a community respiratory service
- Patients with complications of cancer, or have a suspected but not yet diagnosed cancer.

Work with South East Coast Ambulance Trust includes:

- New initiative for crews to view patient summary care records
- Use of care plans uploaded to IBIS, this is a trial happening with Charter Medical Centre GP practice
- Working with nursing homes, looking at data to support developments within nursing homes
- Audit – to look at alternative pathways to attendance at Emergency Departments
- 24/7 single point of access for community services (SCFT)

- Work with SPFT relating to crisis response services but acknowledge the gaps particularly in relation to mental health.
- Falls referrals to SCFT via the IBIS system.

9.10 Transport

There is a patient transport Service available across Sussex, provided by South Central Ambulance Trust.

9.11 Social care

Social workers often work with people at the most difficult times, when they are making decisions about how their care and support is designed and set up. They aim to work with the most vulnerable people and to be part of a larger support system encouraging independence choice and control. Social care provides support to people with multiple long-term conditions across multiple stages of their care, including:

- District and community social work teams supporting people with multiple health and social issues to continue living independently in their own homes and preventing emergency hospital admissions.
- Social workers can participate in multidisciplinary teams in GP practices and hospitals; developing communities of practice, which focus on coordinating support to people within a specific geographical area and improve communication and coordination if a person is hospitalised. Social workers can offer a social model approach and can promote a strengths-based approach as well as undertaking duties under the Care Act 2014, including leading on any safeguarding issues and issues pertaining to mental health.
- Triage assessment teams in A&E, for example through Prevention Assessment Teams (PAT). In Brighton & Hove this is called the Hospital Rapid Discharge Team (HRDT).
- Patient discharge assessments, through involvement in Multi-Disciplinary Teams and the Emergency Care Improvement Programme (ECIP). For example Home First / interventions to avoid delayed transfer of care and enable timely discharge.
- Supporting people in nursing and care homes, in particular ensuring that choice and control is exercised and that people have access to good financial advice as well as good quality of care.
- Supporting people with mental health needs, through dementia or mental health units.

9.11.1 Care and nursing homes

There are 26 Care Quality Commission (CQC) registered care homes with nursing in the city. These homes provide 24 hour nursing care. The majority of homes are independently run, there is a small number of local authority and NHS nursing homes.

There are 68 registered care homes for older people and people with dementia without nursing care. These homes have more beds for younger adults. Care homes provide 24 hour care and support for a range of client groups, including: Brain Injury Rehabilitation,

Dementia, Learning Disability, Mental Health, Older People (65+), Physical Disability and people with sensory Impairment.

9.11.2 Domiciliary care service

Domiciliary care service allows older people to stay in their own homes with support. Two-thirds of this service is provided by the independent sector and Brighton and Hove City Council's (BHCC) home care service called 'Independence at Home', provides a short term reablement service and supports an Extra Care housing scheme.

9.11.3 Extra Care housing services

BHCC is committed to providing alternative more cost effective housing options to enable people to live independently with dignity in their own home in a supported environment which enhances their quality of life. This includes developing alternative solutions for vulnerable adults. Extra Care Housing and Sheltered Housing are preventative services which enable people to stay in their community and maintain their independence for as long as possible.

9.11.4 Rehabilitation services

Reablement is a short and intensive service, delivered in the home, which is offered to people with disabilities and those who are frail or recovering from an illness or injury. The purpose of reablement is to help people who have experienced deterioration in their health and/or have increased support needs to relearn the skills required to keep them safe and independent at home. Reablement services are provided by BHCC at Craven Vale, Knoll House and Independence at Home

9.11.5 Shared Lives

Shared Lives is a CQC regulated service where individuals and families provide care and support to people who live with them in their family home. People using the service have the opportunity to be part of the carer's family and social network. The provision of Shared Lives reflects the national drive for more preventative, personalised, community-based care and support.

9.11.6 Supported living service

Supported living schemes provide personal care to people as part of the support that they need to live in their own homes. The personal care is provided under separate contractual arrangements to those for the person's housing. The accommodation is often shared, but can be single household. Supported living providers that do not provide the regulated activity 'Personal care' are not required by law to register with CQC. Supported living services provided by BHCC include Burwash Lodge, 92 Cromwell Road and 21 Ferndale Road.

9.12 Services for key clinical areas within the need assessment

This section includes details from single condition services of interest in this needs assessment; however there is insufficient detail included here to show how these services work across multiple LTCs. These services are shown as illustrative examples of single condition focused services.

9.12.1 Diabetes Care for you

Consultant led multidisciplinary team. Delivery care in community and primary care. Provides the care of adult service users with diabetes (18 years and over), who are registered with a GP practice from the Brighton & Hove and High Weald Lewes Havens CCGs. Delivers evidence based education for people with diabetes.

9.12.2 Bladder and bowel service

Services aims to deliver patient-centred care across the city, that is evidence based and provided within a quality framework, for patients with bladder and bowel problems and lower urinary tract symptoms (LUTS).

9.12.3 Integrated Respiratory Service

This service aims to provide an integrated respiratory service which improves health outcomes, is patient focused, strongly linked into the localities it serves and deliver a reduced use of unnecessary secondary care activity. The service provides rapid response to patients who are having an acute exacerbation to support their condition within the patient's home. There is a Home Oxygen Assessment and Review (HOS-AR) Clinic to assess, initiate and review use of oxygen by the patient in the home ensuring it is safe, cost effective and clinically necessary.

9.12.4 Community Neuro Rehab Service

This service aims to provide a city wide interdisciplinary, specialist neuro rehabilitation community service for those people who have suffered a recent acute stroke or subarachnoid haemorrhage, acquired Brain Injury or who have a chronic neurological condition. Providing rehabilitation, advice, social and emotional support to people and their carers. The service provides, for stroke patients, an Early Supported Discharge six day a week service with a minimum of 5 days a week therapy input. Adults with specific long-term neurological conditions, that includes:

- Multiple Sclerosis –either new diagnosis or acute, significant change in function
- Parkinson's Disease – either new diagnosis or acute, significant change in function
- Spinal Cord Injury
- Guillain Barré Syndrome
- Space occupying lesion (non-palliative)
- Inflammatory brain injury, e.g. meningitis, vasculitis, encephalitis, hydrocephalus.

9.12.5 Other services to highlight

The below lists other community services that focus on single clinical conditions:

- Chronic Fatigue Syndrome /ME Service (CFS/ME Service) - Sussex-wide
- Community Neurology Disease Nurse Specialists: Parkinson's Disease (PD) and Multiple Sclerosis (MS)
- Community Specialist Nurse / Practitioner (Motor Neurone Disease) Brighton & Hove
- Community Heart Failure Service
- Community Pharmacy Anticoagulation Monitoring Service (CPAMS)
- Community Intravenous (IV) Service

- Osteoporosis and Falls Prevention Service
- Tissue Viability
- Foot Health/Podiatry Service
- Wheelchair and Specialist Seating Service
- Orthotics Service
- Out of hours District nurse and night sitting service.

10. Recommendations

Here we present six key calls to action across Health and Social Care. Under these, there are specific recommendations.

Our findings chime with those from the November 2018 Health Foundation report *Understanding the health care needs of people with multiple health conditions*, which states that the NHS needs to have a clear focus on people with multiple conditions. The report suggests six key steps to improve care for this group which are similar to our calls for action: supporting those with multiple conditions to live well; developing new models of NHS care for those with multiple conditions; resourcing the vital role of primary care; designing secondary care around those with multiple conditions; using data and sharing information to improve care for those with multiple conditions; and evaluating what works.

10.1 Scale up primary, secondary and tertiary prevention across the life course

1. **Develop a one stop prevention referral pathway, including social prescribing**, for all health and social care services with services supported to actively refer. Social prescribing supports people to improve their health and wellbeing by connecting them to non-clinical community services. This needs to be considered in commissioning.
2. More capacity and training for staff to support **self-care and self-management** in primary, secondary, tertiary and social care. Self-management programmes and efforts must be tailored to the individual's culture and beliefs and clinical needs, and underpinned by a collaborative and communicative relationship with professionals. Care must be taken for self-management approaches to be appropriate and not over burdensome.
3. Social care to work more with those not meeting care thresholds to **support wellbeing**.
4. Multi-sector focus on addressing **social isolation and mental health and wellbeing**, including referrals to ageing well and other community and voluntary sector services to prevent social isolation by health and social care services.
5. Primary care to be supported to **identify people with, or at risk of, MLTCs**, opportunistically through routine care and proactively using electronic health records.
6. **Workplace wellbeing initiatives**, starting within the organisations providing care.
7. **Integrate primary prevention**, namely smoking prevention and stop smoking services, physical activity, weight management, substance misuse and alcohol across services. This can be through Making Every Contact Count to encourage all those who have contact with the people to talk about their health and wellbeing and active signposting.
8. **Strengthen secondary and tertiary prevention** in particular screening, early diagnosis, falls, cardiac, stroke and other rehabilitation
9. Adopt a more **person-centred approach**, tailoring support as appropriate and in a targeted way to adults with MLTCs.

10. **Continue to address polypharmacy and inappropriate prescribing** through proactive medication reviews and use of primary care records

10.2 **Integrate mental and physical health**

11. Increase and **strengthen training for the health and care workforce** in all sectors on mental health, to ensure that in all services mental health is prioritised alongside physical health. This is to specifically increase signposting and referrals to mental health (primary mental health care including increasing access to psychological therapies), wellbeing and healthy lifestyle services.
12. Inclusion of psychological / mental health initiatives **within disease management or rehabilitation programmes**. This is shown to be cost effective and results in reduced service use. Increase involvement of primary mental health and wellbeing services across health services.
13. Strengthen support across health and care services for addressing depression to enable people **to better self-manage conditions**. CBT-based interventions improve treatment adherence, psychosocial adjustment and coping skills. People with co-morbid mental health problems can gain most from self-management support programmes.
14. Health and social care services to be supported to strengthen work with the **community and voluntary sector** as they work at the intersection between individuals' mental, physical and social needs and provide support groups and peer-delivered plus other services preventing further exacerbations.
15. Develop a **check list for commissioning** of health and care services to ensure integration of mental and physical health.
16. Develop a more joined up approach to commissioning mental health / illness services **to avoid gaps in services** between primary and secondary mental health care.

10.3 **Focus on adults with multiple long-term conditions**

17. GP practices to be supported to **proactively identify those with MLTCs** who are not yet frail to prevent decline. A gap exists in the identification of the non-frail; however they too may be elderly, complex and often hospitalised. Proactive identification is also relevant for younger patients, particularly with mental health and substance misuse issues.
18. Frailty co-existing with MLTCs implies a significant level of vulnerability and therefore **proactive frailty services** in the community are needed.
19. **Support adults with MLTCs** to access support for prevention. For health and social care to be supported to prevent functional decline and frailty, maintaining a person's mobility. This can be through increased access to physiotherapy, other forms of appropriate exercise plus social interaction.
20. Many carers live with MLTCs, identifying **carers** is essential to increase access to support through the Carers Hub. Health professionals are in a unique position to validate carer's roles and encourage support seeking.

10.4 Target specific conditions, settings and deprived areas

21. **Proportionate universalism** to be applied as part health and social care commissioning and in contracts with providers –so that universal services are provided but with greater resource within the most deprived areas to address increased prevalence of adults with MLTCs in those under 65.
22. GP practices to be supported to conduct **holistic annual reviews** and facilitate better coordination across specialities.
23. Health and social care services to **enable trusted assessments** and **staff to share tasks** as appropriate, reducing duplication of effort and increasing support as required.
24. **Review access to community care and primary care services**, including transport, to ensure that care takes place in the most appropriate setting, to strengthen secondary prevention and reduce exacerbations.
25. **Early diagnosis of dementia** within primary care and care and support for people living with **dementia** to focus more on improving quality of life, independence and patient and carer priorities as well as prevention of exacerbations of MLTCs.
26. **Ensure access to palliative / end of life care** for people with MLTCs without cancer. Provision of palliative care beds within care homes is needed to enable those with MLTCs to receive better end of life care in the community.
27. Primary, community care and nursing homes to carry out **better Advanced Care planning** as a means of extending personal autonomy in the event of lost capacity.
28. Commissioners to review provision of **bariatric care**, in relation to health and care provision and mechanisms (e.g. beds and wheelchairs) for supporting those who are obese.
29. Review and develop **nursing home nursing workforce** provision and training.
30. Review the **role of geriatricians** in residential and nursing homes and community services.
31. Review capacity of primary care to **support adults with learning disabilities**.

10.5 Improve integration and care coordination

32. Senior leaders of all health and care commissioning and provider organisations to commit to giving permission to staff to focus on multi-sector relationships with the specific aim of improving health and wellbeing outcomes for adults with MLTCs. Aspirational intent to work together is needed; **integration is not transactional, it is about relationships and trust**.
33. **A strong, appropriately skilled, multi-disciplinary team** is one of the most effective ways to deliver holistic, long-term care to those with MLTCs. Commissioners and providers to look at ways of working together better across health and social care for all their conditions and with development of multidisciplinary **guidelines** for MLTCs.
34. Health and care providers to add **electronic decision support systems** within information systems to improve care for people with MLTCs.
35. **Continuity of care with GP practices is important, as well as quality interactions with professionals. Resource is required for longer**

- appointments** with appropriate clinicians in primary care for those living with complexity or with five or more long-term conditions.
36. Community care services and GP practices to have better **access to specialist advice** from secondary care and mental health providers.
 37. **Holistic personalised care planning** to be carried out by trusted, appropriate community care or social care professionals and embedded within GP practice systems. This improves people's capacity to manage their conditions and effects are greater when care planning is comprehensive, intensive and integrated into routine care.
 38. **Improve care coordination**, particularly for older adults, which significantly improves outcomes. Successful care coordination has a holistic focus which supports people and carers. Commissioners to invest resources in **the role of the care coordinator**. Providers to ensure that professional support is provided to ensure the role is effective.
 39. **Reduce unplanned hospital readmissions** through structured discharge planning and communication. This includes a system for secondary care to proactively identify and for primary and community care to review patients at high risk of readmission. For there to be a reconciled list of medicines on the GP record following discharge.
 40. **Review and develop a directory of local health and care services** to better connect different parts of the system.

10.6 **Improve data and information sharing and systems**

41. Commissioners and providers to review **sharing of information** between health and social care professionals and to facilitate information sharing to improve individuals' care, appointments, care planning, coordination, prevention and self-management and ensure health and care professionals have access to relevant information in a timely manner.
42. **Invest in commissioning and provider data systems** across health and social care to **enable linkage of non-identifiable data and information to improve evidence based commissioning of services and be able to evaluate programmes**.
43. **Invest in integrated data systems** across health and social care **to identify people with multiple long-term conditions** and prioritise them for proactive care.
44. **Better use of and recording of data** across health and social care (e.g. capturing appointments on GP practice systems). Training for professionals is required to improve data completeness and quality.
45. For data to be collected on **people's experiences** in order to augment routinely collected health and care data and for this to be provided alongside routine health and care data.

11. Appendices

See separate appendices

12. References

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