

Self-care in the context of living with Long Term Conditions:

A report focusing on Diabetes, COPD and Heart Failure, Mid and South Essex JSNA



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Health and Care
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Self-care in the context of living with Long term Conditions: A report focusing on Diabetes, Chronic Obstructive Pulmonary Disease and Heart Failure Mid and South Essex

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Author's note

Mid-way through the development of this paper WHO officially declared the COVID-19 pandemic. Due to lockdown and other disease containment measure taken in England, there was a significant impact on how all care services were delivered. This led to services being fully stopped, accepting only emergency cases, or suffering radical transformation such as a switch to only online delivery. Currently, patients with long term conditions have minimal access to all sectors of care, specifically for routine procedures, and self-care practices are becoming the norm. This report does not reflect these changes as the pandemic is still undergoing.

It is recommended that an update of the local context data and the service map is undertaken once the services across the system are stabilised.

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Abbreviations

A&E - Accident and Emergency

ASC – Adult Social Care

BMI – Body Mass Index

BP – Blood Pressure

BTUH – Basildon and Thurrock University Hospital

CBT – Cognitive Behavioural Therapy

CCG – Clinical Commissioning Group

CHD – Coronary Heart Disease

CMHD – Common Mental Health Disorder

COPD - Chronic Obstructive Pulmonary Disease

CPR – Castle Point and Rochford (CCG)

DALY – Disability-Adjusted Life Years

DoHSC - The Department of Health and Social Care

ECG- Echocardiogram

EPUT – Essex Partnership University NHS Foundation Trust

GBD – Global Burden of Disease Tool

GP – General practitioner

HDL – High-Density Lipoproteins

HF - Heart Failure

HLP – Healthy Living Pharmacy

HoC - House of Care

ICS – Integrated Care System

JSNA – Joint Strategic Needs Assessment

LAC – Local Area Co-ordinator

LDL – Low-Density Lipoproteins

LTC - Long Term Condition

MECC – Making Every Contact Count

NDA – National Diabetes Audit

NELFT – North East London Foundation Trust

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

NHS LTP – NHS Long Term Plan

NDPP – National Diabetes Prevention Programme

ONS - Office for National Statistics

PAM – Patient Activation Measure

PCN - Primary Care Network

PHE – Public Health England

PHM – Population Health Management

PR – Pulmonary Rehabilitation

QOF – Quality Outcomes Framework

QoL- Quality of Life

SES - Socioeconomic status

STP - Sustainability Transformation Partnership

WHO - World Health Organisation

YLL- Years of Life Lost

YLD – Years lost to Disability

Executive Summary

Increasing demand across the NHS and social care system in England, in both the number of patients and the associated cost of service delivery, can largely be attributed to: an ageing population; staffing issue; and, a rising number of people with long-term condition (LTCs).

In primary care, around half of GP appointments take place with patients with LTCs. High workloads are required to review and provide advice to these patients. When complications arise workloads increase further still, alongside the cost of treatment and use of secondary care services. In the last five years, there were large increases in A&E attendances per day and even larger increases in emergency admissions (10.3% and 24.2%, respectively over 5 years). Patients with LTCs account for a large proportion of this activity, with a sizeable number having multiple conditions - one in three emergency patients have 5 or more conditions (2015/16).

As a result of their use of services, the annual health and social care cost per year for a person with an LTC is three times higher than for a person without an LTC. This leads to 70% of the NHS budget being spent on patients with LTCs.

People with LTCs often struggle with daily activities. Social care provides a range of services supporting these activities, with the majority provided informally through individuals' family and friends. Adult social care is the biggest spend for local authority (£17.9 billion, 2017/18). Nationally, the demand for social care support is increasing, with up to 5,000 additional requests per day, but government spend is reducing. This could result in high financial pressures in meeting demand with high quality of care, and could potentially increase the number of informal care arrangements.

Self-care activities support improving the Quality of Life (QoL) and the health outcomes of those with LTCs, and thus could assist in reducing LTC associated demands and costs. However, they are not currently prioritised or sufficiently supported in the health care system. Given the growing demand, need for self-care therefore has begun to be emphasised in newer policies, such as: the *NHS Long-Term Plan 2019*, *Care Act 2014*, *NHS House of Care Framework* and *Public Health England's 2019 prevention green paper*.

In the *Theory of Self Care of Chronic Illness* 'self-care' definition is multifaceted and includes: self-care maintenance; self-care monitoring; and self-care management. Relevant behaviours to self-care include behaviours that promote health, reduce risks for illness and restore wellness. Additionally, the concept of patient activation, which describes the feeling of autonomy and control over health, is essential in understanding barriers and the best ways to support patients to self-care.

This JSNA provides an evidence-based review of local services to support the development and expansion of the self-care provision in the Mid and South Essex STP area, with a focus on three particular LTCs: Diabetes Mellitus (DM); Chronic Obstructive Pulmonary Disease (COPD); and, Heart Failure (HF). These are amongst the most prevalent conditions in England and have a significant impact on both individual's health and the sustainability of the system. Self-care activities are essential to maintaining good health when living with any of the three conditions.

Diagnosis and treatment of these LTCs happens mostly in Primary care. Our analysis shows that there is high gap between the number of people thought to have one of the three LTCs and the

number of people who are diagnosed. Interestingly, when it comes to COPD there is also a concern about over-diagnosing in certain areas, not just under-diagnosing. A common theme is that the prevalence and recording of these conditions varies greatly between the five CCGs within the STP and between GPs in each CCG. Moreover, being diagnosed by a care provider is not sufficient to receive the appropriate care. For example, in 2018/19 only about a half of registered diabetic patients were receiving all 8 care processes as recommended and in Thurrock only 21.6% of patients with COPD and severe breathlessness were referred to pulmonary rehabilitation. The lack of diagnosis, treatment or referral leads to a significant number of ill-health events, making a significant impact on utilisation of secondary care services.

The provision of specialised services outside of primary care comes across as fragmented and inconsistent. Due to services being delivered by different providers, there is a variability of programme structure and delivery across the footprint. For example, pulmonary rehabilitation services vary by offering additional benefits such as psychological support in certain areas. The heart failure services take place mostly in secondary care and seem to be the most consistent across the STP (this is due to the merging of the three main hospitals into the Mid and South Essex Trust).

While there is a wide range of services offered for people with the conditions discussed above, patients, carers and professionals alike identify a series of barriers that make it difficult to access or fully benefit from them. Barriers people face are across the continuum of self-care – from initial diagnosis (lack of advice on self-care or information on support groups and other tools such as online support or apps) to managing the condition and its effects on wellbeing (such as having to manage multiple medications and a lack of equipment or access to services). Moreover, factors affecting self-care do not act in isolation. Self-care should not be thought of solely at an individual level – family and community play a large role in encouraging self-care. A lack of social support highly impact on effectively managing the disease.

Issues identified throughout this report are of multivalent, hence should be addressed at different levels across the system: personal, local, regional and national level.

Six main themes were observed: services that contribute to self-care across the STP are fragmented and irregular (largely due to a lack of strategic direction across the patch); information is not readily available to patients, providers and commissioners (with issues due to lack of data collection and sharing); patients and primary care providers lack the capacity and skills to make the most out of their interaction; multimorbidity is increasing and needs to be addressed; the money is in the wrong place (with most of the funding going towards treatment in secondary care rather than prevention and support in the community); and self-care as a topic is in its infancy and evidence still needs to be developed.

To facilitate a coordinated effort to address these identified issues it is recommended that a joint strategy that aligns the prevention, early intervention and management agendas and addresses place-based barriers to self-care is developed at the STP level. Additionally, the development of a Task Force to include representatives from community care, the voluntary sector, primary care, public health, secondary care and social care could support addressing the variability of outcomes and integrating of local services. While the direction and quality standards have to be STP wide, it is highly important that the commissioning of programmes and delivery is co-produced with the affected residents, is built on local resources and matches the local picture.

Recommendations also focus on education and training of professionals. It is essential that professionals have a good understanding of what self-care is and how to support patients to practice self-care activities. Upskilling programmes in *Making Every Contact Count*, patient activation, coaching and motivational interviewing all empower staff to hold the difficult conversations needed to engage patients in programmes that can support them.

At the neighbourhood level there is an opportunity to pool resources to offer education and specialist support to patients that are harder to manage. Moreover, variation within the CCGs and PCNs reflect struggles that some practices might have locally. Building on other's successes and sharing best practice between these local practices can support with reducing the variation currently seen.

Lastly, patients can also be educated and empowered to use varied tools in their favour and make the most out of a meeting with a health professional. Patients and carers can and should share information and empower each other through face-to-face and online support groups.

CHAPTER 1

INTRODUCTION

The National Health Service (NHS) is facing increasing demand and year-round pressures across all levels of care. Secondary care, and in particular emergency care, is being badly affected with an evident increase in both the number of patients and the associated cost of treatment.

This increased demand is largely attributable to two factors: the ageing population and a rising number of people living with chronic conditions such as diabetes, cardiovascular disease, and depression (1; 2). Furthermore, the complexity of individual cases is increasing (2), with an estimated 2.9 million people in England in 2018 having multiple conditions, also called multimorbidities (3).

As a result, current health policy and research now places greater emphasis on the need for healthcare to adopt the principles of self-care as routine practice. The NHS' 'Long Term Plan' highlights the priority for people to have more control over their own health and personalised care when they need it (4).

Supporting people to self-care is vital and should be a key activity in our health and social care systems. For patients with long term conditions (LTCs) and multimorbidities, optimal outcomes and quality of life depend on engagement in effective self-care activities (5; 6). However, self-care is often not prioritised to the same

level as traditional medical interventions by professionals and the healthcare system. As a result, there is an apparent lack of emphasis on support and referral to services that can assist patients in maintaining or improving lifestyle behaviours or in self-managing their conditions (7).

1.1 Scope and purpose of the document

This Joint Strategic Needs Assessment (JSNA) focuses on self-care. It aims to provide an evidence base for the development and improvement of the care and the ways in which we support and empower patients to self-manage LTCs and their general health.

In line with the current NHS strategy and the Five Year Forward View, this assessment focuses on the local Sustainable Transformation Partnership (STP), Mid and South Essex Health and Care Partnership. This will allow for the report to influence system-wide priorities and contribute to the planning of more coordinated services.

As self-care practices span across numerous health and wellbeing domains, the assessment and recommendations of this paper are focused on three main long term conditions: diabetes, heart failure (HF) and chronic obstructive pulmonary disease (COPD). These have been identified to be of higher need and impact in the covered area

due to their complexity and increased effect on patients and the system alike.

1.1.1

Key question this JSNA will answer

1. What is the local picture in terms of demographics and LTC prevalence and outcomes? (Chapter 2, Section 2.1 to 2.4)
2. What is the support that patients with diabetes, COPD and Heart Failure receive to assist them with self-care? (Chapter 2, Section 2.5)
3. What is the patients' experience of coping with their LTC and what are the barriers to self-care? (Chapter 2, Section 2.6)
4. What does the evidence state should be provided in terms of self-care support? (Chapter 3)

5. What is the impact on services and population if no changes are made and how can we mitigate that? (Chapter 4)

1.1.2

Mid and South Essex STP

STPs join together local NHS organisations and Councils in a specified area to work on shared proposals to improve health and care for the rising number of people who need health services. The Mid and South Essex Health and Care Partnership is one of 44 STPs across the NHS in England and includes the districts and boroughs of Braintree, Maldon, City of Chelmsford, Castle Point, Rochford, Southend, Thurrock, Basildon and Brentwood (see **Error! Reference source not found..1**).

Figure 1.1: Mid and South Essex Map of STP



Source: <http://v1.nhsmidandsouthessex.co.uk/about-the-stp/>

1.2 Definition of self-care

Anecdotal data has shown that the meaning of self-care can differ from person to person. To standardise the understanding of what we mean by self-care in this report, we define it below.

Within this JSNA, the definition applied has come from the Theory of Self-care of Chronic Illness. This addresses both the prevention and management of chronic illness, with core elements of self-care maintenance, self-care monitoring, and self-care management (8).

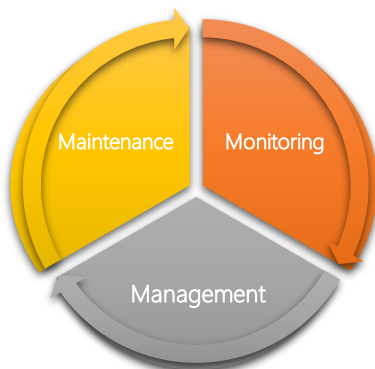


Figure 1.2 – Core elements of self-care

Self-care maintenance involves a process through which the individuals and their families/carers maintain health through health promoting practices and managing illness. This might include adopting behaviours such as not smoking, having a healthy diet, and taking regular exercise.

Self-care monitoring involves a process of self-observation for changes in signs and symptoms. For example this might include regular self-monitoring of blood glucose levels in those who are diabetic.

Self-care management is the process of taking action in response to signs and symptoms when they occur. This might include taking a prescribed medication or seeking immediate GP advice during an illness flare up.

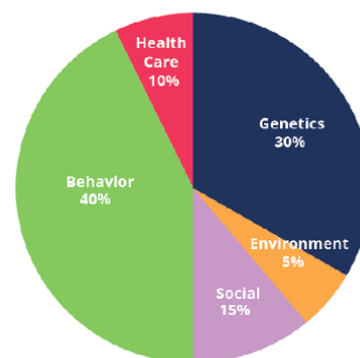
Self-care behaviours

1.2.1

Self-care practices are embedded in one's regular daily activities, whether living with or without a chronic health condition; they range from actions to promote health such as exercising and eating healthily, to more complex approaches to restore health such as receiving medical treatment and rehabilitation activities (9)

There are a variety of factors that are thought to influence our health and wellbeing. The most impactful of these factors is behaviour, accounting for 40% of the total impact on one's health; healthcare use only accounts for 10% (see figure 1.3) (10).

Figure 1.3: Main factors that influence health



Source: National Academy of Medicine

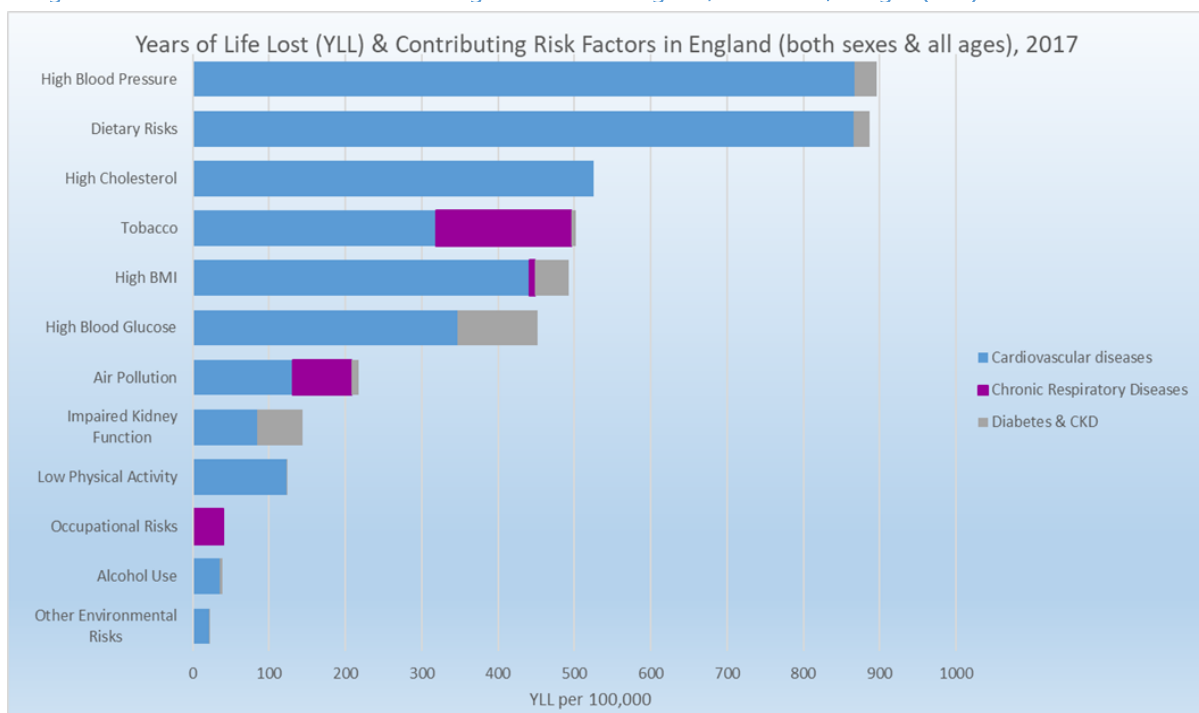
From a general self-care perspective, relevant behaviours include: autonomy and understanding role in own care, having a

healthy and balanced diet, maintaining a healthy weight, exercising regularly and not smoking.

In England, failure to sufficiently adhere to these behaviours is known to be responsible

for a significant amount of years of life lost (see figure 1.4). The incidence of numerous LTCs is directly associated with these behavioural risk factors (11). Much, if not all, of this burden is potentially preventable.

Figure 1.4: Years of Life Lost and contributing risk factors in England, both sexes, all ages (2017)



The most notable benefit of adopting healthy behaviours is reducing the risk of developing LTCs such as type 2 diabetes (see table 1 for more details). People with LTCs must adopt additional self-care behaviours to manage their health and prevent worsening of their condition, which could result in the need for urgent care.

When it comes to self-care as either a preventative measure or a disease management tool, the feeling of control over one's health is highly important. Those who experience greater sense of control tend to display healthier behaviours, are highly motivated, have lower incidence of drug and smoking use, and tend to eat healthier (12). One's engagement in their

own care is also called patient activation. Evidence shows a range of benefits of greater patient activation compared with people who score lower on the activation scale, including:

- Increased likelihood to attend screenings, regular check-ups and immunisations;
- Significant improvement in engagement in healthy behaviours, such as having a healthy diet or exercising regularly; and
- Increased adherence to treatment and condition monitoring, as well as engagement in regular care associated with the condition

Conversely, patients with lower activation are significantly less likely to have:

- Prepared questions for a visit to the doctor;
- Knowledge about treatment guidelines for their condition or to be persistent in asking if they don't understand what their doctor has told them; and
- Met medical needs; they are two to three times more likely to have unmet medical needs and to delay medical care, even after controlling for income, education and access to care (13).

1.2.2

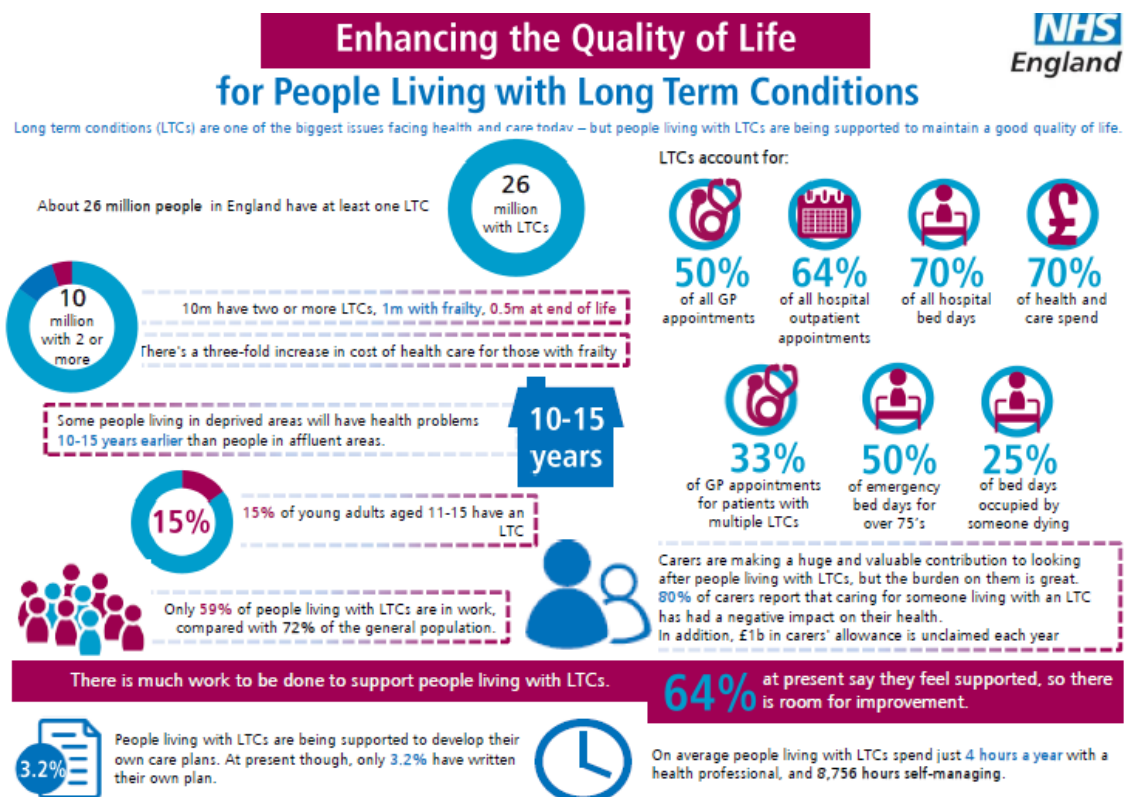
Long Term Conditions

A Long Term Condition (LTC) is defined as “a condition that cannot, at present, be cured but is controlled by

medication and/or other treatment/therapies” (14). More than 15 million people in England are known to have an LTC (3). The most prevalent conditions in England are: diabetes, chronic obstructive pulmonary disease (COPD), chronic heart failure, osteoporosis and dementia. While the total number of people with LTCs is projected to remain stable over the next years, the number of people with multiple conditions is increasing. This is creating an additional pressure on both the NHS and social care (15).

The first three conditions, diabetes, COPD and heart failure, are the main focus of this JSNA as, when living with these conditions, self-care is an essential element to maintaining good health and preventing

Figure 1.5 – LTCs and Quality of Life



More information about enhancing the quality of life for people living with long term conditions can be found at www.england.nhs.uk/house-of-care

Source: <https://psnc.org.uk/wp-content/uploads/2018/02/Infographic-FINAL.pdf>

any secondary health outcomes that could lead to hospital admissions, reduced quality of life, or even death. Further rationale is described below. For local data on each condition, please see Chapter 2: Local context.

Diabetes

Diabetes UK defines diabetes as a condition where your blood glucose level is too high (over a long period of time). This is due to your body being unable to break glucose down into energy because of a lack of insulin in the blood stream.

There are two main types of diabetes:

- Type 1 diabetes – where the body's immune system attacks and destroys the cells that produce insulin; and
- Type 2 diabetes – where the body does not produce enough insulin, or the body's cells do not react to insulin.

It is estimated that 3.8 million people aged 16 years and over in England have diabetes (diagnosed and undiagnosed). This is equal to 8.6% of the population of this age group (16). However, the 2018-19 Quality Outcomes Framework (QOF) report suggests just over 3 million people aged 17 and over have been diagnosed in primary care, equating to only 6.8% of the registered population (17). By 2035, diabetes prevalence is expected to increase to 4.9 million or 9.7% (17).

Regular primary care visits and self-care for diabetes are essential as, if not managed properly, diabetes can lead to life-

threatening complications. Over a long period of time high levels of glucose in the blood stream can irreversibly damage the heart, eyes, feet, and kidneys. Due to these complications, people with diabetes have medical costs that are two to three times more than age and sex matched patients without diabetes (18).

Investing in self-care as a preventative measure for developing diabetes or diabetes complications was recommended as a pressing action in the 2016 Thurrock Annual Public Health report (19).

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease is caused by lung damage due to inhaling toxic substances, most commonly due to smoking. The damage leads to breathing difficulties and other symptoms, such as coughing, wheezing and chest infections.

COPD includes two main conditions:

- Emphysema – damage to the air sacs in the lungs; and
- Chronic bronchitis – long-term inflammation of the airways.

The diagnosed prevalence of COPD underestimates the total burden of the disease because usually the disease remains undiagnosed until severe symptoms appear. General Practices in England have currently identified 1.9% (over one million) of their registered population as suffering from the disease (17). This is significantly lower than Public Health England estimates of 3.2% published in 2015. The United

Kingdom (UK) is among the top 20 countries in the world (third in Europe) for deaths due to COPD, with nearly 30,000 people dying from the disease annually (20). Furthermore, COPD accounts for more than 140,000 hospital admissions (with 97% of them being emergency admissions) and a million bed days each year across the UK (1.7% of all hospital admissions and bed days).

The damage to the lungs caused by COPD is permanent. The breathing problems tend to get gradually worse over time and can limit normal activities. Appropriate treatment and care is highly important for slowing down the progression of the disease. People with COPD are required to implement self-care activities and strategies directed towards the prevention, control and management of the physical consequences of the disease, such as respiratory and sleep problems, limitations in daily activities and exacerbations.

Heart Failure

Heart Failure (HF), sometimes called congestive or chronic HF, is a progressive LTC that cannot be cured; however, the symptoms can often be controlled for many years. In this condition the heart is unable to pump blood around the body properly. It usually occurs because the heart has become too weak or stiff.

It is estimated that only about half of people suffering from heart failure have been identified by their GP and added to the disease register; 0.83% (470,000) (17) compared to 1.4% - total estimates (including undiagnosed) (21). Additionally,

the prevalence of HF is steadily growing, with an increase of 14% from 2002 to 2014 (22). It is likely that individuals not yet diagnosed will only be identified after an acute episode results in the accessing of secondary care services.

Healthy lifestyle changes are one of the top recommendation for treatment on the NHS website, alongside medication and surgery. Furthermore, the National Institute of Health and Care Excellence (NICE) recommends that everyone diagnosed with Heart failure has a care plan which includes follow-up, rehabilitation, and access to social care plans (23). Self-care should therefore be considered of major importance for individuals with HF in order to maintain a stable condition and continue to achieve a good quality of life.

1.3 Current pressures on the health and social care system

The rising pressure on the NHS and Social Care in England can be attributed to a combination of the following factors:

- Ageing population and people living longer
- Increased prevalence of people with health conditions
- Increased prevalence of people with multimorbidities
- Rising incomes and expectations of healthcare
- Demographic changes
- Cost pressures
- Issues with recruiting staff into the NHS and social care e.g. GPs, Nurses, Social Care workers.

1.3.1

Primary care

Patients with LTCs tend to be heavy users of the healthcare system and require greater attention from their care providers. Whilst disease specific figures are not available, we know that between 50-55% of all GP appointments are used by patients already identified as having an LTC (3). As part of the normal care plan, patients with Diabetes, COPD and HF need to have at least one annual review with their GP and regular checks to monitor significant parameters such as blood pressure, glucose and breathlessness.

Furthermore, there is an added burden with some patients not being diagnosed until they experience an acute episode. Treating patients with complications adds to GPs' workloads and the overall cost of care. For example, the cost of prescribing medication for complications of diabetes is around 3 to 4 times the cost of prescribing medication for diabetes itself (18). Moreover, additional to spending time with patients to review and provide advice, GPs also spend a significant amount of time collecting information from secondary and community care providers through communication channels that are not always straight forward.

1.3.2

Secondary care

A failure in the timely identification of patients with LTCs and variable management in primary care may have contributed to a rise in the number of emergency admissions to hospital (24). It is estimated that in England in 2015/16,

patients with LTCs accounted for 61% of all hospital emergency admissions, a 200% increase from 2005/06 (25). The steep increase in the use of secondary care has put a significant strain on the system; 70% of the entire NHS budget is spent on patients with LTCs (3).

Why does this matter?

The annual health and social care cost per year for a person without an LTC is £1,000, this rises to £3,000 for those with one LTC and £8,000 for those with three LTCs (15). Annual inpatient care, to treat short and long term complications of diabetes only is estimated at between £1,807 and £2,552 per diabetic patient (4):. As the number of patients with LTCs and those with multimorbidity rises greater demands and pressures will be put on the NHS.

Clearly some of the demand and costs from patients with LTCs could be avoided through improved self-care of conditions. For example, most of the cost associated with the care of patients with heart failure is the result of rehospitalisation for exacerbations of the condition, many of which can be traced to failed self-care (3).

1.3.3

Social care

Demand for adult social care services has increased by 1.6% since 2015/16 to 2017/18, equating to an additional 5,000 requests for support received per day by local authorities (26).

Individuals with LTCs often have difficulties with activities of daily living, such as

cooking, washing and getting dressed. Social care includes a broad range of non-medical services that support people with these activities. It is common for both health and social care to be required by the same individuals (27).

Social care differs to healthcare in that the majority of social care is provided on an informal basis by family, friends or neighbours, or purchased privately. Estimates of the value of informal care are as high as nearly £100 billion per year (28).

Why does this matter?

The increasing pressures faced by local authorities to meet demand and provide high quality care are of major importance. The cost implications alone of meeting the adult social care burden are placing local authorities under severe financial pressure. However, the importance is not restricted to operational concerns. Individuals themselves are facing ever increasing challenges. People in need of social care are rarely able to be fully involved in society, reducing their quality of life. Additionally, recent reductions in spend alongside increases in demand have the potential to result in more informal care arrangements being made outside of the social care system. This can lead to additional pressures on family members and personal finances.

1.4 Self-care in policy and practice

The growing demands on the health and social care system has led to the

development of policy and practice that places greater emphasis on self-care, including the *Care Act 2014*, the *NHS House of Care Framework*, and the *NHS Long Term plan 2019*. It is clear that people's ability to self-care will impact on their quality of life and the amount and type of care they require from services. This is becoming more important as people live longer and their needs become more complex.

Care Act 2014

1.4.1

Preventing, reducing, or delaying the need for care, where feasible, is a key element of the Care Act 2014. It stated that 'effective interventions at the right time can stop needs from escalating, and help people maintain their independence for longer' (29). The act also talks about the role that local authorities have in promoting wellbeing when carrying out any of their care and support functions in respect of a person.

At the local authority level, Increasing prevention and early intervention efforts are important in realising the planned savings in and adult social care. Additional to reducing Council spend, it contributes to relieving pressures on the most expensive part of the healthcare system, secondary care. The National Audit Office has estimated that 20% of emergency hospital admissions could be prevented if patients are managed effectively by primary, community or social care (1).

1.4.2

House of Care Framework

The House of Care (HoC) framework is a service delivery model for person centred care of all people with LTCs, not just those with a single disease or in high risk groups. It was first introduced in 2011 based on the findings of the Year of Care programme pilot evaluation which revealed improvements in patients' experience of care and in self-care behaviour (30). HoC illustrates a whole-system approach (see figure 1.6) where care planning is at the centre of the house; the left wall represents the engaged and informed patient, the right wall represents the health care professionals committed to partnership working, the roof represents organisational systems and processes, and the base represents the local commissioning plans (31).

Figure 1.6 – House of Care Illustration



The HoC framework assumes an active role for patients, with collaborative personalised care planning at its heart. Implementing the model requires health care professionals to move away from traditional thinking; that they are the primary decision-makers, and instead shift to a partnership model in which

patients play an active part in determining their own care and support needs. A key element of the HoC is supporting the self-care of patients with the aim that people should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life (32).

1.4.3

NHS Long Term Plan 2019

The NHS Long Term Plan (4), published in January 2019, has a greater focus on prevention and supporting self-care. The plan mentions various new programmes and tools for self-care and self-managing health conditions. These included:

- The creation of fully integrated community-based health care where NHS 111 can directly book into GP practices across the country and refer onto community pharmacies who can support urgent care and promote patient self-care. CCGs will also develop pharmacy connection schemes for patients who don't need primary care medical services;
- Shaping the role of pharmacists to support patients to take their medicines to get the best from them, reduce waste and promote self-care;
- Implementation of the Ottawa model for stop smoking in NHS hospitals; all people admitted to hospital who smoke being offered NHS-funded tobacco treatment services by 2023/24;
- Expanding provision of structured education and digital self-management

support tools. This includes expanding access to HeLP Diabetes an online self-management tool for those with type 2 diabetes and is expected to be ready to access in 2020;

- New rehabilitation models for those with mild COPD, including digital tools that provide support to a wider group of patients around rehabilitation and self-management to be implemented over the next ten years;
- Increasing the number of patients with COPD who are referred to pulmonary rehabilitation where appropriate through the use of the COPD discharge bundle; and
- Expanding access to support such as the online version of ESCAPE-pain (which aims to support patients to develop self-management and coping strategies to manage arthritic pain through exercise), a digital version of the well-established, face-to-face group programme.

Additionally, the Universal Personalised Care document, which is the delivery plan for the personalised care that follows the Long Term Plan direction, specifically mentions the need to better include patients in creating their care plans and aid understanding of the level of knowledge, skills, and confidence to self-care.

1.4.4

Community Pharmacy Contracts

The 2019/20 to 2023/24 Community Pharmacy Contractual Framework supports the delivery of the NHS Long Term Plan through the Healthy Living Pharmacy (HLP)

Framework. All HLP will have trained health champions in place to deliver interventions on key issues such as smoking and weight management as well as providing wellbeing and self-care advice, and signposting people to other relevant services (33).

1.4.5

PHE Green Paper 2020

According to Public Health England's new prevention green paper, published in July 2019, prevention is everyone's responsibility, from the NHS to employers, schools, local authorities and individuals. The vision is that in the 2020s, people will not be passive recipients of care but instead will be co-creators of their own health. In order for this to happen, they must be given the skills, knowledge, and confidence to become enabled and empowered to help themselves (34).

1.5 Methodology: How this assessment was conducted

The details of how this assessment was conducted are listed in Appendix 1. In summary, the main activities undertaken to develop this report are:

- engagement sessions with professionals and residents
- collection and analysis of demographic and health measures data from diverse sources such as Public Health England's Fingertips and Global burden of Disease websites, secondary care reports and primary care patient records
- evidence reviews were conducted by Aubrey Keep Library Service by searching peer-reviewed publications from online journal databases.

CHAPTER 2

LOCAL CONTEXT

2.1 Demographics

What does the Mid and South Essex Health and Care Partnership look like as a place?

The areas that are covered by the Mid and South Essex Health and Care Partnership (referred to as the STP from this point forward) are multifaceted, diverse and complex, as illustrated by Figure 2.1 below¹. In terms of the population, the largest proportion of residents are recorded as from white ethnic groups (90.6% average across the STP)². The adult population (18+ year olds), is set to increase across the STP between 2018 and 2038. This means that over the next two decades there are likely to be more people who are diagnosed with an LTC including Diabetes, HF and COPD.

An increasing population does not necessarily mean that people are living healthier lives. Advances in medicine and improved support in the community lead to people living longer, hence the average age is increasing as well. Average life expectancy for both males (79.8 years) and females (83 years) across the STP is lower than both the East of England and England figures (not significantly different).

Across the STP 12.2% (N~150,000) of residents are living in the 20% most deprived areas in England and many residents are engaging in health harming behaviours such as smoking (14.5%) or being physically inactive (22.9%). These behaviours are considered risk factors for some LTCs. The figure below highlights the prevalence of several diseases within the STP. The figure for percentage of obese adults (8.8%) could be an underestimate due to poor recording. Just over a quarter of all residents within the STP are recorded as having Hypertension or a Common Mental Health Disorder (CMHD).

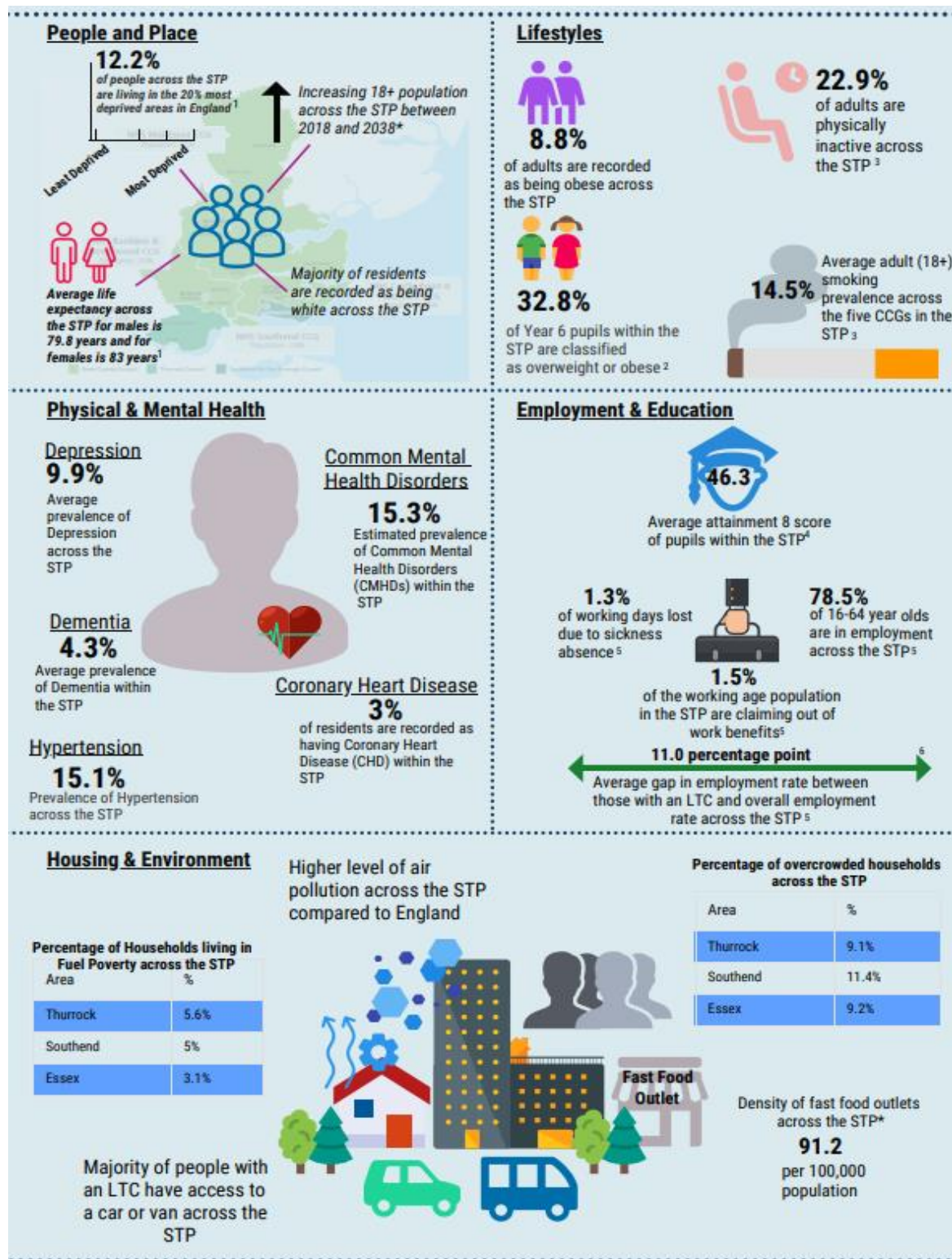
The environment in which people live may also impact on their health and wellbeing. Air pollution levels are higher in all areas within the STP than the regional and national levels (not significantly different). Similarly, the density of fast food outlets in all areas of the STP is higher than the East of England and England rates (not significantly different).

All of the abovementioned factors play a role in the overall health and wellbeing of the population that the STP serves. This JSNA will focus on these demographic and health factors as they relate to the three conditions, in scope and self-care more generally.

¹ The majority of the figures provided within the above infographic are based on calculated averages for the STP by the authors, weighted against the population and therefore, may not show the entire picture in terms of the demographics of the STP. Furthermore, some of the data is at Essex level which is a wider area than the STP covers and may therefore indicate a larger issue than is accurate. Based on how the STP figures were calculated, significance levels compared to the region and national figures were not calculated. This has been represented in the narrative as "Not Statistically Different".

² Some caution needs to be taken when interpreting the ethnicity data as it is from 2011 and we are aware that population changes may have affected ethnicity prevalence for this population. Migration patterns into and out of the borough may also affect the diversity of the STP. Further information can be found in the [Demography JSNA](#).

Figure 2.1: Mid and South Essex Health and Care Partnership as a place



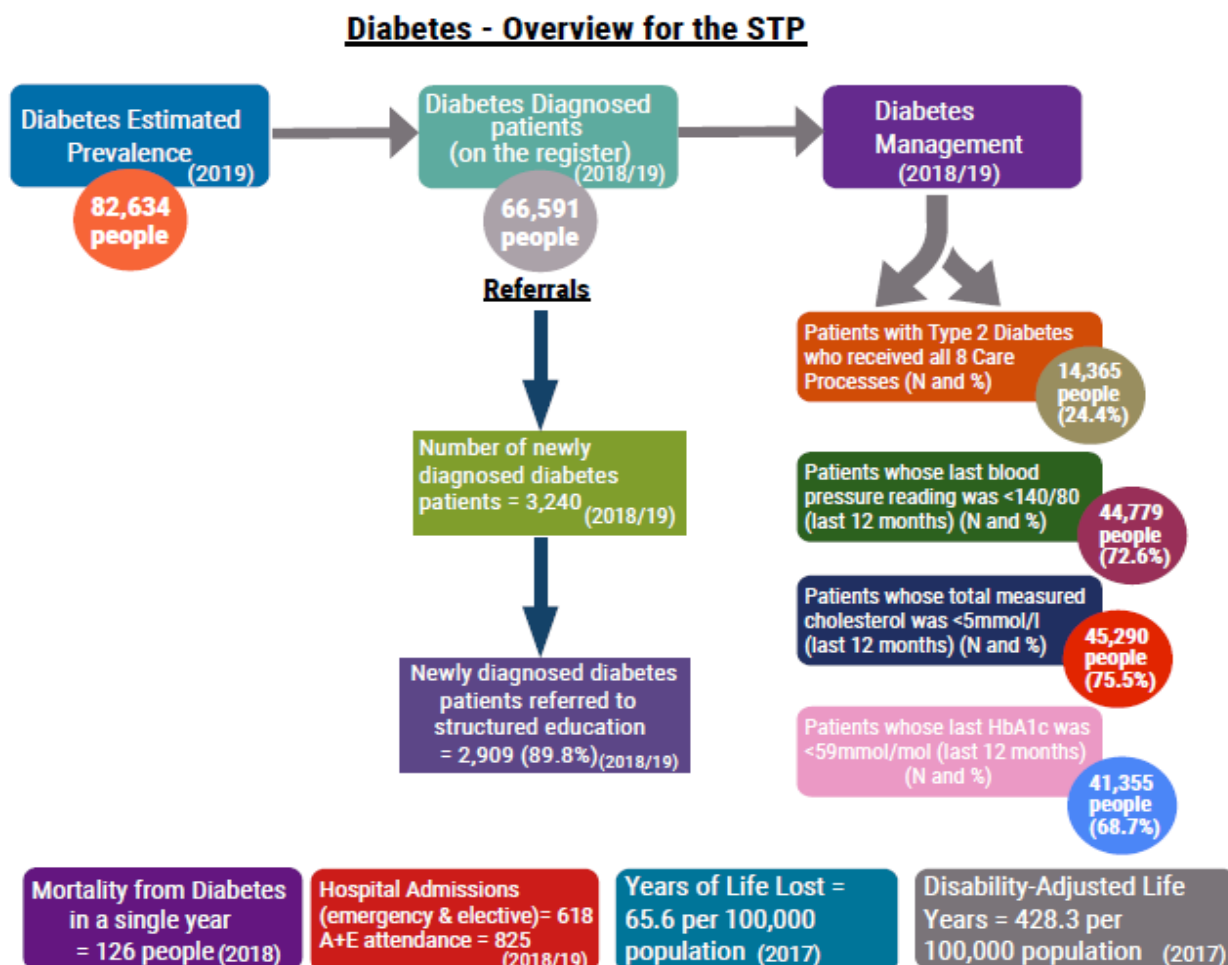
Key for above diagram

- 1 – Figures calculated using an all age population distribution from the total CCG population (2018).
- 2- Figures calculated using the 10-11 year old population distribution from the total CCG population (2018).
- 3 – Figures calculated using an 18+ population distribution from the total CCG population (2018).
- 4 – Figures calculated using the 15-16 year old population distribution from the total CCG population (2018).
- 5 – Figures calculated using the 16-64 year old population distribution from the total CCG population (2018).

Each of the conditions in scope is discussed in turn below. At the beginning of each section there is a diagram which shows key data (e.g. prevalence and mortality) at an STP level. Each indicator within the diagram is then discussed in more detail (e.g. broken down to CCG level) in a series of sub-sections. It should be noted that we are aware that there is variance at a GP practice level across all CCG areas, and for all indicators relating to the conditions of interest, and therefore this should be assumed to be the case where it is not stated. Where data has been broken down to GP practice level, this has been included

for one CCG only (out of all within the STP), to give a picture of the variance but to ensure that the report does not become too onerous for the reader. All of the data at either the CCG or GP practice level takes into account differences in population size and make up (this is stated throughout the chapter at varying points). Finally in terms of Diabetes, some of the data relates to Diabetes as a whole (Type 1 and Type 2), and some is specific to Type 2 Diabetes; this is specified where relevant

2.2 Diabetes



Sources: PHE, 2019; QOF, 2018/19; NOMIS, 2018; CSU, 2018/19; and Global Burden of Disease (GBD), 2017

Figure 2.2: Diabetes Overview for the STP

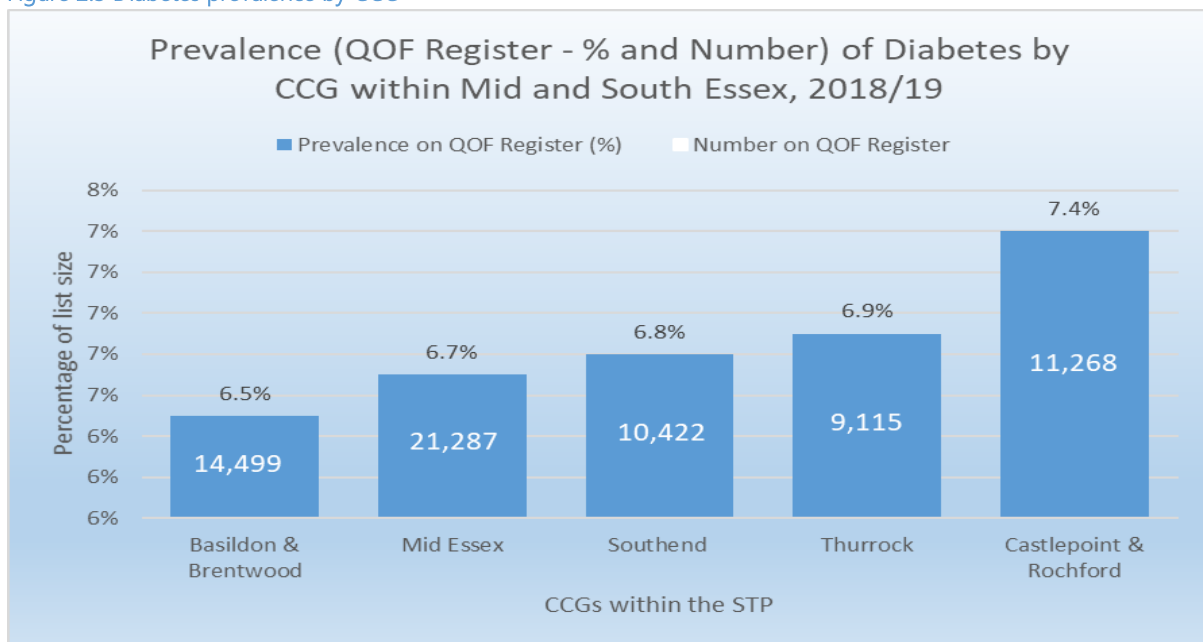
2.2.1

Diabetes Prevalence

Recorded Diabetes prevalence (QOF) across the STP has been steadily increasing year on year since 2012/13, ranging from 5.9% (N=55,789) in 2012/13 to 6.8% (N=66,591) by 2018/19³. This rising prevalence at STP level is in line with the England prevalence during the same time

period. When broken down by the CCGs, within the STP, and taking into account differences in population size, the most recent data (2018/19) shows that Castlepoint and Rochford (CPR) CCG had the highest QOF recorded prevalence of Diabetes at 7.4% (N=11,268) of all patients aged 17+ who are registered at all GP practices under this CCG (see figure 2.3).

Figure 2.3 Diabetes prevalence by CCG



There is quite a lot of variance in prevalence at GP practice level within and across each of the CCGs within the STP. For example, the prevalence of Diabetes in GP practices in Thurrock ranged from 4.3% (Thurrock Health Centre) to 9.9% (The Rigg Milner Medical Centre) of all patients aged 17+ registered at each individual GP practice in Thurrock during 2018/19 (see table 2.1 below)⁴. As well as planning services for the existing and known cohort of patients with diabetes, it will be important to find the 'missing thousands' who are as yet undiagnosed. The modelled estimated

prevalence of diabetes calculated by Public Health England (PHE) in 2019 refers to the total number and percentage of patients thought to have diabetes within a specified area (e.g. at the national, regional, STP, CCG, borough and GP levels), whereas the recorded diabetes prevalence is defined as those who are already diagnosed and included on the disease register (again at the same levels noted above). Figure 2.4 shows the total number/percentage of people thought to have diabetes at each CCG within the STP.

³ See Methodology section for how this was calculated.

⁴ It should be noted that the QOF prevalence for Derry Court Medical Centre is from 2017/18, as the data was not available for this GP practice in 2018/19 due to some data quality and validation issues.

Table 2.1: Range of QOF Recorded Diabetes Prevalence by CCG, 2018/19.

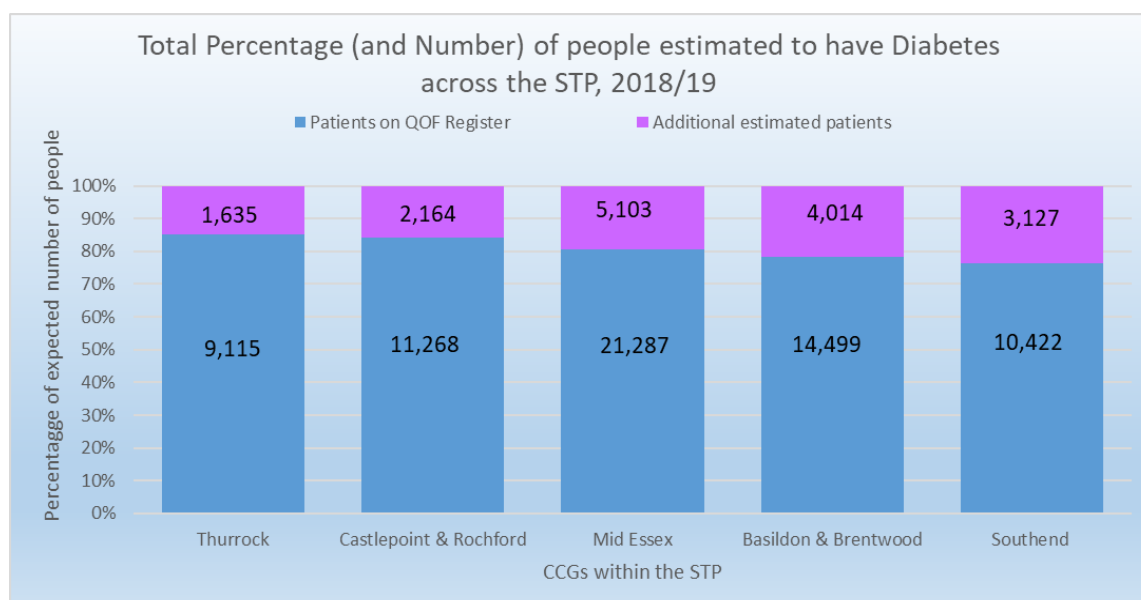
| Area | GP Practice with lowest recorded prevalence (%) | GP Practice with highest recorded prevalence (%) | Difference (percentage point/range) |
|------------------------------|---|--|-------------------------------------|
| Southend CCG | 5% | 8.6% | 3.6 |
| Mid Essex CCG | 4.1% | 8.9% | 4.8 |
| Basildon & Brentwood CCG | 4.3% | 9.6% | 5.3 |
| Castle Point & Rochford CCG | 4.7% | 10% | 5.3 |
| Thurrock CCG | 4.3% | 9.9% | 5.6 |
| Mid & South Essex | 4.1% | 10% | 5.9 |

Source: NHS Digital, QOF

As can be seen it is broken down into the number/percentage of people diagnosed, the estimated number/percentage of additional people who likely have diabetes and the total number expected to have diabetes (calculated by adding the two

former figures together). Taking into account differences in population size, in 2018/19 Southend CCG had the largest gap between the expected and observed cases of the condition; a gap of 23.1% (N=3,127).

Figure 2.4: Total Percentage (and number) of people estimated to have Diabetes across the STP, 2018/19



Source: QOF 2018/19 & PHE Fingertips – Diabetes Profile 2017

2.2.2

Diabetes Management

9 Care Processes

NICE recommend nine care processes for diabetes Type 1 and 2 (prior to 2019 only eight care

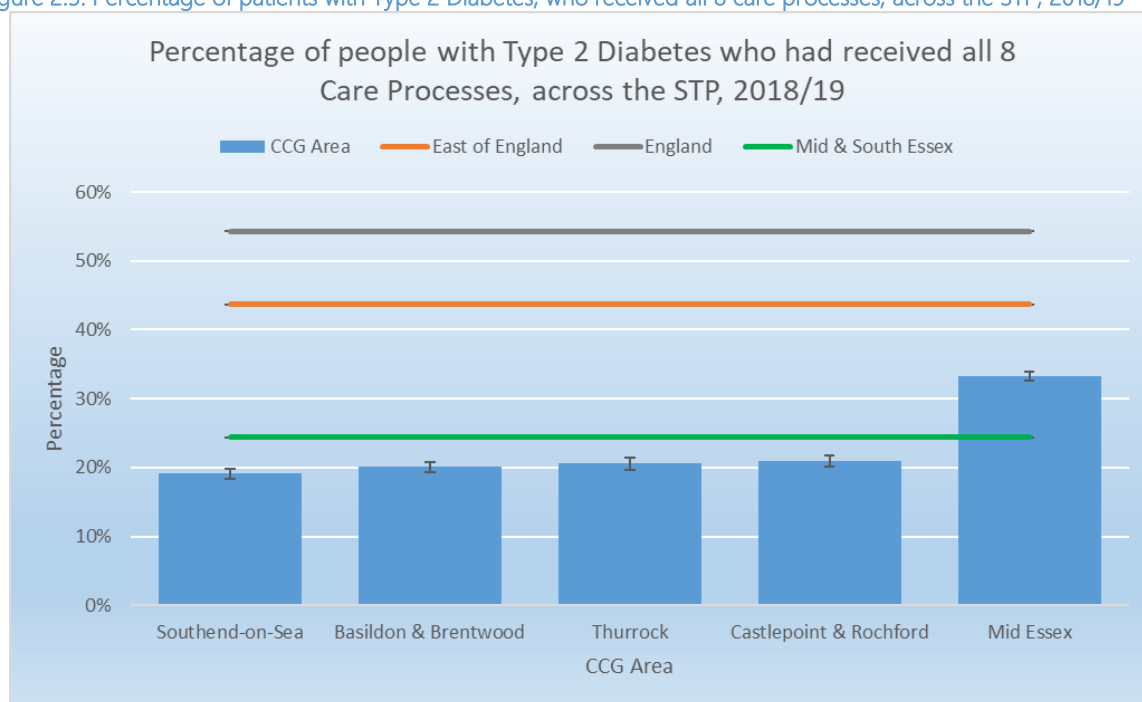
processes were recommended). Five of the processes focus on risk factors including: body mass index (BMI), blood pressure, smoking status, glucose levels (HbA1C) and cholesterol. The remaining four processes

include tests that aim to identify potential complications, namely: urine albumin creatinine ratio, serum creatinine, foot nerve and circulation examination and eye screening (this is held by NHSEDES) (35).

The National Diabetes Core Audit (NDA) is an annual audit that measures the effectiveness of diabetes healthcare within Primary Care and specialist diabetes services against the NICE guidelines. It covers care processes, treatment targets, complications and mortality. For the purpose of this JSNA, examination of the 8 care processes undertaken in Primary Care within the NDA will be the focus (36).

Locally, as depicted in figure 2.2 above (entitled Diabetes Overview for the STP), 24.4% (14,365) of people with Type 2 diabetes across the entire STP received all eight care processes in 2018/19. When broken down to CCG level to explore variation across the STP, the percentage of people who received all eight care processes was significantly lower than the STP, regional and national averages for all of the CCGs; with Southend CCG having the lowest percentage at only 19.1% (see figure 2.5 below).

Figure 2.5: Percentage of patients with Type 2 Diabetes, who received all 8 care processes, across the STP, 2018/19



Source: National Diabetes Audit.

Blood Pressure Checks

Regular blood pressure checks are an important part of Diabetes care, to reduce the risk of complications such as a Stroke. The ideal blood pressure (BP) reading is 140/80mmHG or less to support and

maintain good health (37). Across the STP during 2018/19, 72.6% (N=44,779) of diabetic patients' last BP reading was 140/80mmHG or less, measured within the preceding 12 months⁵. When broken down to a CCG level and taking into account variation in population size and make-up,

⁵ See Methodology section for how this was calculated.

CPR CCG had the lowest percentage of diabetic patients whose last BP reading fell within the ideal range at 69.3% (N=7,351). Conversely Thurrock CCG had the highest percentage of patients with the ideal BP at 78.8% (N=6,843).

Cholesterol Checks

For people with diabetes it is important to maintain a good balance in HDL (good cholesterol) and LDL (bad cholesterol). As such one of the care processes for diabetes involves regular cholesterol checks to monitor levels and reduce the risk of cardiovascular complications. The ideal reading is 5mmol/l or less (38). Across the STP during 2018/19 the percentage of patients' whose total measured cholesterol was 5mmol/l or less (in the last 12 months) was 72.6% (N=45,290)⁶. When broken down to a CCG level and taking into account variation in population size, Southend CCG had the lowest percentage of diabetic patients whose last total measured cholesterol fell within the ideal range at 72.5% (N=6,711). Conversely Mid Essex CCG had the highest percentage of patients with the ideal total measured cholesterol at 77.3% (N=14,450).

HbA1c Checks

Monitoring the blood glucose levels in diabetic patients is of utmost importance in reducing the risk of complications. The ideal HbA1c level is 59mmol/mol or less. In 2018/19 the percentage of patients across the STP whose last recorded HbA1c was at the ideal level was 68.7% (N=41,355)⁷. When broken down by the CCGs, Southend CCG had the lowest percentage of patients

with the ideal HbA1c level at 67.4% (N=6,411). Conversely, CPR CCG had the highest percentage of patients with the ideal HbA1c at 70.9% (N=7,561).

2.2.3

Diabetes Referrals

When an individual is first diagnosed with diabetes, there is an onus on the GP to refer the individual to a structured education programme within nine months of diagnosis. This is included as one indicator within the QOF programme; a voluntary annual reward and incentive programme which encourages GPs to meet various targets in relation to specific disease management. During 2018/19 there were 3,240 newly diagnosed diabetes patients across the STP. Of these patients, 89.8% (N=2,909) were referred to a structured education programme (QOF Code DM014) (see figure 2.2 above – Diabetes – Overview for the STP). When broken down to explore variation within the CCGs that make up the STP, the percentage of newly diagnosed patients referred to a structured education programme ranged from 87.4% (N=466) in CPR CCG to 90.8% (N=638) in Basildon and Brentwood CCG during the same time period.

2.2.4

Diabetes Outcomes

Hospital Admissions, and A&E attendance

During 2018/19 across the STP there were a total of 825 A&E attendances attributable to diabetes. These attendances may have arisen as a result of patients experiencing symptoms for an unknown cause, perhaps leading to a diagnosis or due to complications with their

⁶ See Methodology section for how this was calculated.

⁷ See Methodology section for how this was calculated.

diabetes. Of the total attendances only 661 patients attended A&E, which means that some patients attended A&E on more than one occasion during that year.

Hospital records show a total of 618 admissions; 543 emergency admissions and 75 elective admissions due to diabetes in 2018/19. As with A&E attendance there were fewer patients who were admitted on an emergency basis (N=478) than total admissions, which means that some patients were admitted to hospital on multiple occasions during that time period. Brought together, this suggests that, overall self-care for diabetes is not effective for all patients living within the STP footprint.

Quality of Life

Quality of life (QoL) can be measured in numerous ways. One way of exploring the QoL of people living with diabetes is by calculating the Disability Adjusted-Life Years (DALYs). The World Health Organisation (WHO) define one DALY as one lost year of 'healthy life'. The sum of the DALYs represents the gap between current health status and the ideal health status of a population, if the entire population live to an advanced age and without disability or ill health. In terms of specific health conditions DALYs are calculated as the sum of Years of Life Lost (YLL) due to premature mortality, the Years Lost due to disability (YLD) or the consequences of a disease (39).

The Global Burden of Disease (GBD) tool models DALYs for those with any condition as a rate per 100,000 population. Across the STP the rate of DALYs due to Diabetes was 1032.5 (1021.9–1043.1) per 100,000 population in 2019. At national level, the

rate of DALYs relating to Diabetes for England was similar at 1019.8 (740.5–1344.5) per 100,000 population whereas the East of England showed the higher rate of 1077.2 (777.5–1418.4) per 100,000 population. Years of life lost is a summary measure of premature mortality. As with DALYs, the GBD models this for all conditions as a rate per 100,000 population. The YLL due to Diabetes across the STP was 141.5 (130.3–152.7) per 100,000 population (2019)⁸. Similar rates were observed across England and the East of England, the YLL rate relating to Diabetes across England was 133.5 (124.2–138.7) per 100,000 whereas the East of England YLL rate was 139.7 (125.1–154.02) per 100,000 (2019).

In comparison to chronic kidney disease (CKD), an LTC often concomitant with Diabetes, across the STP the rate of DALYs due to CKD was 246.7 (244.1–249.3) per 100,000 population (2019). Furthermore, across the STP the rate of YLLs due to CKD was 145.9 (144.3–147.5) per 100,000; a similar rate to the rate of YLLs due to Diabetes observed across the STP. National and regional DALY rates for CKD were slightly lower compared to STP DALY rates, in England the rate of DALYs for CKD was 230.9 (202.2–263.8) per 100,000 and DALY rate of 240.5 (207.6–276.4) across the East of England.

Mortality

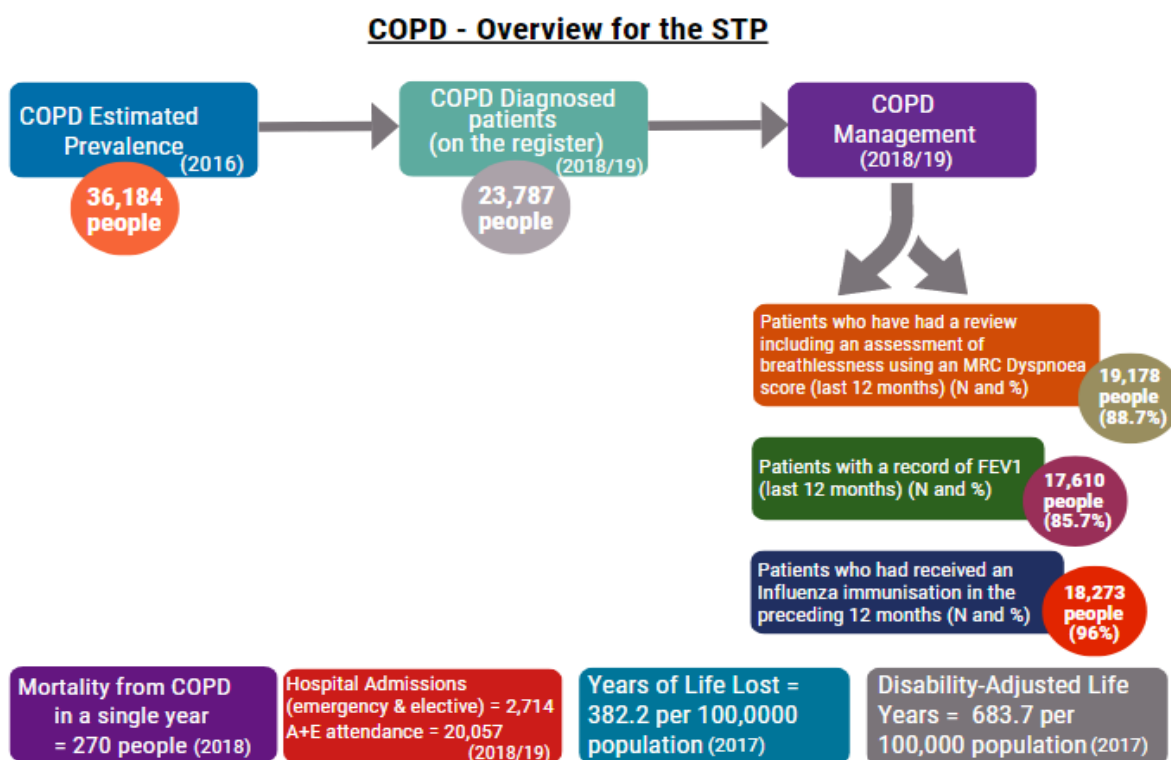
In terms of mortality, across the STP, 0.2% (N=126) of patients died due to diabetes during 2018⁸. It is possible that some of the patients who died during this time period, were not diagnosed with diabetes at the time of their death and that this was uncovered as part of an autopsy. On the

⁸ See Methodology section for how this was calculated.

whole, the modelled rate of mortality attributable to diabetes in the STP is 3.8 per 100,000 population (2017), (40)⁹.

It will be important to reflect all of the above variances in the planning and delivery of interventions and services for diabetes self-care within and across the STP.

2.3 COPD



Sources: PHE, 2016; QOF, 2018/19; NOMIS, 2018; CSU, 2018/19; and Global Burden of Disease (GBD), 2017

Figure 2.6 COPD Overview for the STP

2.3.1

COPD Prevalence

COPD prevalence (QOF) has seen a slight year on year increase across the STP ranging from 1.7% (N=19,970) in 2012/13 to 1.9% (N=23,787) in 2018/19¹⁰. The yearly increases in prevalence are in line with the England prevalence during the same time period.

At the CCG level within the STP during 2018/19 CPR CCG had the highest recorded prevalence of COPD at 2.4% (N=4,383) of

all patients (all ages) who are registered at all GP practices under this CCG (see figure 2.7). As with Diabetes, there is quite a lot of variance at GP practice level in terms of COPD prevalence across all GP practices within the STP. For example, the prevalence of COPD in GP Practices in Basildon and Brentwood in 2018/19 ranged from 0.8% (The Highwood Surgery) to 4.4% at two of the practices (Dr Ma Sims practice and Malling Health – Dipple Medical Centre) of all patients (all ages) registered at each individual GP practice in Basildon and Brentwood (see Table 2.2).

⁹ The modelled mortality attributable (rate) to Diabetes is based on data at Thurrock, Southend and Essex level, and as such may be an overestimate, as Essex covers a larger area than the three CCGs in scope.

¹⁰ See Methodology section for how this was calculated.

Figure 2.7: COPD Prevalence by CCG (2018/19)

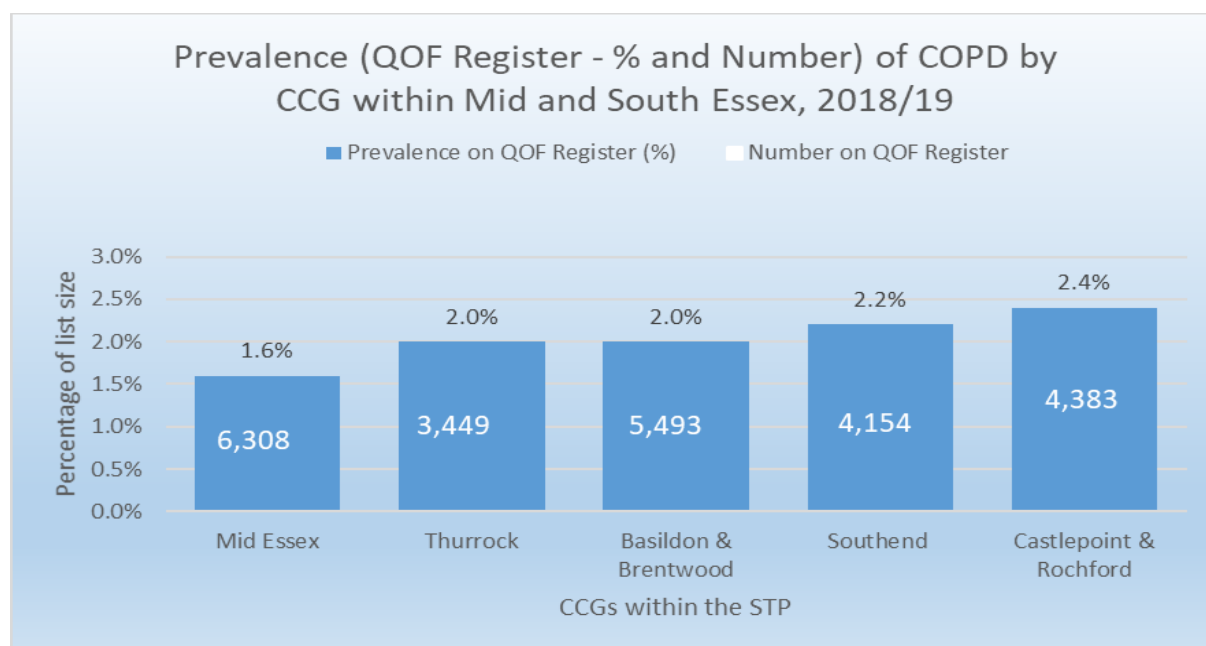


Table 2.2 Range of QOF Recorded Prevalence of COPD by CCG 2018/19.

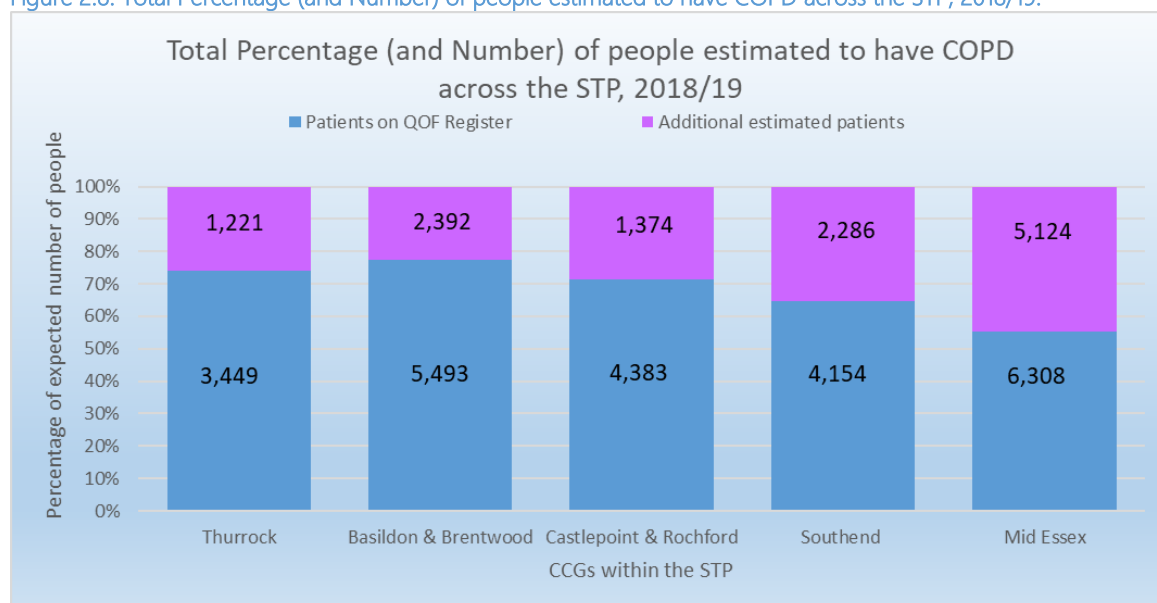
| Area | GP Practice with lowest recorded prevalence (%) | GP Practice with highest recorded prevalence (%) | Difference (percentage point/range) |
|------------------------------|---|--|-------------------------------------|
| Southend CCG | 1.5% | 3.1% | 1.6 |
| Mid Essex CCG | 0.6% | 2.7% | 2.1 |
| Thurrock CCG | 0.7% | 3.4% | 2.7 |
| Castle Point & Rochford CCG | 1.2% | 4.2% | 3 |
| Basildon & Brentwood CCG | 0.9% | 4.4% | 3.5 |
| Mid & South Essex | 0.6% | 4.4% | 3.8 |

Source: NHS Digital – QOF.

As with Diabetes there were differences between the number/percentage of observed (diagnosed) versus expected cases of COPD across all CCGs within the STP in 2018/19 (see figure 2.8 below). Using PHE modelled estimates from 2015/16 it can

be seen that of the CCGs, Mid Essex CCG had the largest gap in the number/percentage of diagnosed versus expected cases of COPD; a gap of 44.8% (N=5,124) as well as the highest total estimated prevalence (N=11,432).

Figure 2.8: Total Percentage (and Number) of people estimated to have COPD across the STP, 2018/19.



Source: QOF 2018/19 & 2016 PHE Modelled Estimates

2.3.2

COPD Management

COPD Review (including Assessment of Breathlessness)

Within the STP in 2018/19, 88.7% (N=19,178) of people with COPD had a review including an assessment of breathlessness within 12 months¹¹. When broken down at the CCG level, and accounting for variation in population size, Thurrock CCG had the lowest percentage of COPD patients who had received a review at 87.1% (N=2,871). Southend CCG had the highest percentage of patients who received a review of their COPD at 90% (N=3,400) during the same time period.

Record of FEV1

One of the QOF indicators that GPs can be incentivised to deliver in the treatment and management of COPD, is ensuring that all patients have a record of FEV1. Across the STP, the percentage of COPD patients who

had a record of FEV1 in 2018/19 was, 85.7% (N=17,610)¹². When broken down by CCG to compare performance across each area of the STP, Mid Essex CCG had the lowest proportion of COPD patients who had a record of FEV1; 83.8% (N=4,296). Conversely, Southend CCG had the highest percentage of patients who had this record at 86.9% (N=3,207).

Influenza Immunisation

The influenza vaccine is one of the main protective factors for those with COPD to support them to manage their condition effectively. Across the STP during 2018/19, 96% (N=18,273) of patients had received their vaccine in the preceding 1st August to 31st March¹³. When broken down by CCG, the uptake of the vaccine ranged from 95.3% (N=4,294) in Basildon and Brentwood CCG to 97.3% (N=3,089) in Southend CCG. It is worth noting that Southend CCG consistently performs better than all of the other CCGs within the STP,

¹¹ See Methodology section for how this was calculated.

¹² See Methodology section for how this was calculated.

¹³ See Methodology section for how this was calculated.

against all of the COPD QOF management indicators, included above.

2.3.3

COPD Referrals

The Pulmonary Rehab service run by NELFT is designed to support COPD patients to manage their condition more effectively. The service is primarily designed for patients who experience breathlessness. It is a 12 week exercise and education programme. Referral data provided by NELFT for Thurrock and Basildon and Brentwood CCGs, suggests that 783 COPD patients were referred to this service during 2018/19. However, we were unable to get any data for the other three CCGs within the STP and as such cannot provide an accurate picture of how many people accessed the service at an STP level. Of those who were eligible (the number of residents who were classified as MRC3+ patients) an estimate of 21.6% were referred during this time period.

2.3.4

COPD Outcomes

Hospital Admissions, and A&E attendance

During 2018/19 across the STP there were a total of 20,057 A&E attendances attributable to COPD. These attendances may have arisen as a result of patients experiencing symptoms for an unknown cause, perhaps leading to a diagnosis or due to complications with their COPD. Of the total attendances only 16,778 patients attended A&E, which means that some patients attended A&E on more than one occasion during that year.

During the same year, there were a total of 2,714 hospital admissions; 2,605 emergency admissions and 109 elective admissions due to COPD. As with A&E attendance there

were fewer patients who were admitted on an emergency basis (N=2,068) than total admissions, which means that some patients were admitted to hospital on multiple occasions during that time period. Brought together, this suggests that, overall self-care for COPD is not effective for all patients living within the STP footprint.

Quality of Life

Across the STP the rate of DALYs relating to COPD was 1335.8 (1322.2-1349.4) per 100,000 population (2019)⁸. Similar rate at national level was observed; across England the rate of DALYs was 1246.2 (1121.6-1363.3) per 100,000 population, whilst the DALY rate due to COPD across the East of England was slightly lower at 1203.1 (1077.8-1318.02) per 100,000 population (2019). Furthermore, the rate of YLL due to COPD was 900.3 (887.1-913.5) per 100,000 population across the STP during the same year⁸. Similar trends were seen across England with YLL rate relating to COPD of 851.4 (745.8-938.3) per 100,000, whereas for the East of England the YLL rate was 792.8 (704.4-878.5) per 100,000 (2019).

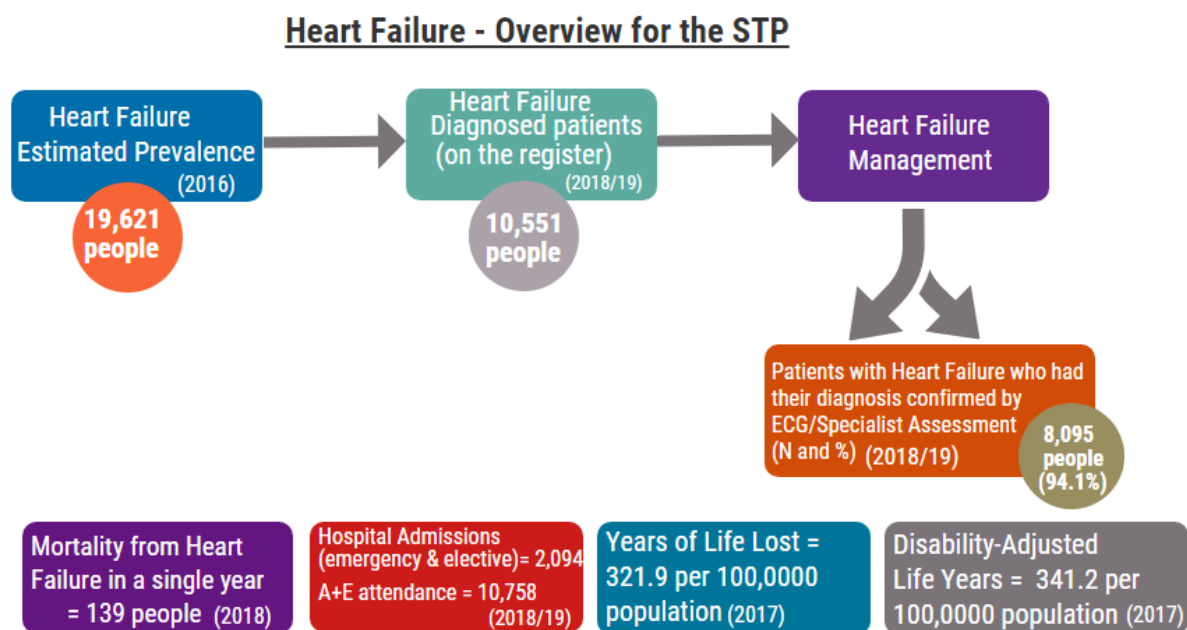
In comparison to trachea, bronchus and lung cancer, another leading respiratory cause of disease burden (1142.2 (1139.4-1145.03) per 100,000 population in 2019⁸), the DALY rate for COPD was higher. Furthermore, the YLL rate for trachea, bronchus and lung cancer was 1124.7 (1121.5-1127.9) per 100,000 population. The higher YLL rate of trachea, bronchus and lung cancer compared to the YLL rate of COPD can be attributed to trachea, bronchus and lung cancer being a highly fatal condition.

Mortality

During 2018, across the STP the percentage of people who died due to COPD was 1.1% (N=270)¹⁴. It is possible that some of the patients who died did not have a diagnosis of COPD at the time of their death and that this was uncovered as part of an autopsy. The overall modelled mortality rate from

COPD across the STP was 27.9 per 100,000 population (40)¹⁵. It is important to reflect all of the above variances in the planning and delivery of interventions and services for COPD self-care within and across the STP.

2.4 Heart Failure



Sources: PHE, 2016; QOF, 2018/19; NOMIS, 2018; CSU, 2018/19; and Global Burden of Disease (GBD), 2017

Figure 2.9: HF Overview for the STP

2.4.1

Heart Failure Prevalence

The prevalence of Heart Failure (HF) across the STP has ranged from 0.7% (N=8,554) in 2012/13 to 0.9% (N=10,551) in 2018/19¹⁶. This is in the line with the England prevalence during the same time period.

When broken down by CCGs, within the STP, Southend CCG had the highest prevalence of HF in 2018/19 at 1.1% (N=2,018) of all patients (all ages) who are registered at all GP practices under this CCG (see figure 2.10). As with the other two conditions there is quite a lot of variance across the GP practices within each area of the STP. For example, in GP practices in Mid Essex the prevalence ranges from 0.3% at two of the practices (Dickens Place Surgery

¹⁴ See Methodology section for how this was calculated.

¹⁵ The modelled mortality (rate) attributable to COPD is based on data at Thurrock, Southend and Essex level, and as such may be an overestimate, as Essex covers a larger area than the three CCGs in scope.

¹⁶ See methodology section for how this was calculated.

and Blyth's Meadow Surgery) to 1.4% (Collingwood Road Surgery) of all patients (all ages) registered at each individual GP

practice in Mid Essex during the same time period (see table 2.3 below).

Figure 2.10: Heart Failure prevalence (2018/19)

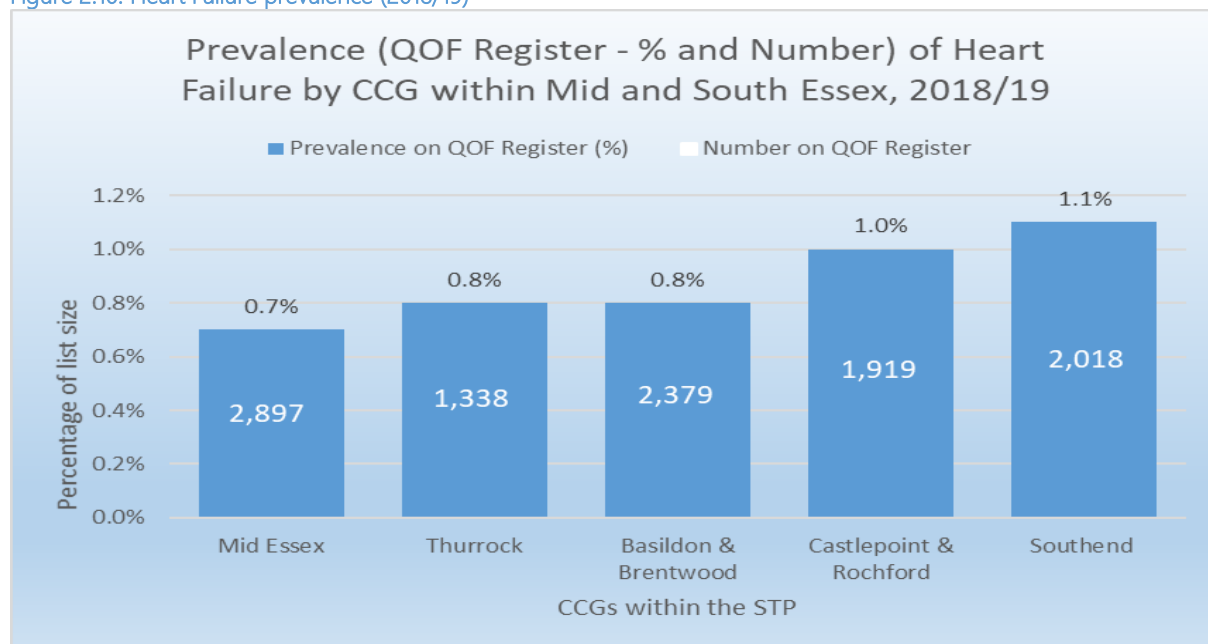


Table 2.3: Range of QOF Recorded Prevalence of Heart Failure by CCG, 2018/19

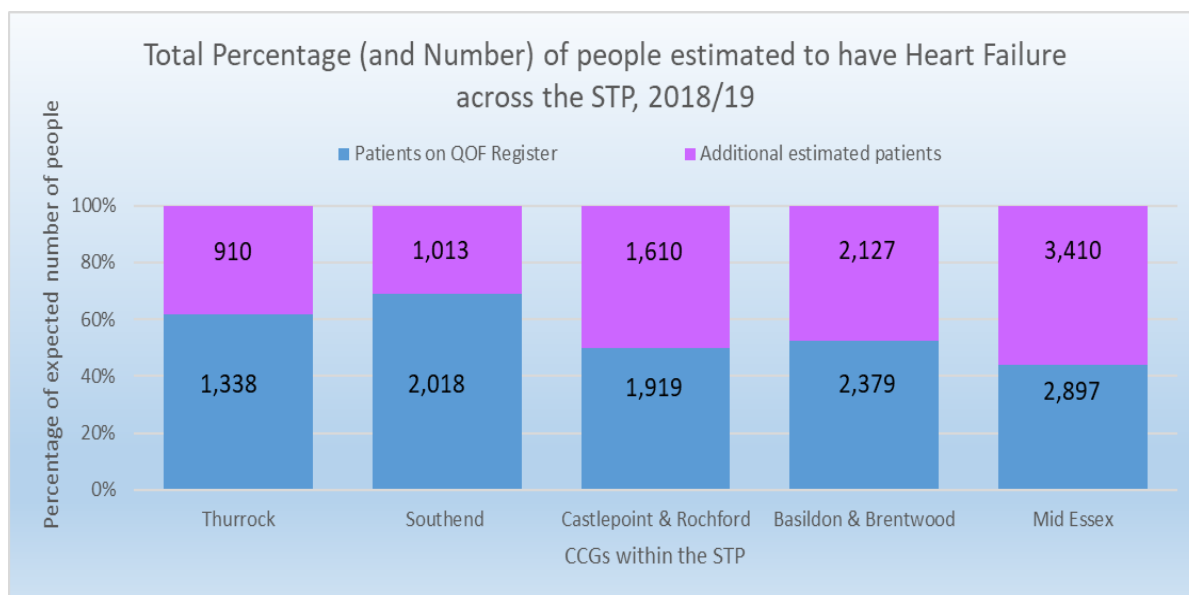
| Area | GP Practice with lowest recorded prevalence (%) | GP Practice with highest recorded prevalence (%) | Difference (percentage point/range) |
|------------------------------|---|--|-------------------------------------|
| Southend CCG | 0.7% | 1.7% | 1 |
| Mid Essex CCG | 0.3% | 1.4% | 1.1 |
| Castle Point & Rochford CCG | 0.3% | 1.5% | 1.2 |
| Thurrock CCG | 0.2% | 2% | 1.8 |
| Basildon & Brentwood CCG | 0.1% | 2.1% | 2 |
| Mid & South Essex | 0.1% | 2.1% | 2 |

Source: NHS Digital - QOF

Figure 2.11 below shows the total number of people estimated to have Heart Failure across each CCG within the STP. As described earlier, the estimated prevalence is the total number of people thought to have a specific condition (based on PHE modelled estimates from 2015/16) and the recorded prevalence is the total number of people who have already been diagnosed

and are recorded on disease registers. The CCG with the largest gap in the number/percentage of patients who were diagnosed with Heart Failure in 2018/19 was Mid Essex CCG; the gap was 54.1% (N=3,410) and as with COPD, this CCG had the highest estimated prevalence of Heart Failure across the STP (N=6,307).

Figure 2.11: Total Percentage (and Number) of people estimated to have Heart Failure across the STP, 2018/19



Source: QOF 2018/19 & 2016 PHE Modelled Estimates

2.4.2

Heart Failure Management

Heart Failure Diagnosis Confirmation Assessment

The main management indicator (QOF) for Heart Failure is confirmation of diagnosis. This is defined as the percentage of patients who have had their diagnosis confirmed by either an echocardiogram (ECG) or via a specialised assessment either three months before, or 12 months after going onto the register. Across the STP, 94.1% (N=8,095) of patients had their diagnosis confirmed during 2018/19¹⁷. When broken down at a CCG level and taking into account differences in population size, the percentage of patients who had their diagnosis confirmed ranged from 92.9% (N=1,830) in Basildon and Brentwood CCG to 95.3% (N=1,045) in Thurrock CCG.

2.4.3

Heart Failure Referrals

The Community Heart Failure Service provides long term management and support for patients living with chronic Heart Failure. Anecdotal referral data provided by NELFT for Thurrock and Basildon and Brentwood CCGs, suggests that 816 (22%) Heart Failure patients were referred to this service during 2018/19. However, we were unable to get any data for the other three CCGs within the STP and as such cannot provide an accurate picture of how many people accessed the service at an STP level. It is likely that the number is higher than depicted here.

2.4.4

Heart Failure Outcomes

Hospital Admissions, and A&E attendance

During 2018/19 across the STP there were a total of 10,758 A&E attendances attributable to HF. These attendances may have arisen as a result of patients experiencing symptoms for an unknown cause, perhaps leading to a

¹⁷ See Methodology section for how this was calculated.

diagnosis or due to complications with their HF. Of the total attendances only 9,551 patients attended A&E, which means that some patients attended A&E on more than one occasion during that year.

During the same year, there were a total of 2,084 hospital admissions; 1,866 emergency admissions and 228 elective admissions due to HF. As with A&E attendance there were fewer patients who were admitted on an emergency basis (N=1,594) than total emergency admissions, which means that some patients were admitted to hospital on multiple occasions during that time period. Brought together, this suggests that, overall self-care for HF is not effective for all patients living within the STP footprint.

Quality of Life

Across the STP in 2019 the rate of DALYs relating to Heart Failure was 2131.4 (1207.7-2155.1) per 100,000 population⁸. Furthermore the rate of YLL due to HF was 1657.2 (1656.02-1658.4) per 100,000 population across the STP during the same year, indicative of the highly fatal burden component of HF. Similar rates were observed across the East of England, DALYs relating to HF were 2103.6 (2050.4-2156.8) per 100,000 population with YLL rates of 2009.3 (1959.2-2060.3) per 100,000 (2019). Whereas England showed slightly higher rates of 2163.2 (1997.5-2329) DALYs per 100,000 population and YLL rates of 2076.4 (1916.9-2235.9) per 100,000 population. Comparing the rate of HF to the rate stroke across the STP shows reduced disease burden, the rate of DALYs relating to stroke

was 1016.2 (1011.3-1021.1) per 100,000 population in 2019, whilst the YLL due to stroke was 869.3 (867.6-871.1) per 100,000 population.

Mortality

In 2018, across the STP the percentage of people who died due to Heart Failure was 1.3% (N=139)¹⁸. It is possible that some of the patients who died did not have a diagnosis of Heart Failure at the time of their death and that this was uncovered as part of an autopsy. The overall modelled mortality rate from Heart Failure across the STP was 63.2 per 100,000 population in 2017 (40)¹⁹.

2.5 Current Service Offer

It is important to reflect all of the above variances in the planning and delivery of interventions and services for Heart Failure self-care within and across the STP. People living with diabetes, COPD and HF in the Mid and South Essex Health and Care Partnership footprint benefit from a large range of services that support them to self-care. Stakeholder engagement and online searches led to identifying a total of 68 services across the STP. Of those, 43 services are for people diagnosed with diabetes, COPD or HF and are commissioned at the CCG or borough level. A majority of these services are offered by community providers such as North East London NHS Foundation Trust (NELFT), Essex Partnership University NHS Foundation Trust (EPUT) and Provide or the voluntary sector, such as Diabetes UK,

¹⁸ See Methodology section for how this was calculated.

¹⁹ The modelled mortality (rate) attributable to Heart Failure is based on data at Thurrock, Southend and Essex level, and as such may be an overestimate, as Essex covers a larger area than the three CCGs in scope.

British Heart Foundation or British Lung Foundation. They consist of: specialist care or rehabilitation geared at managing the disease and complications; structured education to increase knowledge/understanding and to improve self-efficacy; support groups to share experiences and learning; and technology based support such as online platforms and apps. Very few identified services are geared towards multiple conditions despite the fact that most people with diabetes, COPD and HF tend to have multimorbidities. For example, the average number of other conditions at first presentation of HF is five (41). In Southend and CPR, EPUT offers a case management programme, delivered both in clinics and at home, specifically designed for people with complex needs, including multimorbidity, who are or can become very high intensity users of primary and secondary care. The service aims to maximise independence and achieve optimum treatment outcomes through good care navigation and use of advanced clinical skills.

The remaining 25 services, are more holistic and address social or behavioural risk factors. Residents with no record of diabetes, COPD or HF are supported to assess their risk and prevent the onset of any of these diseases. Local Healthy Lifestyle services, pharmacies and Primary Care providers are delivering health checks and screenings and refer those identified to be at risk to tailored programmes. Additionally, self-care support provision has also been identified outside of the historic healthcare or public health settings. Varied Adult Social Care teams and the Job Centres work with residents to enable them to tackle social barriers such as lack of employment or

housing. They aim to support residents to stay strong, safe, well, resilient, independent and connected. Furthermore, patients with complex needs, both health and social, can access services that link them to the appropriate resources. Social Prescribers and Local Area Coordinators (LACs) are trained to act as a one stop shop and offer a bespoke service to these people. However, if multiple needs are identified most of the times patients have to access multiple services on separate occasions – making it difficult for them to stay engaged. Due to a high range of commissioners, providers, and referral pathways, mapping the services in the area proved to be very challenging. Some relevant services might be missing from the service mapping analysis. A full map of the services found can be accessed separately in the appendices section (Appendix 2).

Diabetes

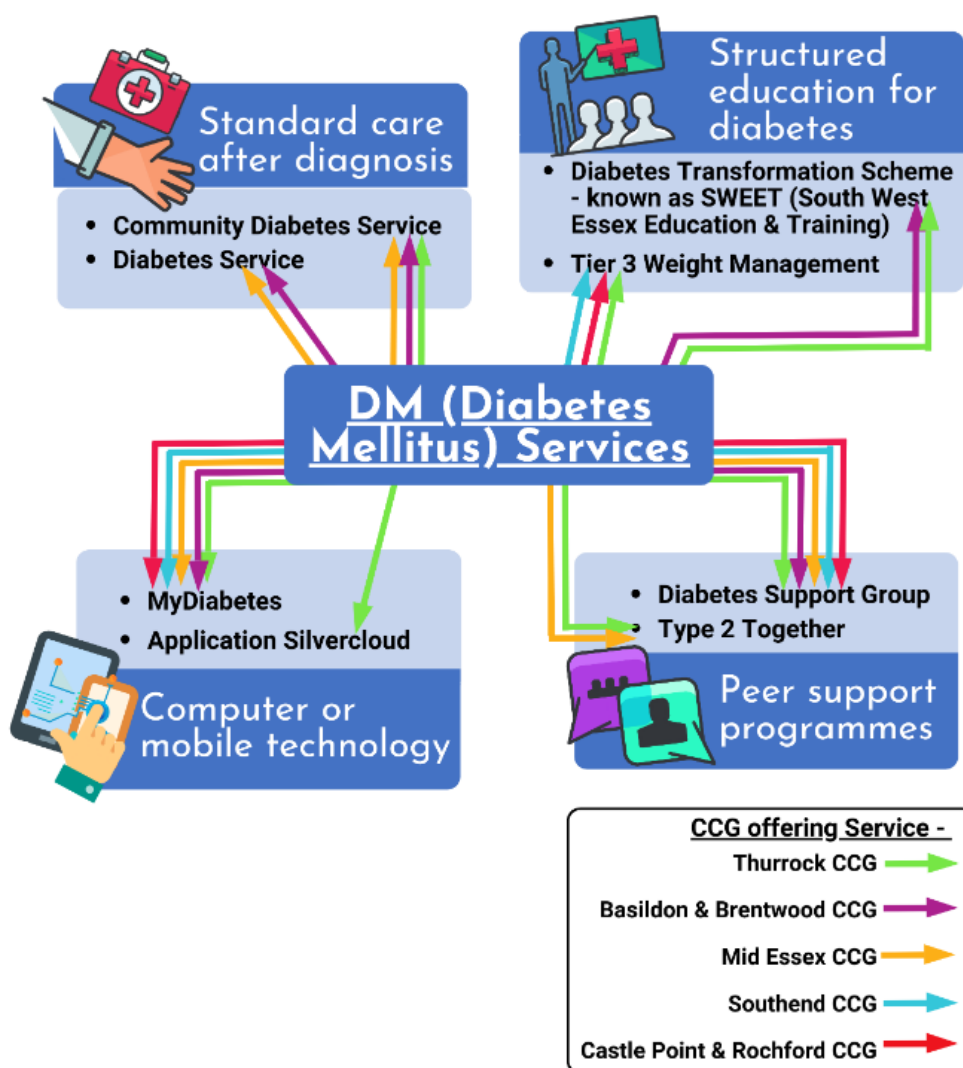
Diabetic patients in Mid and South Essex benefit from a large range of services that support them. Currently, all CCGs offer Community Diabetes Services delivered by multidisciplinary teams usually made up of consultants, diabetes nurses, podiatrists and dieticians. However, the provision came across as fragmented and inconsistent. Due to services being delivered by different providers, there is a variability of programme structure and delivery across the footprint. For example, Mid-Essex services, delivered by Provide, are using a GP with a special interest in diabetes rather than a consultant as the other areas do. Similarly, in Thurrock and Basildon and Brentwood, NELFT is using lay educators for the educational classes instead of healthcare professionals. Additionally, while in most areas the service is either in the

community or Secondary Care, CPR and Southend have recently commissioned an integrated service in conjunction with Secondary Care at Southend Hospital. The service acts as a single point of contact for patients and triages them for a better and quicker experience. These differences in structure and delivery make it very difficult to compare services and ascertain which one is more effective and efficient in supporting patients to self-care.

Similarly, across the STP, diabetes education courses have very different formats in regards to length and content covered.

SWEET in Thurrock is only three hours long, while CREDIT and DESMOND in the other areas are a full day course. DESMOND has been thoroughly evaluated and is proven to be effective, whereas it is unclear whether the other two formats have been evaluated for effectiveness or not. Additional to education, patients also benefit from a number of diabetes support groups run by the voluntary sector, such as Diabetes UK and South East Essex Type 1 Diabetes family support group. Being community led and often under resourced, these groups are struggling with catering to people of different backgrounds in terms of education and language.

Figure 2.12: Diabetes Services Infographic



Knowing that patients with diabetes are at high risk for depression and anxiety, Mid Essex and Thurrock CCGs are also providing mental health support services for patients with diabetes. The treatment offered uses Cognitive Behavioural Therapy (CBT) which is effective at reducing symptoms of low mood, anxiety and other emotional problems.

Additional to face to face support, in 2019 the mHealth app, MyDiabetes, was commissioned across the STP. The app contains a comprehensive diabetes education course for patients with both Type 1 and Type 2 Diabetes and enables them to monitor their blood glucose, HbA1c and other risk factors to reduce the risk of serious long term complications.

A visual overview of the services available for diabetic patients across the STP can be seen in figure 2.12 above.

COPD

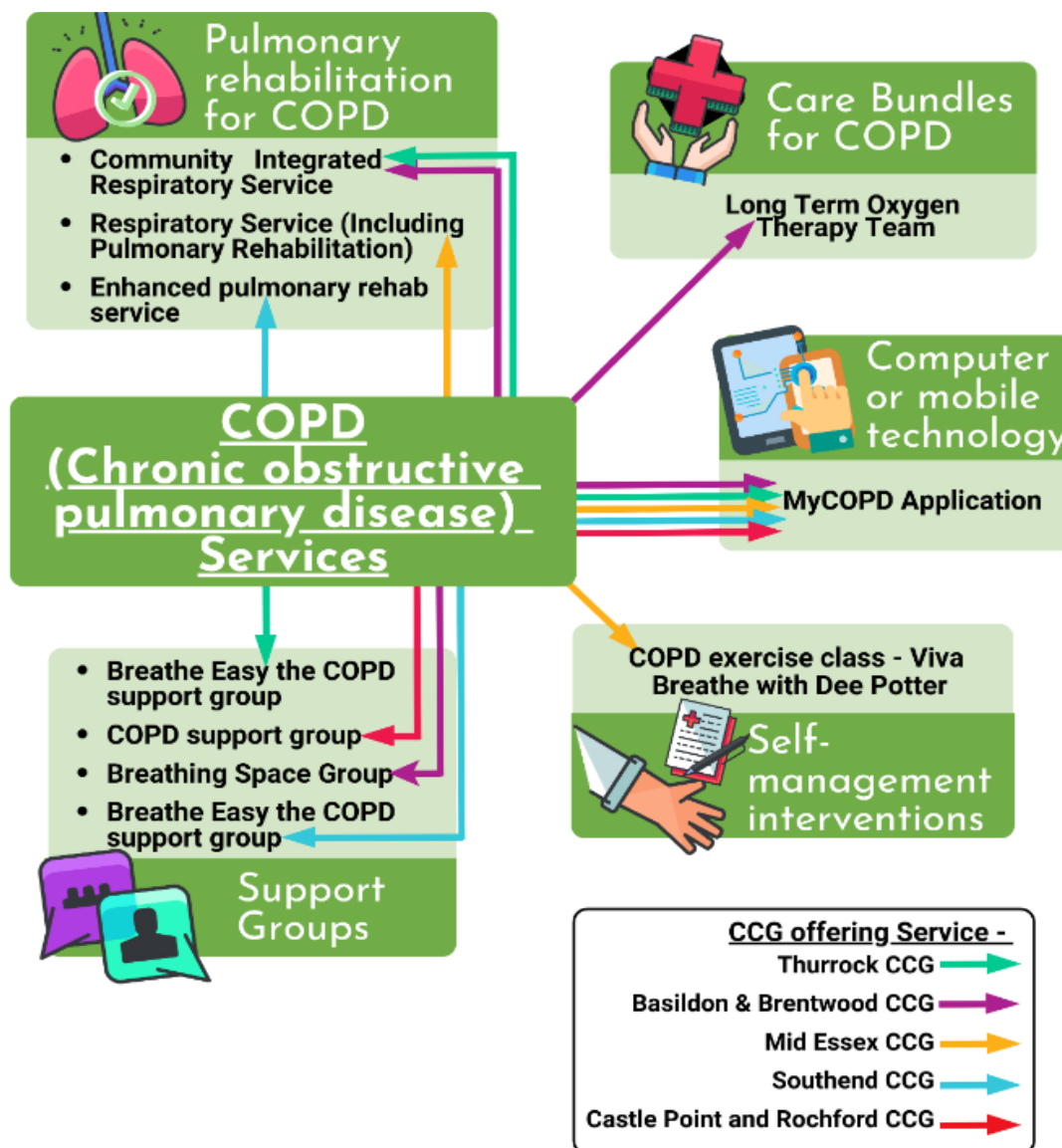
There are a variety of self-care services available to people diagnosed with COPD across Mid and South Essex. They range from face-to-face specialised services to structured education and digital help. All CCG areas offer a Pulmonary Rehabilitation (PR) programme; however, similarly to the diabetes services, there are differences in structure and delivery of the programmes across the area. The Mid Essex programme appears to be more diverse in the service it offers in comparison to the other CCG areas. In addition to the common services amongst the CCGs, such as a PR service, a COPD Team, and Oxygen Therapy, Mid Essex also offer access to a Breathe Easy support group once a month, a telehealth monitoring service, and palliative care. Additionally, from the information provided,

Thurrock, Basildon and Brentwood, Southend and CPR services give patients the option to be referred on to psychological therapy services in case they need extra support or therapy. The Mid Essex service specification does not mention any referral pathway to psychological support services. In terms of location, Southend and CPR services were recently remodelled to deliver pulmonary rehabilitation through either a centre-based, a home-based or a hybrid programme. The hybrid programme offers a mixture of centre-based sessions with exercise and education at home.

Mid Essex also offer their services at varied locations within the CCG, whereas Thurrock's PR service is only based at BTUH. Current research shows that there is a wide provision of free COPD exercise classes across Mid and South Essex. However, most of these classes are located at a single location and meet once a month. It is difficult to ascertain whether these classes reach maximum capacity; however, if that is the case, some patients would have to travel to distant locations to attend a class every month.

There are free COPD Rehabilitation classes available across South East Essex, which we assume would also be the main service available in Mid-Essex, as the current service 'Viva Breathe' in Mid-Essex is a pay as you go service. It could be that the requirement of a payment may deflect patients from attending these classes regularly, especially if there is a free service providing a similar type of service within their locality. However, there are no statistics available to illustrate whether these free exercise classes are at maximum capacity each month and/or patients are willing/not willing to pay for

Figure 2.13: COPD Services Infographic



similar services in their area. MyCOPD app is a digital provision, similar to MyDiabetes, available to people with COPD across Mid and South Essex. There is currently no data which can illustrate how many people have downloaded this App, and/or how engaged app users are. The current barrier around this App is promoting it to COPD patients. Going forward, mHealth is looking to distribute licences via Primary Care and Secondary Care pathways, as well as Social Prescribers. A visual overview of the services available for COPD patients across can be seen in Figure 2.13 above.

Heart Failure

All CCGs in the area offer a specialised Heart Failure Service (Thurrock, Basildon and Brentwood, Southend, and Castle Point and Rochford) or a Cardiac Service (Mid Essex only). The heart failure service aims to increase the patients’ ability to self-manage their heart condition(s) through specialist support and educational programmes.

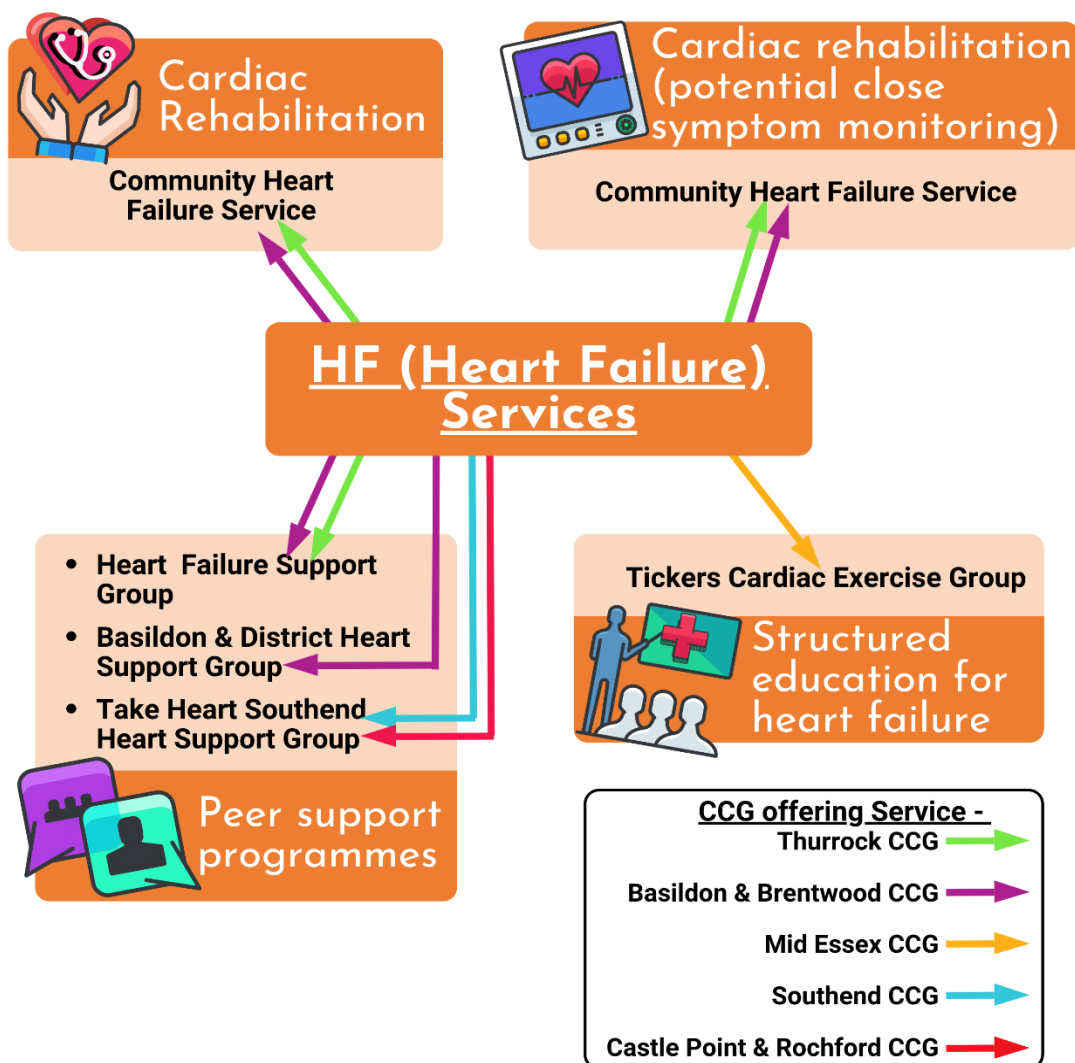
Additionally, people with heart failure can access cardiac rehabilitation services with structured exercise programmes across all areas. In Mid-Essex it is part of the Cardiac Service, while Basildon and Thurrock

Hospitals NHS Foundation Trust (BTUH, for Thurrock and Basildon and Brentwood residents) and Southend University Hospital (for Southend, Castle Point and Rochford residents) have it separately. The programmes are designed for patients who can/do attend sessions at various locations within their area, and for patients who wish to complete the programmes at home.

Of all, the Mid Essex Cardiac Service appears to be more diverse in their service

delivery specifications, and include a larger range of services. While Mid Essex and BTUH run their services in various areas, the service in Southend is only at Southend University Hospital. These variations in service delivery are going to be addressed by the new structure put in place by the merging of Mid-Essex, BTUH and Southend into one hospital trust (see figure 2.14 above for a visual overview of services available for HF patients across the STP).

Figure 2.14: HF Services Infographic



2.6 Stakeholder Views

Professionals' Views

A variety of professionals were involved in consultation work to gather their views relating to the current health and social care system for people with LTCs; either completing an online survey or attending one of a number of workshops/face-to-face interviews (See methodology section for further details about how the consultation was conducted). Analysis of the surveys and minutes from workshops and interviews identified a variety of issues, which have been grouped into five main themes, namely: Professionals' knowledge, skills behaviour and capacity, Patients' attitudes and behaviours, Barriers to Self-care (perceived and actual), Commissioning/Services and the System (see Table below).

Each of the main themes, have a number of sub-themes contained within them. It is important to note that there are overlaps and interlinks between the themes and sub-themes as the self-care landscape is

complex. For example, capacity issues within the healthcare system are cited as an issue in delivering self-care support (Professionals' knowledge, skills, behaviours and capacity) however, some of this may be combatted if services and the system are designed to make effective use of the multi-skilled workforce (Commissioning/Services); see table 2.4 below.

Some of the sub-themes that emerged from this consultation work with professionals are similar to the findings of the evidence review (see Chapter 3). One example of this, is the need for the system to focus on prevention. For Diabetes, this could be through promotion of, and signposting to the National Diabetes Prevention Programme (NDPP), an evidence based prevention programme centred on supporting behavioural and lifestyle change. Furthermore, the perceived or actual barriers to self-care identified by professionals reflect some of the barriers outlined within the evidence review.

The findings of this consultation were used to inform the recommendations of this JSNA (see Chapter 4).

Table 2.4: Professionals' Views on Self-care barriers

| <u>Professionals' Consultation - Key Themes</u> | | | | |
|--|---|---|---|--|
| <i>Professionals' knowledge, skills, behaviour & capacity</i> | <i>Patients' attitudes & behaviours</i> | <i>Barriers to Self-Care (perceived & actual)</i> | <i>Commissioning/Services</i> | <i>The System</i> |
| <ul style="list-style-type: none"> • Increased knowledge of the services/support available required. • Need for improved communication between organisations and services e.g. Adult Social Care (ASC), Public Health and the health system. • Lack of knowledge about where/how to signpost patients to, related to the complexities of service pathways and organisations. • Capacity issues within the healthcare system. | <ul style="list-style-type: none"> • Increased knowledge of the services/support available required. • Patients are concerned that services will be withdrawn. Some patients may perceive signposting as a risk to their care. • Need for patients to engage in their own self-care. | <ul style="list-style-type: none"> • Transport and access issues. • Engaging with harder to reach groups such as those who are homebound, the teenage cohort. • Patients' own attitudes towards their health. • Role of wider determinants of health e.g. density of fast food outlets inhibiting people from making healthier choices. | <ul style="list-style-type: none"> • Need for a single point of access in terms of services, with a unique referral system. • Need for a bottom-up approach and co-production of services with patients • Opportunities to better link services e.g. Primary Care and pharmacies e.g. healthy living pharmacies. • Review how we measure self-care outcomes, moving away from process focused to outcome focused KPIs. • Role of online support targeted towards some population groups. • Gap in specialist support for those with multiple conditions. • Importance of making effective use of multi-skilled workforces. | <ul style="list-style-type: none"> • More focus on prevention needed • No formal shared strategy, vision, and agreed targets/outcomes for self-care. Need for a culture change in how we think about self-care. • Importance of a place-based model for self-care. • Balancing the need for innovative services with making best use of existing services. • Building support within communities. • Role of care navigation in supporting people to self-care. • Role of wider determinants of health in self-care e.g. through improved infrastructure that supports active travel. • Need to understand the demography of a place in order to organise services. |

Residents' Views

A total of 109 residents were involved in consultation work undertaken by Healthwatch Thurrock (N=61) and Healthwatch Essex (N=48) to gauge and understand their experiences of living with an LTC; primarily Diabetes, COPD or Heart Failure. The consultation work focussed on the following: initial diagnosis, experience of support services, perceived barriers to self-care and mechanisms for supporting residents to self-care more effectively (See methodology section for further details on how the consultation was conducted). Healthwatch Southend were unable to complete similar consultation work, and as such we will make the general assumption that patients' views are likely to be similar in this area of the STP to the other two areas. The findings presented in this section will be organised based on the main themes identified as part of analysis of the two Healthwatch reports. These will be applied at a local level, as due to differences in methodology it is difficult to directly compare the findings. However, any similar findings across the STP will be emphasised.

Thurrock

Perceived barriers to self-care

When asked "What may, if anything, be hindering your ability to self-manage at home?" The responses were themed as follows (in order of weighting):

- **Home barriers** – for example needing a bath to make washing easier, stairs making it more difficult to move around the home or the oven being positioned too low down;
- **Health status** – for example having another condition that was making it

difficult to manage and self-care e.g. poor eye sight or pain;

- **Medication management** – for example having to take multiple and/or regular medication;
- **Health Services** – for example lack of nearby services, and not feeling supported by the GP; and/or
- **Social support** – for example needing additional support generally and wanting to have someone available who could provide advice.

"I was shocked to get this diagnosis (of COPD). I have smoked in the past and if I had not smoked I probably would not have got COPD. My GP diagnosed me and referred me to the COPD nurses who have been very helpful. I go online for advice and tips on my condition but I like the rehab exercises that I go to (at Thurrock Hospital) as I find being with others is helpful. I have been told to not smoke again, and also to get more active and lose a bit of weight. I am trying to do all of these things and I don't feel too bad. I am in control of my illness. I wished I had never smoked as this has made me get the COPD."

Female, 48 years, from Thurrock with COPD

Information to support self-care

When asked "What information did you receive that supported you to self-manage?" The responses were themed as follows (in order of weighting):

- **Health Professional's condition specific advice and guidance** – for example from a consultant or specialist;

“Without my husband who is my Carer I could not manage.”

*Female with Multiple Sclerosis
Thurrock.*

- **Take home information** - for example condition specific leaflets;
 - **Medication advice** – for example how to medication such as administering injections; and/or
 - **Information about Local support groups** such as Breathe Easy
-

“It’s helpful because you’re talking to people who’ve got the same thing as you... perhaps theirs is a bit worse or a bit better, but it gives you an idea of what people out there go through”.

Focus Group Attendee, Female, Essex

Further support for self-care

When asked “Is there anything that could further support you to self-care at home?” The responses were themed as follows (in order of weighting):

- **Equipment** - for example, a walk in shower or side rails in bathroom;
- **Advice/knowledge** - for example, more advice and direction when diagnosed;
- **Social support** - for example, more local support groups or someone on the end of the phone; and/or
- **Access** - for example, treatment closer to home and easier access to GP.

Other responses related to financial support and the need for improvements to local

transport routes which are currently causing issues in terms of getting around Thurrock; for example being able to travel to/from medical appointments.

Essex

Diagnosis and initial support

Experience differed between conditions, in terms of ease of getting an initial diagnosis and provision of information following diagnosis. Most people who were diagnosed with COPD mentioned the difficulty in getting an initial diagnosis. However, it was noted that once diagnosis was confirmed the person was given detailed information about the condition and how to manage it. In Essex the opposite appeared to be true for diabetes, with participants commenting that getting diagnosed was easy, but follow up information was patchy or incomplete. Participants often felt that the condition and

“It took five years messing around to diagnose me, I had obscure symptoms and it was only after I got a lot of chest infections... I saw a totally different guy and he said this has gone on too long, so he sent me for a high definition scan... and that showed COPD and Bronchiectasis. It was the first time I had a clear diagnosis... five years... and that changes all the drugs I was on”.

Focus group attendee, Male, Essex, with COPD

next steps were not explained well enough, with a need for more consistent education.

In terms of emotional responses to diagnosis, many participants stated that they wanted to self-manage their long term condition independently but also be able to live their lives. One participant made reference to 'taking charge of your own condition'. Others reported that they felt panicked, depressed and as though their condition was taking over their lives.

Patient experience of support groups

Some participants felt that the NHS run support groups felt more like tick-box exercises and were very target driven, with professionals running the groups needing to be 'more mindful'. For example, one participant recounted their experience in which they sought advice about not being able to get their blood glucose level down, despite removing high sugar foods from their diet. The response they received from the professional running the group was that they doing well as they had cut out high-sugar foods from their diet but this did not address the patient's concerns.

Others mentioned that some of the NHS staff would only recognise certain things relating to the management of a condition. For example, there seemed to be some confusion about what doctors would recognise as 'exercise', with many

participants mentioning 10,000 steps as a benchmark.

A recurring theme was the importance of support groups being run by volunteers who had a long term condition themselves and were self-managing; it was felt that advice provided by someone with the same lived experience would be more useful.

The social aspect of support groups was consistently mentioned as positive and really important to self-care. Some participants talked positively about exercise, especially where this could be undertaken in a social environment, e.g. via walking groups. Some participants suggested that the social element of support groups should be strengthened further.

Local Services and support

Participants highlighted that understanding and empathy from NHS staff is important for people, to enable self-care, with some patients feeling that the attitudes of some health professionals needed to be 'more supportive'. Some individuals felt judged or blamed for the development of their condition due to lifestyle factors such as smoking or being overweight. Other participants cited the excellent support they had received from health professionals.

They also felt that access to services was crucial, with some participants reporting feeling concerned about service closures or sessions coming to an end. One patient reported that a local eye-screening service had shut down and that it now cost them £30 in taxi fares to travel to the next closest service. Another patient reported difficulties in being supported with her foot care, due to waiting times and lack of appointments.

"My feelings are, doctors, because you are of a large frame immediately think "junk food"... had no thought that you might not eat junk food and I find that very difficult"

Focus group attendee, male, Essex, with Diabetes

“It’s nice to know you’ve got a number you can ring and someone to talk to... have that contact it gives you that feeling of security”.

Focus Group Attendee, Female, Essex

The role that specialist nurses play in supporting people with LTCs was consistently praised in terms of their knowledge, understanding and empathy. Conversely, participants felt that other professionals working in other areas of the system did not have the same level of knowledge e.g. pharmacists.

Knowledge of local peer support networks were rated as extremely valuable, however, some participants felt that GPs could be signposting more and supporting local groups more, by attending them to speak to patients directly. It was recognised that health professionals are under a lot of pressure to deliver services with limited time and resources. It was also clear from this consultation work that patients feel that professionals need to know what is available locally, and where they can signpost individuals to for further support.

Findings across the STP

Experience of diagnosis, in terms of ease and initial support offered was highlighted by participants across the STP. In Thurrock, some participants felt that the way they were given their diagnosis was ‘good’ or ‘easy’ with others stating that their experience was ‘bad’ or ‘could have been better’. Although the majority of Thurrock participants stated that they had received

information in a variety of formats, some felt that they did not receive enough information, with a small number stating that they had received no information at all. This is similar to the picture in Essex (as outlined above).

It appears as though the majority of participants across the STP do not believe that the development of their long term condition could be prevented, with some citing genetic and hereditary factors. Although some participants did mention that they could ‘be fitter’ or ‘lose some weight’, others found it difficult when health professionals made assumptions about them relating to their weight status.

Some of the findings from this patient consultation reflect the views of professionals’, particularly in terms of capacity and knowledge about where to signpost patients to. As with the professionals’ views, the findings from this consultation work were used to inform the recommendations of this JSNA (see Chapter 4).

CHAPTER 3

EVIDENCE REVIEW

Key Findings

Self-care practices contribute to maintaining or promoting health, including in improving LTC management. Autonomy, understanding and responsibility, a healthy diet and physical activity, and smoking cessation are examples of self-care behaviours that improve the development or symptom progression of Diabetes, Heart Failure and COPD. For example, such behaviours among diabetes have been found to correlate with improved glycaemic control, decreased complications and increased quality of life.

There are 137 behaviour change techniques (BCTs) to support and empower patients to improve their lifestyle used in primary care. Previous reviews show that behavioural counselling, motivational interviewing, and educational advice and support are most effective in primary care. However, effectiveness has been found to be dependent on the use of different BCTs specific to targeted behaviours, and the programme delivery and structure.

Ability to self-manage LTCs depend on a range of factors: active condition monitoring, treatment adherence, improving or maintaining lifestyle and interacting with health care professionals. Many patients also face difficulties in their personal life, regularly take many medications, and report that their condition limits their ability to carry out daily activities.

A literature review was conducted to assess intervention effectiveness at improving self-management ability among those with Diabetes, Heart Failure and COPD.

Self-care practices are widely varied and are beneficial to anyone, regardless of health status, as they can contribute to maintaining good health or promote improvements to health. Current evidence shows a broad range of self-care interventions (both clinical and behavioural) are effective at improving health outcomes. For the purpose of this review we focus on those directed at promoting healthy lifestyles and management of the three LTCs within scope: diabetes, heart failure and COPD.

The following behaviours and their outcomes make a direct contribution to improving LTC management as they are

3.1 General self-care

factors which impact on the development and/or worsening of symptoms for diabetes, heart failure, and COPD.

Autonomy, understanding self-care and self-responsibility - Not being passive in one's own care and understanding personal responsibility for health varies between individuals. Those with low levels of activation, or sense of control in managing health, have a greater risk of attendance at A&E, hospitalisation or being readmitted to hospital after discharge (13). In contrast,

people who show self-responsibility for their health are more likely to engage in healthy lifestyle behaviours. The current ways in which services are delivered to people may not be set up to support individuals' and families' understanding of their role in their own health, instead taking a paternalistic view historic to the set-up of the NHS.

Healthy Diet - Self-care related to diet can be challenging as often it is focussed on modifying existing behaviour rather than learning a new behaviour such as doing more exercise. This involves changing habitual behaviours that are embedded in culture and may have social consequences (42). In England, average intake of saturated fat, sugar, and salt are above recommendations while intake of fruit and vegetables, oily fish, fibre and some vitamins and minerals are below recommendations in some groups (43). Poor diet is a risk factor for being overweight or obese and makes a significant impact on an individual's physical and mental health and wellbeing (44).

Weight control - Carrying excess weight can have significant implications for an individual's physical and mental health. Being overweight or obese is linked to a

wide range of diseases, most commonly: type 2 diabetes, hypertension, some cancers, heart disease, stroke and liver disease. Of all risk factors for ill health, obesity is the leading cause of premature death and morbidity (45). Additionally, obese adults are more likely to suffer from stigma, hence being obese is associated with poor psychological and emotional health, and poor sleep. Causes of weight gain and obesity are multi-factorial, including: biological, physiological, psycho-social, behavioural and environmental factors (46).

Physical activity and exercise - The Chief Medical Officer (CMO) currently recommends that adults undertake a minimum of 150 minutes (2.5 hours) of moderate physical activity per week, or 75 minutes of vigorous physical activity per week or an equivalent combination of the two, in bouts of 10 minutes or more. The overall amount of activity is more important than the type, intensity or frequency (47). NICE also has a number of clinical pathways that highlight the role of physical activity in preventing and managing illness (48).

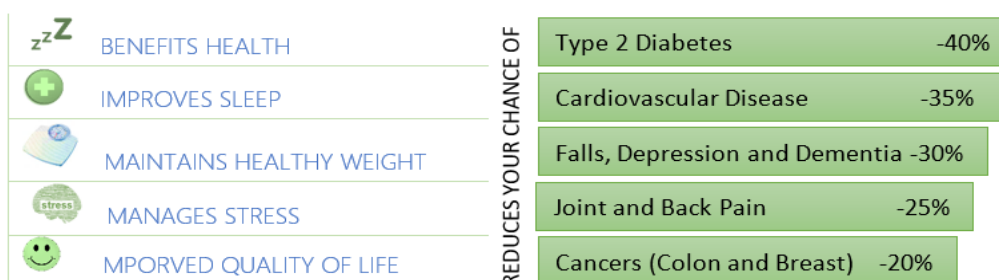


Figure 3.1: Effects of physical activity on health

Strong evidence demonstrates the benefits of physical activity in the prevention of ill-health, maintenance of good mental health and rehabilitation of LTCs, such as, cardiac rehabilitation, pulmonary rehabilitation and reducing weight etc... (44) However, people's physical activity levels are influenced by numerous factors, including: whether their job involves sitting at a desk, their physical health status, social networks and the environment they live in. This makes it difficult for people to follow health professionals' recommendations.

Smoking cessation - Smoking is a modifiable lifestyle risk factor; effective tobacco control measures can reduce the prevalence of smoking in the population (49). However, smoking is still the one of the greatest causes of preventable ill health and premature mortality in the UK. NHS Digital estimates that 484,700 hospital admissions in 2016/17 were attributable to smoking (50). It is a major risk factor for many diseases, such as lung cancer, COPD and heart disease (49).

3.2 Interventions for lifestyle change

Changing behaviours has always proven to be a very challenging task for both health providers and patients. Simple advice about behaviour change is very common practice in our healthcare system; however, there is no evidence of this intervention being effective by itself. A study from 2008 found that there are as many as 137 behavioural change techniques (BCTs) used in primary care (51). Although challenging, it is vital to understand which interventions are the most

effective at empowering patients to make better choices and improve their lifestyle.

When it comes to primary care, a review of evidence from 2012 (52) shows that the most effective ways to support patients to change their behaviour is through behavioural counselling, motivational interviewing, and education and advice. Nevertheless, when it comes to education and advice, a more patient-centred approach seems to be most effective.

There is a lack of evidence to advocate for one particular model over another. However, clusters of intervention techniques particular to behaviours targeted at specific long term conditions (which patients are at risk of or suffer from) which are described in detail by Michie et al (53) could be more effective. For example, for dietary behaviours, applying a theoretically specified cluster of 'self-regulatory' intervention techniques may improve effectiveness (54).

Furthermore, the structure and delivery of the programme is essential to its success.

3.3 LTCs and Self-management

Patients at risk of developing CVD or Type 2 Diabetes, for example, have improved outcomes when the interventions target both diet and physical activity, involve a planned use of BCTs, have a clear plan for supporting the maintenance of behaviour change, and have medium to high frequency contact with patients (54). Because of this added complexity, it is difficult to evaluate whether certain methods such as health coaching and counselling are effective, hence the inconsistent study results (55).

The National Diabetes Prevention Programme (NDPP) is an example of a successful delivery model and combination of BCTs. The national roll-out was based on extensive evidence around lifestyle interventions being effective at preventing type 2 diabetes (56; 57; 58). The structure of the programme also follows NICE guidelines (59), which suggests ongoing tailored advice, support and encouragement, involvement of a family member or friend, use of self-regulatory techniques, and application of a combination of BCTs. Examples of BCTs are: exploration and reinforcement of reasons to change, setting goals, action planning, developing coping plans and relapse prevention. A PHE report (60) on return on investment (ROI) for cardiovascular disease prevention interventions found the NDPP to be the most cost effective of all lifestyle interventions studied; it was the only one to return higher savings over a 20-year period, without monetising health benefits. When taking into account health benefits, NHS England estimates an economic net benefit of £1.2bn over 20 years for a 5-year cohort (390,000 patients) at £270 average cost per patient (61).

How people cope with LTCs varies broadly and is dependent on a range of factors. Self-management requires people to actively monitor their disease, take medication as prescribed, improve or maintain their lifestyle, and interact with healthcare professionals while also maintaining a healthy social life. Evidence shows a third of people with LTCs encounter problems in their personal and social life, such as

financial, marital, employment and housing (62). Furthermore, an estimated 19% of the population in the UK take 5 or more medications on a regular basis (63). Research shows as many as 50% of patients with chronic conditions do not take their medicines as intended (64; 65)

Carrying out basic tasks and activities that support daily life and also general health can become more of a challenge. For example, the 2018 GP Patient Survey (GPPS) reported that among those with a long-term physical or mental health condition, disability or illness, 19.2% responded 'yes a lot' and 39.5% answered 'yes a little' to the question "Do any of these conditions reduce your ability to carry out your day-to-day activities?" (63). Evidence shows that a third of adults with cancer have difficulty with basic activities for daily living such as personal hygiene and walking (66). People with dementia find it more difficult to bathe independently amongst other things (67) and people who have had a stroke may find basic tasks such as walking and eating a challenge (68).

When it comes to disability, whether someone was born with the disability or acquired it during their life plays a great role in how they deal with it. Additional to the physical and psychological burden, people with disabilities can experience an increased level of fear. For example, people suffering from joint or muscle pain can experience kinesiophobia, the fear of movement. Evidence shows that higher levels of kinesiophobia are directly associated with increase in levels of pain and disability and reduced quality of life over time (69).

3.3.1 Diabetes

KEY FINDINGS

Within primary care, there are Quality Outcome Framework (QOF) indicators in place to support diabetes care, such as referrals to structured education. NICE guidelines also recommend 8 care processes to be received annually, including measurement of cholesterol, blood pressure and HbA1c. These support effective condition management, yet many patients do not receive all processes.

Other NICE guidelines for diabetes self-care include: receiving individualised care, tailored to patient needs and circumstances such as comorbidity and polypharmacy; dietary and weight loss advice integrated in a personal management plan, with targets set for those who are overweight; self-monitoring of blood glucose for patients on insulin, with annual structured assessment of skills in interpreting results and action to take; and being offered structured patient education at time of diagnosis with annual reinforcement and review.

Structured education for diabetes has been implemented nationally, with one example being DESMOND. DESMOND includes face-to-face education covering, for example, understanding glucose and complications, lifestyle choices and medication adherence. Although lacking long-term behavioural change, improvements in patient activation and HbA1c levels have been found.

Evidence also suggests potential for multi-faceted interventions, such as the addition of blood glucose monitors to education, with positive long-term biomedical outcomes seen. Family orientated education is also promising via face-to-face or telephone methods with improvements found in blood glucose monitoring, foot care and cholesterol. The face-to-face method had additional benefits in diet and physical activity.

Peer support programmes involve bringing together people sharing similar life experiences and characteristics. There are mixed results of effectiveness in primary care settings in clinical outcomes, self-efficacy and treatment adherence. A meta-analysis showed that these programmes may be more effective for those of minority groups when culturally appropriate interventions are delivered. Self-efficacy also needs to be integrated to support long-term behaviour improvements.

MHealth, mobile phones and other wireless technology such as webchats, are commonly used as educational tools to support preventative behaviours. Technology-enabled education and support programmes for diabetes self-management have potential to improve outcomes, while increasing access and decreasing costs. Studies have found that educational support programmes delivered by such methods improve glycaemic control, with one study showing this in the long-term along with improvements in self-efficacy. Such methods may be most effective when all feedback loop components are included: 2-way communication, patient data analysis, and individualised education and feedback. They may also not be as effective amongst specific demographics, such as pregnant women.

There are several essential self-care behaviours that those with diabetes must adopt in order to manage health. These include healthy eating, being physically active, monitoring of blood sugar, being compliant with medications, having good

problem-solving skills, healthy coping skills and risk-reduction behaviours (70). These seven behaviours have been found to be positively correlated with good glycaemic control, reduction in complications and

improvement in quality of life (71; 72; 73; 74).

Care provided to adults with diabetes should be patient-centred and involve individualised care planning. Patients should have the opportunity to make informed decisions about their care and treatment in partnership with healthcare professionals. Older adults with type 2 diabetes also need to have their broader health and social care needs considered, due to the greater likelihood of co-existing conditions and a potential greater number of medicines (75). Their ability to benefit from risk-reduction interventions (for example structured education programmes) in the longer term may also be reduced (75), although age is not a

The NICE guidelines state that all people with a diagnosis of diabetes should receive the following healthcare checks, known as the **nine care processes**, at least once a year (75):

- Glycated haemoglobin (HbA1c) measurement
- Blood pressure (BP) measurement;
- Cholesterol level measurement
- Retinal screening
- Foot checks
- Urinary albumin testing
- Serum creatinine testing
- Weight check
- Smoking status check

²⁰ The QOF is a voluntary reward and incentive programme. It rewards GP practices, in England for the quality of care they provide to their patients and helps standardise improvements in the delivery of primary care.

reason to dismiss recommending such a programme.

There are also specific quality outcome framework (QOF)²⁰ indicators related to diabetes care within the primary care context (76). These include measures such as establishing and maintaining a register of those diagnosed with diabetes by type, referrals into structured education, dietary review by a suitably competent professional and recording blood pressure.

As discussed in the previous chapter, the national audit of diabetes care in the UK in 2018/19 showed that very low numbers of people with diabetes received all care processes nationwide and locally (36). This indicates that a substantial proportion of people with diabetes may not be receiving the care they need to effectively manage their condition.

In addition to the nine care processes, other NICE guideline actions most pertinent to self-care for type 2 diabetes include the following (75):

Receiving individualised care - An individualised approach tailored to the needs and circumstances of the person. For example, taking into account their personal preferences, comorbidities, risks from polypharmacy, and ability to benefit from long-term interventions because of reduced life expectancy. This approach is especially important in the context of multimorbidity.

Dietary advice and weight loss - Dietary advice should be integrated within a personalised diabetes management plan, including other aspects of lifestyle modification such as increasing physical activity and losing weight. For adults with type 2 diabetes who are overweight, an initial 5-10% body weight loss target should be set. Lesser degrees of weight loss may still be of benefit and larger degrees of weight loss in the longer term will have a positive metabolic impact.

Self-monitoring of blood glucose - Self-monitoring of blood glucose should be offered to patients on insulin. Patients who self-monitor their blood glucose levels should receive a structured assessment at least annually to assess self-monitoring skills ensuring the person knows how to interpret the blood glucose results and what action to take.

Be offered patient education - Adults with type 2 diabetes, and/or their family members or carers, should be offered structured education at or around the time of diagnosis, with annual reinforcement and review. Patients and their carers should be advised that structured education is an integral part of diabetes care.

3.3.1.1

Structured education for diabetes

NICE guidance states that adults with type 2 diabetes should be offered a structured education programme at diagnosis (77). Structured self-management education programmes have been implemented nationally for diabetes.

The Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) intervention is one such programme and delivers face to face educational courses. This covers, for example, thoughts and feelings of the participants around diabetes; understanding of diabetes and glucose; understanding of risk factors and complications associated with diabetes; monitoring and medication; food choices; and physical activity amongst other things. The DESMOND programme has been shown to significantly increase patient activation and improve glycated haemoglobin (HbA1c) levels (78; 79), although evidence has demonstrated a lack of significant sustained biomedical or lifestyle outcomes in the long term (80).

Diabetes Education

DESMOND (Diabetes Education and Self-Management Programme for Newly Diagnosed Diabetics) has been very successful in increasing a patient's understanding on how to manage their condition. It has also improved high blood glucose levels in diabetics. But is it sustainable long term?

In America, the Livongo for Diabetes Programme combines coaching with a certified diabetes educator and blood glucose monitors in order to reduce the occurrence of abnormal blood sugar readings. A 2017 study (81) conducted on 4,544 diabetes patients looked at the effectiveness of the programme. Over one year, results indicate an 18.4%

decrease in the likelihood of low blood glucose (hypoglycaemia) and 16.4% decrease in high blood glucose (hyperglycemia) compared with baseline. The addition of a two-way messaging device delivering blood glucose readings

Diabetes Education – a Family Oriented Approach

Self-Care behaviours, such as better diet control and more physical activity, increased where patients had face to face group sessions with peers

in real time to an otherwise standard education support programme explores the potential of multifaceted interventions for diabetes self-care.

Whilst many education-for-self-care programmes focus on educating the patient, it is worth exploring more family-oriented approaches. A 2017 randomised controlled trial tested the effectiveness of a family-oriented intervention for diabetes patients. The control group was compared to two groups: one group received the education programme in face-to-face sessions, and one group received the education over the telephone. Overall, self-care behaviours increased. For example, blood glucose monitoring, and lipid profiles significantly improved in the groups receiving the education when compared to the control group. Face-to-face sessions had better results for dietary adherence and physical activity while both intervention groups had comparable results for blood glucose monitoring, foot care and cholesterol

levels (82). The family-oriented education trial also demonstrates the potential value of telephone engagement in delivering effective diabetes support.

3.3.1.2

Peer Support Programmes

Peer support programmes are characterised by bringing together a group of people who are sharing similar life experiences or characteristics. Peer health coaching relies on the premise that the patient will connect better to people who have had similar experiences. They have been proven to be effective in primary care settings, but mostly for people who are part of a minority group (83; 84). Randomised control studies have found mixed results in regards to improvement in clinical markers such as HbA1c or secondary outcomes such as self-efficacy or adherence to treatment for the general population (83; 84; 85; 86; 87). Self-reported change in ability to self-care post this type of intervention tends to be positive (87). Yet, there were no definitive answers about the effectiveness and

Peer Support Groups

Where a group of people share similar life experiences and can relate to each other. This has been shown to be positive for minority groups, but changes have not been sustained long term.

possible impacts of these interventions. Despite finding overall small, but statistically significant improvements in HbA1c, a recent (2016) meta-analysis

concluded that peer support programmes are more effective for minority groups (84). When the researchers looked at ethnic subgroups in seven studies, the effect size between the subgroups was statistically significant. However, these results were only seen when culturally appropriate interventions were delivered. Moreover, improvements in behaviour are not always sustained long term post intervention. In order to make results last longer, a focus on patients' self-efficacy and illness perception needs to be integrated into the intervention (88).

3.3.1.3

Technology enabled diabetes self-management

Technology-enabled diabetes self-management education and support was examined in a 2017 systematic review. The results found that the most effective interventions incorporated all components of the feedback loop: 2-way communication, analysis of patient generated health data, tailored education and individualised feedback. These elements should therefore be considered when designing and implementing self-management education and support programmes for diabetes patients (89).

The use of technology, such as webchats and mobile health (mHealth), has the potential to reduce the cost while increasing the accessibility of tailored health education. Mobile health (mHealth) is a general term for the use of mobile phones and other wireless technology in medical care. A common use of mHealth

are educational tools to support preventative behaviours; this makes it well placed for promoting and supporting self-management of conditions.

In China, a diabetes education programme delivered to Type 2 diabetes patients via webchat saw a significant improvement in HbA1c and diabetes management self-efficacy scores at 6 and 12-months follow-up when compared to the control group (90). This suggests that health education of diabetic individuals via a webchat platform in combination with conventional diabetes treatment could therefore improve glycemic control and positively influence other aspects of diabetes self-care skills.

Similarly, a tailored self-management support programme delivered to mobile

Technology and Diabetes

By tailoring educational programmes through patient feedback, digital platforms could be very successful in managing diabetic individuals.

A study in China highlighted that using a web-based chat platform to educate diabetic patients while undergoing their usual diabetic treatment, improved their overall symptoms.

phones via text message (91) resulted in modest improvements in glycaemic control in a group of 366 adults with poorly controlled diabetes. While the clinical significance of these results is unclear, they support the potential of mHealth interventions to assist in diabetes self-care.

3.3.1.4

Two-way monitoring of diabetes

My Diabetes My Way (MDMW) is an online monitoring programme launched in 2008 by NHS Scotland to support patient with diabetes to self-care. In the first year the page was accessed more than 1,400 times. Eight years later, in 2016, the MDMW information website received an average of 101,382 page accesses per month (56.9% increase from 2015) with an average of 1,907 users each month (92). However, findings show that the patients more likely to use the resource are of white background and younger than the average population with diabetes.

My Diabetes My Way Survey results from 2015 show that (92):

- 90.3% of users said that the website helped them improve their knowledge of diabetes;
- 89.3% said that accessing their information helped to improve their motivation
- 89.6% said that accessing the online information has helped them make better use of consultation time;
- 95.9% found the graphs on the website helpful to monitor changes; and
- 83.5% said that online access to diabetes information helped them meet their diabetes goal.

A similar programme, HeLP-Diabetes, was studied in a randomised control trial of 374 diabetes patients from 21 primary care practices in England. The programme is based on an interactive web-based, theoretically informed, self-management platform. Participants in the intervention group had, on average, 0.24% lower HbA1c scores than those in the control, a difference that was found to be significant ($p=0.014$). Subgroup analysis found participants who had been more recently diagnosed with diabetes experienced a beneficial impact on their diabetes-related distress after using HeLP (93). The NHS Long Term Plan suggests rolling out HeLP-Diabetes nationally in 2020.

While online monitoring tools have been shown to have a positive impact on self-care for general groups, evidence for effectiveness amongst specific demographics is not as strong. For example, a web-based support programme trialled on 174 pregnant women with type 1 diabetes showed no improvement for general wellbeing or self-efficacy of diabetes self-management. The web-based support consisted of evidence-based information, a self-care diary for monitoring of daily activities and reporting of self-measured blood glucose, and peer support in a discussion forum. Low activity levels and stressors of motherhood were cited as potential reasons for the lack of efficacy (94).

3.3.2 Chronic obstructive pulmonary disease

KEY FINDINGS

NICE guidelines that support COPD self-care include: development of individualised self-management plan with patients and their family; development of individualised exacerbation plans for those at risk to encourage prompt response to symptoms; and implementation of telephone health interventions. A good individualised self-management plan should have regular review and include a cognitive behavioural component to support patients to cope with breathlessness and anxiety. Other key NICE recommendations include: smoking cessation; assessment of inhaler technique at start of and during treatment; referral to pulmonary rehabilitation, for new patients and within 4 weeks among those admitted to hospital for acute exacerbations; and vaccinations (annual flu and pneumococcal) and anti-viral therapy.

Self-management training is considered increasingly important to the clinical practice of COPD treatment and management, providing emotional support and supporting health behaviour change. A meta-analysis found such interventions effective in reducing respiratory related and all-cause hospital admissions, and long-term improvements in health-related quality of life. Success is dependent on co-operation with health care professionals, with training including how to develop exacerbation action plans more effective in above outcomes.

Pulmonary rehabilitation is a key recommended approach for COPD, with exercise an important component, and can also include other interventions (e.g. education, psychological support, dietary advice). There's strong evidence for effectiveness, with improvements found in health-related quality of life, clinical symptoms (breathlessness and fatigue), and sense of control.

Care bundles are packages of interventions intended for delivery during hospital stay, including: checking inhaler technique; providing written COPD management plan and medicines; assessing willingness to stop smoking and suitability for pulmonary rehabilitation; and arranging a 2-week post-discharge follow-up. However, very few patients receive all 5 interventions, suggesting that there is implementation difficulty.

There is insufficient evidence for effectiveness of computer or mobile technology in supporting COPD self-management. A Cochrane review found some improvements for health-related quality of life versus face-to-face/hard copy delivery, but it's unknown whether this is sustained long-term. One study included also found no effect on health behaviours, and engagement with the programme, crucial to technology-enabled effectiveness, was very low. However, local evaluations of Sound Doctor, an online education platform found improved disease understanding and reductions in GP visits.

Telehealth care involves remote data exchange of patient physiological measures and symptoms to optimise and coordinate COPD management, and has been used in primary care alongside coaching to promote smoking cessation, increase physical activity, medication management and action planning. Evidence shows potential for telehealth coaching in improving self-management behaviours among people with COPD, with benefits in related outcomes (increased physical activity rates, receiving a care plan, and provision of an inhaler skill assessment) found.

For the management of COPD there are a range NICE guidelines that support self-care from primary care, community care and secondary care upon discharge (95). One of the guidelines focuses directly on self-management and includes actions such as:

- Development of an individualised self-management plan in collaboration with the patient and their family members or carers, and reviewing the plan at regular intervals;
- Development of an individualised exacerbation action plan in collaboration with each patient who is at risk of exacerbations, and encouraging them to respond promptly to exacerbation symptoms by following their action plan;
- Discussing and reviewing treatment options;
- Considering a cognitive behavioural component in their self-management plan to help them manage anxiety and cope with breathlessness; and
- Implementing Telephone Health Interventions.

Furthermore, there is a strong association between lower socio economic status and COPD incidence and outcomes; therefore, interventions should focus on reducing health inequalities in this group (96).

Other key recommendations from NICE include, but are not limited to, the following:

Stop smoking - All COPD patients still smoking, regardless of age, should be encouraged to stop, and offered help to do so, at every opportunity.

Inhaler technique - People with COPD who are prescribed an inhaler should have their inhaler technique assessed when starting treatment and then regularly during treatment.

Pulmonary rehabilitation (PR) - People with stable COPD and exercise limitation due to breathlessness should be referred to PR. People admitted to hospital for an acute exacerbation of COPD should start a PR programme within 4 weeks of discharge.

Vaccination and anti-viral therapy – Patients with COPD should be offered the pneumococcal vaccination and an annual flu vaccination.

Additionally, people with COPD are advised to consider planning ahead daily tasks such as showering or shopping as well as taking steps in response to the weather (certain conditions may exacerbate COPD symptoms such as hot and humid conditions) (97)

3.3.2.1 Self-management training

Self-management training is considered to be an increasingly important component of treatment and management of COPD; it provides emotional support and assists people with COPD to make changes in their health behaviours that will help them to control the disease and lived well. A 2016 meta-analysis (98) of data from 3,282 patients found that self-management interventions resulted in positive effects on respiratory-related and all-cause hospitalisations and modest effects on 12-month HRQoL. This evidence supports the implementation

of self-management strategies in clinical practice.

Exacerbations Action Plans

Self-management interventions with exacerbations action plans have improved the health related quality of life (HRQoL) for COPD individuals. They have also reduced the number of hospital admissions due to respiratory-related conditions.

However, success is dependent on effective co-operation between patient and healthcare providers (99). Using action plans for managing exacerbations of COPD within a self-management intervention provides training for people with COPD to recognise symptoms earlier, accelerate the initiation of appropriate treatment, and lead to better control of deteriorating symptoms. Robust evidence from a Cochrane Review²¹ in 2017 shows that COPD self-management interventions that include exacerbation action plans²² are associated with improvements in health-related quality of life (HRQoL) and lower probability of respiratory-related hospital admissions when compared to 'usual COPD care' (99).

3.3.2.2

Care Bundles for COPD

Care bundles are packages of interventions which aim to improve care and ultimately outcomes. They are intended to be delivered during hospital stay (either at admission or before discharge) and include:

- Checking inhaler technique and medication use;
- Providing a written plan for COPD management and supply of emergency medicines;
- Assessing willingness to stop smoking (where applicable);
- Assessing suitability for pulmonary rehabilitation; and
- Arranging for follow-up within two weeks of discharge.

COPD Care Bundles

Designed to be delivered during hospital stays or prior to being discharged. Care bundles are made up of certain interventions/processes which need to be delivered, to improve care for COPD patients. A recent study showed not all interventions are generally delivered and there is no evidence to suggest that these are effective in preventing readmission or reducing lengths of stay in hospital.

However, a recent large-scale study of 31 NHS hospitals over two years found that

²¹ Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are internationally recognised as the highest standard in evidence-based health care. They investigate the effects of interventions for prevention, treatment and rehabilitation.

²² COPD exacerbation plans provide a guide to the individual to follow if their COPD related symptoms get worse or flare-up (COPD exacerbation).

less than 30% of people admitted with COPD received all five interventions in the care bundle (100). There was also no evidence of benefit found in terms of readmission rates, length of stay or costs. The study suggests that very few tasks were delivered as planned, as care bundles are difficult to implement. More research is therefore needed to find out which components of the care bundles for COPD are hard to implement and why. Until this is understood, the care bundles approach is unlikely to be cost-effective.

3.3.2.3

Pulmonary Rehabilitation for COPD

Pulmonary rehabilitation (PR) is one of the key recommended approaches in the treatment and management of COPD. Exercise is an important component of PR; however, other interventions such as education, psychological support, and dietary advice can be included. There is strong evidence for the benefits of PR. It has been found to improve the health-related quality of life (HRQoL), relieves dyspnoea (breathlessness) and fatigue, improves emotional functioning and enhances the sense of control that individuals have over their condition (101). These improvements are moderately large and clinically significant.

An example of a comprehensive community-based rehabilitation programme for COPD patients is COPE-active in the Netherlands. It is a community-based physiotherapeutic exercise programme within a self-

Pulmonary Rehabilitation

Evidence highlights that exercise can significantly improve COPD symptoms, such as breathlessness and fatigue. A PR programme in the Netherlands showed that the exercise programme enabled patients to effectively maintain higher levels of daily physical activity after 2 years. Although, the intervention did not increase their maximal exercise ability, it was still effective in allowing patients to maintain daily physical activity.

management programme, with a main goal of achieving behaviour change towards exercise in daily life. One study of 153 participants randomly assigned them to either the intervention (COPE-active) or the control group. All patients attended four self-management sessions, and patients in the intervention group participated in an 11-month community-based exercise programme led by physiotherapists. Intervention group patients trained three times per week for six months and two times per week during the subsequent five months. Results found the exercise programme to be effective in maintaining higher levels of daily physical activity (avg. 1193 steps per day more) after 2 years. However, the intervention did not result in increased maximal exercise capacity (102).

3.3.2.4

Computer or mobile technology

A Cochrane Review in 2017 evaluated the effectiveness of interventions delivered by computer and mobile technology versus face-to-face or hard copy/digital documentary-delivered interventions, or

Technology and COPD

There is insufficient evidence to suggest that the use of technology, over face-to-face or digital interventions, is more effective in supporting COPD self-management.

both, in facilitating, supporting, and sustaining self-management among people with COPD. The review showed some evidence for improvements to HRQoL but it is unknown whether this can be sustained past 4 months. Overall, there is insufficient evidence of effectiveness of computer or mobile technology as a means to support COPD self-management (103).

One of the studies in the above review, a 2015 Dutch trial, tested the effectiveness of a web-based, computer-tailored COPD self-management intervention on physical activity and smoking behavior. Of the 1,325 participants, 1,071 (80.8%) completed the 6-month follow-up questionnaire. No significant treatment effect was found for either physical activity or smoking. However, the web application was used by only 36% of the participants in the experimental group. As

engagement with the programme has been shown to be crucial for the effectiveness of computer-tailored interventions, this may be the reason for lack of efficacy (104). It is key to ensure that patients attend support sessions and make regular use of resources in order to achieve self-care benefits.

3.3.2.5

Telehealth for COPD

Telehealth care involves the remote data exchange of physiological indicators and symptoms, allowing health care personnel to optimise and coordinate the management of individual patients' chronic disease. To evaluate the effectiveness of telephone health coaching on COPD self-management, 577 patients from 71 general practices in England participated in a trial of a telehealth coaching intervention. The coaching was delivered by a nurse to support self-management in a primary care population with mild symptoms of COPD. The intervention was underpinned by Social Cognitive Theory and the

Telehealth and COPD

There is great potential in implementing telehealth interventions to increase self-management activities in COPD patients. A trial study showed that the COPD individuals who received coaching by a nurse on self-management reported more physical activity, with more receiving a care plan, antibiotic rescue packs, and inhaler use technique demonstrations.

coaching promoted accessing smoking cessation services, increasing physical activity, medication management, and action planning (4 sessions over 11 weeks; postal information at weeks 16 and 24). The control group received a leaflet about COPD and no coaching. Compared with patients in the control group, the intervention group reported greater

physical activity, more had received a care plan, rescue packs of antibiotics, and an inhaler use technique check. However, there was no difference in HRQoL scores between the groups after 12 months. This trial shows potential for telehealth interventions to increase self-management activities in COPD patients (105).

3.3.3 Heart Failure

KEY FINDINGS

NICE guidelines state that certain actions should be done to support people with heart failure to self-care. These include giving the person regular monitoring & clinical assessments, providing lifestyle support, and offering personalised rehabilitation & vaccination programmes.

A Cochrane review found evidence that cardiac rehab leads to a reduction in hospitalisation of people with heart failure, and an improvement in health-related quality of life. Evidence from the review suggested that these improvements are seen if people with heart failure have access to *any* level of cardiac rehab.

There is some evidence that collaborative care – where the patient is seen by a range of health professionals, rather than just their GP – can potentially help in supporting people with heart failure to self-care. A study on heart failure patients who were engaged in a symptom-directed, collaborative care (CASA) intervention showed a reduction in levels of depression and fatigue experienced by participants.

Mental health issues are common in people with heart failure, and can have an impact on a person's self-care behaviours. Depression can increase the risk of hospitalisation and mortality in people with heart failure. Cognitive Behavioural Therapy has been shown to be an effective treatment for depression in people with heart failure.

There is mixed evidence on the effect telehealth interventions have on people with heart failure.

For most people, heart failure (HF) is an LTC that can't be cured. Nevertheless, treatment can help keep the symptoms under control, possibly for many years. Three key self-care behaviours important to health outcomes include medication adherence, diet (low sodium intake), and seeking timely medical care for escalating symptoms (5). Patient's ability to recognise symptoms and take

appropriate steps in a timely manner is an area where self-care commonly fails (5).

As with diabetes and COPD, treatment and care for those with HF should take into account the needs and preferences of the patient. It is recommended that patients, in partnership with healthcare professionals, are involved in making informed decisions about their care and treatment.

NICE guidelines state a number of actions that should be followed in order to provide the person with the best care and best chance of self-managing their condition effectively; these include, but are not limited to:

Monitoring treatment – regular monitoring including clinical assessments, cognitive status, nutritional status and reviews of medication. More detailed monitoring if the patient has significant comorbidity or if their condition has deteriorated since the previous review;

Advice and support around lifestyle support - Patients with HF should receive lifestyle advice including salt and fluid intake, advice about not smoking and alcohol consumption;

Cardiac Rehabilitation (CR) - Adults with stable HF should be offered personalised, exercise-based CR programme. The service should include a psychological and educational component; and

Vaccination and anti-viral therapy - Patients with HF should be offered the pneumococcal vaccination and an annual flu vaccination.

Evidence demonstrates that patients with HF can be supported to change their self-care behaviours and have better health outcomes. However, not all interventions are effective (106). A recent meta-analysis of 20 randomised trials (5624 patients) evaluating self-care interventions in HF patients found that interventions of longer duration reduced mortality risk, risk of HF related hospitalisation, and HF-related hospitalisation at 6 months post-intervention (106).

3.3.3.1

Cardiac Rehabilitation

A Cochrane review of 44 trials of exercise-based CR found improvements in HRQoL, and all-cause and HF-specific hospitalisations (although did not reduce risk of all-cause mortality). Additionally, when looking at the structure of the programmes and delivery, improvements appeared to be consistent, with no differential effects found. This suggests that no matter how comprehensive the programme is, it is likely to see positive patient outcomes (107).

A simple intervention that does not

Cardiac Rehabilitation
With consistent results and improvement in the health related quality of life in HF patients, cardiac rehabilitation programmes have yielded positive outcomes for patients.

require a lot of resource to support is diary use. Evidence has shown that patients who were engaged in diary use to monitor weight and symptoms had better survival rates (108).

3.3.3.2

Close Symptom Monitoring

The Collaborative Care Model (CCM) has previously been proven to be effective for a number of mental health conditions and emphasises the need for close monitoring of patient progress and systematic adjustments to treatment. CCM incorporates three core concepts:

population-based care, measurement-based care and stepped care. In CCM, provision of care and health outcomes are defined based on the population of patients; each patient's progress is closely tracked using validated clinical rating scales; treatment is systematically adjusted, i.e., if patients do not improve as expected, initial adjustments can be made.

A 2017 trial explored the efficacy of CCM for HF patients (109) by administering the intervention to an experimental group and monitoring the results through caregivers and the case nurse. Compared with usual care, CCM significantly enhanced self-care abilities of patients with chronic HF, including self-care maintenance, self-care management and confidence. Moreover, CCM significantly improved the physical and mental quality of life of participants. This suggests that, compared to usual care,

Collaborative Care Model (CCM)

The provision of care in CCM is based on the population of patients receiving a personalised and collaborative approach, between the care team and caregivers, for the patients' health needs.

A CCM trial for HF patients showed that their overall physical and mental quality of life significantly improved, in comparison to receiving the usual care for HF.

a personalised, collaborative approach has the potential to improve self-care, quality of life and the cardiac function of patients with HF.

However, a further study (110), involving a multidisciplinary, symptom-directed, collaborative care intervention (CASA) did not show any health outcome improvements in patients with HF. The CASA intervention included three components: symptom care by a nurse, psychosocial support by a social worker, and palliative care, treatment review and tests by a specialised multidisciplinary team. The intervention was focused on the patients' choice of one of the following symptoms: pain, breathlessness, fatigue, or depression, and was carried out mostly by telephone. There were no significant changes to heart-failure specific health outcomes or mortality, but there was an improvement seen in secondary outcomes such as depression and fatigue.

Overall, this suggests the collaboration of the care team with caregivers might be more effective in improving health outcomes and self-care ability in heart failure patients rather than adding highly specialised professionals to the team.

3.3.3.3

Structured Education for HF

There is limited evidence to show how structured education (SE) impacts the ability to self-care in HF patients. The delivery of SE can take multiple forms and can be delivered by varied clinical and non-clinical staff. Current evidence focuses on groups of patients from rural areas, and has found improvements in self-management skills and self-care behaviours, but limited impact on rehospitalisation.

For example, one trial was conducted in rural China, a trial of a nurse-led structured educational intervention (111) delivered during hospitalisation and after discharge. This resulted in improved self-management skills in patients with chronic HF and reduced the readmission rate within the first 12 months of implementation.

Structured Education for HF

Currently there is not enough evidence to highlight whether SE is effective in impacting a patient's ability to self-manage their HF condition.

Results from clinical trials in rural areas have highlighted different results, though the programme structure was similar. One trial reduced the readmission rate within first 12 months after an SE intervention, but a similar trial elsewhere showed the readmission rate to be higher after 30 days.

A similar study, the PATCH intervention (a home-based activation intervention) was trialled on 100 HF patients discharged from a rural critical access hospital. PATCH consists of a 12-week self-management training and coaching programme delivered by telephone and tailored to clients' activation levels²³. The intervention group reported significantly greater improvement in self-care behaviours (weighing themselves, following a low-sodium diet, taking prescribed medication, and exercising

daily) than the usual care group. These improvements were maintained at 3- and 6-months following discharge. However, the readmission rate after 30 days was higher in the PATCH intervention group (19.6%) than the control group (6.1%) though these differences were not seen at 90 or 180 days (112). This shows that such approaches might be of particular effectiveness for populations which have reduced access to cardiac management services.

3.3.3.4

Mental Health Interventions for HF

A more light touch way of delivering structured education (SE) is through SMS messages or structured telephone support. One study looked at the impact of SMS messages and structured telephone support versus usual care on self-care ability and hospital readmission following discharge.

This intervention involved educational information through text and reminder SMS. The educational messages were condensed with information about HF

Technology and HF

Due to the low cost and positive effects, SMS based interventions and telephone support could be a useful tool for HF patients in self-managing their condition.

²³ Patient activation level is the level of knowledge, skills and confidence an individual has to manage one's own health and healthcare. It refers to one's understanding of the importance of self-managing their condition and the confidence that they can do so. Patient activation is assessed with the Patient Activation Measure (PAM).

(e.g. symptoms of HF decompensation), while the reminder SMS were brief messages that prompted patients to take action (e.g. taking medicine or weighing). It was found that SMS was associated with a reduction in all-cause mortality/readmission at 180 days as well as improved self-care behaviour when compared to usual care (113). Due to the low cost and potential positive effects seen in this trial, this suggests integrating SMS interventions into HF management could be a useful aid.

Cognitive Behavioural Therapy (CBT)

Effective in treating mental health issues and changing behaviour, CBT has been proven to be effective in reducing anxiety and fatigue in HF patients, as well as increasing the health related quality of life. Though there was no improvement in self-care behaviours, this evidence suggests that CBT can improve mental health and quality in life in HF patients.

Depression and inadequate self-care are common, interrelated problems that increase the risks of hospitalisation and mortality in patients with HF. Cognitive behavior therapy (CBT) has been found to be effective in treating a wide range of mental health issues as well as changing behaviour.

A 2015 clinical trial tested the efficacy of a CBT intervention for depression and HF self-care on 158 patients. Compared to usual care, anxiety and fatigue scores were lower while mental health, HF-related QoL and social functioning scores

Telehealth and HF

Evidence suggests that telehealth may not be the most cost-effective option in delivering self-care for HF patients. Trials and studies have showed varying results, with significant improvements in mental health, but no consistent advantages in physical health.

were higher after 6 months in the CBT group. Additionally, fewer hospitalisations were registered for those receiving the intervention. However, self-care behaviours saw no improvements in either group (114). Cognitive behavioural therapy may be an appropriate accompanying therapy for improving mental health and QOL in HF patients.

3.3.3.5

Telehealth for HF Patients

Evidence of telehealth interventions for patients with HF is mixed. For example, an RCT in 2019, demonstrated statistically significant improvements in HRQoL when looking at mental health measures, but not in physical health (115). Similarly, a 2017 meta-review of telehealth interventions to support self-care of long-term conditions (including HF) compared results from 53 systematic reviews (9 of which were HF specific). The meta-review did not find a consistent advantage of telehealth support compared to usual care, though some of the reviews included did indicate reduced mortality and hospital admissions and no negative effects were reported (116). This suggests that telehealth care is a safe option for delivering self-care

support for HF, but may not be the most effective option. A heart failure specific meta-analysis of studies looking at the effectiveness of telemonitoring and telephone support found that cost

effectiveness was dependent on the intensity and the technology used in the intervention. However, most studies showed decreased costs due to fewer hospital stays (117).

3.3.4 Self-care in the presence of multimorbidity

KEY FINDINGS

At the time of this report, there are no QOF measures for multimorbidity. This makes it difficult to look at STP level variation in self-care support offered to people with multimorbidity.

The evidence base on interventions designed to support people living with multimorbidity is underdeveloped and mixed.

A 2012 Cochrane review looking at interventions for improving outcomes in people with multimorbidity found no clear improvements in terms of clinical outcomes, health service use, medication adherence, health behaviours, or cost. Other reviews have shown modest improvements in terms of patient mental health, and functional outcomes.

The review suggests that interventions designed to target specific risk factors (e.g. support with depression) may be more effective.

Multimorbidity is usually defined as the presence of two or more LTCs in the same individual (118). NICE defines the LTCs that multimorbidity can include as being wider than this traditional definition. The guidance also suggests including: ongoing conditions, such as a learning disability condition; symptom complexes, such as frailty or chronic pain; sensory impairments, such as sight or hearing loss; and alcohol or substance dependency (119).

People with multiple conditions face a greater challenge in that they are required to manage multiple medications, treatment and appointments whilst also attempting to maintain their general physical and emotional health.

As of 2018/19, there were no QOF indicators specifically for multimorbidity. However, NICE guidelines published in 2016 set out

key good practice actions that relate mostly to care within Primary Care settings (119). These include:

- The use of validated tool such as eFI, PEONY or QAdmissions, if available in primary care electronic health records, to identify adults with multimorbidity who are at risk of adverse events such as unplanned hospital admission or admission to care homes;
- Assessment for frailty within primary care or community care;
- Establishing disease and treatment burden of the patient and being alert to possible mental ill-health; Reviewing ways to reduce treatment burden, for example through non-pharmacological means; and

- Establishing patient goals and ways to stay independent, and agreement of an individualised management plan.

The evidence base on interventions designed to support people living with multimorbidity is still underdeveloped (120). This group are the most challenging to support particularly through a single intervention or activity. For example, a Cochrane Review in 2012 (121) of interventions for improving outcomes in patients with multimorbidity in primary care and community settings found mixed results. There were no clear positive improvements in clinical outcomes, health service use, medication adherence, patient related health behaviours, health professional behaviours or costs. However, seven studies included in the review illustrated modest improvements in mental health outcomes for patients with depression. Two other studies targeting functional difficulties in participants also found improvements in functional outcomes. The review suggests that interventions designed to target specific risk factors (for example treatment for depression) or interventions focused on difficulties that people experience with daily functioning (for example physiotherapy treatment to improve capacity for physical activity) may be more effective.

Patients with COPD and chronic HF face similar problems relating to breathlessness and disability. Research in the UK in 2016, suggests that existing pulmonary and cardiac rehabilitation services should seek to provide sufficient flexibility to accommodate patients with both

conditions. Development of new services could consider adopting a patient-focused rather than disease-based approach. Exercise training is a core component, but rehabilitation should include other interventions to address wider symptoms such as breathlessness, psychological and educational needs of patients and needs of carers (122).

3.4 Patient Activation and PAM

There is growing evidence that person-centred approaches to care can lead to improved health outcomes, especially for people with multiple conditions (120). Patient activation describes the knowledge, skills and confidence a person has in managing their own health and care. People with greater patient activation benefit from better health outcomes, improved experiences of care and fewer unplanned care admissions (13). Rather than making assumptions about a person's ability to self-manage, tools such as the Patient Activation Measure (PAM) can help determine which types of support people may need by building on existing capabilities.

The Patient Activation Measure (PAM) is particularly helpful at assessing the activation level and quantifying improvement. To assess the activation level, individuals are asked to answer a series of questions and are scored accordingly. The total score places the individual at one of the four levels of activation, from level 1, where individuals tend to be disengaged and overwhelmed, to level 4, where

individuals are highly engaged in their care and have adopted many healthy behaviours.

However, understanding the level of patient activation is not sufficient for a successful intervention; support needs to be built on assessing and addressing barriers faced by ill patients. A recent study of more than 12,000 PAM questionnaires from 9,348 patients found that the most activated patients (level 4) have the lowest utilisation

of healthcare, with fewer GP appointments, outpatient and A&E attendances, or emergency admissions (123).

Following the Kings Fund Report on patient activation (13) in 2014, the NHS has piloted PAM in 5 CCGs and the UK Renal registry. Due to positive results, in partnership with Insignia Health, NHS purchased licenses and pushed for a national use of PAM. By April 2019, 138,000 licenses were used across more than 100 sites nationwide.

3.4.1 Barriers to self-care

KEY FINDINGS

Factors affecting self-care do not act in isolation. Self-care should not be thought of solely at an individual level – family and community play a large role in encouraging self-care.

A 2019 literature review by the Aubrey Keep Library & Knowledge Service identified two types of barriers to self-care: the built system and personal factors:

- Built system barriers include access to services. This barrier particularly affects people with multimorbidity, due to a lack of access & coordination, poor communication between service providers, and little to no data sharing. People in vulnerable or underrepresented groups are also affected by this barrier. They often find it harder to access services. This can act as a driver for health inequalities.
New models of care and integrated care partnerships are aiming to reduce these inefficiencies
- Examples of personal factors which impact on self-care are where people live (personal home & community), and the work they are employed in. Personal home & community barriers include transport links, and the level of support people receive from close friends & family members. Experience of stigma or lack of support from close friends & family members can negatively influence a person's capability to self-care.

A recent metasynthesis by Schulman & Green found that three major factors which influence self-care are financial resources, self-care equipment, and psychosocial support. Access to, or lack of, any of these factors can have a large impact on a person's capability to self-care.

Personal characteristics also have an impact on self-care. An individual's culture and beliefs play a role in self-care, and health professionals should be mindful of this when supporting people to self-care. A lack of knowledge about their long-term condition, and life transitions (such as losing a job, or birth and bereavement) have also been identified as potential triggers which make it hard to maintain self-care routines.

To better support people to increase their activation and ability to self-care, it is essential that healthcare professionals assess the existing barriers to accessing resources and building the skills required to self-care for individual patients. A recent literature review (December 2019) completed by Aubrey Keep Library and Knowledge Service²⁴ identified evidence that describes barriers in two categories, the built system and personal factors.

The built system refers to both environmental factors and the healthcare system. The healthcare system is particularly inefficient for people with multimorbidity due to a lack of access and coordination, poor communication with and between service providers, and little or no data sharing (124; 125). Access to care services is predominantly a barrier to those who are part of vulnerable groups, acting as a driver for further health inequalities. New models of care and integrated care partnerships are aimed at reducing these inefficiencies; however, while proven to be cost-effective and positively impacting patients' health, implementation is key to their success.

When it comes to the environment, where people live (personal home and community) and work plays a great role in their ability to self-care. For example, the most notable barriers in the community are transportation and availability of healthy food options. The lack of both hinders the ability to adopt healthy lifestyle behaviours. Additionally, relatives and friends can play an important role in negatively influencing a person's capability to self-care. A lack of understanding of one's chronic illness, or,

even worse, stigmatising them for their illness can result in a lack of support and pressure that prevents them from properly self-caring. Simple actions such as serving unhealthy foods at family dinners or social events act as barriers to maintaining or adopting a healthy diet. Furthermore, those who work can face additional barriers to adopting healthy diets, exercising, or complying with their medication dues to time and schedule constraints (125).

Personal characteristics are grouped into three main areas: lifestyle characteristics, health status and resources (see figure 3.1 for more details on the type of barriers in each area).

Some notable examples of lifestyle characteristics that health professionals should be mindful of are those relating to culture and beliefs. For example, studies show that patients of Vietnamese ethnicity might consume foods that are not recommended if offered by others to avoid offending them (125). Furthermore, healthcare professionals should be mindful of patients who are practicing Ramadan or other types of fasting, and advise them accordingly. Patients who come from different cultures might struggle to adhere to a prescribed diet and lifestyle if it is against what they believe in.

Additional to the resistance to change due to culture and beliefs, patients might struggle to adhere to prescribed programmes due to a lack of knowledge about their condition. The health belief model (126), a behavioural change model, explains how understanding of the

²⁴ Evidence search: Barriers to accessing long term conditions self-management interventions. Lisa Burscheidt. (6th December, 2019). ILFORD, UK: Aubrey Keep Library and Knowledge Service.

susceptibility to complications, severity of the disease and benefits of the treatment

are critical to successful lifestyle changes or treatment adherence.

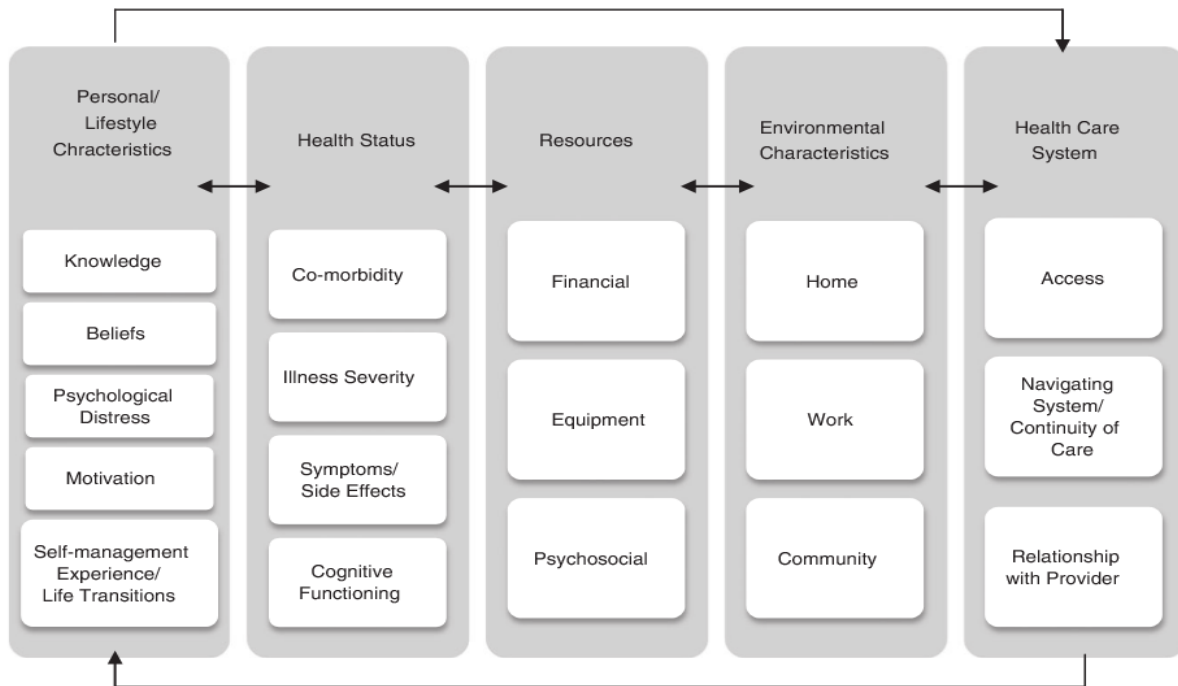


Figure 3.1 Barriers to self-care

Life transitions can also add difficulty to adopting and maintaining healthy changes. For example, the uncertainty unemployment brings, the lack of a structure in a college student’s life, and life changing events, such as giving birth or bereavement, highly impact on adherence to certain healthcare routines (125). Getting older is also a life transition that has been documented to impact on self-care. People of older age might struggle with physical and mental abilities, have comorbidities and other complications, and take numerous medications at a time (127).

Health status also influences how people adhere to self-management practices. Comorbidities and complications add complexity to health regimens, and

contribute to symptoms that reduce one’s self-efficacy²⁵ and overall effort (125). The prescription of numerous medications or treatments, known as polypharmacy, to one individual can result in a high treatment burden and can be difficult and stressful to manage (128). Co-morbid mental health problems can reduce ability and motivation to self-manage, and people with these forms of co-morbidities may need particular support if they are to self-care effectively. It is also complicated by the fact that those with mental health problems also have higher rates of unhealthy behaviours such as smoking, and also higher rates of non-compliance with medication compared to those without mental health as a comorbidity (129). Recent evidence

²⁵ Self-efficacy is a person's estimate or confidence of his or her own ability to succeed in reaching a specific goal, for example, quitting smoking or losing weight. Enhanced self-efficacy has been shown to be a consistent positive influence self-care.

indicates 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 targets for referral. Peer support may also play an important role in empowering people with co-morbid mental health problems to manage their own condition (130).

According to Schulman-Green's metasynthesis (125), resources that influence self-management include: financial resources, equipment and psychosocial support. Financial resource barriers are more likely to impact on vulnerable groups and play a key role in health inequalities. Financial instability leads people to focus on their economic survival and basic needs, rather than focusing on living a healthy lifestyle or following a prescribed treatment (125). The high cost of medication, healthy foods, and gym memberships can act as barriers to accessing resources that support self-care. Moreover, assistive devices such as smartphones, internet, and other electronic equipment cost patients money if not offered by the care team (125). Additional to the financial burden, the need of such equipment can act as a barrier to people

with lack of digital literacy²⁶. The internet could also hinder the ability to self-care because of the overwhelming amount of information available and the difficulty to distinguish between factual and non-factual information (131).

Factors affecting self-care do not act in isolation, and can interact and affect the ability and motivation to engage in proper self-care (125). Self-care should not be thought of solely at an individual level, but also at the family and community level. Isolation is an important factor that influences people's ability to self-care. People of older age tend to struggle with this the most (132). Peer support groups have been highlighted as extremely beneficial for people, enabling them to find a community and feel supported and connected (125).

3.4.2 Condition specific barriers

Each condition people suffer from has its own particularities and self-care can be affected by barriers specific to that condition. The table below (Table 3) lists the condition specific barriers described by the current literature.

Table 3 LTC specific barriers

| | |
|-----------------|--|
| Diabetes | <p>Personal</p> <ul style="list-style-type: none"> • Health literacy and knowledge , specifically knowledge of a diet plan, lack of understanding of the plan of care (133; 134) • Helplessness and frustration from lack of glycaemic control and continued disease progression despite adherence (133) • Lack of formal education (135) • Language barriers (peer support programmes) • Lack of awareness of existing programmes |
|-----------------|--|

²⁶ Digital literacy refers to an individual's ability to find, evaluate, and compose clear information through writing and other mediums on various digital platforms. While digital literacy initially focused on digital skills and stand-alone computers, the advent of the Internet and use of social media, has caused some of its focus to shift to mobile devices.

| | |
|------|---|
| | <ul style="list-style-type: none"> • Age (135) • Perception that the physician needs to manage the disease with little or no input (136) • Low perception of seriousness and susceptibility to complications (136) • No or low perceived benefits of attending structured education (136) • Polypharmacy as diabetics tend to have comorbidities (134) • Comorbidities, for example shortness of breath could contribute to inability to exercise (128) • Symptoms and side effects, particularly pain and fatigue (128) • Cost of medication or assistive devices (134) • Lack of time – competing priorities (134) <p>Community</p> <ul style="list-style-type: none"> • No social support (134) <p>Care provider and healthcare system</p> <ul style="list-style-type: none"> • Patient-physician communication and relationship (135; 134) • Lack of physician or care provider follow-up with the patient (134) |
| COPD | <p>Personal</p> <ul style="list-style-type: none"> • Patient knowledge and understanding of the disease and beliefs about medication (137; 138) • Health literacy (137) • Language barriers (137) • Cognitive problems (137) • Disease severity (137); Patient frustration with the disease taking over their life (139; 138) • Patient lack of self-efficacy and digital literacy to use digital technology (139) • Patient perception of services being too stretched to treat them (138) • Fear of being judged for unhealthy behaviours – such as smoking (138) • Lack of motivation particularly within older or multimorbidity population (138) • Short time since diagnosis, lack of trial and error, adaption, and normalisation. (138) • Mental health: Anxiety, panic, and fear due to symptoms; frustration, depression, low mood, and worthlessness due to loss of functionality can impact on motivation (138) <p>Care provider and healthcare system</p> <ul style="list-style-type: none"> • Physician time constraints and insufficient resources to create an action plan (137; 138) • Physicians or care providers lacking trust that the patient is able to self-manage or understand the instructions (137; 138) • Physicians lack of knowledge and skills to create an individual care plan or action plan (139; 137; 138) • Physicians feel more comfortable with a traditional health care approach (139; 137; 138) |

| | |
|----|---|
| | <ul style="list-style-type: none"> • Lack of a pathway or structured programme, poor communication between health professionals and lack of understanding regarding referrals (139; 138) • Frustration with conflicting information from health professionals (138) • Patient perception of services being too stretched to treat them (138) |
| HF | <p>Personal</p> <ul style="list-style-type: none"> • Depression (20-30% of HF patients) and depressive symptoms (42; 140) • Cognitive decline (30-75% HF patients) commonly includes: deterioration in memory and learning, attention, executive function, psychomotor speed, and visuospatial recall (42; 140) • Decreased levels of self-efficacy (42) • Physical limitation, feeling a lack of energy (140) • Feelings of hopelessness relating to decision making and motivation for symptom management (140) • Perceived social support (42) • Avoidance, acceptance and/or denial to obtain new information about caring for themselves, and to participate in decision making (140) • Misconception about CHF / medical and regimen adherence (140) • Cultural issues, health seeking behaviours, using herbal medicine (140) • Lack of understanding about the benefit of self-care action such as salt limitation (140) • Financial burden (140) • Side effects of medicine and interference in work and normal life (140) • Multimorbidity (42; 140) • Insufficient knowledge (140) • Poor communication skills (140) • Adverse coping mechanisms (140) • Atypical and puzzling symptoms of CHF (140) <p>Community</p> <ul style="list-style-type: none"> • Loneliness (140) • The size and diversity of one's social network or capital (informal connections available for support, help, and information) (42) • Poor family functioning (140) • Lack of family knowledge/ misconception about treatment preference (140) <p>Care provider and health system</p> <ul style="list-style-type: none"> • Lack of facilities / access to medical care (140) • Conflict between values of patients and nurses (140) • Insufficient knowledge of educators and nurses (140) • Dissatisfaction with care received (140) • Lack of trust physicians / medical system (140) • Confusing or contradictory information provided by multiple healthcare providers (42; 140) • Complexity of the self-care process (140) |

CHAPTER 4

DISCUSSION AND RECOMMENDATIONS

4.1 Impact Modelling

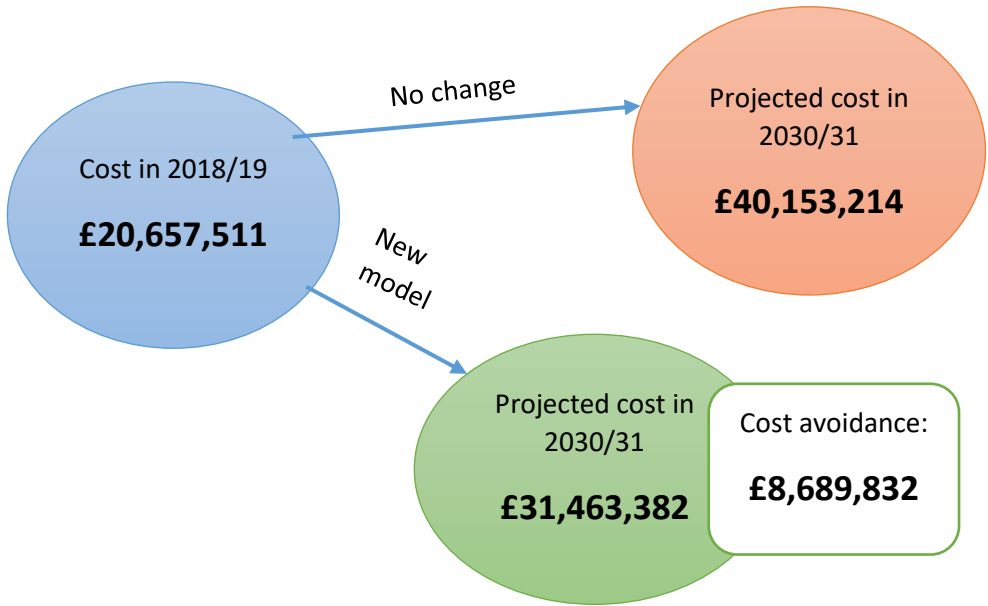
Mid and South Essex, similar to the whole of the UK, is facing pressing challenges and struggling to meet service demand. The STP population is growing and ageing, adding complexity to their needs. The health and social care system needs to rapidly adapt in order to remain financially sustainable and effective. Based on our analysis, in 2018/19 more than £20 million was spent on hospital care alone across the STP for patients with Diabetes, COPD and HF. This is an under-estimation of how much these LTCs cost the system as we only quantified visits to A&E, emergency admissions and elective admissions which were coded as being related to the three LTCs. With no change to how we support patients to self-care, this amount will almost double by 2030 (see figure 4.1).

A good collaboration between service providers and patients, where patients are supported to self-care, is essential to this. The King’s Fund describes this shift as a cultural change towards ‘shared responsibility for health’ and proposes patient activation as a way to conceptualise and measure patient engagement in their own care (141).

The NHS Long Term Plan also highlights the need for a fundamental shift in the way care providers are working with patients and their caregivers. The report calls for a more patient-centred approach where patients are fully involved in planning their care. The 10-year long plan commits to facilitating better support for patients to improve their skills to self-care, particularly for patients suffering from long term conditions (LTCs).

Investments in building a model of care that supports patients to self-care better are

Figure 4.1: Projected acute care cost for diabetes, COPD and HF



proven to be very cost-effective. For example, studies looking at patient activation show that proper support in primary care results in decreasing utilisation of services, specifically in secondary care. With a 20-point increase in Patient Activation Measure (PAM) scores, evidence shows 9% fewer GP contacts (95% CI, 0.89–0.93), 20.90% fewer A&E attendances (95% CI, 0.75–0.83) and 23.3% fewer emergency admissions (95% CI, 0.71–0.83) per person (123). Moreover, increase in PAM scores also contributes to decreased length of stay, fewer hospital readmissions and reduced 'did not attend' rates for primary and secondary care appointments (25). For Mid and South Essex Health and Care Partnership, this means an opportunity to avoid costs of over £8.6 million by 2030.

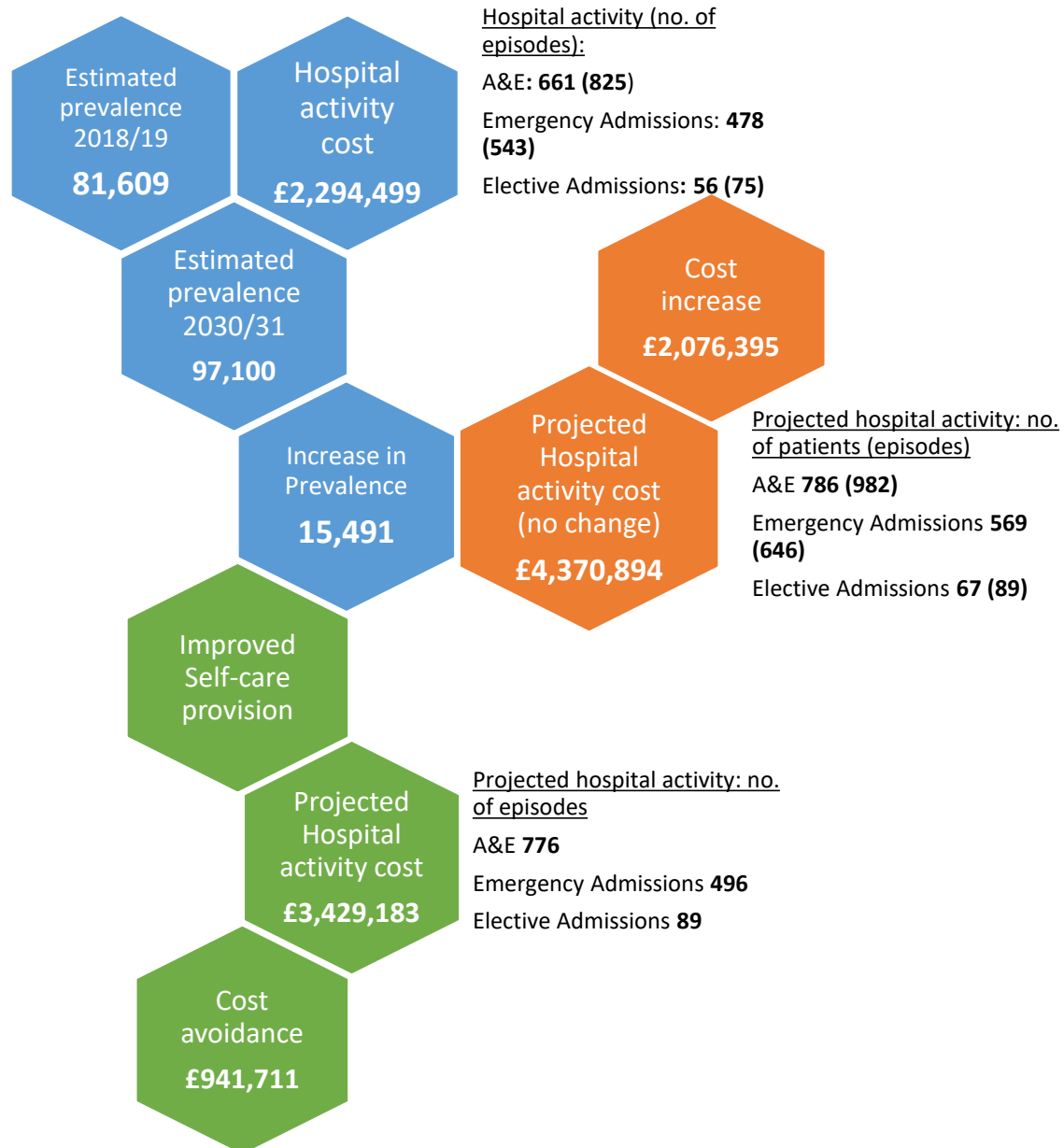
Diabetes

As discussed in the Local Context chapter, the estimated number of people with diabetes in Mid and South Essex in 2018//19 was 81,609. Based on local hospital data, eight in 1,000 patients with diabetes accessed the A&E department, six patients in 1,000 were admitted as an emergency and less than one in 1,000 were admitted electively during the year. Modelled estimates show, based on changes in population size and disease prevalence,

that by 2030 the diabetes prevalence will increase to more than 97,000 people. Applying the same rate of secondary care activity, it is estimated that A&E attendances will increase by 157 people and emergency and elective admissions by 103 and 14 people, respectively. The financial burden of the increased activity is estimated at almost £700,000. Moreover, when taking into consideration cost increase due to inflation (4% per year (142)), the increase in spend on hospital activity (A&E attendances, emergency and elective admissions) is £2,076,395, almost doubling the current total cost. A model to support decreases in hospital activity is therefore imperative. Due to inflation, even the same level of activity will cost more in 2030. An improved model of care can alleviate the burden by supporting patients to self-care, hence decreasing the activity in secondary care and the cost of each visit.

Currently, every patient attending the secondary care services has a 25% chance of revisiting A&E in the same year, 14% being readmitted via an emergency admission and 34% being readmitted via an elective admission. Despite a steep increase in diabetes prevalence, investment in self-care support can return a decrease in hospital activity as follows see figure 4.2.

Figure 4.2: Projected acute care cost due to Diabetes (scenarios)



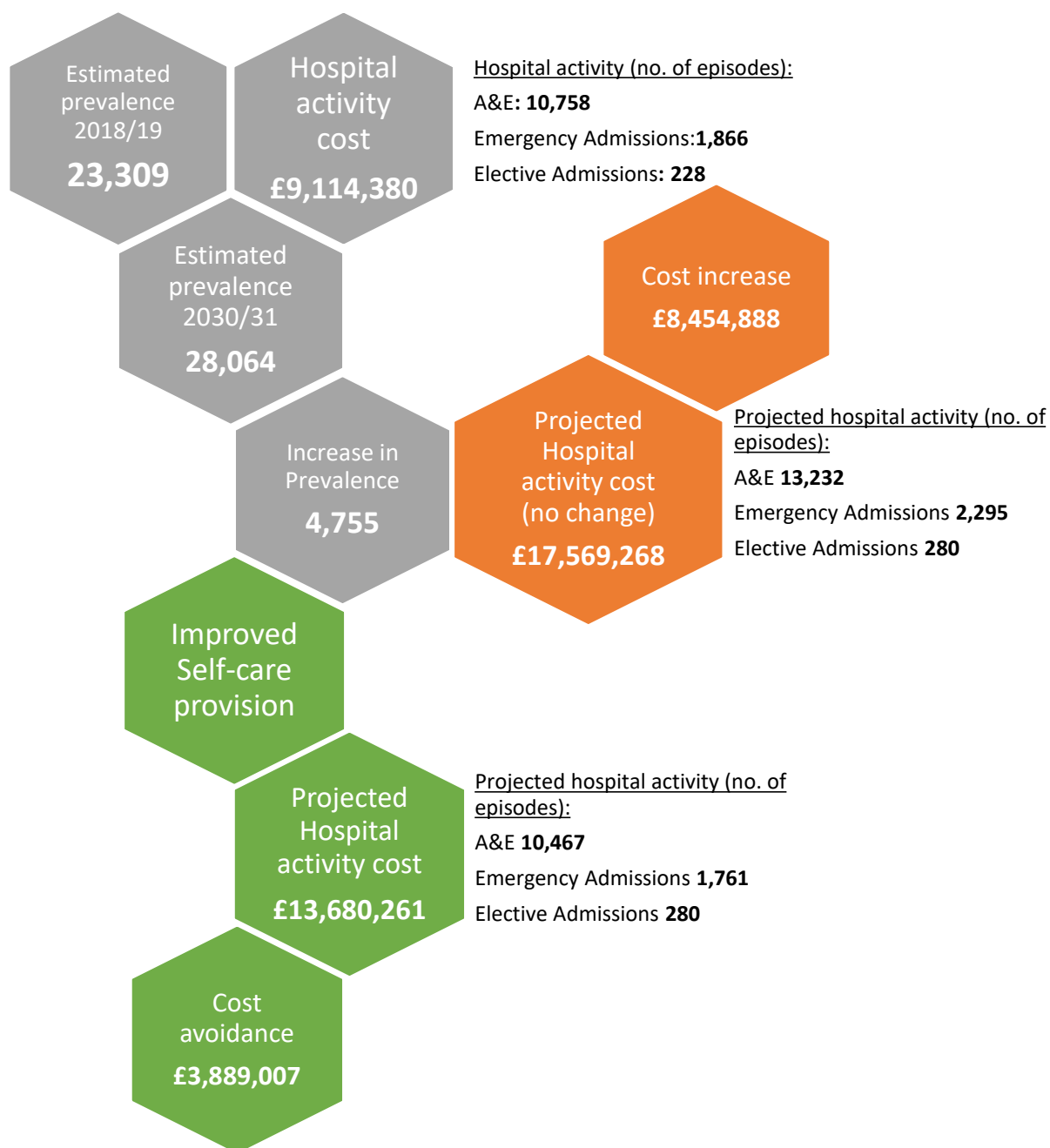
COPD

Similarly to diabetes, COPD cases are projected to increase by 4,755 people across the STP by 2030. Modelled estimates show that no changes to how patients are managed (in primary care and at home) will lead to an increased burden on secondary care of an additional 4,092 A&E attendances, 531 emergency admissions

and 22 elective admissions. The total cost of secondary care activity due to COPD in 2030 is estimated at £17,569,268, £8,454,888 more than in 2018/19.

With the appropriate measures in place to empower people to self-care, an estimate of £4 million can be saved through a reduction in hospital activity (see figure 4.3).

Figure 4.3: Projected acute care cost due to COPD (scenarios)



Heart Failure

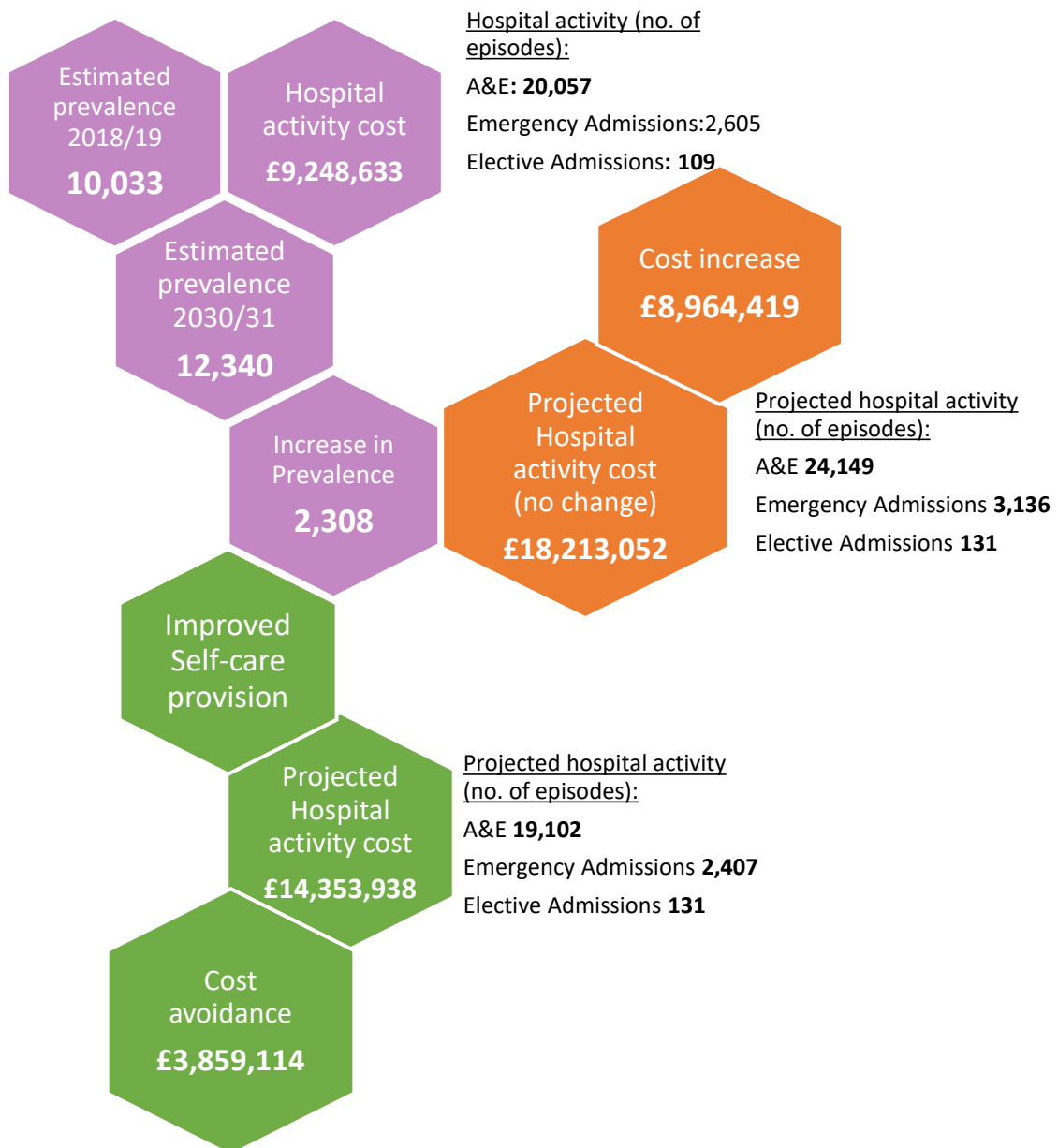
Heart failure hospital use is the most expensive of the three conditions. In 2018/19 a total of £9,248,633 was spent on hospital care for HF patients (based on local hospital data for A&E attendances). On average, there was at least one attendance to A&E

per HF patient (107%), one emergency admission per five patients (19%) and two elective admissions for every 100 HF patients (2%). Data shows an average cost of £200 for A&E, £4,208 for emergency admissions and £2,998 for elective admissions for each patient attending the

hospital with an HF related diagnosis. When adjusting for an increase in prevalence and inflation, the estimated hospital cost across

the STP for HF in 2030 is £18,213,052. An improved model can save almost £4 million (see figure 4.4 for more details).

Figure 4.4: Projected acute care cost due to HF (scenarios)



4.2 Recommendations

This report aims to support the implementation of an infrastructure which enables patients to build and improve skills to self-care, to prevent or manage their conditions. Therefore, we are forming recommendations at four different levels: the individual (patient and caregivers), the neighbourhood (GPs, PCNs and local groups), the place (CCG, Council and local organisations) and the system (STP and NHS). The recommendations address the six main themes identified in the previous sections.

4.2.1 Services that contribute to self-care across the STP are fragmented and irregular

Our analysis shows a high number of services from different level providers making an impact on self-care across the STP. However, we identified that people with diabetes, COPD and HF receive a different service based on where they access the services. There is a variability in the offer each area has in place for patients needing support to self-care (see the service map for more information in Appendix 2). The evidence suggests the most effective support has to be multifaceted, with a mixture of direct support, education and online access to resources. This calls for a whole system, coordinated approach to self-care. Moreover, the same type of services seem to have a different structure and format based on the locality they are offered in, and often there is no evidence to back their effectiveness. Additional to aligning the LTC

support offer across the STP, there is an increased need to make services consistent and equal by commissioning evidence based services and replicating examples of high performance across the patch.

Case Study 1

In Leeds a three-month long programme involving 11 practices aimed to reduce the variation in nursing care and administrative processes.

Each practice mapped how they worked in some specific areas and then all of the maps were compared. This highlighted a striking variation within practices, leading to a locality wide collaboration and development of a consistent approach. The outcome was reduced misdiagnosis, reduced waiting times and increased information sharing.

“The programme helped us continue building on working on a wider scale, finding out what good practice is and taking the best bits to roll out across the locality.” Andrea Mann, Managing Partner, Colton Mill and The Grange Medical Centre and Head of Nursing Quality and Governance Leeds CCG Partnership.

Source:

<https://www.england.nhs.uk/gp/case-studies>

We know from the previous section that the ability to self-care is not only dependent on the built environment, availability of resources or access to healthcare services. Personal characteristics, one's lifestyle and health status are also possible barriers. Despite these being already documented by evidence, the services that aim to support self-care are rarely jointly produced

Case Study 2

Six rural practices in West Cheshire came together as the Rural Alliance. As part of the Learning in Action programme run by the NHS, they worked collaboratively to tackle common issues and improve patient experience.

The practices implemented a system of sharing GP specialties, IT support, bookings (e.g. diabetes clinics) and best practice, leading to improved access to services across the area.

Making these services available closer to patients' homes, the Alliance is saving them time and money spent on travelling. Patients no longer have to travel into the city for specific clinics and services such as diabetes clinics, sexual health services or dressings.

"In working together we have all found ways to become more efficient and improve patient care. [...] We are no longer re-inventing everything six times." Kate Evans, Practice Manager, The Village Surgeries Group

Source:

<https://www.england.nhs.uk/gp/case-studies>

with the users. In order to firstly understand what the desired outcomes are for people who are affected by diabetes, heart failure and COPD, and then to engage with them throughout the entire process of designing, delivering and monitoring and evaluating the services the right systems need to be

put in place. Co-production²⁷ goes beyond the traditional engagement or involvement of users in the process, it recognises that those who use the said services should have an equal say throughout the entire design and delivery process. (143)

Co-design and co-delivery help to:

- uncover and leverage existing assets, resources and networks
- identify opportunities for co-delivered support, taking account of both professional and user perspectives
- better identify opportunities for recovery and independence
- focus on the aspirations of service users, breaking down barriers between services and sectors
- share responsibility for outcomes and a move away from over-dependency on particular services and methods of care
- facilitate a conversation around the possibilities of experience-based evidence

Source: [the power of co-design and co-delivery.pdf \(nesta.org.uk\)](https://www.nesta.org.uk/publications/the-power-of-co-design-and-co-delivery)

Since 2013 when the aforementioned NESTA report was published, co-production, co-design and co-delivery became frequently used terms nation-wide. However, it is often the case that commissioners and health and social care leaders are using the term inappropriately.

²⁷ Co-production is a method used when designing, delivering and evaluating public health and care services and it involves service user involvement from very early stages of planning. This means working in equal partnership with communities in spaces where power is shared, making services more effective and efficient, and in the long-term more sustainable.

With no changes within the system to put in place the necessary structures for service users to have the power to influence how services are shaped, these terms are only seen as a rebranding of the previous engagement and involvement. A collective ownership of health is only possible when service users feel empowered and are involved in shaping services at all layers of the system. It will require for clinicians to start from the position of not necessarily knowing the right answer and commissioners to build the necessary trust with service users and creating safe spaces for users to genuinely influence the service redesign.

The new development of Integrated Care Systems (ICS) is an opportunity to homogenise services across the area whilst ensuring high quality. Furthermore, Primary Care Networks (PCNs) can additionally support with ensuring quality and reducing the variance at the neighbourhood level. This allows for services to be customised to the specific need of the community they are offered in, whilst following a high level of standards.

The practical guide The King's Fund and Picker have produced on behalf of NHS England and NHS Improvement in 2021 (144) highlights the importance of community involvement in order to accelerate the integration of services. Integrated care is all about person-centred care. Its aim is to increase coordination of services and bring them closer to people for an increased impact on people's health

outcomes and experience. However they recognise there is no one-size-fits-all solution and that good involvement requires a range of methods and approaches, but that listening and learning from each other should sit at the core of this.

Anecdotal evidence from Mid and South Essex shows there is overall lack of confidence in adopting co-production methods. This is due to a lack of both skills and resources. This is not to say good quality co-production is not happening locally. Local Healthwatch bodies are at the front of championing community involvement and are currently supporting partners in Mid and South Essex to deliver co-production. Unfortunately, this is not widely spread and there is no clear local framework that commissioners, providers and system leaders can follow.

| Issue | Recommendation | Responsible party |
|--|---|---|
| <p>There is a need for strategic direction to support a whole system self-care programme</p> <p>As evidence in chapter 2 Service map section and professionals' view, there is variability of offer across the area and no clear understanding of what needs to be done for self-care to become easier to practice.</p> | <p>Develop a joint self-care strategy and joint targets to support the development of a self-care programme that aligns the prevention, early intervention and management agendas and addresses place-based barriers to self-care. The strategy should prioritise:</p> <ul style="list-style-type: none"> • A consistent approach to education programmes for patients diagnosed with diabetes, COPD and HF, and other LTCs; • New models of care where non-clinical staff, such as social prescribers, coach and support patients to navigate the system; • A digital offer for continuous education and self-monitoring; • Mental health support for patients with a long term condition; • Guidance on health coaching for the newly diagnosed; and • Integration of services between local authorities, Adult Social Care (ASC), and CCGs in order to address the wider determinants of health. | <p>MSE ICS Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> <p>And for Diabetes: piloting the MyDiabetes app with 500 newly diagnosed Type 2 diabetics to support them to understand and better manage their condition</p> |
| <p>Services across the STP are fragmented and outcomes vary</p> <p>For all three conditions discussed and all levels of care – prevention, management and referral – there seems to be a variation in outcomes both at system and place level.</p> | <p>Develop a monitoring and evaluation system for Diabetes, COPD and HF programme outcomes to address high variability at the PCN, CCG and STP level.</p> <p>Start a Task force to include representatives from community care, voluntary sector, primary care, public health, secondary care and social care to address variability of outcomes and support with integration of services.</p> <p>Plan Quality Improvement activities to share best practice and address variability of clinical outcomes for the three LTCs at the PCN level.</p> <p>Pool resources to offer education and specialist support to patients who are diagnosed:</p> | <p>MSE ICS Aligned with the MSE Five Year plan for Diabetes: Reducing the impact of diabetes among harder to reach/less engaged groups</p> <p>MSE ICS Aligned with the MSE Five Year plan for Diabetes: Reducing the impact of diabetes among harder to reach/less engaged groups</p> <p>PCN</p> <p>PCN</p> |

| | | |
|--|--|------------------|
| | <ul style="list-style-type: none"> • Diabetes specialist support for those newly diagnosed with diabetes; • Clinical pharmacists to educate newly diagnosed COPD patients and review patients with exacerbations; • Telehealth capability for online coaching (evidence shows cost-effectiveness for COPD); • Social prescribers to identify mental health needs of patients with long-term conditions; and • Technical support with identifying high impact users of the healthcare system. | |
| | Develop queries to aid GPs with finding the missing thousands (from disease registers) and patients who are on registers, but are not receiving the recommended treatment and support services. | CCGs/CSU |
| <p>Service users are not consistently involved in the design, delivery and monitoring and evaluation of the services</p> <p>Recommendations based on the Co-production model from Coalition for personalised care</p> | <p>Develop a clear framework for co-production and a system structure to support providers and commissioners to practice it:</p> <ul style="list-style-type: none"> • Champion co-production at most senior leadership level, including co-production in local plans such as the local Health and Wellbeing Strategies • Name a co-production lead and assign it under a board such as the Health Inequalities Board • Use open and fair approaches to recruit service users, with an emphasis on under-represented groups • Put systems in place that reward and recognise the contribution people make – pay people for their contribution on order to balance the power • Map system-wide areas where co-production would make most impact and make it mandatory • Involve service users in the shaping of projects and programmes at the very early stages • Provide training and resources on co-production such as the toolkit from Point of Care foundation EBCD: Experience-based co-design toolkit - Point of Care Foundation • Regularly review and report back on changes and progress to maintain residents' involvement | MSE ICS/HI Board |

4.2.2 Information is not readily available to patients, providers and commissioners

Providers and patients alike find it difficult to identify services and resources that support self-care. Due to the very diverse and dynamic provision of services, keeping track of available services and their specifications is challenging. This leads to a local lottery where access to services is dependent on which GP you are seen by and the level of information they possess. Investing in a publicly available signposting system to all of the different community services available could be the solution. However, a lack of accountability can make updating it particularly difficult. Such a resource needs constant capacity dedicated to maintaining the database and requires financial investment. Nevertheless, local areas are already moving towards building such tools. For example, Southend Council is currently working on developing a local online library of services which directs users to service providers' websites for more information. The limitation of developing such a tool at the local level is that there is a significant number of patients across the STP who access primary care services in a different jurisdiction than where they live. A few areas in the UK such as London, Greater Manchester and East Midlands are currently using an online platform, 'Making Every Contact Count (MECC) Link', which serves the exact same purpose, but on a broader area. This platform is available to both patients and caregivers, and those who offer an intervention. Expanding it to Mid

and South Essex could be the solution. Currently, Public Health England is working on ways to bring this service to East of England.

Moreover, the current service offer proved to be very difficult to map by the team working on this report. Not only that we couldn't develop a full map of services, it was difficult to analyse the demand and capacity to make recommendations in

Case Study 3

MECC Link was developed by the MECC Community of Improvement for Yorkshire and the Humber to help enable MECC to happen in the area. The strategic network recognised the need for a signposting system to support MECC providers to raise awareness, motivate and signpost patients to services.

Since April 2019 MECC Link became a multi-regional service with 6 regions hosting information about their local services, including London.

Source:

<https://www.mecclink.co.uk/about-us/>

regards to patient engagement and referrals. There is an increasing need to improve partnerships between NHS organisations and the local authorities to facilitate the flow of such information (within information governance limits). The development of Mid and South Essex STP is a great opportunity for improving the collaboration between the two, also therefore facilitating the development of JSNAs and similar products.

| Issue | Recommendation | Responsible party |
|---|--|---|
| <p>Information about existing services is not readily available to patients and providers</p> <p>As expressed by both residents and professionals and discussed in Chapter 2, people do not know what services are available even if they are professionals working in the field. This proves to be even more difficult if those advised live in a different area within the STP.</p> | <p>Develop a single point of access platform for services that assess risk and provide self-care interventions, to be made available to both patients and health and social care providers.</p> | <p>MSE ICS/ Place Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |
| | <p>Contribute to maintaining and promoting a single point of access platform and engage providers in using it.</p> | <p>CCGs/ Place</p> |
| <p>There is difficulty in the process of data collection between local authorities, CCGs, and service providers making the development of JSNA products challenging and acting as a barrier to improvement.</p> <p>As discussed in chapter 2, it was very difficult to collect information on existing services across the system and their outcomes. This left gaps in the analysis and required us to take caution in how we interpret the results of this report.</p> | <p>Lead a data sharing team (BI virtual hub) to support the development of JSNA products across the STP.</p> | <p>MSE ICS</p> |
| | <p>Make aggregate data sharing with ICS partners a contractual obligation for community care providers and ensure regular data quality and completeness activities are undertaken.</p> | <p>CCGs and other commissioners</p> |
| | <p>Shift towards outcome based targets and KPIs rather than performance based.</p> | <p>CCGs and other commissioners</p> |
| | <p>Fund a technical solution for data integration across the ICS to enable access to aggregated data for all partners.</p> | <p>MSE ICS</p> |
| | <p>ICSs will have a key role in helping to deliver these programmes and in working with local authorities, the voluntary sector and other local partners to improve population health and tackle the wider determinants of ill health.</p> | <p>MSE ICS Aligned with the MSE Five Year plan for prevention: Work on reducing childhood obesity and increasing physical activity in adults through adoption of programmes delivered in schools and private</p> |

4.2.3 Patients and primary care providers lack the capacity and skills to make the most out of their interaction

GPs and other health professionals are not trained in motivational interviewing and coaching, which would enable them to effectively identify needs and motivate patients to take action in regards to self-care. On the other hand, patients lack the understanding of what their responsibility is when it comes to managing or monitoring

Case Study 4

In South Somerset as a response to the current pressures on healthcare and GP shortage, the South Somerset GP Federation (19 practices), Yeovil District Hospital, Somerset Partnership NHS Foundation Trust and Somerset County Council partnered and created the Symphony Programme.

The network developed a new model of care to improve support for LTC patients, improve the working lives of staff and relieve the pressure on secondary care.

The model has three tiers all focused on supporting people to understand and manage their own conditions, linking into the voluntary sector locally and navigating the healthcare system through a team-based approach where different professional groups operate at the top of their license.

The introduction of health coaches was essential as they work directly with patients to develop their self-efficacy and also effectively liaise patients who need services.

Source:
<https://www.england.nhs.uk/gp/case-studies>

their disease or do not possess the right skills or resources to do so. Similarly, when caregivers or family members are not receiving any form of education in this regard, they might act as a barrier to self-care. The solution to this is improving education and training offered to both clinical staff and newly diagnosed patients or their carers.

Case Study 5

Champs Public Health Collaborative is a partnership approach in Cheshire & Merseyside. Their aim is to embed MECC into organisational strategies to create a culture shift towards prevention across the STP and wider system.

Three task and finish groups have been established to support training, communications and engagement, and evaluation. Each organisation identified a MECC champion to ensure that MECC maintains a high profile within each organisation, embedding MECC into existing policies, processes and initiatives so that MECC is seen as part of the everyday practice. Additional financial resources were secured through a bid to the Local Workforce Action Board.

The partnership is a great example of collaboration between public health, the STP, Public Health England and individual care organisations.

Source:
<https://www.makeeverycontactcount.co.uk/media/>

Moreover, even when these skills are not lacking, professionals find it difficult to find the time to have meaningful conversations with their patients. Motivational interviewing and coaching take a long time to be effective and time is what primary care does

not have. As discussed in the Local Context chapter, Mid and South Essex is a heavily under-doctored area with a particularly high need due to a number of factors including deprivation. To overcome these local challenges, new models of care need to be piloted to explore ways of using, in addition to GPs and nurses, a higher range of non-clinical staff to support patients with LTCs.

Also, where possible, it is recommended that support for people with LTCs is brought

outside of primary care and into the community. For example, new evidence shows that local pharmacies can successfully deliver interventions for health promotion (145). There is an opportunity to build on current NHS efforts, described in the LTP, to expand the use of pharmacies from carrying out medication reviews to seeing patients with minor injuries. Their role can slowly evolve into supporting patients to self-care.

| Issue | Recommendation | Responsible party |
|--|--|--|
| <p>Primary care staff lack the skills to identify needs and barriers to practicing self-care and to address them</p> <p>As discussed in Chapter 2 – professionals’ views, many professionals working with those needing to manage a condition are not confident in offering counselling/coaching support.</p> | <p>MECC training to become mandatory at least every two years for primary care professionals who are patient facing.</p> | <p>MSE ICS Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |
| | <p>Plan an upskilling programme to equip primary care professionals with coaching and behavioural change skills.</p> | <p>MSE ICS</p> |
| | <p>Deliver Motivational interviewing and other coaching techniques training to GPs and primary care staff.</p> | <p>CCG/ Place</p> |
| <p>Patients are not educated about their role in health maintenance, and disease monitoring and management</p> <p>Discussions with residents show us that many of them have never been taught what and how to do to self-care.</p> | <p>Plan self-care forum events across the STP to inform patients and carers about their role in managing their health.</p> | <p>Place Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |
| | <p>Commission digital programmes to deliver patient education throughout every stage of the disease.</p> | <p>MSE ICS Aligned with the MSE Five Year plan for prevention:</p> |

| | | |
|--|---|---|
| | | Providing information and support for people to look after themselves including on-line and digital options. |
| | Prepare and write down questions for a medical visit prior to seeing a care professional. | Patient and caregiver |
| | Ask care professionals for reliable sources of information to do own research about the conditions they are suffering from. | Patient and caregiver |
| | Develop and distribute 'Making the most of your consultation' guide to educate patients across the STP. | MSE ICS Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options. |
| | Plan group meetings for patients with multi-morbidity to facilitate share of resources and experience. | PCN |
| | Commission self-care education in pharmacies for clients who pick up specific medication. | MSE ICS/Place Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options. |

4.2.4 Multimorbidity is increasing and needs to be addressed

Despite evidence showing that patients with diabetes, COPD and HF increasingly tend to have a comorbidity, the NHS LTP fails to address this. Patients with multiple LTCs receive a varied number of interventions to support their needs, but most of the time these are delivered in silo. The focus on

single diseases fails to recognise that unhealthy behaviours tend to cluster and are further deepening health inequalities. Our analysis shows there is a lack of integration between LTC services, which causes engagement from people with multimorbidity to be time consuming. Moreover, patients receiving multiple interventions sometimes receive conflicting

information. For example, someone suffering from COPD and diabetes might be advised to limit their brisk exercising to avoid COPD exacerbations, but when attending a diabetes class they learn to do the opposite. This leads to confusion and frustration, therefore resulting in an overall

lack of engagement. Likewise, when there is no communication between providers, the prescribing of multiple drugs for diverse conditions can lead to confusion and lack of compliance to treatment. Programmes need to acknowledge multimorbidity and address the challenges that come with it.

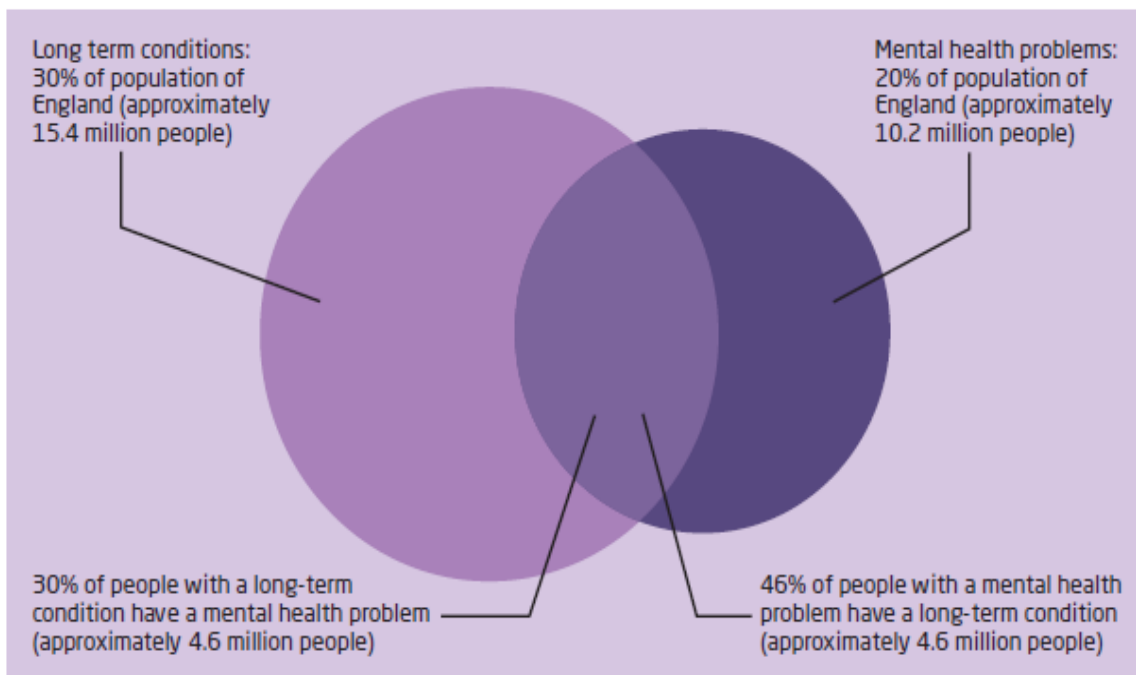


Figure 4.5: Long term conditions and mental health

More specifically, mental health is a very prevalent co-morbidity among patients with LTCs. Recent evidence indicates 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 targets for referral (130). Peer support may also play an important role in empowering people with co-morbid mental health problems to manage their own condition.

This has started to be recognised both locally and nationally, hence more efforts are being put in place to address it. The

Case Study 6

Since 2010 Cornwall general practices are working directly with Age UK to support older patients. The initial cohort of 106 patients saw a 30% reduction in emergency admissions.

After expanding to 9 sites, supporting 4,000 patients, they observed a 31% decrease in all hospital admissions and 26% decrease in emergency admissions for the cohort. Additionally, GP workload reduced while community providers' workload stayed the same.

Source:
<https://www.england.nhs.uk/gp/case-studies>

NHS LTP reaffirms increases in mental health funding, committing to developing new models of care and increasing funds by £2.3 billion by 2023/24 (141). Locally, as seen in the service map, Inclusion Thurrock now offers mental health services specific to patients who have diabetes. Local third sector organisations, such as Thurrock and Brentwood Mind, could build on their local

expertise and complete this offer with peer support groups. The voluntary sector is an essential asset and building relationships with them can support the development of a more personalised offer at the local level.

These types of services need to be properly evaluated and rolled out across the STP if proved to be effective.

| Issue | Recommendation | Responsible party |
|--|---|--|
| <p>Multimorbidity is increasing and self-care programmes are not addressing it sufficiently</p> <p>As evidenced in the discussion about current services, Chapter 2, most services are not fit for people who have multiple conditions. If multiple needs are identified most of the times patients have to access multiple services on separate occasions – making it difficult for them to stay engaged. For example, the average number of other conditions at first presentation of HF is five (41)</p> | <p>Develop a multimorbidity upskilling programme to educate providers (particularly GPs) on polypharmacy and multimorbidity patients' needs.</p> | <p>MSE ICS/CCGs</p> |
| | <p>Commission a social marketing research project to explore the barriers to self-care for patients with multimorbidity which can be used to inform the commissioning of programmes.</p> | <p>MSE ICS Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |
| | <p>Promote the use of a validated tool such as eFI, PEONY or Qadmissions in primary care to identify adults with multimorbidity who are at risk of adverse events such as unplanned hospital admissions or admission to care homes.</p> | <p>MSE ICS/CCGs</p> |
| | <p>Create a pooled resource at the PCN level with social prescribers, care navigators/coordinators and health coaches to support more complex-need patients.</p> | <p>MSE ICS/PCN Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |
| | <p>Extend the offer of personalised budgets to patients with multimorbidity to support them with getting personalised care that fits their needs.</p> | <p>CCGs/Place</p> |

| | | |
|--|--|---|
| | Research the most common association of conditions across the STP to inform a more robust offer for patients with multiple conditions. | MSE ICS |
| <p>Many people with Long term conditions have mental health needs and not enough support</p> <p>As evidenced in chapter 2, most services are not fit for supporting people with a long term condition and mental health needs. Statistics show that 30% of people with long term conditions have a mental health condition as well.</p> | Commissions a CBT offer for HF patients to reduce anxiety and improve Quality of Life. | CCGs/Place |
| | Log symptoms in a diary each day. | Patient/resident |
| | Access free online resources available, such as Every Mind matters from PHE and NHS. | Patient/resident |
| | STP wide audit of Severe Mental Illness (SMI) Health checks delivery to better understand the needs of people with SMI. | MSE ICS |
| | Commission national interventions such as Every Mind Matters to develop tools specific for patients with long term conditions. | NHS |
| | Commission support for close family members and carers of these patients to enable knowledge sharing and empowerment. | CCG/Place Aligned with the MSE Five Year plan for Mental Health: Creating safe places for people to walk-in such as community cafés |

4.2.5 The money is in the wrong place

Diabetes

Evidence shows structured education such as DESMOND to be effective at increasing patient activation. This paired with coaching and a two-way monitoring system can deliver significant return. The NHS LTP suggests rolling out a two-way monitoring system, HeLP-Diabetes, nationally. This is a great opportunity for the STP if implemented properly. The NDPP model can be replicated to create a structured education offer across the STP for diabetes and other LTCs.

Patient education should be supplemented with online platforms; they support patients with continuous education, are easier to

access and have the potential to be tailored to the needs of people belonging to

Case Study 7

Local evaluations, based on patient feedback, show that education delivered through online platforms, such as the Sound Doctor, could improve the understanding of the disease and confidence to manage it. Wolverhampton CCG's survey of 46 patients and carers found that those using this tool reported to have visited their GP less often than prior to using it.

Source:

<https://www.surveymonkey.com/stories/SM-CRPKC9Y/>

minority groups. MyDiabetes was rolled out in Mid and South Essex in 2019. Proper monitoring and evaluation of the programme should inform quality improvement projects that can improve reach and engagement. Additionally, patient and carers can greatly benefit from peer support groups, especially those belonging to a minority group. These are very sporadic across the STP and tend to be under-resourced since they are community-led. Being community-led is an advantage and this service should stay in the community. However, the CCGs supporting these groups could lead to an improved structure and reach, hence increased impact and returns.

COPD

The key recommended approach for COPD management is pulmonary rehabilitation. Currently, all CCGs in the STP commission this service. Our analysis shows there is a variance in how the programme is offered,

Case study 8

A notable example of an STP wide programme that has been very successful is the NDPP. Geared towards prevention of diabetes rather than management, the programme teaches skills that are helpful for diabetic patients too.

In the past 2 years the programme has seen a steep increase in Mid and South Essex, referrals surpassing its capacity in 2019/20. Hence, the current focus is on improving the quality of referrals rather than increasing referrals. This allows for a better targeted approach where the most vulnerable are identified and offered support.

but we were unable to evaluate which one is more effective due to lack of access to information. With the STP coming together as an organisation, there is an opportunity to share best practice and align services to specific standards. For example, evidence shows better results when education, psychological support and dietary advice are embedded in the programme.

Case study 9

Islington CCG commissions GP practices to offer collaborative care and support planning consultations with their patients with a list of long-term conditions, historically agreed in collaboration with Islington Public Health department. These conditions include chronic obstructive pulmonary disease (COPD), diabetes, heart failure and many more.

Commitment to engagement with the PAM project was embedded into the long-term condition work, which was initiated in October 2013. Practices were incentivised to calculate and register PAM scores to patient records.

An independent evaluation of the Year of Care diabetes care planning work was conducted in 2015 and found that high performing practices (in terms of number of care plans completed) were achieving better patient outcomes. Additionally, the evaluation found that care providers were willing to adhere to the new approach, however, they lack some skills in coaching and motivational interviewing.

Source: Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England, The Health Foundation, April 2017

Additionally, computer or mobile technology and telehealth can support by reaching out to patients who find it difficult to engage with services in person. Essex Council commissioned SoundDoctor in 2019 to make it available to all patients, including COPD patients. A thorough evaluation of the impact can inform an STP wide programme.

Evidence also shows that primary care is essential to ensuring proper training and continuous monitoring of the disease. A further analysis of how patients' training is delivered in primary care can inform whether there is an opportunity for additional resources to be allocated. For example, telehealth support alongside coaching has been proven to be cost-effective for improving self-care behaviours.

For patients attending secondary care, interventions delivered in the hospital are proven to be very effective at preventing readmission (as described in the evidence chapter). STP data from 2018/19 shows 2,605 emergency admissions for COPD for 2,068 patients that were admitted. This shows that each patient admitted had a 26% chance of being readmitted in the year. Similarly, there were 109 elective admissions for 92 patients, an 18% chance of readmission.

Secondary care interventions for COPD, also called a care bundle, can include: checking inhaler technique; providing written COPD management plan and medicines; assessing willingness to stop smoking and suitability for pulmonary rehabilitation; and arranging a 2-week post-discharge follow-up.

Heart Failure

Similar to pulmonary rehabilitation, cardiac rehabilitation is fragmented and varies in structure across the STP. Evidence shows that any level of cardiac rehabilitation is effective. However, the service mapping process identified possible issues with access due to what is currently available. There is an opportunity for the STP to implement collaborative care (CASA) interventions where the patient is seen by a range of health professionals, rather than just their GP. This approach also shows a reduction in levels of depression and fatigue.

Wrong incentives

Our analysis shows that most Key Performance Indicators (KPIs) and quality indicators, such as the Quality Outcomes Framework for primary care, are focused on the process rather than the outcomes. Moreover, these incentives can drive conflicting priorities, sometimes leading to healthcare providers choosing not to follow the best practice guidelines. Additionally,

Case Study 10

Cumbria Quality Improvement Scheme was developed to improve the health outcomes of residents, reduce inequalities, ensure cost-effectiveness and enable primary care practices to work together.

The Scheme measures improvements on a value-added basis while recognising each practice is different and has varied needs. It incentivises practices on outcomes for seven indicators using the triple aim approach from the Institute for Healthcare Improvement, rather than incentivising for processes.

Early outcomes from the scheme in 2017 show:

- 83% of practices achieved metrics for Cancer;
- 61% of practices are achieving the metrics set for unplanned hospitalisations for chronic ambulatory care sensitive conditions; and
- 81% of practices achieved metrics on End of Life care.

Focussing incentive schemes upon outcomes instead of processes can lead to reductions in unwarranted variation and improved outcomes for patients.

critics of the pay-for-performance scheme claim that it diverts attention from inter-personal elements of care provision with a higher impact on those with multiple

conditions. (146) A clear focus on health outcomes provides a framework for providers to offer personalised care while maintaining a good quality of service.

Additional to incentivising on health outcomes, reinforcement of quality improvement work can lead to improved processes and increased efficiency of care. (147) The NHS now recognises this and QOF 2019/20 has a quality improvement domain with two indicators. However, with lack of training and capacity in primary care, quality improvement work can take varied forms. This again leads to this scheme working more effectively for better resourced practices. The new development of PCNs can support with creating a good quality improvement infrastructure.

| Issue | Recommendation | Responsible party |
|--|--|--|
| <p>The current incentives and KPIs are not outcome focused, hence are not conducive to increased impact</p> <p>Evidenced by the analysis discussed in chapter 2 – local context and discussions with local professionals.</p> | Revise QOF indicators to become more outcome focused or create a similar scheme locally. | NHS/MSE ICS |
| | Incentivise GPs to keep a record of markers of good self-care such as patient activation, BMI or overweight/obese status, Smoking status and physical activity. | MSE ICS/CCGs |
| | Additional to existing incentives to increase referrals into self-care services (including weight management services due to its link with Diabetes and cardiovascular disease), incentivise reduced Did Not Attend rates. | CCG and commissioners |
| <p>Peer support groups are under-resourced and struggle to function</p> <p>Based on information gathered at workshops with both professionals and local residents.</p> | Inform and support hard to reach patients to engage with support groups. | <p>GP</p> <p>Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options.</p> |

| | | |
|--|--|--|
| | Co-support development of free support groups (e.g. with space, engagement, promotion, materials and translation) while still keeping them community led. This will ensure increased accessibility of such groups. | CCG/Place |
| | Get involved in leading or participating in peer support groups to share experiences and learn from peers with similar conditions. | patients and caregivers |
| There is a poor take-up of the national patient activation programme | Improve the availability of PAM licenses to roll out across primary care. | NHS/MSE ICS |
| Evidenced by discussions with professionals and the national team rolling out PAM. | STP to support CCGs and GPs to embed PAM use in practice. | MSE ICS |
| | Embed PAM in initial assessments and action plans. | Community providers and social prescribers |
| | Primary care to use PAM to evaluate the level of patient activation post diagnosis and at regular reviews. | GP |
| | Roll out training and education sessions to improve primary and community care engagement with PAM. | CCGs/Place |
| The digital offer is poor and sporadic | Develop an infrastructure for offering online classes and consultations/follow-up for patients with long term conditions. | MSE ICS/CCGs Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including on-line and digital options. |
| As evidenced in chapter 2 – professionals’ views and service map. | Commission online services for patients with multimorbidity who might struggle with accessing services in a traditional way. | MSE ICS |
| | Support enrolment in self-help online programmes such as: Silver Cloud, MyDiabetes app, MyCOPD app, HeLP-diabetes programme. | GP Aligned with the MSE Five Year plan for Diabetes: Piloting the MyDiabetes app with 500 newly diagnosed |
| | Commission an online group offer (e.g. on social media) to provide peer support with self-care. | CCG/Place Aligned with the MSE Five Year plan for prevention: Providing information and support for people to look after themselves including |

| | | |
|--|---|---|
| | | on-line and digital options. |
| | Evaluate variance in self-care online programmes enrolment and share best practice with GPs who are lagging behind. | PCN |
| <p>Funding goes towards treatment rather than prevention</p> <p>As evidenced in Chapter 4 – impact modelling, the lack of prevention and poor management of the conditions lead to high cost acute episodes and this creates a vicious cycle.</p> | Improve funding and links into mental health support such as IAPT & talking therapies, or online mental health services for patients with LTCs. | <p>CCGs/Place</p> <p>Aligned with the MSE Five Year plan for Mental Health: Improving how we support people with a personality disorder and creating safe places for people to walk-in such as community cafés</p> |
| | Identify local cost-effective primary and secondary prevention programmes and extend commissioning across the STP. | <p>MSE ICS</p> <p>Aligned with the MSE Five Year plan for Prevention</p> |
| | Provide health promotion services in pharmacies within the new pharmacy referral model. | NHS/LPC |
| | Commission group consultations (in person and online) for patients with long term conditions and multimorbidity. | CCG/Place |

4.2.6 Self-care as a topic is in its infancy and evidence still needs to be developed

Evidence for self-care is still under development. A significant number of identified interventions have not been evaluated yet and are not backed by any data to show their impact. Moreover, self-care is multifaceted and difficult to quantify; therefore, where there is evidence, it lacks consistency across the outcomes measured, making it difficult to compare. This gap acts as a barrier to securing funds and trialling

innovative ideas that could potentially be successful.

A lack of evidence should not discourage providers and commissioners to trial new ways of delivering interventions. However, it is imperative that measures are put in place to collect and analyse appropriate information to evaluate and create the evidence needed to back up the new programmes.

| Issue | Recommendation | Responsible party |
|---|---|---|
| <p>There are many innovative solutions to supporting self-care, but there is not enough evidence to support them</p> <p>As evidenced in Chapter 2 – service map - and Chapter 3 there is not enough information to support a specific approach to self-care and some innovative solutions are not properly evaluated to create evidence.</p> | Evaluate impact of the Sound Doctor in Essex to inform a possible rollout across the STP. | Essex county Council |
| | Trial integration of SMS intervention in HF management services. | HF service providers and CCG |
| | Develop a systematic trial/pilot to evaluate the impact of Care-bundle use in Secondary care for COPD patients. | Mid and South Essex Hospital Trust |
| | Evaluate MyCOPD and MyDiabetes programmes to inform future decisions across the STP. | <p>MSE ICS</p> <p>Aligned with the MSE Five Year plan for Diabetes: Piloting the MyDiabetes app with 500 newly diagnosed</p> |
| | Identify examples of best practice and positive impact and share with the appropriate commissioners across the STP. | MSE ICS |

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Appendix 1

Methodology of the assessment

| Report Section | Activity |
|------------------------|---|
| Local Context | |
| Demography data | <ul style="list-style-type: none">Data contained in the demographic infographic (entitled “What does the Mid and South Essex Health and Care Partnership look like” – see Figure 2.1) was calculated using available data. Where possible, already calculated STP level data was used. Where this was not possible CCG level data was used to calculate an STP average. For some of the indicators the only available data was at a |

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| | <p>borough level. Where this was the case, the Essex level data was applied to each of the 3 CCG's populations (Basildon and Brentwood, Mid Essex and Castlepoint and Rochford). Additionally, all figures contained within the infographic were weighted to account for population size (using 2018 population figures), or the population sub-group of interest for the indicator (see the key on page 19 for more details). For example, for the percentage of Y6 pupils categorised as obese, figures were calculated using 10-11 year old distribution from the total of each CCG's populations. Significance level compared to the regional and national figures were not calculated, where the data was not already available at an STP level, and therefore no comparison has been applied to those figures.</p> |
| <p>LTCs data</p> | <p><u>Prevalence of conditions</u></p> <ul style="list-style-type: none"> • The STP level prevalence (%) of Diabetes was calculated by dividing the total combined number of people diagnosed with Diabetes in each CCG, by the total number of people (aged 17+) on all GP practice registers across the STP and multiplying it by 100. • The STP level prevalence (%) of COPD and HF were both calculated by dividing the total combined number of people diagnosed with COPD or HF in each CCG, by the total number of people (all ages) on all GP practice register across the STP and multiplying it by 100. <p><u>Management of Conditions</u></p> <p><i>Diabetes</i></p> <ul style="list-style-type: none"> • 8 Care Processes - The STP figure was calculated by adding together the total number of people with Type 2 diabetes who had received all 8 care processes at each CCG to get a number for the STP. This number was then divided by the total number of patients with Type 2 diabetes at an STP level (again by adding the total number of people on the register in each CCG to get an overall total for the STP) and multiplying by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure. • Blood Pressure – The STP figure was calculated by adding together the total number of people with diabetes who had a blood pressure reading of 140/80 or less (QOF Code DM003) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have the blood pressure check (the denominator; this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance |

level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure.

- **Total Measured Cholesterol** – The STP figure was calculated by adding together the total number of patients who had total measured cholesterol of 5mmol/l or less (QOF Code DM004) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have the cholesterol check (the denominator; this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure.
- **HbA1c** – The STP figure was calculated by adding together the total number of patients who had an HbA1c level of 59mmol/mol or less (QOF Code DM007) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have their HbA1c measured (the denominator: this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure.

COPD

- **COPD review** – The STP figure was calculated by adding together the total number of patients who had an annual review (QOF Code COPD003) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have the annual review (the denominator; this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure.
- **Record of FEV1** – The STP figure was calculated by adding together the total number of patients who had a record of FEV1 (QOF Code COPD004) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have the record (the denominator: this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has

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| | <p>not been calculated, and therefore no comparison has been applied to this figure.</p> <ul style="list-style-type: none"> • Influenza Vaccine – The STP figure was calculated by adding together the total number of patients who had received an Influenza Vaccine (QOF Code COPD007) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have the vaccine (the denominator: this figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure. <p><i>Heart Failure</i></p> <ul style="list-style-type: none"> • Confirmation of diagnosis – The STP figure was calculated by adding together the total number of patients who had, had their diagnosis of HF confirmed (QOF Code HF002) at each CCG to get an overall total for the STP (the numerator). This was divided by the combined CCG total (to give an overall STP number) of patients who were able to have their diagnosis confirmed (the denominator: the figure excluded those who had been exception reported) and multiplied by 100. This means that the significance level compared to the regional and national figure has not been calculated, and therefore no comparison has been applied to this figure. <p><u>Mortality from all conditions</u></p> <p>This percentage of mortality attributable to each condition was calculated using the number of people diagnosed with Diabetes/HF or COPD on the Disease Register in 2017/18 divided by the total number of deaths attributable to Diabetes/COPD or HF in 2018 and multiplied by 100.</p> |
| <p>Service mapping</p> | <p>Service information was collected during engagement with professional stakeholders (please see the row below for more info). Additional to face to face engagement, internet search and remote liaising with provider and commissioner organisations was carried out. Each council collected information for their covered areas and Thurrock Council Team collated the information.</p> |
| <p>Professional stakeholder views</p> | <p>Thurrock Council employed hosting workshops and various meetings in order to engage with local stakeholders. In addition, Essex County Council employed an online survey approach and face-to-face meetings with key professional stakeholders. There was a lack of capacity to undergo similar activity in Southend. However, the engagement included professionals serving all areas across the STP:</p> |

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| | <ul style="list-style-type: none"> • Public Health Commissioners at Essex County Council, Southend Borough Council and Thurrock Council • Thurrock Clinical Commissioning Group (CCG) • Essex Partnership University Trust (EPUT) • Adult Social Care (ASC) in Thurrock including the Community Led Support Team and the Local Area Coordination (LAC) Team • North East London Foundation Trust (NELFT) Community LTC Services • Healthwatch Thurrock • Thurrock Community and Voluntary Services (CVS) • Southend Voluntary Services (SAVS) • Chronic Health Psychology Service (CHPS) • Thurrock Housing Services • Essex Local Pharmaceutical Committees (LPC) • Basildon & Brentwood CCG |
| Patient views | <p>To understand people’s experience of diagnosis of an LTC, perceived barriers to self-care and what could help support them to better self-care a range of engagement activities were carried out. In Thurrock, local Healthwatch engaged with a total of 66 people through group surveys and in-depth interviews. Similarly, Healthwatch Essex engaged with 48 residents living with long term conditions using the same methods. Southend Council did not have enough capacity to commission this work.</p> |
| Evidence chapter | |
| LTC interventions | <p>To find evidence for specific interventions that are effective at improving the ability to self-manage the three chronic conditions (diabetes, heart failure, and COPD), an initial search was conducted by Aubrey Keep Library Service on the 16th May, 2019 and a refresh was done on the 25th February 2020. The main sources searched were CINAHL, EMBASE, KnowledgeShare, and MEDLINE. Only articles in English and published in the past 10 years were included.</p> <p>Additional to this, the public health team also conducted searches in PubMed using combinations of the terms: self-care, self-management, COPD, chronic obstructive pulmonary disorder, heart failure, diabetes, type 2, intervention. The following filters were applied to narrow down usable results: English, full-text available; preference was given to research published in the last 5 years, projects from the UK, and evidence reviews or studies with sample sizes greater than 100.</p> |
| Barriers to self-care | <p>For general barrier to self-care, Aubrey Keep Library ran an evidence search in December 2019: Barriers to accessing long term conditions self-management interventions. Studies specific to the three long term</p> |

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| | conditions (diabetes, COPD and HF) were searched independently by the authors. |
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Appendix 2

| Service Name | Long Term Condition /Target | Type of Service/Support | Provided in | CCG | Provider/Teams/Centre | Service description | Eligibility/Access | Referral Type | Notes |
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| ACE Lifestyle Southend | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | Southend on Sea | Southend/ Castle Point and Rochford | Anglian Community Enterprise | The service includes a personalised programme to help people reach their health goals. This could include 1-to-1 support or referral to other programmes such as weight management, physical activity or stopping smoking. | This service is for residents of Southend who wish to make positive changes to their lifestyle to improve their health and wellbeing. | GP/ Healthcare professional / Self | |
| Brain in Hand | Mental Health | Digital | All areas | All | Thurrock Council | Brain in Hand is an app that gives people access to detailed personalised support from their smartphone, putting the individual more in control of their own support. It gives easy access to reminders, notes, coping strategies and a team of trained professionals to give help when and where it's needed. | It is aimed particularly for people living with autism, a mental health condition or learning difficulty. | Social Care Professional referral | Service is running as a small pilot in 2019/20. |
| Breathe Easy the COPD support group | COPD | Community/Support Group | Southend on Sea | Southend/ Castle Point and Rochford | British Lung Foundation | This is a support group for people with COPD and their family or carers. The group meets once a month. | People with COPD, their family or carers | Self-Referral | |
| Breathe Easy the COPD support group | COPD | Community/Support Group | Thurrock | Thurrock | British Lung Foundation | A support group for people with COPD and their family or carers. The group meets once a month. | People with COPD, their family or carers | Self-Referral | |
| Breathing Space Group | Heart failure | Exercise Programme | Billericay | Basildon and Brentwood | British Lung Foundation | This group provides self-management plans for people diagnosed heart conditions. | People diagnosed with heart conditions | Physiotherapist | |

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| Breathing Space Group | Heart failure | Exercise Programme | Canvey Island | Southend/ Castle Point and Rochford | British Lung Foundation | This group provides self-management plans for people diagnosed heart conditions. | People diagnosed with Angina and long term medical management for those with heart failure, from diagnosis to end stage. | Physiotherapist | |
| Cardiac Rehabilitation | Heart failure | Rehabilitation/Lifestyle Management Support and Education | Southend University Hospital | Southend/ Castle Point and Rochford | | <p>The programmes focus on the long-term nature and management of coronary heart disease, helping patients to come to terms with it and facilitate any recommended changes to their lifestyle. It encompasses psychological support, education and information, smoking cessation, physical activity, healthy eating and medication in order to help patients improve their health, prevent further problems related to the patients' heart health, and reduce symptoms to improve a patients' quality of life.</p> <p>They also offer a telephone programme for those who do not wish to or are unable to attend the hospital programme.</p> | <p>Any patient from the Southend, Castle Point and Rochford area who has had a recent cardiac event may access the service following:</p> <p>A heart attack Angioplasty and/or insertion of stent Coronary Artery Bypass Surgery</p> | | |
| Cardiac rehabilitation psychology service | Heart failure | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | North East London NHS Foundation Trust (NELFT) | <p>This service is based in a hospital setting. A psychologist works with patients on difficulties associated with having a heart condition. Difficulties include: depression, anxiety disorders, overcoming trauma/the shock of diagnosis, loss of confidence, difficulty in adjustment, change of lifestyle.</p> | Adults who have experienced major heart acute conditions that require rehabilitation, educational and psychological input. | | |

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| CTC cardiac rehabilitation | Heart failure | Rehabilitation/Lifestyle Management Support and Education | Basildon and Thurrock University Hospital | Hospital Provision | | <p>The cardiac rehabilitation process starts in hospital and continues to provide support for many weeks after. There are three phases of the rehabilitation process which The Essex Cardiothoracic Centre facilitates.</p> <p>Phase 1 happens while the patient is in hospital, phase 2 when the patient is at home and phase 3 is an exercise and education programme which can be attended locally or done at home.</p> <p>This service also has a cardiac support group called Hearts and Minds, run by previous patients. They have an informative website that includes patient stories of their experiences, a question and answer section and much more - www.basildonheart.org.uk</p> | For patients requiring rehabilitation due to heart issues. | | |
| Cardiac Service | Heart failure | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide - Care Co-ordination Centre | This service provides self-management plans for people diagnosed with heart conditions. Angina and long term medical management for those with heart failure, from diagnosis to end stage. | For people diagnosed with heart conditions, such as Angina and long term medical management for those with heart failure, from diagnosis to end stage. | GP | Provided at Home or in Mid Essex local hospitals and clinics |

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| Case Management Long Term Conditions | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | Essex Partnership University NHS Trust (EPUT) - Specialist Nursing | This service provides case management and advanced clinical skills to patients with one or more long term conditions, that have, or would have become Very High Intensity Users (VHIU's) of primary or secondary care health services without the intervention of case managers/community matrons. | For people with one or more long term conditions and are high users of primary/secondary care services. | Any health care professional. | Provided at Home or in Local Centres/Clinics |
| Chronic Health Psychology Service (CHPS) | Mental Health | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | NELFT | The CHPS is a service for people with LTCs and comorbid mental health needs. the service uses Cognitive Behavioural Therapy (CBT) and Mindfulness training. CBT is a talking therapy. They utilise CBT to help clients to look at the relationship between thought, feelings and behaviours enabling them to better cope with difficulty. | People with LTCs and comorbid mental health needs | Patient need to screen positive for depression or anxiety | |
| Community Diabetes Recommended Education in Type 2 Diabetes (CREDIT) programme | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide - Care Co-ordination Centre | This educational programme is designed to support the patient in making decisions about the day to day management of their diabetes; whether this is diet, tablet or insulin controlled. | Diabetes patients | Free access | |

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| Community Diabetes Service | Diabetes | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | EPUT - Specialist Nursing | The Community Diabetes Service is a nurse led service that facilitates self-management, enabling people with diabetes to make the necessary adjustments to remain well, reducing mortality, morbidity and the need for hospitalisation. The Service is delivered through a combination of satellite clinics in the community, sessions in GP practices, education programmes, telephone support, domiciliary visits, school visits and multidisciplinary clinics at Southend Hospital. | Diabetes patients | Self-referrals accepted for drop in clinics or advice line. For on-going care GP or other healthcare professional referral is required | The Service also provides care to patients in nursing and residential care homes. |
| Community Diabetes Service | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | NELFT | The service is offered by a multidisciplinary team including Diabetes Specialist Nurses and Diabetes Specialist Dietician, associate practitioner, lay educators and consultant diabetologists. The community based service provides specialist advice and support for adults with diabetes. The service delivers specialist clinical management and care to people with diabetes, assessing their needs, working to stabilise their condition, optimising their diabetes control and treatment, and giving them confidence through self-management. The aim is to discharge back to care of the GP once condition is stable and targets met. It includes community based support, education programmes, for type 1 and type 2 diabetes, telephone support, domiciliary visits and multidisciplinary clinics. | For adults (18+) diagnosed with type 1 and type 2 diabetes, their carers and other healthcare providers. | Referrals must come from a healthcare professional. For education programme self-referral or HCP referral is accepted. | The service is community based with satellite clinics in the various locations, sessions in GP practices. Also provides care to patients in nursing and residential care homes. |

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| Community Heart Failure Service | Heart failure | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | NELFT | <p>The Community HF Service provides long-term medical management and support for patients suffering from chronic HF. The service aims to be patient centred and provides specialist nursing and support, titrate medication and therapy. Education and resources are provided to patients, carers and health practitioners to enable increased self-management. There are local clinics and home visits to those who are housebound. The service offers a help/advice line for patients/ carers/ GPs etc. which operates during office hours.</p> | For patients suffering with chronic Heart Failure | Referrals are accepted by faxing, posting, via SystemOne, or telephone call. Patients can also self-refer. | |
| Community Heart Failure Service | Heart failure | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | EPUT | <p>The Community Heart Failure Service provides a patient centred, community based, specialist nursing, education and therapy service for heart failure. The overall aim is to enhance a patient's quality of life, improve physical health and optimise their social and psychological well-being and reduce acute hospital readmissions. Specialist support, education and resources are provided to patients, carers and health practitioners to enable increased self-management and delivery of community based integrated, proactive and personalised care across south east Essex.</p> <p>The service offers a help/advice line for patients/carers/GP and others which operates during office hours.</p> | For patients suffering with chronic Heart Failure | Referrals are accepted from all primary and secondary healthcare professionals. | |

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| Community Integrated Respiratory Service | COPD | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | NELFT | <p>The service offers specialist care for patients with respiratory disease, which may cause breathlessness, particularly COPD. The three main services are Pulmonary Rehabilitation, the COPD Service and the Oxygen Service.</p> <p>Pulmonary rehab is offered to increase fitness levels and also confidence around breathing techniques particularly when feeling breathless.</p> <p>The COPD service aims to provide holistic clinical assessment and management of COPD by giving specialist support through carrying out annual reviews, performing annual spirometry and titrating their inhaled therapy as per NICE guidelines and GOLD stratification. Breathlessness management is incorporated into the long term management plan for these patient groups. The Oxygen service is provided by Home oxygen Nurses to meet the long term oxygen demands of patients in the community. The service works closely with Fire service to identify patients with high risk of fire and put measures in place to minimise identified risks.</p> | For patients with respiratory disease, which may cause breathlessness, particularly COPD | Referrals must come from a healthcare professionals - GPs, Acute hospitals, specialist centres other community services. | The Integrated Respiratory Service links to the Chronic Health Psychology Service and can refer patients with potential depression or anxiety for support therapy. |
| COPD Rehab Classes | COPD | Exercise Programme | Basildon and Southend on Sea | Basildon and Brentwood Southend/ Castle Point and Rochford | British Lung Foundation | <p>This service aims to create a healthy lifestyle and encourage life extending habits by allowing the patient to exercise together with others that understand the patient's thoughts and worries.</p> | COPD patients | COPD Rehabilitation units can refer following the patient's attendance at their in-house sessions. | |

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| Diabetes Service | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide - Care Co-ordination Centre | This service provides specialist care for people with type 2 diabetes, and some with type 1, to help them self-manage their condition. | Adults (19+) with diabetes who are registered with a GP in the NHS Mid Essex area | Referral by healthcare professionals | Provided at selected locations in the community |
| Diabetes Care service profile (hospital based care) | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide | <p>The Mid Essex integrated diabetes service delivers an integrated care pathway for patients with Type I and Type II Diabetes Mellitus, on both an inpatient and an outpatient basis at Broomfield Hospital. The team also works closely with the paediatric service to deliver transition care.</p> <p>The service includes new patient diabetic assessment, telephone advice for admission avoidance and treatment titration, inpatient care, education programme for Type I and Type II patients, including insulin conversion, continuous Blood Glucose monitoring, education for both primary and secondary staff, insulin pump service and pre-conceptual care clinic</p> | Diabetes patients | GP referral | Provided at Broomfield Hospital Some specific services under this umbrella includes foot care, nutritional support, education and assessments, and/or midwifery services for pregnant diabetics. |
| Diabetes Support Group | Diabetes | Community/Support Group | All areas | All | Diabetes UK | Diabetes UK provides support in terms of resourcing and training for the establishment of support groups in local areas. The local groups provide people the chance for peer support through meeting other people with the condition and sharing experiences and tips on living well with diabetes. Groups typically meet once a month, but they often also take part in many other activities such as fundraising, campaigning and raising awareness. | Diabetes patients | Self-Referral | |

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| Enhanced Pulmonary Rehab Service | COPD | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | Southend University Hospital | <p>This service is a rehabilitation service which consists of 12 supervised sessions run over a six week period by qualified health professionals. It delivers pulmonary rehabilitation through either a centre-based programme, a home-based programme or a hybrid programme offering a mixture of centre-based sessions with exercise and education at home.</p> <p>An additional centre has also been set up in St Luke's community centre in Southend.</p> | COPD patients | GP/ Healthcare professional | Provided in Local Hospital/Clinic |
| Essex Heartbeat | Heart failure | Community/Support Group | All areas | All | British Heart Foundation | <p>Essex Heartbeat offer support to people in Essex who are living with heart rhythm problems or with an implantable cardiac device, including Pacemakers and Implantable Cardioverter Defibrillators (ICD). They provide support and information to individuals and their family and friends.</p> | For people living with heart rhythm problems or with an implantable cardiac device, including Pacemakers and Implantable Cardioverter Defibrillators | Self-Referral | Provided in Basildon and Chelmsford |
| Exercise on Referral (EOR) scheme | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid and South Essex | All | Lifestyle Teams | <p>The EOR scheme is a prescribed exercise programme offering specific programmes for people with LTCs who are inactive, of which there are 9 different conditions eligible. The participant are placed into a group with people with the same or similar condition. The course is run over 12 weeks with two sessions per week. The programme has physical and mental health benefits to the participant. Also being in the group provides a social opportunity useful for sharing ideas and tips around self-management of their condition.</p> | People with one or more long term conditions | GP/ Healthcare professional | Provided in Leisure Centres |

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| Expert Patients Programme (EPP) | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon | Thurrock and Basildon and Brentwood | NELFT | This is a self-management support (free courses) service for people living with long-term health conditions. The courses run for six weeks and each session is 3 hours long including a refreshment break. | Adults over 18 years old are eligible. The courses are not suitable for patients with dementia, those who are house bound and patients whose mental health is not well controlled. | Patients can be referred by their GP/health professional and can also self-refer | The courses are held at local venues which provide appropriate facilities and comfort |
| Health in Mind | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | | This service offers Cognitive Behavioural Therapy (CBT) which is effective at reducing symptoms of low mood, anxiety and other emotional problems. The service is provided by working alongside GPs and health professionals in mid Essex to provide better support to patients with diabetes. | Diabetes patients | Self-Referral | |
| Heart Failure Support Group | Heart failure | Community/Support Group | Basildon and Brentwood | Basildon and Brentwood | St Luke's Hospice | This is a voluntary support group, which meets once a month. | Heart Failure patients | Self-Referral | |
| Heart Failure Support Group | Heart failure | Community/Support Group | Thurrock | Thurrock | St Luke's Hospice | This is a voluntary support group, which meets once a month. | Heart Failure patients | Self-Referral | |
| Hearts and Minds | Heart Failure | Community/Support Group | Basildon | Basildon and Brentwood | British Heart Foundation - Hearts and Minds | Hearts & Minds is a self-funding and voluntary group, which has been started by people with heart problems so that they can offer support and information to others in the Basildon district area who are suffering from heart problems. | People in the Basildon district area with angina, heart attack and other heart related problems. | Self-Referral | |

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| Inclusion Thurrock | Mental Health | Community/Support Group | Thurrock | Thurrock | | A psychological therapy service and Recovery College Inclusion Thurrock offers a simple gateway for those wanting to access talking therapies. | Adults worried about their mental health | | |
| Integrated Community Team | Mental Health | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Brentwood | Thurrock and Basildon and Brentwood | NELFT - Thurrock Pathway Services | This service offers a wide range of nursing care to people who are unable to leave their homes even with the support of family, friends or carers. Qualified nurses and experienced competent health care assistants work with the patient to provide care such as: chronic wound management, pressure ulcer management, diabetes management, elderly and frail with a nursing need and end of life care. They support the patient in looking after their own general health and wellbeing, giving advice, support and reassurance to the patient and their family and carers. | For house-bound/bed-bound patients | | Provided at Home or Local Community Hospitals |
| Integrated Diabetes Service | Diabetes | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Hospital Provision | Southend University Hospital/EP UT | The new Integrated Diabetes Service has been commissioned by local Clinical Commissioning Groups (CCGs) and is being delivered through a partnership arrangement with Southend University Hospital Trust and Essex Partnership Trust. The aim of the service is to improve patient experience and reduce ill health and complications due to diabetes through: single point of contact and triage for all diabetes referrals; consultant-led Multi-disciplinary Team (MDT) one stop clinic to develop a collaborative care plan; support ranging from dietary needs to podiatry needs; increased patient education; and repatriation of Insulin Pump service | Diabetes patients | All community and hospital diabetes patients are automatically transferred to the service | Multidisciplinary clinics are being held in various locations across Southend, Castle Point and Rochford. Individual clinics continue across the south east Essex area. |

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| Long Term Oxygen Therapy Team | COPD | Rehabilitation/Lifestyle Management Support and Education | South East Essex | All | EPUT - Specialist Nursing | This service is a nurse/physiotherapist led community service providing assessment, treatment and management of patients in the community who require home oxygen therapy, long term oxygen therapy (LTOT) and ambulatory oxygen. | For people who require home oxygen service | GPs and other healthcare professionals | Provided at Home or Care homes & Clinics in Southend and Rochford |
| Managing Health Programme | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide - Essex Lifestyle Service | The Managing Health Programme supports individuals through tools and tips to help them better self-manage their long-term conditions. There are several programmes available, as well as group programmes and telephone support services, so the patients will have a choice about what feels right for them. The programme looks at how to improve health, self-management, and how to get the best from consultations with health professionals. | People with one or more long term conditions | | Courses are run dependant on demand and delivered in accessible community venues across Mid Essex. |
| MyCOPD Application | COPD | Digital | All areas | All | mHealth | The app, named MyCOPD, is a clinically approved NHS app and is a registered class one medical device. It helps users to manage breathing difficulties caused by COPD by offering useful advice including inhaler technique videos, education from experts and a complete online pulmonary rehabilitation class. It can be downloaded onto any internet connected smart device using a licence code provided by specialist doctors and nurses at hospitals and community services when treating people with the condition. | COPD patients | Free via secondary care services | CCGs aiming for licences to be distributed by primary care services. |
| MyDiabetes Application | Diabetes | Digital | All areas | All | mHealth | The myDiabetes app contains a complete, structured, online, comprehensive diabetes education course for patients with both Type 1 and Type 2 Diabetes and enables them to monitor their blood glucose, HbA1c and other risk factors to reduce the risk of serious long term complications. | Diabetes patients | | |

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| NHS Diabetes Prevention Programme (NDPP) | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Mid and South Essex | All | NHS England/PHE /Diabetes UK - ICS Health & Wellbeing | The NDPP is for people who have been identified as having a high risk of developing type 2 diabetes based on clinical markers. It is a behaviour change programme consisting of a series of predominantly group based sessions delivered in person across a period of at least 9 months. There are at least 13 sessions and 16 hours of contact time. Sessions last between 1 and 2 hours and cover topics geared towards the programme's main goals of dietary improvements, increased physical activity and weight reduction. | Those at risk of developing Diabetes | Referrals must come from a healthcare professional or patients can self-refer by registering online | Digital NDPP service is also an option for those who are unable to attend face to face. Referral forms are available in SystemOne & EMIS to be completed by Primary care then emailed to the provider. |
| Physiotherapists | Mental Health | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | EPUT | This service is provided by Physiotherapists specialising in mental health needs. They have specific physical and mental health training to bridge the gap between physical and mental health needs of patients. | General Service for people with any physical and mental health needs | | |
| Rapid response and assessment service (RRAS) | All Conditions /General | Response Service | Thurrock | Thurrock | NELFT - Thurrock Pathway Services | The rapid response and assessment service (RRAS) provides rapid health and social care assessment for service users and carers who are in or approaching a crisis. The team includes advanced nurse practitioners (independent prescribers); social workers; health care assistants and administration support. | For service users and carers who are in or approaching a crisis. | Via Telephone | |

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| Recovery College | Mental Health | Rehabilitation/Lifestyle Management Support and Education | Thurrock | Thurrock | | Recovery College is a partnership between its students, Inclusion Thurrock, part of the NHS and Thurrock Mind (a local charity with a proud tradition of helping those experiencing difficulties with their mental health). | For those who are experiencing difficulties with their mental health needs | | |
| Respiratory Service (Including Pulmonary Rehabilitation) | COPD | Rehabilitation/Lifestyle Management Support and Education | Mid Essex | Mid Essex | Provide - Care Co-ordination Centre | <p>This service provides an oxygen assessment service, and care and support for people with Chronic obstructive pulmonary disease (COPD). This includes a self-management programme for patients with pulmonary disease.</p> <p>Other services include: Pulmonary rehabilitation (an exercise programme, education and nutrition advice to help improve the independence of people with lung disease); Palliative care; and a Telehealth service (a self-monitoring system which checks the patient's blood pressure, oxygen saturations and changes to the patient's breathing pattern). The team includes respiratory and oxygen assessment nurses, physiotherapists, healthcare support workers and admin staff. They work closely with various other healthcare professionals, such as GPs, respiratory consultants, hospital and community teams.</p> | COPD patients | Referrals must come from healthcare professionals. Patients who have been seen by the service previously can self-refer. | Provided in local Hospitals |
| Silvercloud | Mental Health | Digital | Thurrock | Thurrock | Inclusion Thurrock | SilverCloud is an online course to help manage stress, anxiety and depression by use of cognitive behavioural therapy (CBT). It currently includes a specific programme for patients with diabetes. | For people who need help managing stress, anxiety and depression. | | |

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| Social Prescribing | All Conditions /General | Community/Support Group | Mid and South Essex | All | Local Councils | The Social Prescription Programme aims to support people with health and well-being needs including chronic conditions. Patients may have a social need or chronic condition and regularly attend the GP surgery or are at risk of unplanned admission. Navigators will meet patients referred by their GP at their practice and will signpost them to appropriate services from a range of over 500 available in Thurrock. Referrals from the social prescriber may include information, advice and guidance to support health, finance and social isolation. | For Patients who may have a social need or chronic condition and regularly attend the GP surgery or are at risk of unplanned admissions. | | |
| Sound Doctor | All Conditions /General | Digital | Mid and South Essex | All | Essex County Council & The Sound Doctor | The Sound Doctor is a film and audio programme designed to help healthcare professionals advise their patients on managing long-term conditions safely and effectively at home. The programme includes courses of educational material focusing on the causes, symptoms, risks, treatment and management of each condition. | People with one or more long term conditions | | |
| Southend Chronic Obstructive Pulmonary Disease (COPD) Psychology Service | COPD | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | EPUT - Essex Mental Health Services | This service includes various courses to help manage stress associated with COPD. The service also provides Psychological input and joint work in Hospital Pulmonary Rehab program. As well as specialist support, education and training to other professionals to enable them to understand and work with the emotional needs of our client group. | COPD patients | | Provided in Southend University Hospital |
| Southend Health Information Point (SHIP) | All Conditions /General | Community/Support Group | South East Essex | Southend/ Castle Point and Rochford | Southend Borough Council Southend CCG Vibrance SAVs | SHIP is the central point for information, advice and guidance on local services and organisations that aim to help increase independence and wellbeing in Southend Residents. http://www.southendinfopoint.org/ | For Southend residents' general health and wellbeing | | |

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| Southend Therapy and Recovery Team (START) | All Conditions /General | Response Service | South East Essex | Southend/ Castle Point and Rochford | EPUT - Specialist Nursing | START are a joint health and social care domiciliary rehabilitation and reablement team, providing short term, goal based rehabilitation programs to patients in their own home to prevent admission or facilitate early discharge from hospital. | For Southend patients in their own home to prevent admission or facilitate early discharge from hospital. | GP | |
| Southend Responsibility Deal | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | South East Essex | Southend/ Castle Point and Rochford | | This service assists employers in managing the health of their workforce, to include those suffering from long term conditions via support, assessments and health checks. | For Southend employers to manage the general wellbeing of their workforce | | |
| SWEET (South West Essex Education and Training) | Diabetes | Rehabilitation/Lifestyle Management Support and Education | Thurrock and Basildon and Brentwood | Thurrock and Basildon and Brentwood | NELFT | This course is a Structured Education (SE) scheme aiming to improve self-management and reduce complications caused by poor management of Type I and Type II Diabetes. Structured as a 3 hour, group based, one off session to help newly diagnosed patients manage and cope with diabetes and improve long-term outcomes. | Newly diagnosed Diabetic patients | Self-referral and Health Professional referral | |
| SWIFT | All Conditions /General | Response Service | South East Essex | Southend/ Castle Point and Rochford | EPUT | SWIFT is a community team structure which helps patients stay at home when they are feeling unwell, rather than be transferred to hospital. The SWIFT service is designed with a 'home first' ethos and will provide specialist, nurse-led care in people's own homes. They will visit patients within two-hours of receiving a referral from their GP practice to stabilise their immediate health need. They will support patients to feel better by visiting at home to provide the necessary assessments, medication and nursing interventions and aim to stabilise patients within five days. | For residents who would benefit from being seen at home prior to being transferred to a hospital. | GP referral | |

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| Take Heart Southend Heart Support Group | Heart Failure | Community/Support Group | South East Essex | Southend/ Castle Point and Rochford | British Heart Foundation - Essex Cardiac Group | Take Heart is a cardiac support group covering the areas of Southend, Castle Point, Rayleigh and Rochford, Essex. Their aim is to offer a support network for all who have become affected by Cardiac problems whether as a patient, carer or family members. They are a non-medical voluntary group, helping the patient to consider a new approach to life both during and after cardiac problems, in order to restore the patient to a more active life. | For patients, carers or their families who have been affected by a cardiac condition | Self-Referral | |
| Thurrock Diabetes Support Group | Diabetes | Community/Support Group | Thurrock | Thurrock | Local group | The Thurrock Diabetes Support Group gives people in Thurrock the chance to meet with others and share experiences and tips on living well with diabetes. | Thurrock Diabetic patients | Self-Referral | |
| Thurrock First | Mental Health | Community/Support Group | Thurrock | Thurrock | NELFT | Thurrock First is the first point of telephone contact for adults living in Thurrock who want to talk to someone about: adult social care, mental health, health problems that have been diagnosed and for which on-going care is needed or care that is available in the community. | Adults in Thurrock who want to talk about any health problems, mental health needs, or local care | | Telephone Service |
| Thurrock Mind | Mental Health | Community/Support Group | Thurrock | Thurrock | Local Mind Charity | Thurrock Mind provide a range of interventions including talking therapies, supported housing, peer mentoring, positive pathways and advocacy. They are also active participants in a 'shared care protocol' which supports clients discharged from EPUT services to stay well and reduce re-admissions to secondary care. The Emotional Well Being Forum supported by Thurrock Coalition and MIND is an opportunity for those with lived experiences of services and mental health and carers to meet together for support, to gain information and to influence service developments | For people who want to extra support for their physical and mental health needs. | | |

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| Tickers Cardiac Exercise Group | Heart Failure | Rehabilitation/Lifestyle Management Support and Education | Chelmsford | Mid Essex | British Heart Foundation | This group provides exercise sessions for people with heart failure | Heart Failure patients | Referred by a healthcare professional on completion of a phase 3 exercise programme | |
| Tier 3 Weight Management | All Conditions /General | Rehabilitation/Lifestyle Management Support and Education | Mid and South Essex | All | More Life | The MoreLife programme is delivered and supported by weight management practitioners and a range of health and research clinicians such as GPs, Dieticians and psychologists. The programme is delivered in a group format and lasts for 12 months in total starting with a 14-week intensive programme, then monthly meetings and finally ongoing drop in support. | For people with health conditions which would be better managed and controlled through weight loss. | GP/ Healthcare professional | |
| Type 2 Together | Diabetes | Community/Support Group | Mid Essex | Mid Essex | Diabetes UK | 'Type 2 Together' is a patient led diabetes group, offering a friendly environment for patients to discuss any aspects of Type 2 diabetes and support each other in making healthy lifestyle changes. | For patients with Type 2 Diabetes | Self-Referral | Provided in local surgeries |
| Viva Breathe | COPD | Exercise Programme | Chelmsford | Mid Essex | Charity/Voluntary | This class provides self-management plans for people diagnosed with Angina and long term medical management for those with heart failure, from diagnosis to end stage. | For people diagnosed with heart conditions | Self-referral | Paid service |

