Community Asset Mapping: Chronic Obstructive Pulmonary Disease

November 2024

Full Report

healthwatch Essex

North East Essex Community Asset Mapping

Chronic Obstructive Pulmonary Disease

North East Essex
Health & Wellbeing Alliance

November 2024

Table of Contents

To visit a chapter or page, click on the heading above.
Click on any page number below to return to the Table of Contents.

Contributors

Community360 is a registered charity and company limited by guarantee. Originally formed in 1968, the charity is an established anchor organisation working to achieve positive outcomes for local people across Essex, but with important bases in Colchester and Braintree. The charity's purpose is "Through partnership working we will foster resilient, thriving, and inclusive environments so everyone can live their best lives." Our activities and the effects of what we do are diverse. We endeavour to provide voluntary organisations with passionate, intelligent leadership, investing in bringing people together to co-develop and deliver impactful programmes of work that address local priorities.

Community Voluntary Services Tendring (CVST) is the local infrastructure organisation for Tendring. A registered local charity run by local people for local people we support local communities by empowering individuals and groups.
CVST provides a range of services including volunteer recruitment, training, assistance with project development, funding advice, and organisational guidance and support for local charities and community groups.
We work to promote community wellbeing, social inclusion, and collaboration among local residents. By fostering volunteer-ism and enhancing community connections, CVST plays a crucial role in strengthening the social fabric and improving the quality of life in Tendring.

Healthwatch Essex are an independent voice for the people of Essex, helping to shape and improve health and social care services in the county.
We believe that people's views and lived experience of health and care matter, so we're here to make sure your voice is heard and responded to.
Healthwatch Essex collects data and lived experience from the public of Essex relating to health and social care services, and uses that information to inform the way services are designed and delivered. It is important to us that the work that we do creates meaningful change.

Introduction

This report is the latest in a series of voluntary and community sector asset mapping reports which have been produced to support the health and social care system since 2019. Each report has been designed to explore how we can better understand our places in North East Essex by accessing situated knowledge from the experiences of community-based groups and leaders and providing recommendations which have the potential to impact upon our collective outcomes.

The original reports, collated by Community360 (C360) and Community Voluntary Services Tendring (CVST) were created as standalone overviews of the voluntary sector in Colchester and Tendring respectively. Once this foundation was established, the opportunity to expand the programme with targeted reports was recognised and strengthened with a deeper understanding of citizen's voices, co-ordinated by Healthwatch Essex.

From 2020, C360, CVST and Healthwatch Essex spent three years working together in partnership to produce seven reports, reflecting upon the consequences of the pandemic on the sector, and reviewing the role of community-based activities in supporting people across all six Live Well domains in respect of different life stages and in consideration of different health needs. The working partnership is now entering the next phase of insight and concentrating upon five priority conditions in alignment with the Suffolk and North East Essex Integrated Care Board's (SNEE ICB) plans.

This report contains the findings of the first of the asset mapping topics:
Chronic Obstructive Pulmonary Disorder (COPD).

COPD is an umbrella term used to classify a number of different conditions, including emphysema (damage to the air sacks and lungs) and chronic bronchitis (the long-term inflammation of the airways) (NHS England, Last Accessed August 2024). COPD occurs when the lungs become inflamed, damaged, or narrow, with the primary cause being smoking, although it can also be caused by long term exposure to fumes, dust or mould or genetics.

Fig. 1 below shows a list of symptoms that people living with COPD may experience, with less common typically seen when the condition progresses to an advanced stage:

COMMON SYMPTOMS	LESS COMMON SYMPTOMS
Shortness of breath	Weight Loss
Persistent chesty cough with phlegm	Tiredness
Frequent chest infections	Swollen ankles from a build-up of fluid
Persistent wheezing	Chest Pain and coughing up blood

Fig. 1 Symptoms of COPD (NHS, Last Accessed August 2024)

While there is currently no cure for COPD, a number of treatments are offered to help those living with the condition manage their lives, which will be detailed in the following sections. Patient pathways for COPD are split into six tiers of care:

1. Primary Prevention
2. Early Accurate and Complete Diagnosis of Respiratory Symptoms
3. Treatment and Management of COD in Acute and Stable Phases
4. Complex/Severe Disease Treatment
5. High Cost/High Need Patients
6. End of Life Care

(NHS Right Care Pathway: COPD, Last Accessed August 2024)

As such, for the purposes of understanding the various clinical and community assets, this report will be structured into three stages that group together these tiers of care, consolidating the six tiers of care into three stages: Prevention, Diagnosis and Effective Treatment, and End of Life.

To introduce the dimension of place and the impact of possible differences between them, this asset mapping research conducts research in two wards, one each in Colchester and Tendring, where the prevalence of COPD is highest. Through data provided by SNEE ICB, St. Anne's & St. John's ward has the highest prevalence of people living with COPD in Colchester and Jaywick & West Clacton ward in Tendring.

With a population of 10,563 people as per the ONS (2017) mid-year population estimates by ward, St. Anne's & St. John's ward is the 11th most populated ward in Colchester. On average, the ward has more older people living there than the rest of Colchester at 24.6% compared to the city average of 17.2%. One out of the seven LSOAs in St. Anne's & St. John's are amongst the most deprived pentile the country (Essex IMD, 2019).

Jaywick & West Clacton a LSOA within Tendring has a higher-than-average age of population compared to the rest of the Tendring area. With 62.2% of the population being over 50yrs compared to Tendring that sits at 51.14%. The average age within Jaywick & West Clacton is 52.4yrs. East of the Jaywick area is measured as the most deprived neighbourhood in England according to the IMD2019 Population numbers of people living with COPD 2023/2024 fingertips within Tendring is 4868 (3%), compared to the East of England which sits at 1.8%.

Methodology

Asset Mapping Research

Following from Kretzmann and McKnight's (1993) seminal Asset Based Community Development (ABCD) framework, assets can be understood as the internal resources, skills and experiences that can be found within a certain community, with the subset of health assets being those which enhance *"the ability of individuals, groups, communities, populations, social systems and/or institutions to maintain health and wellbeing"* (Morgan and Zigilo, 2007).

Rather than taking a deficit approach, which focuses on what a community does not have, the ABCD approach looks at building a community by focusing on its strengths and potential (Kretzmann and McKnight, 1994).

To begin to strengthen the assets within a community, one must first identify the assets within a particular area, at which point it is necessary to undertake asset mapping research. (Kretzmann and McKnight, 1994).

This entails a descriptive element, where one geographically plots out the landscape of different assets within an area (Corrigan et al, 2024; O'Connor et al, 2019), as well as an explanatory element where asset mapping identifies the different relationships that are formed between community members and assets based on local needs (Thirsk and Clark, 2017).

Taking stock of the landscape in this way, and then identifying assets to strengthen in the community, allows for effective recommendations to be made to commissioners to then allow for efficient resource allocation that directly benefits the community.

For the purposes of this research, we have reviewed the definition of assets and agreed to adopt the description which has been applied in research conducted in North East Essex, including Overcoming Barriers to Health and Wellbeing, which states:

"A community asset is defined as any factor or resource which enhances the ability of individuals, groups, communities, populations, and/or institutions to maintain and sustain health and wellbeing and to help reduce health inequities." (Morgan and Ziglio, 2007).

"Community assets can take a variety of forms including activities, support groups, social networks, and community spaces/places. A defining feature is that they have their roots in the community with the aim of benefiting community members." (Corrigan et al, 2020)

As such, with those ABCD principles and definitions in mind, the asset mapping portion of this research, undertaken by Community360 and CVST, has been conducted as thus:

First, the clinical pathways and NICE guidelines for COPD were reviewed, providing both a reference point by which assets could be judged as useful for someone with COPD based on treatments and clinical pathways, as well as providing a way to categorise relevant assets and as a result a structure by which this report is structured.

Next, an initial mapping exercise was undertaken within each community to begin to identify the assets within each area. Search engines such as Google were used with reference to the above guidelines and pathways, as well as indexes of registered assets such as Companies House and the Charity Commission. We also used local intelligence, including our own databases, engaged with other networks such as One Colchester and Tendring Together and spoke to local professionals to facilitate introductions.

Researchers then conducted semi-structured interviews, lasting between 30-45 minutes, with representatives from relevant assets to gain a high-level understanding of the services provided, along with any challenges they may face and how they may support people with COPD. Given the lack of COPD-specific assets within the target areas, researchers also expanded this asset search and data collection method to clinical practices in order to get a real insight into the care pathway experience of someone with COPD.

Next, for the Lived Experience aspect of this research, researchers from Healthwatch Essex conducted semi-structured interviews with frontline workers and people living with COPD, lasting between 30-60 minutes. Participants were identified in partnership working with local services, with GP surgeries within the catchment areas sending texts out to their patients advertising the interviews, researchers attending local groups and door knocking exercises that form a part of other programs.

In total, 20 people with COPD in Greenstead and St. Anne's & St. John's and 20 people in Jaywick & West Clacton were interviewed. They were asked about the nature of their condition, diagnosis, and subsequent medical treatment, as well as the impact on their lives and challenges they may face. Interviews were then opened up and follow up questions asked based on participant responses to allow their experience to be effectively captured. In terms of the frontline workers, over 10 were interviewed including Respiratory Nurses, Community Respiratory Nurses, Acute Respiratory Nurses, Advanced Clinical Practitioners, Community Wellbeing Officers, and local Pharmacists.

They were asked first about their role and how they support people with COPD, observations about the target areas and any challenges they may experience before the interviews were opened up further.

Participants were fully informed of their rights within this research and consented fully. Thematic coding was then used to analyse this data, with the findings then being grouped thematically into sections within this report and also used as case studies.

Stage One - Prevention

3.1 Social Determinants of Health

To say someone is in good health is not just to say that they are in a state of physical of biological wellness, but it also concerns health equity – the setting in which they are born, work, live and age (WHO, 2006). Health, under this definition, concerns questions about the overall wellbeing of a person and the inequalities they may experience regarding healthcare or living more generally as a result of their background.

Various intersecting traits can affect someone's health and subsequent needs: socio-economic position, local infrastructure, disability, gender, and race, amongst other things, contributes to someone's overall health and wellbeing. Someone who is socially deprived, for instance, may not be able to afford private health care, meaning they must be placed on an NHS waiting list and potentially experience worse health outcomes as a result of the wait. For instance, someone with a chronic disability may need reasonable adjustments, such as regular breaks, in the workplace to be able to work to the best of their ability without feeling unwell.

Some people who may experience health inequalities as a result of their condition may require extra practical support in order to be attain good health. COPD patients are not different, experiencing a number of challenges that arise as a result of their condition that mean they have to access extra assets.

Yet the risks of developing COPD are exacerbated by some social determinants, including healthy lifestyle behaviours and housing conditions. Therefore, this report begins by reflecting upon available assets which meaningfully contribute to prevention.

3.2 Smoking Cessation

The prevalence of smoking in the East of England is 13.2%, which sits over the national average of 12.7% (OHID Fingertips, 2020). Colchester sits under the national average at 12.1%, whereas Tendring has a higher prevalence than the region at 14.3%.

Given that smoking is the main cause of COPD in adults, smoking cessation stands as the cornerstone of prevention measures.

Smoking rates in Tendring, Essex, are higher than the national and regional averages, reflecting certain socioeconomic challenges in the district. Tendring has some of the highest smoking prevalence rates in Essex, particularly in deprived areas like Jaywick, which significantly impacts public health outcomes. Addressing the underlying socioeconomic challenges is crucial for long-term reductions in smoking.

In Essex, Provide manage services under the banners of Essex Wellbeing Service (hereafter, EWS) and Essex Lifestyle Service (ELS) that deliver NHS stop smoking services. Their standard offer provides smokers an 8-week program that aims to change the behaviour of smokers to cut tobacco products out of their routines, using techniques such as Cognitive Behavioural Therapy, nicotine replacement initiatives (NRI), online seminars and education around the drivers of smoking.

Importantly, in addition to this, they have also introduced a harm reduction approach, Cut Down to Stop, where they encourage people to cut down their smoking over 4 weekly calls and processing fortnightly calls, to ensure that less damage is being done to themselves even if people are not necessarily going to quit smoking. This approach comes as a result of the EWS to take a more positive, hope-based, message around stopping smoking, rather than the traditional discourse around smoking which simply highlights the negative effects it has on your body. Doing so creates a more accessible avenue whereby heavy smokers (including people with COPD) can begin their journey to stopping smoking and change their habitual behaviour more gradually.

Stop smoking services operate in some pharmacies offer stop-smoking services, providing free advice, NRT products, and support for those wanting to quit. Pharmacists offer practical help to monitor progress and provide ongoing motivation.

All initiatives do this in conjunction with larger campaigns and awareness programmes, such as Stoptober and No Smoking Day, which are promoted help to raise awareness about the benefits of quitting smoking to encourage smokers to quit.

Targeting Vulnerable Groups

Special programs target groups with high smoking rates, such as pregnant women and people with mental health conditions. Support is available through local healthcare providers and charities to reduce smoking-related health risks in these vulnerable populations.

One example of this is Smokefree Pregnant Households project which is currently being delivered within Colchester and Tendring. Suffolk & North East Essex (SNEE) ICB has a population of approximately 1 million people, aligned to two county councils and has three maternity units with an annual birth rate of approximately 9000. The pilot adopts a whole household approach to support women and optimise outcomes. Currently 70% of pregnant women have engaged in the pathway alongside 47% of household members of pregnant women.

The project delivers a public health approach to reduce additional risk factors to woman and child which addresses the root cause of addiction e.g. wider determinants of health, through personalised care and non-judgemental care. Women are supported to access community assets to create ongoing network of support.

Provision also exists within Colchester Hospital to help cut down smoking. In taking brief and very brief interventions in the form of a chat with patients (NICE Behaviour Change Interventions, Last Accessed October 2024), the Making Every Contact Count (MECC) initiative facilitates simple conversations between frontline staff and patients about their health, planting the seeds of health behaviour change in patients. Conversations centre around lifestyle choices – primarily smoking, weight and physical activity - with the goal of helping the patient understand how this can have a big impact on their existing health conditions and co-morbidities. This kind of light-touch approach provides a pressure-free and accessible way for heavy smokers (and people with COPD) to initiate a conversation about their smoking and encourage them to then get referred into the EWS smoking cessation program.

Given that smoking is the main cause of COPD in adults, smoking cessation stands as the cornerstone of prevention measures. The link between poverty and smoking is a significant barrier to reducing smoking rates in particularly in West Clacton and Jaywick as smoking-related illnesses disproportionately affect poorer communities, placing additional strain on local health services. The district has higher rates of smoking-related illnesses and hospital admissions compared to the rest of Essex and the national average.

3.3 Anti-Mould

Research has shown that the presence of acute damp and mould within a property can lead to adverse respiratory effects, causing general symptoms such as coughing, wheezing and shortness of breath, then worsening the symptoms that a patient with COPD displays if they live in close proximity to damp and mould (UK Gov, 2024: Last Accessed September 2024).

Mould growth in homes is a significant issue, particularly in areas with older housing stock or poor ventilation. Mould is often caused by excess moisture, inadequate heating, or poor insulation, and can lead to health problems like respiratory issues, especially for vulnerable groups like children and the elderly.

Social Housing Regulation Bill - Statutory Responsibility

In Colchester, Social housing providers Eastlight Community Homes and Colchester Borough Homes (CBH) both offer a free mould removal service to their tenants should they need the service, undertaking any essential works to combat penetrating dampness to the external structure of the property or dampness caused by internal disrepair issues.

Likewise, Tendring District Council is committed to ensuring that the homes it provides are well maintained and of a decent standard. Its Housing Damp and Mould policy sets out the activities and responsibilities involved in the control of damp and mould within properties owned by Tendring District Council.

Tendring District Council recognises the importance of addressing the problems damp and mould and of having measures in place to tackle and reduce these issues and condensation in its properties and treats all reports of damp and mould seriously and understands the physical and mental health implications it can cause.

Mould and damp create extra challenges during the winter, as homes are not as warm as during the summer meaning that mould and damp caused by condensation and poor ventilation is more prevalent during this time of year. Central heating is thus needed to help keep mould and damp at bay, providing another challenge to those who may be economically deprived.

Jaywick Sands Healthy Homes Initiative is a 2 year project which commenced in March 2023 which is being run by Tendring District Council and comprises environmental health officers based within the Jaywick community at the Enterprise Centre in Lotus Way.

The project is to improve living conditions within Jaywick, where residents and get advice and assistance from the officers, who will liaise with landlords etc. They are based within the Jaywick area to gain the trust of the community and hopefully will be more utilised than being within the town hall or office buildings in Clacton town.

The funding of £900,000 for the project came from The North East Essex Health and Wellbeing Alliance, this will fund the officers and workspace. Any home improvements that are needed will be funded by the landlords or any existing local grant schemes.

Colchester and Tendring each have their own Private Sector Housing team who are responsible for undertaking regulatory housing enforcement. Using the Housing Health and Safety Rating System (HHSRS), representatives of the private sector housing team will go to a property to survey it, to then provide recommendations to landlords around changes that need to be made to the property.

The councils have enforcement powers under the Housing Health and Safety Rating System (HHSRS), which allows them to act against landlords who fail to address serious damp and mould problems. This could involve issuing improvement notices to ensure that landlords fix any structural or maintenance issues causing mould.

Anti-Mould Initiatives in Essex

Healthy Homes Project

The Healthy Homes Project, which operates in parts of Essex including Colchester and Tendring, aims to improve living conditions for vulnerable residents. The project focuses on addressing damp and mould issues by offering home visits to assess housing conditions, provide advice, and help households access funding for home improvements, such as better ventilation and insulation.

Energy Efficiency Grants and Schemes

Several government-funded schemes and grants are available to help residents improve their homes' energy efficiency, which in turn can reduce mould caused by condensation and inadequate heating. These include:

- Energy Company Obligation (ECO): A government initiative that provides funding for energy efficiency improvements like insulation and heating upgrades, which can reduce moisture build up in homes.
- Local Authority Delivery (LAD) Scheme: This helps local authorities, including Tendring District Council, fund energy-efficient upgrades for low-income and fuel-poor households.
- Warm Homes Essex: An initiative that provides advice and support on reducing heating costs and improving home insulation, which can help combat dampness and mould.

Community Support and Advice

Local organisations, such as Citizens Advice Tendring and others, provide guidance and support for tenants and homeowners dealing with damp and mould issues. They offer advice on tenants' rights, how to deal with landlords, and how to access grants or funding for home improvements.

Private Landlord Responsibilities
Private landlords in Colchester and Tendring are legally required to ensure that their properties are free from serious damp and mould issues. Tenants who experience mould growth can report the problem to the Environmental Health Department, and the council can intervene if the property is deemed a health hazard.

Education and Awareness
The councils and local NHS organisations promote awareness around mould prevention. This includes advising residents to:

- Improve ventilation by using extractor fans or opening windows.
- Use dehumidifiers to reduce moisture levels.
- Heat their homes consistently to prevent condensation.

National Initiatives
National initiatives, such as the Government's Social Housing Regulation Bill, which focuses on ensuring housing standards are upheld, are also pushing for more robust responses to issues like mould and damp. Following high-profile cases of mould-related health issues in the UK, there has been increasing attention on addressing these problems. These combined efforts aim to reduce mould-related health risks and improve living conditions for Tendring's residents, particularly those in vulnerable housing situations.

3.4 Fuel Poverty

Fuel deprivation in the UK has become an issue in recent years: *"It is estimated there has been a significant increase in the number of people experiencing fuel poverty in the UK since energy prices started to increase in 2021. Renters, young people, large households, lone parents, and those with young children are disproportionately impacted by fuel poverty"* (NCP, 2023: Last Accessed August 2024).

The Department for Energy Security and Net Zero estimating that 13% of households (3.17million) are in fuel poverty in England (Annual Fuel Poverty Statistics in England, 2024: Last Accessed September 2024).

A household can be classified as in fuel poverty if they are on a low income and face high energy costs (Fuel Poverty Efficiency Rating Methodology, 2024: Last Accessed September 2024). If a deprived household faces fuel deprivation, and cannot heat their homes during winter, then they will therefore be at greater risk of mould build up within their property.

In Colchester, St. Anne's & St. John's ward was found to have 10.2% of households in fuel poverty in 2019 (Colchester Ward Summaries and Profiles, 2019) but based on rising fossil fuel costs since the COVID-19 pandemic and the recent cost of living crisis, we estimate those numbers to be higher.

The Jaywick and District Energy Hub
The Hub aims to help residents save energy and money on their energy bills and is operated in partnership with Tendring District Council and Citizens Advice Tendring. The Energy Hub can help people living in Jaywick Sands and surrounding areas to get support for a range of services relating to energy including:

- Applications for government grants to improve the energy efficiency of their home, including the Energy Company Obligation (ECO4Flex), the Home Upgrade Grant (HUG2) and the Great British Insulation Scheme (GBIS).
- Improving an owned or rented property’s Energy Performance Certificate (EPC)
- Home energy visits
- Benefit checks
- Food and fuel vouchers
- Energy advice
- Reducing bills

In Tendring CVST run a Cost of Living Action Group which pulls together initiatives across Tendring that can help local residents to reduce their outgoings or increase their incomes so that they are less affected by the current cost of living crises. An example of the work that has come from this is the ‘Bills Clinic’ which can help households swap to more cost effecting utility tariffs.

For people living with COPD who live in fuel poverty may be at greater risk of exacerbations of their symptom there are also a number of community assets to help keep homes warm and free of damp in the Colchester community.

Winter resilience programmes present the opportunity to respond to such issues, as in 2023/24 when free dehumidifiers were available for community members facing fuel poverty from Community360. Colchester Borough Homes and the Colchester City Council Private Sector Housing Team also provide these to their tenants in need.

Further to this, there are a number of schemes across Colchester and Tendring that can offer financial assistance to people facing fuel poverty, the list below shows how both public and voluntary sector groups are seeking to co-ordinate financial support in different ways:

SCHEME	USED FOR	ELIGIBILITY	AMOUNT
CCC Disabled Facilities Grants	Heating Upgrades and Installation.	Referred through ECC after Recommendation from Occupational Therapists.	Up to £30,000 grant per application.
CCC Energy Efficiency Grants	Boiler Upgrade Scheme ECO4 Flex Home Upgrade Grant Insulation Scheme	Subject to Earnings Threshold and Home Assessment.	Varied
Macmillan Cold Weather Payments	Payment to help heat homes.	Benefit Recipients Conditional based on temperature of the home across a week.	£25 per day per 7-day period.

Winter Fuel Payment	One-off payment to help pay for fuel.	Pension Age People Means Tested.	£200 if under 80 £300 if over 80.
Fuel Vouchers CCC Citizens Advice Colchester Food Bank Signpost	Emergency vouchers to top up fuel meters.	Anyone	Various
Turn2Us	National Specialised Grant Finder.	Anyone	Various

Fig. 2 Energy and Fuel Poverty Grants in Colchester

3.5 Physical Activity

Physical Activity and Health Promotion

"We still get out and do stuff, but I can't run or nothing anymore. I was getting out on my bike and I noticed on there that I get short of breath really quickly, but I take my blue pump out with me now and I stop to get my breath back. I'm just muddling my way through here."
- *Colchester Participant*

Promoting physical activity among people with COPD is essential for improving their quality of life and reducing the burden of the disease on healthcare resources. Programs like pulmonary rehabilitation, community walking groups, and other initiatives play a crucial role in helping residents with COPD stay active and manage their condition.

Around 60-65% of adults in Tendring meet the national guidelines for physical activity, slightly below the national average. Physical inactivity is particularly prevalent among older adults and those in deprived areas, who are at greater risk of chronic conditions like COPD. In Colchester, activity levels vary across the place, with the most severely compromised levels of activity concentrated in parts of South and North Colchester, including significant parts of St. Anne's & St. John's and Greenstead (ELDP Physical Activity Dashboard, October 2024).

People with COPD may be less physically active due to breathlessness, fatigue, and a reduced ability to exercise. This creates a cycle where inactivity worsens the symptoms of COPD, leading to further physical decline and increased reliance on healthcare services. Overcoming barriers, particularly around fear of exercise and accessibility, will be key to increasing physical activity levels and improving health outcomes in this vulnerable population.

"They're not doing exercise, because they can't. It hurts. And then you're sitting in a chair all day. It's not the best position to be in if you're struggling to breathe."
- *Pharmacist (Tendring)*

“I would definitely be interested in accessing different services that might benefit my condition. Exercise being the main one. I would like to look at exercise as being my main goal for the new year.”
- Tendring Participant

General Physical Activity Initiatives in Colchester and Tendring

Essex Lifestyle Service

The Essex Lifestyle Service supports people, including those with COPD by offering free, tailored advice on how to stay active and manage their lifestyle in support of their general health. They provide one-on-one coaching and resources to help individuals build an exercise routine that fits their abilities and limitations.

Walking and Community Programs

Walking for Health groups offer regular walks tailored for people with health conditions, including COPD. These group walks provide social interaction, which is important for mental health, and encourage gentle physical activity in a supportive environment. Other initiatives, such as chair-based exercise classes, and singing are designed for older adults or those with limited mobility, making them accessible for people with COPD who struggle with more vigorous forms of activity.

Active Essex - Local Delivery Pilots in Tendring and Colchester

While Active Essex does not directly provide pulmonary rehabilitation, they often work in partnership with local health services to promote these programs. Active Essex offers a range of physical activity programs specifically tailored for individuals with long-term health conditions, including COPD. These programs focus on improving cardiovascular health, muscle strength, and overall fitness, all of which are vital for managing COPD symptoms. Active Essex also collaborates with local healthcare providers to deliver workshops and training that help healthcare professionals incorporate physical activity into the management plans for people with COPD. This ensures that people receive tailored exercise recommendations from their doctors and respiratory specialists.

Stage Two - Diagnosis and Effective Treatment

4.1 Primary Care Pathways

If people present to a local chemist they will be advised to visit their GP as COPD can only be diagnosed by certain tests. Most clinicians follow the NICE guidelines or the Gold Standard to make a diagnosis of COPD.

Local GPs surgeries have respiratory nurses within the practice. There is approximately a 3-6 month wait to see Respiratory Nurses for diagnosis within GP surgeries in Tendring.

Once a referral to them has been made they can diagnose and help patients to manage their symptoms and give advice on their condition. They can also refer on to other services including respiratory consultants if required.

If a patient is within the local community hospitals at Harwich and Clacton, and they present with COPD symptoms but have no diagnosis as such and are stable, this information would be added to the Transfer of Care referral (TOCH) which goes home with the patient and is forwarded to their GP. They are also advised to approach the GP regarding COPD to follow this up.

As part of the diagnostic process for COPD, GP Primary Choice (GPPC) have been commissioned by the ICB to support the delivery of spirometry diagnostic testing in Primary Care. This includes the introduction of a COPD and Asthma pathway agreed by the ICB to ensure that all spirometry tests are carried out in line with NICE guidance.

GPPC offer a hybrid model that allows practices to complete their own tests, or their trained staff deliver a clinic to their patients. In addition to this, GPPC also delivers the Targeted Lung Health Check programme in NEE on behalf of practices. Eligibility is anyone between the ages of 55 and 74 who has ever smoked. They are contacted and invited to book an appointment. The patients are asked a set of questions to determine the health of their lungs. At the end of the questionnaire, a score is produced, and patients are then either discharged from the programme as low-risk or referred to the hospital for a low-dose CT scan.

One of the incidental findings from a scan is the identification of emphysema, which is reported back to practices as part of the hospital discharge. This can mean introducing treatment early to patients before they begin to display symptoms or become unwell. All smokers are offered a referral to the NEE smoking cessation service, and this is made by the team on behalf of the patient if consent is gained.

For inpatients in the community hospital in Tendring, during the day there will be an Advanced Nurse Practitioner or Doctor present. If a patient is stable with COPD and is having an episode, they can prescribe an inhaler or utilise one if they already have one prescribed. If the patient’s condition then worsens, they would be referred to the inpatient respiratory team to be seen as soon as possible.

4.2 Secondary Care Spotlight

Integrated Respiratory Service

In Northeast Essex, the Integrated Respiratory Service (IRS) forms and coordinates secondary care services for COPD and other respiratory diseases. While the early stages after diagnosis are managed within primary care, the IRS help patients manage their symptoms as their conditions worsen. In this way, the IRS COPD service aims at preventing readmissions. This occurs through prescribing and creating personalised self-management programs, where patients will create an action plan as to what they will do if they have an exacerbation, regarding what doses of medicine to take or who to contact for instance, as well as how that patient may seek to improve their overall wellbeing, through various forms of exercise for example.

Creating such a plan allows the patient to stay calm if an exacerbation arises and act accordingly to their current symptoms, thereby preventing any unnecessary admissions to hospital. As a part of creating self-management plans, IRS clinicians will review and optimise medication, conduct a clinical oxygen assessment, and encourage patients to undertake smoking cessation programs.

Separately to this, the IRS offers two other forms of self-management programs to aid patients in taking control of their condition.

1. Respiratory Physiotherapy is a type of physical therapy, aimed to treat disorders of the respiratory system, which helps patients manage breathlessness and improve lung strength, as well as facilitating an initial return to physical activity. Treatments as part of the program include airway clearance techniques, such as postural drainage and provoked coughs, to allow the patient to remove phlegm from their lungs, sinus clearance, dysfunctional breathing pattern management, thoracic expansion exercises, and manual clearance techniques. These techniques aim at providing patients with ways in which they control and clear their airways to improve their day-to-day functional ability of their lungs. These sessions run at Portland Medical Centre in Colchester and the Fryatt Hospital, Harwich in Tendring.

2. Pulmonary Rehabilitation is a program of tailored movement based and resistance training exercise aimed at people who experience breathlessness as a part of a long-term lung condition. Patients must be able to commit to two sessions per week for 6 weeks and be stable enough in their breathing to complete light exercise, meaning that respiratory physiotherapy is first required for patients who are experiencing more severe symptoms.

Exercise in this way improves the patients muscle strength so oxygen can be used more efferently and learn to manage their breathing during physical exertion. Doing so means that patients with COPD are better able to manage their symptoms, thus regaining a better quality of life as they are able to physically exert themselves in more diverse ways.

Pulmonary Rehabilitation sessions run in Colchester at Colchester Hospital and Greenstead Community Centre and at Jaywick and Tendring District Scout Hut in Tendring. During these self-management courses, IRS clinicians and nurses will also educate patients with the disease around the condition and living with the condition to further this.

Another important aspect to self-management for some higher-need patients is receiving oxygen. Through a Home Oxygen Assessment, IRS clinicians can prescribe ambulatory or long-term oxygen to patients, as well as advise patients on the best type of equipment to suit their needs.

Essex County Fire and Rescue Service

Patients using oxygen at home qualify for a home safety check, following onward referral from the contracted oxygen supplier for NHS services to the Essex County Fire and Rescue Service's (ECFRS) Safe and Well Team. A home safety visit will take account of the need and status of smoke alarms, adaptations of home safety devises for people with sensory loss, general advice on home fire safety, hazards, carbon monoxide and gas safety, crime prevention and additional support for carers or people who may be 'at risk' and vulnerable residents.

Consultation with teams at ECFRS has highlighted opportunities to increase referral numbers and strengthen support, for example, for people living with COPD who may use oxygen at home. At present, referrals are received from a wide variety of health and social care agencies, but the rates of referral are uneven across different sources.
The team would welcome more embedded referral processes and the opportunity to conduct targeted interventions associated with population health management approaches. Referrals for visits to people with oxygen supply are not mandatory. Patients must opt in for the review through the oxygen contract provider.
Therefore, ECFRS cannot confirm that every home user has been assessed.
Reverting to an opt-out policy may help to increase take-up. Boosting the available knowledge and training at all levels within referral agencies would also benefit the programme by improving understanding of the range of supports available through these visits, and the ability to timetable regular follow-ups.

4.3 Health Literacy and Sustained Self-Management

Clinical and community partners, notably IRS also offer pathways for patients to other supports. IRS work with patients who have finished the pulmonary rehabilitation program to ensure that any benefits patients may have gained are sustained and they can continue to manage their condition, referring to the Life Enhancing Program (LEAP), located at Leisure World Colchester.

LEAP is a scheme which Health Professional can refer their patients to for a specialised exercise program to suit their condition. After an initial consultation and wellness assessment, LEAP create a tailored exercise program for the patient, offering gym-based exercise, cardiac rehabilitation, water mobility classes, back rehabilitation classes and circuit training. After their 12-week program and a review has been conducted, Health and Wellbeing Personal Trainers will discuss what other suitable options may be available for the patient going forward.

When their condition improves, for patients with COPD, LEAP offers a pathway out of secondary care services that allows them to stay active under close supervision to sustain their improvement going forward. Elsewhere in Colchester, a number of other accessible physical activity groups are available for people with COPD to get involved in:

TYPE OF EXERCISE	ORGANISATION	LOCATION
Walking Football	Phoenix FC Stanway Rovers FC	St. Helena School, CO3 Stanway, CO3
Walking Netball	England Netball	University of Essex, CO4
Seated Yoga	COLTE Partnership Happy Yoga Life Changing Lives	Referral Based Stanway, CO3 City Centre, CO1
Zumba (Standing and Seated)	Independent	One Colchester Hub, CO1
Various / Accessible Sport	Disability4Sport Making Fitness Accessible	Various Various
Seated Dance	Dance Network Association	Greenstead, CO4
Working Age Exercise Group	University of Essex	University of Essex: Health, Wellbeing and Care Hub, CO4

Fig. 3 Accessible Exercise Groups in Colchester

In Tendring, CVST run a Healthier Independent Longer Lives project focussing on those who are more likely to be socially isolated and less likely to be empowered to take control of their good health. Examples of the physical activities within Jaywick & West Clacton are:

TYPE OF EXERCISE	ORGANISATION	LOCATION
Swimming / Swimming Lessons	Community Voluntary Services Tendring – HILL	Valley Farm, Clacton
Jaywick Walking Group	Community Voluntary Services Tendring – HILL	Sunspot Bus Stop
Community Allotment	Community Voluntary Services Tendring – HILL	London Road Allotment, Clacton
Online Fitness	Community Voluntary Services Tendring – HILL	Zoom
Multicultural Ladies Seated Yoga	Community Voluntary Services Tendring – HILL	Imperial House, Rosemary Road, Clacton
Jaywick Seated Exercise Group		Jaywick Community & Resource Centre

Fig. 4 Accessible Exercise Groups in Tendring

"We do sit-down exercises set to music at the Jaywick Community Centre every Friday morning. I can't do anything standing up, so everything I do is sat down anyway. It's a lovely group, there's about 30 of us there and it's quite a laugh."
- Tendring Participant

Physical exercise is not, however, the only way in which someone with COPD must sustain their health: there are other determining factors that may affect overall health that may mean a COPD patients health may deteriorate should they not get the right support around by accessing the right assets. Below are examples of how different assets can help patients with COPD to manage the social determinants which affect their ability to live well with their condition:

Determinant	COPD Challenge	Example Asset(s)	Asset(s) Description
Suitable Housing	Due to mobility issues as a result of breathlessness, someone living with COPD may not be able to maintain living areas.	CBH Sheltered Housing	Sheltered housing schemes offer staffed support to aid residents with any challenges they may be experiencing.
Suitable Housing	Due to mobility issues as a result of breathlessness, someone living with COPD may not be able to move around their home easily, thus requiring home adaptations to make them more mobile.	Colchester City Council	Disabled Facilities Grant To keep people independent in their homes, DFG can offer up to £30,000 grants for the following: Extensions Stair Lifts Level Access Showers Wash and Dry Toilets Ramp Access.
Quality of environment	Due to ability some patients fall behind on housework, which then builds up, which results in hoarding/clutter.	CVST and C360 Social Prescribing Funds to able client to stay safe within home setting	One off clean to help set client back to an acceptable level.
Social Deprivation	Inadequate food and heating.	Citizens Advice, CVST and C360 resilience team funding	Food and fuel vouchers, when available. Funds to purchase white goods and bedding.

Social Isolation	Reduced mobility and social contact through the requirements of condition management.	Age Well East Befriending Services or CVST Community Groups & Activities	Befrienders can either visit people at home or engage in a telephone befriending scheme to increase regular contact to improve wellbeing. There are many community groups in the Tendring area, drop ins, chats, lunch club.
Transport Difficulties	Diminished mobility due to the condition can mean that some patients are not able to drive or require assistance to travel to therapy and appointment.	Community Transport	Facilitate social car and minibus trips which can accommodate for equipment. Leisure and medical appointments.
Work	People living with COPD may be limited in what kinds of work they can access.	DWP Disability Advisor	DWP Disability Advisors can help people experiencing disabilities that form barriers to working find accessible work, as well as understand reasonable adjustments to their work environment may be required in the form of a Health Adjustment Passport. They can also help people living with COPD to receive support from the access to work scheme, which provides funding to help with costs of travel and reasonable adjustments.

Fig. 5

These assets often stand outside clinical pathways, within the Voluntary or Public Sectors, and only being accessed as part of a patient's healthcare journey through ad hoc referrals from clinical staff whose knowledge of these assets will vary from professional to professional. The separation of these services from the clinical pathways and the wide variety of different organisations points to a compartmentalisation of practical support, which COPD sufferers may not be aware of due to their disparity.

Previously, the Asthma + Lung UK Breathe Easy group in St. Anne's & St. John's, as well as the St. Helena Breathlessness Group, offered a peer support space where people living with COPD could go and share experiences, practical advice, and support others. These two groups served as a nexus where people could go to get information and be introduced to different services available to them.

Now, without these groups and due to a lack of integration of these assets into the clinical pathways, there is no centralised place where people living with COPD can receive this information, leading to worse health outcomes for patients in the area.

"I noticed recently that there was a breathing class at the local community centre, but when I asked for more information on whatever it was they told me that particular one had finished. So I didn't get to know what it was all about. There is line dancing on still, that's great if you can get up and do it. I can just imagine me doing that. I'll be on the floor after five minutes and I won't be able to get up again."
- Colchester Participant

The Greenstead Community Centre is an example of how integrated working can succeed. It hosts a Pulmonary Rehabilitation program, as well as a number of other essential services also being located within the building or nearby, including Citizens Advice drop-ins, carers support, dance groups, Slimming World, Councillors Drop-ins, Greenstead Library, Greenstead Foodbank, the Compassionate City Program, Signpost and Hawthorn GP Surgery, amongst others.

If someone needed to access general support when they went to a Pulmonary Rehabilitation program, then they could easily do so within the Greenstead Community Centre, given the wide range of services that are integrated into a small area – and this will only get better as the Multi-use Community Hub is developed as a part of the Heart of Greenstead program.

Without Breathe Easy as a specialist support in North East Essex, there is no local integrated asset in which people with COPD can access peer to peer knowledge and networks. They will have to travel to access support from multiple services in a less coherent form or rely on national online resources.

"When I saw that Breathe Easy group, I thought, 'Oh, that's good. I'm going to meet people there that have got the same conditions.' But then when I looked again it had gone, and that was the end of that. There aren't any groups around to say, 'We've all got this problem. What can we do about it?'. It's very frustrating. I've looked, I've scoured the internet, but there's nothing, not locally, anywhere. I haven't found anything."
- Colchester Participant

4.4 Digital Support and Exclusion

Digital Support Options for COPD in North East Essex

One of the benefits of digital support is that information can be collated and shared with large numbers of people at a minimal cost. Benefits of Digital COPD Support for local people are:

- **Accessibility:** Digital resources allow COPD patients to manage their condition from home, reducing the need for travel and in-person visits, which can be difficult for those with mobility or severe symptoms.
- **Self-Management:** Tools like symptom trackers, medication reminders, and exercise programs help COPD patients take control of their condition.
- **Peer Support:** Online communities and support groups enable patients to connect with others who share similar experiences, which can be particularly beneficial for mental wellbeing.
- **Remote Monitoring:** Some apps and digital tools allow patients to track their symptoms and share this data with healthcare providers, enabling more personalised care.

There are a number of UK wide resources that people living in Tendring and Colchester can access:

NHS Digital Support and Advice
The NHS Digital COPD Care Pathway includes access to COPD-related content via its website and apps. Residents can visit the NHS website to access:

- Symptom management guides.
- Information about treatments, medications, and lifestyle adjustments.
- Links to virtual health services where patients can consult with their GPs or specialists about their condition.
- NHS Apps Library provides a range of free apps designed to help people manage COPD and other chronic conditions.

MyCOPD
A digital tool specifically designed for people with COPD, it helps users learn about their condition, track symptoms, access pulmonary rehabilitation exercises, and manage medication. It is widely recommended by healthcare providers and offers both a free and premium version.

Patients Know Best (PKB)
This app allows patients to access their medical records, communicate with healthcare providers, and manage their COPD through a centralised platform.

COPDFoundation.org
COPDFundation.org is a national charity that provides online support through its website and social media platforms. COPDFoundation.org offers a digital support group on Facebook, where patients from across the country, including Tendring, can interact with others, share advice, and access helpful information about managing their condition. They also provide a variety of educational resources, including webinars, podcasts, and downloadable materials on the latest COPD research and self-care tips.

Patients can access educational materials, breathing exercises, and lifestyle tips to help manage their symptoms. They also have a helpline and offer an online community where COPD patients can connect with each other and receive support from LungUK.org.

Within Essex digital support is provided through:

Essex Lifestyle Service

The Essex Lifestyle Service, which serves North East Essex, provides digital support and coaching for people living with chronic conditions, including COPD. Their website offers access to resources, and they also provide virtual consultations for lifestyle advice, including physical activity, nutrition, and smoking cessation, all of which are crucial in managing COPD. They offer online COPD support groups, where patients can connect with others to share experiences, ask questions, and receive peer support from the comfort of home.

Virtual GP and Healthcare Services

Some GP practices in Tendring and Colchester offer telehealth services. Patients with COPD can book virtual appointments with their doctors, allowing them to discuss their symptoms, get advice, and receive prescriptions without needing to visit the surgery in person.

Some GP practices also offer access to the NHS app, where patients can monitor their health, book virtual consultations, and request medication renewals online.

Despite the wealth of online resources available to support people with COPD, there still exist some additional challenges to digitally supporting someone with COPD. During the lived experience interviews, one respiratory nurse remarked the challenges that a lack of digital skills brings for some people living with COPD:

"I give them links, but it's not something that everybody that can access. The elderly people, they don't have smart phones. They have landlines. So they'll say 'send it to my daughter,' and their daughter won't have authorisation to access their records. So you can't do that."
- *Respiratory Nurse*

A lack of digital knowledge means that people – often within the older generations (and, incidentally, those who are living with COPD) - do not have the capacity to use digital technologies and as such do not have the same levels of access to resources. This consequently means that their care experience will not be the same as someone with digital skills, as they are limited to in person or over the phone resources – which someone with COPD may find more difficult to access anyway.

Someone who is lacking digital skills may find it more difficult to book GP appointments in advance, as they cannot do so online, and so may find themselves struggling to book appointments over the phone (especially at a busy practice) or even having to attend walk - in appointments. Likewise, they also would not be able to access prescription delivery services due to them all being online, meaning that they must obtain them in person, which may prove a challenge if they are experiencing an exacerbation. In addition to creating barriers to accessing the digital resources above, a lack of digital skills excludes people with COPD from accessing other assets – uniquely including assets that can be accessed over the internet.

Psychological Wellbeing

With the loss of the peer-to-peer support from the Breathe Easy Group and the St. Helena Breathlessness program, respiratory nurses reported having to refer patients on to Therapy For You for psychological wellbeing support. The Therapy For You service consists of remote online or phone cognitive behavioural therapy sessions, aimed at treating common mental health disorders such as anxiety or depression. During an asset mapping interview with some members of the IRS, one COPD nurse noted that people with COPD may even struggle to hold the phone up to their ear or to talk for extended periods of time due to breathlessness, meaning that they may not be able to fully engage with a session due to their breathlessness or even attend the session at all. Research shows that anxiety and depression impacts negatively upon someone's respiratory symptoms, making wheezing and coughing worse, as well as reducing blood oxygen levels (Leander et al, 2014), leading to worse health outcomes for COPD patients if they cannot access these services due to their breathlessness.

Smoking Cessation

EWS Smoking Cessation programs offer 8 weeks of online or telephone-based support to encourage people to change their behaviours and stop smoking. People with COPD benefit greatly from stopping smoking, with it being one of the main treatments (NHS, Last Accessed September 2024), but suffers with COPD may experience the same problem as accessing Therapy For You services: if they cannot use the telephone for extended periods of time, then they will not be able to access the 1:1 support services, therefore giving them a worse chance of stopping smoking and potentially having worse health outcomes – all of which is out of virtue of their breathlessness. EWS currently provide one in-person smoking cessation drop-in in Colchester at Beacon House, with previous drop-ins at the One Colchester Community Hub no longer running. Given their unique digital challenge of using the phone, people with COPD would greatly benefit from accessing more in-person services within Colchester

"The general vibe is they've tried, it hasn't worked and they don't want to do it again. But at every point, it's always encouraged because we've got in-house smoking cessation. When it comes to an outside agency, let's say we refer a patient to Provide, it's then adding another step, another daunting process, to their journey. That's why it's really good if you have in-house smoking cessation advisors in the surgery because you've got that rapport already established."

- Respiratory Nurse (Tendring)

4.5 Transport

As noted above, travel can be challenging for someone managing COPD. As a part of this research, we have taken time to consider how people may move between assets and the challenges they may face.

For people living in St. Anne's & St. John's, their closest GP surgeries are Parson's Heath Surgery and Hawthorn Surgery, and a person with COPD living in St. Anne's & St. John's ward would undertake the following indicative journey times to the below essential health assets*:

ASSET	CLOSEST LOCATION	DISTANCE	ROUTE	JOURNEY TIME
Pulmonary Rehabilitation	Greenstead Community Centre (GCC)	1.4 miles	No. 2 Bus to Old Coach Road, No. 1 Bus to GCC.	19 minutes
Respiratory Physiotherapy	Portland Road Medical Centre	3.0 miles	No. 2 Bus to Greyfriars Bus Stop, walk 2 mins to Queen Street, S8 Bus to Plum Hall, walk 8 mins to Portland Road Medical Centre.	26 minutes
GP Appointments	Parson's Heath GP	0.7 miles	Walk 10 mins.	10 minutes
LEAP	Leisure World Colchester	1.9 miles	S10 bus to Greyfriars, walk 12 mins.	22 minutes

Fig. 6 Journey Times to Health Assets in St. Anne's & St. John's. *Typical journey starting centrally from St. Christopher's Road. Times recorded during non-peak hours and of an average person from Google Maps.

ASSET	ROUTE	JOURNEY TIME
Clacton Hospital	Walk 1 min to Brooklands Gardens, No. 4 bus to Tower Road, walk 1 min to Clacton Hospital.	13 minutes
Colchester Hospital	Walk 1 min to Brooklands Gardens, No. 4 bus to Police Station, walk 4 mins to Jackson Road, No. 76 'Seasiders' bus to Head Street, Colchester, S8 bus from Head Street to Colchester Hospital.	1hr 34 minutes

Fig. 7 Journey Times to Hospitals from Brooklands, Jaywick

For someone with COPD, using public transportation can, however, be troublesome. The typical journeys as shown contain prolonged periods of walking to access the assets (except the Pulmonary Rehabilitation at the Greenstead Community Centre).
Walking for this amount of time for someone with COPD can prove difficult – especially when considering that people living with COPD reported finding it difficult to even walk to the bus stop.

“No good me trying to walk to a bus stop. I’d never do it. It’s too far.”
- Tendring Participant

If someone with COPD were to walk as part of those routes to health assets, they may experience extreme breathlessness, leading to worse health outcomes.
Given that difficulty, those journey times above will be longer, demonstrating that taking public transportation to health assets is a clear challenge for someone with COPD.

Another option that someone with COPD living in both St. Anne’s & St. John’s and Jaywick & West Clacton can take to get to health assets is taking community transport.

Community transport provision is designed to support individuals who have limited access to public transportation, particularly those who are elderly, disabled, suffer from long-term health conditions or those who are living in rural areas where public transport infrastructure may be lacking. By providing accessible and affordable end-to-end transport, community transport services aim to help residents maintain their independence and access essential services, such as healthcare, shopping, and social activities.

Given the nature of COPD, where people may struggle to get to public transport links or bus stops and also may not be able to afford local taxi services if they cannot work, community transport can greatly benefit people living with COPD in being able to access primary care appointments, self-management programs, obtain medication and access any other assets that may benefit them.

In Colchester, Community360 holds the offer for local community transport scheme, where they offer support for people in accessing medical, health and therapy appointments; shopping trips, hairdresser appointments and other socially related events; excursion trips; and discharge from hospital trips. Currently, there is high demand for community transport services, and over the last year, services have had to operate a waiting list for membership. The scheme is seeing interest increasing in some areas and below examples of the five wards with the highest existing membership list and those with the highest waiting list figures:

WARD	NEIGHBOURHOOD	NO. OF MEMBERSHIPS	NO. ON WAITING LIST
Prettygate	Central	63	15
Castle	Central	61	20
Berechurch	Central	49	19
Greenstead	South	48	9
Old Heath & Hythe	South	49	13

Fig. 8 Largest Community Transport Membership Areas in Colchester

WARD	NEIGHBOURHOOD	NO. OF MEMBERSHIPS	NO. ON WAITING LIST
St. Anne's & St. John's	North	38	20
Castle	Central	61	20
Mersea & Pyefleet	South	27	19
New Town & Christchurch	Central	32	16
Prettygate	Central	63	13
Shrub End	Central	18	15
Tiptree	South	13	15

Fig. 9 Largest Community Transport Waiting List Areas in Colchester (Community360 Community Transport Stats, as of July 2024)

Given the challenges that someone with COPD has when accessing community transport, and the financial challenges they may face if they cannot work as a result of their condition, meaning they cannot afford taxi services, the importance of community transport services is recognisable if someone with COPD is going to easily access health assets without adverse effects on their health.

The two key Community Transport Providers in Tendring are two local charities; Tendring Community Transport, who also run a Social Car Scheme, and Harwich Connexions. Both of these are dependent on non-recurrent funding from a variety of sources.

Tendring Community Transport and Harwich Connexions play a critical role in ensuring that Tendring's vulnerable and isolated residents can stay connected and continue participating in community life.

Tendring Community Transport
Tendring Community Transport (TCT) provides a range of accessible transport services for residents of the Tendring district, particularly for those who have difficulty using conventional public transportation due to age, disability, or living in remote areas. Their services aim to enhance mobility and independence, ensuring that residents can access essential services, social activities, and medical appointments.

- **Hospital Car Service:** A volunteer-run service providing transport to hospitals for medical appointments. It is designed for those who need to travel to hospitals outside the Tendring area, such as Colchester General Hospital, Ipswich Hospital, or others within Essex.
- **Transport for Health Appointments:** In addition to hospital transport, TCT offers services to assist residents in attending local GP or other health-related appointments when public transport is unavailable or unsuitable.

- **Dial-a-Ride:** A door-to-door transport service for individuals who are unable to use regular buses due to mobility issues or lack of public transport in their area. Passengers must book in advance, and the service collects them from their homes and takes them to their destinations, such as shops, medical appointments, or social events. Vehicles are wheelchair accessible, and drivers are trained to assist passengers with special needs.

Harwich Connexions
Harwich Connexions operates community transport services for residents of Harwich, Dovercourt, Parkeston and the surrounding villages. They provide transport to help individual passengers, including those experiencing disability, ill health, or geographic isolation. All their buses are suitable for people with mobility issues.

- **Hospital Hopper:** A direct community bus service linking Harwich to the Colchester hospital sites for patients and hospital visitors. The weekday timetable for the Hospital Hopper bus service includes the main Colchester health site including General Hospital, The Oaks Hospital, the Primary Care Centre, and St. Helena Hospice. The Hospital Hopper buses have tail lifts for passengers who have difficulty accessing the steps and drivers are trained to assist passengers if they so require.
- **Dial-a-Ride:** A flexible bus service operating in the Harwich area, enabling people to travel to appointments, go shopping, to clubs, or visit friends.
- **Shuttle Community Bus:** Serves towns and villages in the Tendring District area. This is a joint service provided by Harwich Connexions and Tendring Community Transport working in partnership. Operating from Harwich and Clacton the shuttle buses can be used by those who are isolated from everyday transport for shopping, medical appointments, social outings, visiting friends, education, work, sport, and any other activity that helps connect people with community opportunities.

There are also several ‘Good Neighbour Schemes’ - one example is Great Bentley Good Neighbours - which provide more informal community transport through Volunteer-led social car schemes to offer informal transport to help residents attend medical appointments, go shopping, or participate in social events. Drivers often use their own vehicles and are reimbursed for fuel expenses.

Stage Three - Severe Cases and End of Life

St. Helena Hospice
The hospice provides 24 hour specialist care from an experienced team of qualified staff and volunteers for local people who have complex needs that cannot be managed at home.

“With cancer you can say ‘maybe you’ve got three months’ but with COPD it tends to be more of a yo-yo, where they will go down with a bad infection and then pick back up and carry on for a bit. It’s really hard to predict when patients are going to go downhill and not bounce back”
- Community Respiratory Nurse

Admissions to the hospice are usually for a short period of time, the aim is for 7-10 day stays. During this time, they work collaboratively with patients and their loved ones to address a specific problem. Problems may be physical in nature, such as pain or nausea, or people may need complex emotional or spiritual support.

Their physiotherapists, occupational therapists and clinical support workers work with patients to help them achieve their goals, supporting them with exercises and fatigue management, or planning for home adjustments and equipment needs that may be required.

Counsellors, family support, a social worker and chaplains are also available to provide additional emotional, practical, and spiritual advice and support for patients and their families.

The hospice service is available to patients with COPD and other respiratory issues, in 2023/2024 they treated 252 patients with cancer and 182 with COPD.

Singlepoint
The Singlepoint service within St. Helena’s, is a one stop advice, guidance, and medical service team. The phone lines are open 24/7, with a professional team that can assess over the phone and then access the support that is required.

They work closely with GPs, community nurses and out of hours teams. Expert nurses and medical professionals can visit the home if needed. This helps patients stay within the home setting at end of life where possible.

My Care Choices
My Care Choices is aimed at helping individuals with life-limiting conditions make informed decisions about their care. The program is designed to ensure that patients can communicate their wishes for care and treatment, especially as they approach the end of their lives. It prioritises patient choice, dignity, and quality of life, allowing people to express preferences about where they would like to receive care, treatments they do or do not want, and other important aspects of their care journey.

The My Care Choices Register is an electronic record of a person's decisions about the kind of care they wish to receive in the future if they were more unwell, and their preference for the place of care.

It is held online and can be accessed securely only by staff responsible for their care, such as GPs, community nurses, hospital staff, ambulance services, and St. Helena, who host the register. They can access it any hour of the day or night, so people can be confident that everyone looking after them knows the care they want.
So far in 2024, 200 patients have taken this up and will be cared for how they want to when the time comes.

The booklet is accessed through the St. Helena's web page to be downloaded and printed off. Once the booklet is updated it is taken to the patients GP surgery, where it will be uploaded onto their records where it can be accessed by the hospital and other medical services.

Breathlessness Group

St. Helena's used to run a breathlessness community group, to help patients within the COPD and respiratory remit, but due to lack of funding this had to be stopped, having an impact on those people with COPD who were benefiting from the group.

"I went to St. Helena's Hospice. It was a one-to-one with a nurse and she taught me different breathing exercises and techniques, and what to do when you have a problem breathing. They gave me a lot of information I was quite happy with, and she went into great detail which was really good."
- *Colchester Participant*

"The hospice used to do a group, it was really good for those patients who couldn't do the Pulmonary Rehab because it was too advanced, but they could get the breathlessness management tools tailored to them. We are definitely missing that. This winter, there's going to be a number of patients that we're like, 'Well, what do we do with them?' They're not ill enough for the palliative side, but they're not fit enough for the pulmonary rehab side."
- *Acute Respiratory Nurse*

Compassionate Cities

During inquiries of the Die Well Report (2022), researchers found a need to improve death literacy in Colchester, as a result of a number of barriers within health and care systems which meant that My Care Choice Records were not as complete as they could be.

They recommended that stigma-free discussions around death should be facilitated in the community so the idea of dying is normalised amongst people facing the end of their life, which includes information around will writing, funeral planning, power of attorney and advance wishes, amongst others.

As a result of this recommendation, a lot of headway has been made to improve death literacy in NEE, with Colchester being the first city in the East of England to be nationally recognised as a Compassionate City.

Led by St. Helena Hospice, this work has been targeted at a number of key sites across Colchester as part of the Compassionate Cities Charter Commitments, including:

- Schools, Colleges, and Universities
- Workplaces
- Places of Worship
- Arts and Cultural Institutions
- Health and Care
- Neighbourhoods
- Sites of Diversity

For the purposes of our inquiry, we are primarily concerned with the work that has been done within local Neighbourhoods. Important local assets such as the Greenstead Community Centre, One Colchester Delivery Board, and the Neighbourhoods project amongst others – have been employed to drive up engagement, create wider networks within the scheme and deliver death literacy education sessions at a local scale.

St. Helena have also been delivering their ‘Demystifying End of Life Care’ workshops, which are a series of themed workshops which seek to demystify end of life taboos, helping to raise aware of care provision and support available to be who are approach their end of life or are in bereavement.

Coffin Club Colchester / Libitina CIC
Based on a model that has successfully run in New Zealand, Coffin Club Colchester is for the elderly, people who are terminally ill or their carer’s, and anyone interested to come and work out their funeral wish-list, plan and cost their funeral and if they wish, assemble and personalise their own coffin.

Living with COPD - Voices of Patients and Frontline Workers

6.1 Overview: A Sense of Place

This section of the report offers a detailed examination into the experiences of individuals managing Chronic Obstructive Pulmonary Disease (COPD) in North East Essex.

In order to capture a broad and diverse range of perspectives, interviews were conducted with twenty participants in Jaywick & West Clacton and twenty participants in both Greenstead and St. Anne's & St. John's wards, both in person and over the phone. Additionally, over ten healthcare workers were interviewed either in person or via video call about their observations and experiences supporting patients with COPD. They included local respiratory nurses, community respiratory nurses, acute respiratory nurses and pharmacists, who work in either one (as indicated) or both of those regions. All interviews were conducted confidentially, with identifying details removed where necessary to encourage open and honest discussions.

The key themes that emerged from these interviews have been presented here, along with two case studies that highlight local organisations that offer support to those living with COPD who might otherwise have fallen through the gaps in the healthcare system.

The areas studied, Jaywick & West Clacton in Tendring and Greenstead and St. Anne's & St. John's in Colchester, report the highest levels of COPD diagnosis in their respective districts. However, the unpredictable nature of COPD and the disparities in healthcare and community resources create unique challenges for both patients and healthcare providers in each area.

A common sentiment echoed by participants was encapsulated in the phrase, *"some days are better than others."* This perfectly summarises the exhausting and unpredictable reality of living with a chronic respiratory condition like COPD, where, on bad days, even the simplest tasks like walking to the bathroom or putting on socks could become an arduous undertaking.

"Some days I just can't breathe or do anything at all and I just have to sit there. Others I'm good and I can do a little more, a bit of housework and things like that."
- Colchester Participant

Located by the sea, many of the participants who were living with COPD in Jaywick & West Clacton spoke of having moved from the outer London boroughs like Ilford and Romford to the Essex coast for the cleaner air, stronger sense of community, and more affordable living. A number had already been diagnosed with the condition before moving to the area.

"The community down here reminds me of when I was a kid in East London. Everyone knows everyone."
- Tendring Participant

"I've got damaged lungs. That's why I live by the sea, fresh air."
- Tendring Participant

"Greenstead probably doesn't see it as much but we get a lot of people in Jaywick that were already diagnosed and have retired there from London for the better air."
- Community Respiratory Nurse

Greenstead and St. Anne's & St. John's, located in the east of Colchester, are primarily residential areas with a mix of social and private housing, and a younger, more diverse population. Unlike Jaywick, most residents I spoke to had lived in the area for much of their lives.

"Lived in Colchester all my life, born and bred. I've been on this estate since 1977."
- Colchester Participant

Every healthcare professional I spoke to noted that the high prevalence of COPD in these specific locations was largely influenced by a number of intersecting socio-economic factors, while the lower-cost housing draws in those already affected by these conditions.

"I find a lot of the time the issue in a lot of deprived or low income areas is that it's generational. Mum and dad are smoking, so the kids get into smoking. If their mum and dad are unemployed, that follows down the line. Poor health, poor education and poor lifestyle choices. Because of the nature of those environments influences the cost of housing, it's a cheaper place to live. All these different factors come in and sadly it kind of links together and then that's where they end up, where they're living."
- Community Respiratory Nurse

Although both Jaywick and Greenstead benefit from strong community ties, they have been deeply impacted by long-term deprivation. Social, environmental, economic, generational, and lifestyle factors such as smoking, occupational exposure, poor health literacy, inadequate nutrition, and limited education perpetuate a cycle that contributes to chronic conditions like COPD, particularly in lower-income neighbourhoods.

6.2 Examining the Causes of COPD in North East Essex

Chronic Obstructive Pulmonary Disease is a condition that has long been associated with smoking. Almost all of the participants I spoke with reported being long-time smokers and attributed this as the primary contributor to their COPD diagnosis.

"I was a heavy smoker, but that was what you did back then. You could smoke on trains, buses, the lot. It was on hoardings and everywhere. 'Smoking makes you feel better', 'Smoking helps with your stress levels', all that sort of thing. But they never said anything about the dangers. Knowing what I do now, I would never have started."
- Colchester Participant

"I've very rarely had a patient with COPD that hasn't smoked."
- Respiratory Nurse (Tendring)

However, smoking isn't the only risk factor. Many participants reported working in industries such as construction and manufacturing, where they were exposed to dust and other harmful substances without wearing protective gear. Strict health and safety standards, a common requirement today, were often absent when they started their careers decades ago.

"I'm in construction. I still work on building sites. My job's got a lot of dust in it so I have to wear a mask, they're very strict on it now. But when I first started doing it years and years ago, we thought we were invincible. We didn't wear a mask. So that's not done me any favours."
- Colchester Participant

"I had my own business metal polishing. It was a filthy job, but I enjoyed working with my hands. I couldn't wear a mask, because it just steams your glasses up and you need to be able to see what you are doing. I've always been a heavy smoker too. I'm not now, but I used to smoke 40 a day. Always had a fag in my mouth when I was working."
- Tendring Participant

"I worked in the foundries as a furnace man for a few years. I was melting the metal, and pouring it into moulds as well. At the first foundry that I worked in, some days you couldn't even see your hand in front of your face. It was that bad. No one wore a ventilator then. It was too hot to wear anything like that really."
- Colchester Participant

Healthcare workers confirmed that they often see patients who, on top of smoking, had also been consistently exposed to dangerous materials throughout their careers.

"For many of our patients in those areas who are older, back then health and safety wasn't around when they were working. There was occupational exposure to asbestos, cement dust and different chemicals that nowadays you wouldn't dream of breathing in. Everyone thinks smoking with COPD, but actually we see a lot of patients that were welders or builders in the past. Roles that were more at risk of those pneumotoxins."
- Community Respiratory Nurse

Out of 40 participants interviewed, only 3 had never smoked. Coincidentally, 2 of them had worked in garages during their youth, exposed to harmful substances like brake dust and second hand smoke in poorly ventilated working environments.

"I worked on diesel lorries at a big commercial workshop in the early 60s. These old lorries, they revved their engines and of course you would be enveloped in clouds of stuff. The first time I was there in the summer of 62, I worked with a fitter who was a terrible man and universally hated by everyone in the firm. In those days hardly any lorries had disc brakes, they were all drum brakes, and when you took them off they would have three or four pounds of dust in them, which in them days was asbestos. And of course before you could tip it out, this fitter would creep up behind you with the airline and blow it over you. I used to get covered in it. That was one of his tricks. I think that's where I've probably got it from. Of course, a lot of the people I spoke to didn't believe that I'd never smoked. It's so uncommon, it really is."
- Tendring Participant

Notably, several frontline workers reported seeing an alarming increase in younger patients developing COPD due to drug use, particularly smoking crack cocaine and cannabis.

"The younger patients who are smoking cannabis and the crack, they are probably the most severe cases we see. It just burrows holes in their lungs, and there's no getting back from that. Their body will compensate for only so long. We're now seeing people in their 30s and 40s with really bad lung disease, whereas before you wouldn't have had that."
- Acute Respiratory Nurse.

Treating these patients is challenging, as they frequently avoid medical appointments and fail to renew prescriptions, allowing their condition to worsen until often it was too late.

"They're the ones that are hardest to engage with. They don't attend the appointments and they don't renew their prescriptions. Weed and crack burns a lot hotter than cigarettes and it damages the top of the lungs more. You start seeing patients normally in their early 40s with COPD, and they can often be quite severe. I've had patients that have died in their mid 40s. You're really limited as there's only so much you can do, the damage is already done sadly and then it's more about engaging with the palliative teams."
- Community Respiratory Nurse

Case Study - Open Road

Open Road, a drug and alcohol recovery service with centres in Colchester and Clacton, has seen a sharp rise in clients using crack cocaine, many of whom are developing COPD as a result. For this case study I spoke to Emma Earl, a lead recovery worker based in Colchester.

"A lot of our clients have got the onset of COPD due to the amount of crack cocaine and cigarettes they're smoking. COPD among our clients is definitely on the increase, with younger people as well. We do try and encourage them to see their GP. We had funding for a COPD worker a couple of years ago, and she was here for eight months. We would refer people to her, but the nature of our clients… they just can't. They just cannot do it."

Unlike heroin addiction, which can be treated with medicinal substitutes like methadone, there is no equivalent treatment for crack cocaine dependency. This makes it particularly difficult to manage.

"Crack cocaine is the hardest one to work with, because it's purely psychological. With opiate dependence, we can get clients on a prescription for methadone and help them manage it. That's the easy part. But with crack cocaine, I would say that is the hardest part of our job. It's a real problem. That's where your COPD cases are coming from. It makes them really poorly, mentally and physically. If you think you can't breathe, it's really scary. And then with the mental health issues that our clients already have, they go to the drugs because it's their comfort. It's medicinal. But that makes their physical issues worse. It's a vicious cycle."

Open Road assigns clients a recovery worker to guide them through their journey, addressing all aspects of their life that contribute to drug use as part of a person-led care plan. This could include career support, housing assistance, and help rebuilding family relationships. The service also offers drop-in support groups, art classes, and yoga, and signpost clients to additional outside resources like Narcotics Anonymous and the Crisis Café.

When it comes to COPD, Open Road clients are usually encouraged to see their GP. However, as noted, many face challenges attending appointments, often due to stigma or a lack of prioritisation around their health.

"There is an issue around our clients not attending GP appointments. They even struggle to come here for their prescribing. They don't think like how you or I would do about our physical health. If we're unwell, we go to the doctor. They don't. It's just not their first priority. Stigma is a big thing as well, I think that puts them off in the long term. They feel like they're not listened to. There's definitely that barrier of discrimination."

One client from Colchester shared his struggles with COPD and accessing medical care.

"I've smoked pretty much all my life, since secondary school, but I daresay it was the crack that brought it on. The damage is done now. Sometimes I can't even cross the room without getting out of breath. I struggle getting the phlegm off my chest, I can't cough it up. Had a few chest X-rays done a couple of years back and they just told me I had it and that was that. Not what it does or what stage it was at. I don't really know much about it. The doctors don't seem that bothered anymore. Just going on experience, you get fobbed off. It's sad to say but the way you are treated, you get labelled when you are an addict."

The stigma, barriers to accessing healthcare and the psychological impact of regular crack cocaine use often leave these clients without the support they need, worsening both their physical and mental health.

6.3 Barriers to Accessing Primary Healthcare

A recurring theme among participants was the difficulty in accessing healthcare both before and after receiving a diagnosis. COPD is a progressive condition that develops gradually, and delays in diagnosis or treatment can lead to severe consequences.

Many participants only sought medical attention once their symptoms had significantly worsened.

"I think the hard part is that often with COPD people get diagnosed later on. Sometimes they have just put up with the breathlessness and the cough, until it gets quite bad or they have a bad infection. If you can't access a surgery or don't engage with health care, you're going to put it off and then by the time they get diagnosed it's actually quite advanced."
- *Community Respiratory Nurse*

Many patients shared similar stories of attributing early symptoms, such as a persistent cough and breathlessness, to aging, lifestyle choices, or common respiratory infections.

"It got to a point that one of my daughters said, 'Mum, you're wheezing.' You make excuses. 'Oh, everybody wheezes at my age.' 'Why don't you go and have a health check, because it is quite bad. They sound like bagpipes.' So I went and got my lungs checked over, and I got the shock of my life. The nurse said to me, bearing in mind I was under 60 at the time, 'You've got the lungs of a 75-year-old woman.' Oh my God! I kept thinking that if my daughter hadn't kept on and on at me to go the doctor, I probably would have kept plodding along, wheezing away."
- Colchester Participant

"When I got diagnosed, I was already stage 3. It was my own fault because I've never been one for going to hospital or going to the doctor. I knew something was wrong but I refused to go and get it confirmed. I didn't even go when I was coughing a lot."
- Tendring Participant

Caring for family members also contributed to delays in seeking treatment. One participant from West Clacton shared how caring for her husband, who had dementia and COPD, prevented her from addressing her own symptoms

"My second husband had COPD, and I noticed that I was doing much the same as him. But he was very senile, and when you're dealing with that you don't pay much attention to what is happening to you. Of course after he died, I noticed it more. I had difficulty swallowing and started having trouble breathing."
- Tendring Participant

A significant number of participants spoke of the difficulties in securing GP appointments. Many highlighted their frustration at trying to make appointments over the phone, only to be repeatedly told that none were available.

"I've been trying to see a doctor. They've told me to phone up, but then it's 'Sorry, no appointments.' 'Sorry, no appointments.' So I go up to the surgery and I say, 'Don't bother.'"
- Tendring Participant

"The first thing I hear after I say to customers 'I really think you need to see a GP' is usually 'Have you tried getting through?'"
- Pharmacist (Tendring)

The conversations for this report highlighted significant disparities in the quality of healthcare experiences between locations.

In Colchester, patients from Greenstead and St. Anne's & St. John's reported more positive experiences and felt confident that support would be accessible if they needed it.

"I have to say, they're brilliant. They've been so good."
- Colchester Participant

"There's an open surgery in the mornings. So even if I couldn't get an appointment, I'm absolutely certain I'll still get in to see someone."
- *Colchester Participant*

In contrast, a high number of participants from Jaywick & West Clacton reported having had negative experiences with their GP surgery. The most common grievances involved poor interactions with reception staff, which often left participants feeling belittled, disrespected, and discouraged from seeking further medical care.

"I'm sick and tired of going to the doctors. Because I do what they say, I call the surgery and they fob me off. What's the point? They don't bother to understand. They don't want to know. There's a couple of receptionists there that almost act like they're above the doctors."
- *Tendring Participant*

"I think it's because they look down on us at Jaywick. When I've been sitting there waiting to see a doctor or the COPD nurse, I've heard the way some of them talk to people on the phone. You can't talk to people like that. Years ago I used to do telephone work, and we was taught to speak to people the way you'd want to be spoken to."
- *Tendring Participant*

"I had a review a few weeks ago and they've put me on a new inhaler, but it feels completely inadequate. I don't want to go back to the surgery though, and end up having a row with the receptionist. She's very condescending to people."
- *Tendring Participant*

One participant in Jaywick highlighted how receptionists often directed patients to Colchester Hospital or Clacton Urgent Care, placing additional strain on emergency services.

"I kept going to Colchester Hospital with bad chest infections. It got to the point where the GP receptionist was like, 'If it's what you think it is, just go to Colchester.' Unless you fight to see the doctor, they just tell you to go to Colchester or Urgent Care in Clacton."
- *Tendring Participant*

Healthcare professionals also noted the increased burden on hospitals, with some COPD diagnoses being made in emergency departments due to patients' inability to access primary care.

"We've heard that. 'If you've got a problem, just go to hospital.' 'We've got no appointments, go to the hospital.' And that's what we're seeing. We've never been so busy. Just the other day, there was 120 people in A&E. It doesn't hold 120 people. How many of those actually need to be here? We shouldn't be, but we're actually diagnosing COPD. Last week, I think there was three or four patients who were admitted with new diagnosis of COPD."
- *Acute Respiratory Nurse.*

Several participants mentioned avoiding their GP surgery altogether, seeking medical advice from the local pharmacy or the Urgent Treatment Centre in Clacton.

“You’re better off going to the walk-in centre than the GP surgery. I try not to go there. Only if it’s desperate.”
- Tendring Participant

Others have considered or successfully switched GP practices outside their immediate area due to dissatisfaction with the local services.

“I tend to think I’m awkward, so at first I thought it was me. But since changing doctors, I’ve realised that it’s not just me. They’ve had a lot of people move from that surgery.”
- Tendring Participant

“I feel trapped, but I can’t move because no one else is taking on new patients. They’re all full.”
- Tendring Participant

Despite that, some participants expressed sympathy for the receptionists, recognising the acute pressures on our frontline healthcare workers and the challenging nature of their roles within the Jaywick community.

“You’ve got a couple working on reception that are friendly and sympathetic, and then you’ve got a couple that are a bit standoffish. But I suppose that’s like any service provider. They’re inundated, they’ve not got enough staff and their hours are long. I understand because I worked in the NHS myself. But when you’re at a crisis, it’s all well and good saying ‘you can ring 111’ but I don’t want to speak to strangers over the phone. I want to see a comforting face that’s familiar.”
- Tendring Participant

The sentiment was echoed by several healthcare professionals who, while recognising the challenges endured by receptionists positioned as the public facing side of the GP practice, empathised with how it must be for patients to experience poor or hostile customer service while often unwell and scared.

“From what my patients tell me, receptionists are seen as a barrier in their eyes. I would probably feel the same way if I walked into a surgery and the receptionist was like that. I’d already have my back up before I even went in. I think that a lot of the time it’s because they’re frightened with the breathlessness and they’ve had bad experiences in the past.”
- Community Respiratory Nurse

“I went in to work this afternoon and there was a man shouting at a receptionist. I could see their barrier go up straight away and I can understand why it does, but that patient wasn’t having a go at them personally. At the end of the day, there is probably a reason why they’re like that. Because they’re frustrated or in ill health. They want to see someone, but it’s such a struggle to do that now.”
- Respiratory Nurse (Tendring)

A significant concern, raised by older and more vulnerable participants, was the difficulty in arranging home visits. Many expressed frustration at being told they needed to visit the surgery, even when they were physically unable to do so.

“When I’ve been really poorly, my daughters have asked at the surgery if they’ll come out to see me because my breathing has been so bad. And they go, ‘No, no, she’ll have to come up.’ Because I’m not down as being housebound. So I find that a bit frustrating when I’m really not well. With COPD, one day could be good and another can be really bad.”
- Colchester Participant

A consequence of this is an increased reliance on emergency services to plug the gap in primary health care, with one participant stating they were taken to Colchester Hospital by ambulance almost monthly.

“I used to walk around to the surgery and back, but now I haven’t got the energy to do it at all. And I can’t travel, I’ve been told not to go out the house because I will fall. So I stay in here. I didn’t feel very well the other week so I rang up the surgery and said, ‘Would the doctor come out please? I can’t get to the surgery’. The receptionist said just call an ambulance, so that’s what I had to do.”
- Colchester Participant

“If they do need somebody desperately, they will lean on 999 and 111. And it may have been a simple problem that could’ve been sorted by the GP, who won’t do home visits because there isn’t a word saying housebound on the top of their notes. I don’t know what people have to do to prove to GPs that they’re housebound. Because the nature of their emphysema, some of them are wafer thin and could be blown over in the wind, but they’re still attending appointments when they can barely stand up. It’s just ridiculous really. There’s an element of caring being lost.”
- Community Respiratory Nurse

As Colchester and Clacton see increasing numbers of refugees and asylum seekers, healthcare providers are facing additional challenges in supporting patients with limited English proficiency.

“Sometimes there is a language barrier. We have to phone up translators or use translation apps on our phones. Trying to get to the bottom of how to help or to find out what patients want help with can be very difficult.”
- Respiratory Nurse (Tendring)

Case Study - RAMA

RAMA (Refugee, Asylum seeker & Migrant Action) is a voluntary organisation based in Colchester, dedicated to supporting refugees and asylum seekers who have no recourse to public funds and nowhere else to turn. They offer help with housing applications, asylum claims and settlement processes and benefits like Universal Credit and PIP. Additionally, RAMA provides referrals to legal services and counselling for those in need.

I spoke with Maria Wilby, RAMA’s operational lead and director, about the wide array of challenges faced by their clients. Many of the individuals they support suffer from chronic health issues such as COPD, conditions that have often been exacerbated by the hostile environments they fled from.

“When you are coming from a country where there’s chemical warfare like Syria and Eritrea, it’s basically fast-tracked them to having COPD because their lungs have been damaged. It’s also really common for people who’ve been forced into working at cannabis factories due all the chemicals they spray, so quite a few of our trafficked clients have had COPD.”

A recurring issue for asylum seekers is registering with a GP and making appointments. Many face obstacles due to surgeries not understanding the rights of those without ID to access local healthcare.

“Getting a GP is a massive issue for our clients. Reception staff are often one of the biggest barriers. Every single time, we send our clients in with those yellow NHS GP Access Cards. It says on the front that they don’t need proof of address or identification to register, while on the back you can tick to say ‘I would like help reading and understanding’ and most of the time, it goes completely unrecognised. They just get turned away or told that they need to bring back their ID, and because our clients have been treated so horribly at the front door, they just go away and never go back again.”

Despite repeated efforts to educate local GP surgeries and offer training, the problem often persists.

“We do write to the GP surgeries. We’ve spoken to the practice managers and staff. We’ve offered training. We’ve done everything we possibly can. We’ve stopped arguing about the ID now and send clients in with their bail document, which in itself is a form of ID given by the Home Office, but I think that gives a really negative impression because it makes them look like they’re criminals. And they often treat our clients as though they are.”

One of RAMA’s clients, who was recently housed in Greenstead for 3 years as part of their dispersal, shared with me some of their experiences trying to get support with COPD.

“I do not have good memories of living in Greenstead. It was a shared house. They were all asylum seekers, like me, waiting for an answer from Home Office. The condition of the house was good but there was no cleanliness and they smoked, which made my illness worse.”

With RAMA’s help, their client was eventually granted status and could apply for PIP. They also supported them in securing housing, as their health issues had worsened over that time.

“When I was in London, before I was moved to Colchester, I searched on the internet and I found RAMA. They have helped me a lot and I thank them. When I was in the hospital, Maria personally contacted me. They also provided me with a bus ticket so I could move around. For people who have severe respiratory problems, the council gives them a free bus pass but when I applied they said it was not possible. After that, I didn’t apply again. I do not know if I can get one or not.”

They also described the frustration of dealing with GP services, feeling as though they were treated differently for being a refugee.

“Even though I had a respiratory problem and was suffering, the GP surgery did not treat me well. They helped me medically, but I had a strange and heavy feeling there. I don’t know if this is true or not, but I think because I was a refugee they didn’t have a very good relationship with me. I asked for a translator, because I could not speak English well, and they said that they did not have one.”

Many asylum seekers are hesitant to fully disclose how ill they are, fearing it may affect their immigration status. This often leads to delays in seeking care until their conditions become critical, resulting in hospital admissions and higher treatment costs.

“In the UK, it takes a very long time to see a specialist unless you are very unwell and go to the hospital by ambulance. When my breathing gets worse and my lungs bleed, I call the ambulance. I have been admitted to the hospital twice. It has been 4-5 months that I have had very hard and painful breathing. How long will the situation continue? For a while now I have not been able to control my bladder, and this problem has added to my illness. I still haven’t been able to see the specialist and I don’t know why it’s taking so long. I am tired of this life.”

6.4 Respiratory Nurses and the Limits to Remote Care

Despite the unpredictable challenges of managing COPD, participants from both areas expressed deep appreciation for the support provided by their respiratory nurse. In Jaywick & West Clacton, the local nurse was particularly well-regarded within the community.

“She’s great. Everyone loves her. She looks after me whenever I go in.”
- *Tendring Participant*

“I wouldn’t say anything against her. She is absolutely brilliant.”
- *Tendring Participant*

These positive interactions helped patients feel reassured and supported in managing their condition. Across both regions, participants highlighted how their nurses provided practical guidance and positively impacted their health and wellbeing.

In both Greenstead and St. Anne’s & St. John’s, as well as Jaywick & West Clacton, every person I spoke with reported that the respiratory nurse at their GP surgery conducted annual reviews. However, a clear disparity emerged in how these reviews were carried out between areas. The majority of people in Colchester said that they had face-to-face appointments with their respiratory nurse.

“I see the COPD nurse in person. She’s lovely.”
- *Colchester Participant*

“Everyone has an annual review. It can be every six months, but that’s for more severe patients. There’s a few that might not want to come in, but generally most appointments are face-to-face because they are better.”
- *Respiratory Nurse (Colchester)*

In contrast, most participants in Jaywick & West Clacton reported that their annual COPD reviews had shifted over to phone consultations following the COVID-19 pandemic. Many expressed dissatisfaction with the limitations of phone-based appointments, particularly regarding the inability to conduct thorough assessments.

"It's supposed to be an annual check-up with the Asthma Nurse, but I don't see her. Not anymore. Just by phone. Everybody says that, don't they? She phones me up and asks me how I am doing, am I taking my medicine, do I remember how to use the inhaler etc."
- Tendring Participant

"The last few times I've done it over the phone. It's a joke. It definitely needs to change."
- Tendring Participant

"Since the pandemic, you no longer get to see the respiratory nurse. What's the point of trying to describe my COPD over the phone? She calls me up, and goes 'how are you doing?' Well, what can I say? It's an absolutely pointless exercise."
- Tendring Participant

A respiratory nurse based in Clacton acknowledged the limitations of remote care.

"I'm very much a face-to-face person to be quite honest. Telephone calls are alright for people who would prefer them or those whose conditions are well controlled, but as soon as they are not, it's best to be in person. I can't listen to a chest on the phone. I can't do Spirometry on the phone. People seem to think it's easier, but it's not really. You get the same amount of time to do a phone call, so it's not going to make any difference there. If it was up to me I'd much prefer to see people face-to-face."
- Respiratory Nurse (Tendring)

The shift from in-person to phone-based reviews was largely driven by the COVID-19 pandemic, which necessitated remote consultations. However, both participants and healthcare professionals observed that these changes have remained in place long after restrictions were lifted, often to the detriment of patients' care.

"I think, sadly, COVID-19 changed a lot. Before then, most yearly reviews were face-to-face. Now because they've realised phone reviews are actually a lot easier, that's just carried on. Some surgeries have got really good respiratory nurses and that's fine, they are more aware of their patients' conditions. But some surgeries don't. So we'll get a referral because they have a patient that is really breathless, however when we go out to see them, they have got raging heart failure but their COPD is okay. They haven't done a full-on assessment, whereas you get so much more from looking at someone face-to-face. It's a numbers game sadly and I don't think that's necessarily going to change. If surgeries can do twenty phone reviews in a day, as opposed to ten face-to-face, they're going to do the twenty phone reviews."
- Community Respiratory Nurse

Many participants highlighted the benefits of in-person care and how seeing their respiratory nurse face-to-face positively impacted their health.

“I did have the COPD nurse explain how to use the inhaler. That was quite helpful, because I hadn’t been using it properly. They never really explained it to me before I saw her. My first check-up was about a year or so after being diagnosed by the doctor. Once she took me through how to use it, and I started using my inhaler as they told me, my breathing was better. I could have had a year where it wouldn’t have been so bad.”
- *Colchester Participant*

This underscores the important role of face-to-face consultations in the effective management of COPD and the need for healthcare services to prioritise in-person care.

6.5 Patient Understanding and Adherence

Most COPD patients interviewed appeared to have a reasonable understanding of their medications, particularly around their inhalers. Many shared their experiences with using a combination of two inhalers each day, though some expressed frustration with the effectiveness of their blue Salbutamol inhaler.

“To be honest I just don’t know what I’m expecting to feel from it, because what’s happening might be as good as it gets. The one I take in the mornings, that’s not a problem. I just literally inhale that, one puff, when I get up. I can feel that going in, you know it’s getting down there. But I’d say the blue one is a waste of time. I hardly ever use it. For me, when I’m out of breath, the best thing I can do is just stand still, breathe slowly and then get to a stage where you’re ready to go again.”
- *Colchester Participant*

One of the most common concerns highlighted by frontline workers was the rise in improper inhaler techniques, exacerbated by the shift to remote consultations during the COVID-19 pandemic. Without face-to-face appointments, healthcare providers were unable to ensure patients were using their inhalers correctly.

“I have a supply of dummy inhalers in my drawer here, but I can’t show someone over the phone. If they’re not using their inhalers properly, then the medication is not going to help, and it’s no good just changing one inhaler over to a different one. I think inhaler technique is really important, and it has been starting to lack because a lot of reviews have gone remote.”
- *Respiratory Nurse (Tendring)*

Pharmacists also observed customers struggling with using their inhalers, attributing it to the lack of hands-on guidance at GP surgeries. One pharmacist pointed out the pressure on healthcare providers to fit detailed consultations into short appointment windows.

“I feel there’s pressure on the surgeries for a 10-15 minute appointment window but it’s getting the time needed at the diagnosis stage, education at source from the person who’s actually instigating the treatment. If they’re given enough information at the beginning, there’s more likelihood of patients complying. The nurses say ‘go to the pharmacy and ask them’, but how many times can we show a patient how to use a different inhaler?”
- *Pharmacist (Tendring)*

Improper inhaler use can lead to ineffective treatment and worsening symptoms, potentially increasing the number of emergency call outs and hospital admissions.

“A lot of appointments are done over the phone now but with the annual reviews, you would hope that they would check inhaler technique because this leads back to concordance and compliance. You could have a patient who says they are using their inhalers correctly but if they are not taking it properly then there’s poor deposition of the drug in the lungs and, of course, it’s not going to be effective. So they’ll carry on getting lots of inhalers that are of no use whatsoever, and patients still clog up A&E or the ambulance service because they’ve got a bad chest infection that maybe could have been reduced and avoided.”
- Community Respiratory Nurse

Some participants expressed frustration at the reduced availability of rescue packs, which include standby antibiotics and steroids for patients to use in case of a chest infection. The absence of rescue packs has led to an increased reliance on emergency call outs, particularly on weekends and holidays when GP surgeries are not accessible.

“They don’t give you rescue packs anymore, which is a bit of a pain. If I get a chest infection, I end up in hospital. Simple as that. The last time I got a chest infection, it was a weekend and I couldn’t go and see my GP. I had to get an ambulance out because I didn’t have a rescue pack. If we need them, then they should be available. I can understand if somebody was having a rescue pack every other month, that’s a little bit different. But if you’re only asking for one and maybe six months later saying ‘I’ve had to use that, can I have another’ then I can’t see what the issue would be.”
- Colchester Participant

“I asked for a rescue pack. We’d only used it in an emergency, but the surgery rejected that. ‘Well, you’ve only got to come to the doctor if your wife is ever rough and we’d get her one straight away.’ But I can’t get one straight away if they’re closed on a weekend. If she is ill on a Friday night, I can’t get there till the Monday. They’re life-saving for her, but I’m not allowed to have one.”
- Tendring Participant

Healthcare professionals, however, emphasised the need to restrict rescue packs to prevent overuse, which can lead to antibiotic resistance.

“It feels like nobody is able to get a rescue pack from their surgery at the moment, but it should be tailored to each person. Some know their symptoms and would be sensible, and for those we would recommend the GP continues to give them out. But then you’ve got the other end where they’re literally taking them because, ‘It makes me feel better, it’s the only thing that works when I can’t breathe’. You can’t do that. We’re in an antibiotic crisis, this is why we’ve got multi-resistant bacteria in their sputum. They’ve chewed through too many antibiotics.”
- Acute Respiratory Nurse

Patients living with COPD often rely on antibiotics and steroids for treating recurrent chest infections, however there is a growing dependence on prescriptions by GP surgeries to plug gaps in care. Several people spoke about the ease of getting antibiotics and steroids prescribed over the phone.

“If I want antibiotics, I just phone up and I’ll get them. I don’t have to walk all the way up there. They are delivered so I don’t even have to go out to get them.”
- *Tendring Participant*

A couple of participants reported long-term use of antibiotics and steroids, without seeing improvements in their symptoms.

“I’ve had this cough for three months and it’s just driving me round the bend. All they keep giving me is antibiotics and steroids, and they don’t do no good at all. Hasn’t got rid of the cough, but they haven’t asked me to go down there to see if I’ve got a chest infection. They ask you what colours of phlegm you’re bringing up and if you say to them green, then they give you antibiotics and steroids.”
- *Tendring Participant*

This trend, according to healthcare workers, may be a result of remote consultations, where patients are repeatedly being prescribed medication without in-person evaluations, and raised concerns that it’s obstructing the diagnosis of more serious underlying issues.

“Something that we’ve been seeing a lot more recently, and I think that may be a leftover from COVID-19 and remote working, are patients who have been on steroids and antibiotics for three or four months in a row. You shouldn’t be having that. If a week’s course is not working then there’s a reason why. We are picking up lung cancers on the background of patients coming in who have had multiple rounds of antibiotics and steroids. When you say to those patients, ‘Have you seen anyone?’ ‘No, you can’t get to see anybody.’ They’re not getting that face-to-face review. They’re just phoning in and repeating the prescription, and nobody is checking up on that. That is quite worrying.”
- *Acute Respiratory Nurse*

Several participants expressed a desire for more accessible, practical information and guidance about managing their condition, feeling that the information provided during diagnosis was insufficient.

“I don’t even know what services there are out there. All that has happened so far is my GP prescribed me an inhaler. More useful to me would be information on how to prevent it from getting any worse. Should you still exercise, and to what extent? Are there any other things you can do to help? It does seem that the medical profession just wants to prescribe rather than anything else.”
- *Colchester Participant*

Healthcare professionals acknowledged that sometimes patients don’t absorb all the information provided during a consultation and stressed the need for a patient-centred approach, where respiratory nurses have adequate time with their patients both during and after diagnosis to ensure they fully understand their treatment and are able to address any questions or concerns.

“I know from personal experience, when you go to a consultation you can only take on so much. I would always say come and speak to a nurse because, no disrespect to doctors, they probably have a bit more time to explain things to them.”
- *Respiratory Nurse (Colchester)*

“When somebody tells you that you’ve got something like COPD, you go into a bit of a panic mode. ‘What is that?!’ You’re not listening, because you’re panicking.”
- Colchester Participant

A healthcare worker noted that the limited time available during appointments makes it challenging to provide a comprehensive education on managing COPD, especially for newly diagnosed patients. To address this, they recommended offering information in various formats that patients can access after the consultation.

“I think the thing with education around COPD is that if it’s given during a nurse’s appointment, they have such a short amount of time to work with. If someone’s just had a diagnosis, they’re then being given all this information about how to manage it and the risk factors involved. So maybe the way we share information could be looked at. I think that there needs to be multiple sources. So online resources, physical resources, picture and video resources etc. We’ve got a high demographic of non-English speaking patients here, so resources in other languages as well.”
- Respiratory Nurse (Colchester)

Many healthcare workers and patients supported the idea of developing a comprehensive and accessible COPD information pack to provide patients with easy-to-understand guidance on managing their condition. A similar resource exists for diabetic patients, but there is currently no equivalent for COPD

“I’d love a wealth of resources to be able to say ‘you can have this, this and this.’ I think the North East Essex Diabetes Team put together a pack for newly diagnosed patients, but we don’t do the same for the respiratory, so that would be brilliant. I think the only issue is that it needs to stay updated, because every now and then we may recommend something and it’s changed to something else. We don’t always get to know that.”
- Respiratory Nurse (Tendring)

One community respiratory nurse highlighted how they have something similar that they give to patients when undertaking home visits.

“We give out a big pack when we see patients which has lots of information about the inhalers and breathing techniques, as well as phone numbers and websites such as Asthma & Lung UK on the back. But to my knowledge they don’t give anything out at the surgeries. It’s difficult because you are relying on that patient to engage with it, but I always think a bit of paper is good because at least you know that you’ve given them that information to take away.”
- Community Respiratory Nurse

Accessibility, particularly in areas with low literacy rates, was raised as another concern, but one participant suggested ways to make the information more accessible.

“You’ve seen the leaflets that come with medicines. Tiny little writing, no good for my eyesight, and it’s just written in a way that you have to go on Google to understand what it means. It has definitely got to be in layman’s terms. It would need to have pictures. And that’s when the Asthma Nurse can come in. Because she could distribute it. That could be part of the appointment.”
- Tendring Participant

6.6 Signposting and Pulmonary Rehabilitation

"They sent me to a sort of breathing class or club. You had to do different exercises; getting up from a chair and sitting down, throwing a ball up against the wall, marching round in a big circle. Loads of us, all marching round and round."
- Tendring Participant

I spoke with respiratory nurses based in Colchester and Clacton to explore where they would typically direct patients for further support, following an initial COPD diagnosis. The responses were notably consistent, with an emphasis on the roles of social prescribers with the surgery, online resources available from Asthma & Lung UK, and the benefits of pulmonary rehabilitation.

"We always try and refer to pulmonary rehabilitation because they are really good classes. Anyone that's been has really found them beneficial to help with their breathing and learn more about their condition. We also have social prescribers in the practice, and they can then signpost on to other groups within the community if we felt the patient would benefit from that extra support. Asthma & Lung UK have got a lot of COPD information so I print that off for them or I'll send it over via Accurx depending on what their preference is. It's helpful because they've got a lot of information in different languages and it's at a nice accessible level too. I always try and give them extra information to digest later."
- Respiratory Nurse (Colchester)

Healthcare professionals unanimously agreed that pulmonary rehabilitation was excellent for respiratory patients, as it offers education, exercise, and breathing techniques that help patients manage their symptoms more effectively. These programs also allow patients to engage with others facing similar challenges as themselves, adding an important social aspect to the experience.

"We do try and get them into pulmonary rehab. They get that little bit of social interaction a couple of times a week, they get education and advice, they improve their health, wellbeing and their stamina and can hopefully then control their symptoms better."
- Community Respiratory Nurse

However, despite the clear benefits, access to pulmonary rehab is restricted by long waiting lists.

"The COPD nurse put me down to go to these classes where they do breathing exercises and all that. I'd said that I would like to go, it sounds really good to me. I spoke about it again, when I went in last week for my 6 month review and she said, 'You haven't heard anything?' 'No.' She looked through her records. 'Oh, yes, that was back in April.' Then I had an email come through only the other day to say that 'yes, you are still on the list.' So there must be a lot of people who are interested in going to have such a long waiting list."
- Colchester Participant

Last I heard, the waiting list was about 200 patients and I think they only take on 12, every 6 to 8 weeks. So there's obviously quite a long waiting list for that."
- Respiratory Nurse (Tendring)

Eligibility is also limited by the requirement of a Medical Research Council (MRC) breathlessness score of three or above. Several healthcare professionals expressed frustration with this criterion, noting that it limits access for those who might really benefit from early intervention.

“The research tells us that pulmonary rehab is fantastic and should be offered to all. However, our limitation is that they have to have an MRC score of three or above. One is where you’re just short of breath when exercising, five means you’re too out of breath to leave the house. So we could have a patient that would really benefit from going to pulmonary rehab, but if they present a score that’s not too bad then you don’t meet the referral criteria. Personally I think anyone with a COPD diagnosis should be able to access pulmonary rehab.”
- *Respiratory Nurse (Tendring)*

Healthcare professionals also noted a common reluctance among patients to attend pulmonary rehab, often citing concerns about group settings, anxiety, travel difficulties, or the time commitment required for the program.

“I see lots of patients that I want to refer to pulmonary rehab because I know they’re going to benefit, but it’s, ‘Oh, no, I don’t like groups.’ ‘Oh, no, I can’t get there.’ There’s always a reason. We have a pulmonary rehab class in Greenstead because so many of our referrals are from that area, we knew that there was a need there.”
- *Community Respiratory Nurse*

“I try not to say that it’s exercise, because people are like ‘I’m not going to the gym’ so we describe it as a course to help with your breathing. It’s exercise to keep your lungs fit and to keep you going. Sometimes that works, sometimes they still say no, but the feedback from people who have done the course is that it does make a difference.”
- *Acute Respiratory Nurse*

These sentiments were echoed by some of the patients I interviewed in Colchester.

“The thought of getting there puts me off. I wouldn’t even know what bus to get or where to get off. No, I couldn’t go all that way, not unless there’s one very close.”
- *Colchester Participant*

“I was offered pulmonary therapy but I’ve not taken them up on it. At the time I just thought I might not have the energy to do it. I was a worried about that, but obviously they knew that my health was going to be the way it was, so I’m an idiot really. I don’t know why I didn’t go, but I should have gone.”
- *Colchester Participant*

“I got a phone call and they told me there’s a course of six weeks that you can go on, but it means that I’ve got to go up to the hospital twice a week and it’s just the commitment. I use Community Transport but sometimes they’re fully booked. I’ve got a friend who helps a lot, but she works 12-hour shifts, so it would depend on what days they wanted me. I just couldn’t guarantee being there twice a week. So I said to them, ‘can you just leave it for now and phone me again’ and they have taken me off and put me back on the waiting list.”
- *Colchester Participant*

6.7 The Impact of COPD on Mental Health

“Oh, it’s a nightmare. You are feeling like you’re drowning all the time.”
- *Tendring Participant*

One of the most poignant themes to emerge from these conversations around COPD was the profound sense of loss. Participants often experience not just a decline in physical capabilities, but also a loss of identity.

“Once upon a time I could walk for miles and miles and miles and I felt nothing about it. But now I can hardly do anything because I get so out of breath. I can’t sit down without needing to get my breath back. I feel so limited.”
- *Tendring Participant*

Frontline workers noted that this frequently leads to patients developing mental health problems, as they come to terms with their new reality.

“A lot of patients we see find it really difficult, because before they may have been quite active and busy in their lives. There’s a point where the realisation sets in but, because it’s such a slow and progressive disease, it kind of just trickles at first. I think that’s how they end up with depression and anxiety, because they’re like, ‘Oh, right, this is me now and I can’t be who I was.’”
- *Advanced Clinical Practitioner*

Despite the massive emotional impact that COPD has, some participants adopted a stoic approach to their condition, determined to continue living their lives as fully as possible.

“I put up with the COPD. I say to myself, ‘Well, I’ve got it. Live life to the fullest and do what you can.’ On the odd occasion it does get me down, I feel that I want to do things and I can’t because I get so breathless. I try and put that aside though, because if I start going down that path then I’ll just want to give up. I don’t let it get that far. I persevere with it.”
- *Tendring Participant*

However, for many, the toll on their mental health remains substantial, with feelings of shame, isolation, anxiety, and hopelessness being common.

A recurring theme was the stigma associated with COPD, particularly the assumption and judgement by others that the disease is a result of smoking. This stigma often exacerbates feelings of shame and leads patients to avoid social interactions altogether, further contributing to their isolation.

“What I would like is for people to not look down their noses at people with COPD when they are coughing, or out and about with their oxygen tanks. I know it’s just human nature, but it’s not very nice. This is one of the things that happens to people when they get COPD, you don’t want to go out the house anymore. You do not want to bump into anybody you know and have them see you struggling for breath. That’s when the anxiety comes on. Everybody thinking, ‘Oh, you should have cut the fags out 20 years ago mate’. But it’s not always cigarettes, it’s lots of other stuff.”
- *Colchester Participant*

Many participants described how losing their independence and ability to participate in social activities led to a profound sense of loneliness and hopelessness.

"It's the loneliness. I'm finding it really frustrating and debilitating, more so than the COPD itself. I've always been such a strong character that's worked all my life and brought up three kids practically on my own. Suddenly life has changed so much and I feel ashamed. All the things that I would love to do, like going up to London and going to theatre with my friends, I can't anymore because I just haven't got the strength and energy to do it."
- *Colchester Participant*

"I knew I was going to get old, but I never thought I would end up like this. I'm stuck all on my own, and I don't see a living soul from one day to the next. Sometimes my daughters and their partners turn up every few weeks or so, because they live miles away from me, but I'll watch their car going up the road and then shut the door on my living tomb. That's the way I feel about it. The only time I'm going to get out is feet first through that front door."
- *Tendring Participant*

"I haven't been outside of this bungalow since Christmas except by ambulance. All I want is to go to the door and, if I felt like it, maybe take a few steps. Believe me, if I could get outside then I'd be in my element. It's so sad that you can't do these things. I've never been somebody to give up, but I'm starting to give up now if I'm being honest."
- *Colchester Participant*

Regular social contact was highlighted as a crucial factor in helping patients manage their condition and feel less isolated. Participants who had close family and friends nearby reported being better able to cope with their condition.

"I've got family around me, so I'm not like a lot of people who might be isolated and struggle because they haven't got that support."
- *Colchester Participant*

However, others felt guilty about asking for help or felt hesitant to reach out for social support.

"I feel like I'm a bit of a fraud asking for help to meet people, if that makes sense?"
- *Colchester Participant*

Some participants expressed anxiety about being around strangers, especially after the COVID-19 pandemic, deliberately choosing to remain isolated even after restrictions had eased.

"If I go out places and I'm around crowds of people then I just start panicking and gasping for breath. I don't really like to go out now unless I have to. I don't socialise very much, only with my family. It's just because of COVID and that. When you get that letter off the government telling you to stay indoors. I've been in for so long that I get a bit paranoid about going out now."
- *Colchester Participant*

The unpredictability of COPD symptoms, particularly severe breathlessness, often causes significant anxiety, with some participants experiencing full-blown panic attacks as a result.

“When it’s really hot, I can’t breathe. I’ve passed out a few times rolling about on the floor having a panic attack because I can’t catch my breath. You feel like you’re drowning. That’s the only way I can describe it. It’s horrible. They need to make people more aware, try to explain what you’re going to suffer if you don’t go and get it sorted early.”
- Tendring Participant

Healthcare professionals noted that some patients struggle to differentiate between anxiety-induced breathlessness and actual exacerbations of their condition, leading to frequent reliance on emergency services for reassurance and support.

“If you’re breathless and scared in the middle of the night, what do you do? You dial 999 and then, 9 times out of 10, the ambulance will take them to A&E. A lot of our patients get admitted quite often but they’re not necessarily poorly, and that’s the really hard part because we don’t have a cure for breathlessness. It’s really difficult to stop the readmissions, because 999 is often their safety net.”
- Community Respiratory Nurse

“We’ve got a regular cohort of COPD patients that have a lot of contact with the out-of-hours services and go in and out of hospital like a revolving door. Usually that’s an indication of other underlying issues like social isolation, anxiety and depression. You can teach them how to do the breathing exercises, but there’s not a lot of understanding about how COPD is going to cause breathlessness.”
- Community Respiratory Nurse

Several healthcare workers spoke about the challenges of addressing COPD patients’ mental health needs, particularly the limitations in referring them to appropriate services. Mental health providers like Therapy For You often have long waiting lists, and many patients prefer face-to-face support over the phone or online consultations on offer.

“It’s very limited what you can actually refer people into. It’s just Therapy For You, but there is that long waiting list and it’s usually over the phone or online. Some people don’t mind taking on the phone, but many need that face-to-face. There’s something that’s lost over the telephone. If you are breathless, some people find talking on the phone very difficult as well. Especially if you become emotional. The number of patients I go and see that just sit and cry. You’re the first person they’ve seen. You go around there to just check their inhaler technique, and you get the mother load of all that grief. They tell you everything. I think we, as clinicians, do sometimes get leaned on for that emotional support, which is not really what we’re meant to be doing. Us nurses are the keepers of many secrets.”
- Community Respiratory Nurse

The emotional and psychological burden of COPD is profound. Feelings of loss, isolation, and anxiety are prevalent among patients, compounded by stigma, social isolation, and the unpredictable nature of the disease. Effectively addressing these mental health needs is absolutely crucial to improving the quality of life for individuals living with COPD.

“It’s nice to actually air my views to somebody, to be quite honest. Apart from nurses and doctors, that’s all you see. You don’t get other people that go, ‘Oh, gosh, how do you feel? What’s it like? What can we do together to make it better?’”
- Colchester Participant

6.8 Challenges to Quitting Smoking

“Until they make that change, we can’t do anything. When we say ‘give up smoking’ the common answer back is ‘Well, the damage is done. It doesn’t matter.’ It does. We know that it’s just going to get worse, but at the end of the day it’s the patient’s choice.”
- Acute Respiratory Nurse

The challenge of quitting smoking for COPD patients is complex, despite the clear need for it to slow the progression of the disease. For those motivated to quit after diagnosis, the journey is often riddled with emotional and physical challenges, particularly for individuals who have smoked for decades.

“I stopped after I was diagnosed with COPD. It still took me a while to actually break the habit, because after 40 years of smoking it’s really hard, but I got there in the end and I’m glad I did. I had given up for 3 months at one stage, and then my mother died of lung cancer on Boxing Day. The following morning, I’m driving on the A12 to go buy tobacco because I’ve got to have a fag. That’s how addictive it is. If you said ‘we can cure COPD now’, I could quite happily have a cigarette again. It’s just one of those things that just never leaves you, which is frightening really.”
- Colchester Participant

Many participants shared similar experiences, admitting that the early symptoms of COPD, like shortness of breath and persistent coughing, were mild enough that they did not feel compelled to stop smoking right away.

“When you first get diagnosed, you feel a little bit out of breath. It’s not that extreme. You know you’re not right, so you go and see someone, but you think to yourself afterwards, ‘I can carry on like this’. Then before you know it, your condition has got considerably worse. That’s an eye opener. That’s when you start thinking, ‘I’m an idiot, I should have quit smoking when I got diagnosed. Now it’s too late.’”
- Colchester Participant

Despite the obstacles, over half of those interviewed had managed to quit smoking, often relying solely on willpower without external support.

“I haven’t smoked for 6 years and I’ve noticed that has really helped my breathing, whereas before, walking up a hill I would feel like my eyes were going to pop out of my head. There were a few times I got really frightened. That’s why I just woke up one morning and thought ‘I don’t want to do this anymore’ and I haven’t smoked since. I had tried quitting before and gave up after a matter of days, but this time something must have triggered in my brain that enough was enough.”
- Colchester Participant

For others, gradual reduction was more effective. Although not a complete solution, cutting back significantly helped some participants feel in control of their habit.

"I've already got it down to four or five a day, which ain't bad. I used to smoke about forty a day."
- *Tendring Participant*

The psychological aspects of quitting smoking are often harder to overcome than the physical addiction. Many participants admitted that smoking helped them manage their stress, anxiety, or depression, making the thought of quitting even more daunting.

"I probably smoke twenty a day. I have tried giving up, but I end up getting stressed out and I having a fag again. It's just one of my comforts. I'll have a couple of beers and fag. I suffer with anxiety, so to take away things from me just makes it worse."
- *Colchester Participant*

For some, the emotional distress associated with quitting led them to resume smoking.

"I got rid of the craving, but I was getting in a terrible depression. I couldn't stop crying and that frightened me. So I went round the shop, bought some tobacco and started smoking again."
- *Colchester Participant*

Not all participants were motivated to quit smoking, even after receiving a COPD diagnosis. For them smoking had been a lifelong habit, and was one of the few remaining pleasures in life.

"I still smoke now. I'm nearly 80, take that away from me and what have I got? My lungs ain't going to get better, not now. I can't see with my condition, even if I stopped, that I would live that much longer."
- *Colchester Participant*

"I suppose the biggest problem in Jaywick is that people won't think about giving up smoking. They've got nothing else. The ones you speak to who are being treated for COPD, they're coming to collect their inhalers and are still puffing away. We have frequent conversations with same ones, over and over again, where we try and explain that things won't improve if they don't give up, but it's not easy to do."
- *Pharmacist (Tendring)*

Others even feared that quitting might have serious negative repercussions on their health.

"I don't know if this is true, but I've heard from two or three people whose mother or friend had COPD. They've packed up smoking and within a couple of months, they're dead. That doesn't give me much encouragement."
- *Colchester Participant*

Respiratory nurses can have a challenging time encouraging smoking cessation, particularly when patients feel that quitting may not improve their condition. However, many recognise that how they approach the topic plays an important part in whether patients are receptive.

"I think it's always how you approach smoking cessation as to whether they'll take on board what you're saying or not. If you go in with a 'you must stop smoking' approach, then the barriers go up. You can offer all the services that are there to stop smoking, but they won't want to engage with it. Or they say they will, but then when it actually comes around they don't."
- Community Respiratory Nurse

There was also some scepticism over the delivery method of smoking cessation services in North East Essex, with healthcare workers advocating for having more in-person and community-based support available to patients.

"The one frustration I have with the stop smoking service around North East Essex is that it's all on the phone. I think if you want to engage with someone properly, face-to-face is always better. They're going to listen and understand more. Home visits or something at the community centres where the stop smoking team visit once a month. I'm not saying they would get many people, but try and make it more available and nearby."
- Community Respiratory Nurse

6.9 Peer Support and Community Health

"I think that peer support is really important with these chronic conditions. Group sessions where people can come together and share their experiences."
- Respiratory Nurse (Colchester)

There is a strong desire among both participants and healthcare professionals for local peer-led respiratory support groups in North East Essex. These provide essential social, emotional, and physical support, helping individuals with COPD manage their symptoms, reduce isolation, and improve their overall quality of life. However, outside of pulmonary rehabilitation, the nearest social respiratory group is located in Southend-on-Sea.

"The sad thing about the Breathe Easy group in Colchester going, is that a lot of patients used to do the Pulmonary Rehab course and then they'd go to the Breathe Easy group. It was an exercise class for the patients, by the patients."
- Community Respiratory Nurse

"When I saw that Breathe Easy group, I thought, 'Oh, that's good. I'm going to meet people there that have got the same conditions.'"
- Colchester Participant

"A lot of people do find it beneficial when you've got the support of others as well as a tutor. Hearing stories of someone saying, 'Well, I'm finding it really hard' and someone else going, 'Well, actually, I am too but I didn't like to admit it.' So I think that can help, especially if it's local."
- Respiratory Nurse (Tendring)

Several participants, especially in Colchester, expressed a clear interest in attending a COPD support group, recognising the mental and physical health benefits from connecting with others facing similar challenges.

“I would love to do that. I’ve been to meetings before, parenting classes where you meet loads of people and do fun tasks, while getting told about things you didn’t know. It was quite good. I really enjoy stuff like that. Some people don’t and just clam up, but I’d happily go there and listen to what other people have got to say.”
- Colchester Participant

“I always say, ‘You need to talk.’ There are so many out there like me with their own breathing struggles, I think that it would make people much happier in their lives to be able to do this. Hearing other’s stories tends to put things into perspective.”
- Colchester Participant

Despite the demand for respiratory support groups in areas like Colchester and Clacton, there are significant challenges to establishing and maintaining them. A primary obstacle is the lack of resources and facilitators to manage these groups.

“If somebody wanted to start a support group down here that would be absolutely fabulous, but then it’s who would help facilitate that going forward. There’s lots of little seeds of potential out there but it’s just having the infrastructure and the manpower to go and support that.”
- Community Respiratory Nurse

In addition to logistical barriers, some participants were reluctant to engage in group settings. A few expressed discomfort at the idea of seeing others in later stages of COPD, fearing it might serve as a stark reminder of their condition’s potential progression.

“I don’t know, to be honest. I suppose as my condition gets worse, maybe I would. At the moment I don’t think I’d want to go, because I don’t want to see how bad it could get. But when I got to that stage, I’d like to know what help is out there.”
- Colchester Participant

Others were open to trying a group but questioned its overall purpose and effectiveness.

“I might well go. I wouldn’t not go. But honestly I’d be quite sceptical to think what I could get out of it. Because at the end of the day you can talk about something as much as you like, but go home and you’ve still got that disease.”
- Colchester Participant

Healthcare professionals also noted that existing community support and pulmonary rehab groups often do not reach individuals with more complex needs, those who are housebound, isolated, or struggling with their mental health and would benefit the most.

“Breathe Easy was a great patient-led group, but it was only the ones that were really motivated and doing all the exercises that went. They’re not capturing the people that actually we need to focus on. I see a lot more patients that are housebound, and I think that’s the difficulty. They’re the ones that sit in front of the TV for twelve hours a day till they go to bed, because they haven’t got anyone to see them. Unless we signpost them to a befriending or cleaning service, because a lot of patients are not online necessarily, they are not aware of what’s available and it’s really hard for them to find that information.
- Community Respiratory Nurse

6.10 Inequalities in Housing and Transportation

Access to quality housing and reliable transportation are vital in mitigating the aggravation of chronic respiratory conditions such as COPD. However, the realities faced by many individuals highlight stark inequalities that exacerbate these health issues.

The surge in electricity and gas prices is forcing many to make difficult choices around heating their homes. This dilemma is particularly troubling for individuals with chronic respiratory conditions like COPD, who face increased health risks from living in cold, damp environments.

"The heating is on now. I don't like putting it on because of the cost. I've noticed how much it has gone up since I moved in, but I'll have to put up with it. If I don't put the heating on, I'm going to get ill. I'll worry about the cost at a later date."
- *Colchester Participant*

Many homes in Jaywick, built in the 1930s as short-stay holiday chalets, were never intended for long-term habitation. Despite efforts to insulate some properties, issues such as damp, mould, and drafts remain widespread. These problems are compounded by the fact that heating costs for these homes are far higher than for better-insulated purpose built housing.

Some of the most severe housing issues in Jaywick that were highlighted involved long-standing structural problems, including asbestos found in walls and floors.

"I took this property on to rent but there were major issues. The bathroom floor collapsed when they were changing it from a shower room to something more accessible for my needs, and that was when they came across the asbestos. It was everywhere, in all the walls and ceilings. I had nowhere else to go, so it was a case of just putting up with it."
- *Tendring Participant*

In some cases, residents moved into their home intending to renovate them but found that their worsening health made even basic maintenance difficult.

"I took this on thinking 'yeah, I can do this.' Thinking I would still be fit and healthy. I started, then my breathing and my stamina got worse. I'm having to get people to come and help me. I bought the kitchen second hand, but I didn't get the sink unit fitted. I had a worktop and I've been boiling kettles to wash up. I've managed to get the landlord to contribute £1400 for my plumbing to be finished, so now I finally have hot water and a shower."
- *Tendring Participant*

Even daily household maintenance, tasks which may seem simple to many, become monumental challenges for those with COPD

"The worst thing is changing the bed, changing the quilt and the bottom sheet. Sounds like a simple thing, but I start to do it and then I've got to sit on the bed and give myself a break before doing a bit more. I lose my breath all the time. It's a bloody nightmare."
- *Tendring Participant*

In Jaywick, where most of the housing is privately rented, tenants often have little power to demand repairs and are often left with unresolved long-term issues at the mercy of landlords. Many hesitate about reporting these to their landlords due to the risk of eviction.

“The housing is awful around here. They’re all pre-fab, not meant to be lived in. There’s no gas mains down this way at all. It’s either electricity or Calor gas. We hear all sorts of stories, one lady was telling me about having holes in the floor and they can’t complain because the landlord will just chuck them out. They’re scared to make a fuss, you know?”
- Pharmacist (Tendring)

“I’ve been evicted, through no fault of my own. The council don’t want to know. They’re saying that COPD don’t count as an emergency. It’s not a priority. I’m stage four, my respiratory nurse sent them a letter and everything. So I don’t know what we’re going to do. They’re not going to give me anything. We should have been out on the 1st of September, but I’ve been staying put until they get a court order.”
- Tendring Participant

In contrast, areas like Greenstead and St. Anne’s & St. John’s, with more social housing, renters are offered more recourse to report and resolve issues through local housing authorities.

“We had damp but that’s all been sorted now. It came from nowhere, like damp does, but it wasn’t overly bad and we got it taken care of before it was. We don’t have to pay for repairs because this is a housing association property, so they sent contractors in to do it for us, and so far there’s not been any more problems since.”
- Colchester Participant

Healthcare professionals who visit patients in their homes have reported that poor housing conditions, especially in areas like Jaywick, significantly worsen COPD symptoms.

“Poor housing conditions in Jaywick is a big aggravator for COPD, especially in the winter time. You open their front door and you can smell the damp. There are little drafts coming through the windows and the insulation is not very good, as you would expect from chalet bungalows that are 60 years old. Cheap to rent, but if they have problems with their heating or mould and raise it with their landlord then, depending if they’ve got a good or bad one, ‘if you don’t like it out you go’. That’s what our patients are saying. A lot of the housing in Jaywick tends to be private landlords whereas there is more social housing in Greenstead, so they’ve always got someone to go to if things aren’t great. In Jaywick, you can try and raise it as a concern but it’s not a quick process and the council don’t have houses sitting empty waiting for people to move into them. We do what we can from our side, but we’re limited by those other environmental factors that we can’t control.”
- Community Respiratory Nurse

Living in substandard housing takes a toll on someone’s mental health as well. Being trapped in a cycle of poor living conditions, high energy bills, and the constant fear of eviction can lead to an enormous decline in both physical and emotional wellbeing.

For many participants, their car is more than just a way to get around, it's a lifeline to the outside world. The convenience and immediacy of car travel allow those with limited mobility to retain a sense of independence and access to essential services, which would otherwise be difficult to maintain given their condition.

"I've got a mobility car. I wouldn't get around if I didn't have that. If I had to walk to the bus stop from here, I wouldn't make it. That's how bad I get."
- Tendring Participant

Even those who no longer drive often depend on being offered a lift by family, friends, or neighbours to access essential services.

"I used to drive, but I don't now because I'm partially blind. My neighbour's brilliant though. If I need to go to the doctors, he'll take me."
- Colchester Participant

"I've got a bus pass, but I don't use it because my wife takes me everywhere. But if I'm somewhere like the hospital, and I'm out of breath and can't get back home, then I can use my bus pass. I've never used it yet. It's just for emergencies."
- Tendring Participant

For residents without access to cars, the situation becomes more difficult. Although public transport is available, many participants expressed a reluctance to use it, citing physical limitations, concerns about reliability, and the difficulty of navigating bus routes. Those with chronic respiratory conditions like COPD often find that walking short distances can be exhausting, making public transport impractical. For some, even getting to the bus stop is a significant challenge.

"If I walked down to the bus stop, I would be knackered."
- Tendring Participant

"When my husband was alive, we used to go up the town maybe once a week on the bus. I wouldn't dream of doing that now. I don't think I could. Too much walking."
- Colchester Participant

The disparity in public transport services between urban areas like Greenstead and more rural or deprived areas like Jaywick underscores broader issues of transport inequality in North East Essex. Residents in better-connected areas can rely on more consistent bus services, giving them easier access to essential services like supermarkets and GP surgeries.

"Transport is a big thing. I would say Greenstead is better connected than it is in Jaywick, because you've got a lot more buses going in and out regularly. Jaywick doesn't have much, so it's the logistics of getting to places. If you've got COPD in Jaywick but you have a car, then great. If you don't have the money, then you can't afford to finance and maintain a car. The bus that might turn up or not. Taxis are expensive. A lot of people have to get them to the surgery and it costs £5 each way. They're not going to go if it's that much, not unless they really poorly. That is a real hindrance."
- Community Respiratory Nurse

In Jaywick & West Clacton, participants frequently reported that buses were unreliable, prone to being cancelled, and difficult to rely on for planning medical appointments.

"The buses are terrible. You'll get two double deckers coming along together, and then you won't see another bus for two hours. And no one knows they have been cancelled."
- Tendring Participant

For those comfortable with technology, transport apps help mitigate some of the unpredictability, allowing users to check real-time bus schedules and receive notifications about cancellations. However, this solution is not accessible to everyone, particularly older or economically disadvantaged residents who may not have smart phones or the necessary skills to use these apps.

"Some people haven't got the bus app. Some people haven't even got smart phones. When it gets to the older generation, they don't necessarily know how to use them. If someone has got an appointment at the hospital, and they don't drive, then they are relying on the buses. And they just take buses off for no reason around here."
- Tendring Participant

6.11 Aging Populations and the Transition to Online Services

"I've got my iPad, which I use for most things. This tablet is my lifeline."
- Tendring Participant

The ongoing transition towards adopting online only access to health and social care platforms has presented significant challenges for many elderly residents of North East Essex trying to find out information about what support and services are available to them.

"There is the MyCOPD app but there are people that wouldn't know what to do with a computer. Don't have a computer, don't have a smart phone, can't use apps."
- Community Respiratory Nurse

"You need somebody to help, because I don't know what's available out there at all."
- Colchester Participant

This shift is particularly problematic for those who are digitally illiterate or economically disadvantaged as it restricts their ability to engage with these essential public services, leaving many, who are only going to grow more reliant on them for support as they become older and more vulnerable, feeling increasingly marginalised.

"The world has changed so much. And I know I've got to go along with that to a degree, because that's the world now, but I do find it really difficult to come to terms with everything being tech and nobody talking anymore."
- Colchester Participant

"Don't just write people off when they retire, because that's how I feel. I'm 72 now and I've been written off."
- Tendring Participant

“No, I don’t do that, I can’t do all that. I can’t read properly. I don’t like to do them internet things.”
- *Colchester Participant*

For those living with moderate to severe COPD and unable to walk long distances or use public transport, digital exclusion creates physical barriers to accessing critical services. The online application process to apply for benefits such as Blue Badges have been moved online and has become yet another hurdle to overcome by those lacking digital skills or access to technology.

“A Blue Badge would be helpful. I did ask at the doctors, and there was one of the miserable ladies on the reception. She said, ‘Oh, go on the website.’ Well, I’m no good with computers, and my wife’s not very good either. We haven’t even got a computer. So I’ve never bothered to apply for it.”
- *Tendring Participant*

“It’s a nightmare. Even for those of us that are tech savvy. I’ve tried some of the websites and even I’m having trouble working out how to navigate it.”
- *Pharmacist (Tendring)*

As a result of these challenges, many elderly residents rely heavily on charities and third-sector organisations like Age Well East and Citizens Advice for help with online applications and navigating digital platforms. Unfortunately, the ongoing cost-of-living crisis has placed additional strain on these services, leaving them with limited resources and struggling to meet the increased demand for support.

“I’m waiting for a Blue Badge at the moment. It’s the application form. It just makes everything so difficult, especially for someone like me that’s not computer literate. My smart phone’s smarter than I am. I went last week to Citizens Advice and they sat there for two hours helping me complete it all, which was wonderful because I couldn’t do it by myself.”
- *Tendring Participant*

“I just can’t believe how us oldies are getting pushed out. I phoned the council up, because I thought that’s where you go to get the Blue Badge from, and they said, ‘You have to do it online. It’s ever so easy.’ My neighbour next door said, ‘I’ll see if I can do it for you.’ Well he couldn’t do it either, so his sister gave me the phone number for Age Well East. They are coming round tomorrow to do it for me on my iPad.”
- *Colchester Participant*

This shift toward digital services has led to a growing disconnect between elderly patients and healthcare providers. Many older residents are now struggling to access the care and support they need, with some feeling increasingly frustrated and isolated as a result.

A pharmacist based in Tendring summarised this best.

“You shouldn’t be in a position where you don’t know how to book a doctor’s appointment.”

Recommendations

Primary Care

1. **Prioritise In-Person Annual COPD Reviews**

   Challenge:

   Although phone consultations offer convenience for routine check-ins, in-person annual assessments by respiratory nurses remain essential for effective COPD management. Key aspects like lung health, oxygen levels and inhaler technique cannot be adequately assessed over the phone. While most GP surgeries in Colchester seem to have resumed in-person reviews, the majority of consultations with the respiratory nurse in Jaywick & West Clacton are reportedly still being conducted by phone.

   "It's supposed to be an annual check-up with the Asthma Nurse, but I don't see her anymore. Just by phone. Everybody says that, don't they? She phones me up and asks me how I am doing, am I taking my medicine, do I remember how to use the inhaler etc."
   - *Tendring Participant*

   Opportunity:

   GP surgeries must prioritise reinstating in-person annual reviews as the standard for COPD patients, enabling more accurate assessments and preventing lapses in inhaler technique. If phone consultations are being used to manage higher patient volumes, additional respiratory staff may be necessary to ensure that quality face-to-face care is not compromised in the pursuit of efficiency.

2. **Improve GP Appointment Availability**

   Challenge:

   Participants frequently faced difficulties booking GP appointments. The unpredictable nature of their symptoms makes it difficult for those living with COPD to join the morning queue for same-day appointments, leaving them at a significant disadvantage in the current 'first come, first served' booking system. In some cases, patients were instead directed to emergency departments at their local hospital, which are already under strain due to increasing patient numbers, resulting in longer wait times and delays in care. With few alternatives, many are forced to seek emergency care when their symptoms escalate. Frontline hospital staff noted a rise in COPD diagnoses during hospital admissions.

   "They are also the cohort that can't get a GP appointment for love nor money because they have to be on the phone at eight o'clock. COPD patients don't do eight o'clock in the morning. Some of them are very breathless at that time. They're still coughing up lots of phlegm. They are nebulising. They can't be waiting on the phone or down in a queue at the surgery."
   - *Community Respiratory Nurse*

Opportunity:
Consider implementing a priority or next day booking system for patients with debilitating chronic conditions like COPD. Improve GP appointment systems by enhancing telephone triaging, offering additional online booking options or increasing appointment availability to accommodate patients who cannot access services in the early mornings. Introduce dedicated early intervention respiratory clinics locally where patients experiencing early signs of COPD exacerbation can be seen and diagnosed quickly, reducing the demand on GP surgeries and emergency departments.

3. **Increase Early Diagnosis Efforts**
   Challenge:
   Many participants delayed seeking treatment for symptoms of COPD such as breathlessness and persistent coughs, attributing these to aging, lifestyle choices, or minor respiratory issues. This often led to advanced-stage diagnosis.

   "I've coughed for years, and I used to get out of breath, but I thought 'old and smoking, puffing and panting'. But I woke up one morning and I couldn't breathe. My daughter-in-law took me to the doctors, and he sent me to the hospital for a chest X-ray and that's where they found it. I don't know how long I'd had COPD, but that didn't feel like it got worse gradually. That hit me straight away."
   - *Colchester Participant*

   Opportunity:
   Raise awareness of COPD through education and awareness campaigns targeting at-risk populations, particularly older adults and smokers, to recognise the early signs of COPD and the importance of seeking timely medical attention. Partnering with local assets, community groups and pharmacies can help with spreading the message.

4. **Reassess Home Visit Policies for Vulnerable Patients**
   Challenge:
   Due to the unpredictable and debilitating nature of moderate to severe COPD symptoms, several participants reported being unable to visit their GP surgery, yet struggled to arrange home visits as they were not classified as housebound. This results in an unnecessary workload increase for emergency services and hospital staff who are then picking up responsibility of care for these patients.

   "There's only certain criteria that meet the requirement for doctors to do a home visit. My nan is 84 years old with a collapsed vertebrae and six fractures in her spine, and she still has to go up to see her doctors. She's shouldn't have to struggle all the way to Clacton when she's not feeling right. If you've ever had flu or a bad chest infection, then you know just how hard it is to walk anywhere."
   - *Tendring Participant*

   Opportunity:
   GP Practices should reassess and potentially broaden their criteria for determining when a home visit is appropriate. This could involve a more compassionate approach to assessing housebound status, considering the day-to-day variability of chronic conditions like COPD. Implementing flexible home visit policies for older, vulnerable or more severe COPD patients would reduce their reliance on emergency services.

Rather than waiting for patients to request home visits, GP practices could adopt a proactive approach by identifying high-risk patients based on age, severity, frequent hospital admissions and co-morbidities that are flagged for regular check-ins.

5. **Enhance Reception Staff Training**
   Challenge:
   Participants in Jaywick & West Clacton frequently reported poor interactions with GP reception staff, leading to feelings of disrespect, frustration and discouragement from seeking further care. Some turn to instead local pharmacies, 111 services and Clacton Urgent Care Centre for medical support.

   "It all depends who's behind that armoured plate of glass. Some of them have been OK, some of them just rile you up straight away. I'm sick and frightened, you're supposed to be helpful and pleasant to people."
   - *Tendring Participant*

   Opportunity:
   Implement customer service training for reception staff, encouraging empathy and understanding, improving community trust and patient engagement.

6. **Introduce Tailored Rescue Pack Distribution**
   Challenge:
   Participants voiced frustration over the difficulties in obtaining standby rescue packs, which has resulted in more emergency call outs and hospital admissions due to unpredictability of chest infections and limited GP access outside of working hours.

   "The last time I went to see the COPD nurse I asked about one for the winter, and she said, 'Oh, they've stopped doing it now.'"
   - *Colchester Participant*

   Opportunity:
   Reinstate rescue packs for COPD patients with a standardised distribution policy across all GP practices, along with clear guidelines for both prescribers and patients to ensure appropriate use and prevent over-reliance. As a safeguard, GPs should assess prescription history and the frequency of infections when determining eligibility. By tailoring distribution and educating frequent users on the risks of overusing rescue packs, we can reduce patient frustration, minimize unnecessary emergency call-outs, and help combat antibiotic resistance.

7. **Create Additional Resources for Recently Diagnosed Patients**
   Challenge:
   Some participants reported receiving little advice or guidance on their condition after initial diagnosis, while some healthcare professionals highlighted the challenge of providing sufficient information and answering questions within the limited consultation time allotted. As a result of the compartmentalisation of practical support, it becomes difficult for patients to know what they can access, with patient knowledge varying. Online resources also often do not contain localised knowledge, with most being national resources.

"It's a struggle sometimes knowing what is out there in the community, I couldn't tell you. I'm sure there are loads of different groups that could help, but I don't know how to access that information."
- Acute Respiratory Nurse.

Opportunity:
Create a comprehensive information pack for patients newly diagnosed with COPD. The pack should provide practical tips for managing symptoms, suggest lifestyle changes, mindfulness techniques, and what to expect regarding breathlessness and its impact on mental well-being. Ensure the materials are accessible, written in simple, easy-to-understand language, and using illustrations and diagrams. Customise the pack with details of local support services and resources available in the NEE area. Regularly update the content to reflect changes in treatment guidelines or best practices. Collaborate with patients, healthcare providers, and organisations like Asthma & Lung UK to ensure its relevance and effectiveness. Provide the pack to patients at diagnosis, and schedule a follow-up session with the respiratory nurse by default a week later to address any questions and reinforce key information.

8. Address Language Barriers Faced by Refugees and Asylum Seekers

Challenge:
Refugees and asylum seekers with COPD face difficulties registering at GP surgeries and accessing healthcare due to language barriers and lack of recognised ID.

Opportunity:
Work in partnership with organisations like RAMA to ensure GP practices understand the rights of refugees and asylum seekers to healthcare, regardless of ID. Providing training to GP receptionists and staff on handling patients with language barriers, alongside the availability of interpreter services, would help make healthcare more accessible to these vulnerable groups.

Secondary Care

9. Expand Access to Pulmonary Rehab

Challenge:
Long waiting lists and strict eligibility criteria (e.g. MRC breathlessness score) limit access to pulmonary rehabilitation for COPD patients who might have otherwise benefited from attendance at an earlier stage.

"To refer a patient, they have to meet a MRC score of 3, but it might be a bit too late for some because they're already at that 'I can't do it, so I won't do it' stage."
- Acute Respiratory Nurse

Opportunity:
Revise the MRC breathlessness score requirement to allow patients with less severe symptoms to benefit from early intervention. Address the lengthy waiting lists for pulmonary rehab by increasing capacity or offering additional sessions where possible, ensuring more patients can access the service sooner.

10. Invest in Additional Mental Health Support Around COPD

Challenge:

Many participants expressed feeling disconnected from their former selves due to a loss of independence, mobility, and identity, which contributed to mental health challenges such as depression and anxiety. Patients reported that societal judgment and stigma—especially the assumption that COPD is self-inflicted through smoking—intensified feelings of shame and led them to withdraw from social interactions. This isolation further exacerbated mental health issues. For some, the unpredictability of COPD symptoms, particularly severe breathlessness, triggered anxiety and panic attacks, resulting in unnecessary hospitalisations and the use of healthcare resources.

"I get anxiety sometimes and it's crippling. This fear suddenly comes across me. It feels like you are suffocating. I just thought it was the end of the world."
- *Colchester Participant*

Opportunity:

It is clear that mental health support should be considered an integral part of COPD care. Educate patients and caregivers on distinguishing between COPD exacerbations and anxiety-related breathlessness, while providing breathing exercises, mindfulness techniques, and panic attack management to help patients regain control over their symptoms [See Recommendation 7]. Reduce waiting times and increase access to mental health services tailored for COPD patients, making interventions faster and reducing emergency call outs and hospital admissions. Many patients struggle with long conversations over the phone, offering more face-to-face counselling would address their needs better. Ensure healthcare professionals are trained to handle the emotional and psychological needs of COPD patients, addressing stigma, reinforcing positive self-image and encouraging the attendance of social groups where patients can meet and share experiences, helping to reduce isolation and provide mutual emotional support [See Recommendation 14].

11. Modify Home Oxygen Assessments

Challenge:

Patients prescribed oxygen are entitled to a Home Safety Check. However, because it is an opt-in service, many checks are not completed, leaving the ECFRS unaware of the safety conditions in these homes, which can pose potential fire risks. At present, these checks are not mandatory.

Opportunities:

Make the Home Safety Check an opt-out service to increase participation. Enhance training for healthcare staff within referral agencies to ensure the ECFRS Safe and Well Team is fully integrated into the referral process.

12. Access to In-Person Smoking Cessation Support

Challenge:

Smoking cessation was difficult goal for many participants, even after receiving a COPD diagnosis, with some feeling that the damage was already done or that quitting wouldn't improve their condition. Emotional dependence on smoking was a coping mechanism for stress, anxiety, and depression which makes quitting even harder. Smoking cessation services are mostly limited to phone consultations in North East Essex, which may not be as effective for many patients.

"At every point it's always encouraged, but the general vibe is that they've tried, it hasn't worked, and they don't want to do it again. When it comes to an outside agency, let's say we refer a patient to Provide, it's then adding another step and another daunting process to their journey. That's why it's really good if you have in-house smoking cessation advisors in the surgery because you've got that rapport already established."
- Respiratory Nurse (Tendring)

Opportunities:

While there isn't a simple solution, offering in-person smoking cessation services, such as support groups or one-on-one consultations in GP surgeries, community centres or patients' homes, could improve engagement and success rates. Since some patients find phone-based services challenging, face-to-face options may foster a more personal and supportive connection. In addition to traditional smoking cessation methods, interventions should address the emotional and psychological factors behind smoking. For instance, patients who smoke to cope with anxiety or depression may benefit from mental health counselling or stress management techniques alongside nicotine withdrawal support. Smoking cessation could also be integrated into local peer-led community groups [See Recommendation 14].

Community Health

13. Raise Awareness of the Respiratory Risks from Recurrent Drug Use

Challenge:

An increasing number of younger people are developing COPD as a result of repeated drug use, particularly from smoking cannabis and crack cocaine. These substances burn at significantly higher temperatures than cigarettes, causing greater damage to the lungs.

"There's a lot of marijuana use around here. Maybe a bit more education about the problems of smoking drugs would help. All the risk warnings about smoking are around cigarettes and tobacco."
- Pharmacist (Tendring)

Opportunity:

Implement targeted harm-reduction initiatives aimed at raising awareness of the respiratory effects of smoking drugs. Partner with drug recovery services like Open Road to educate individuals on the dangers drug smoking poses to lung health and incorporate respiratory support into their programs.

14. **Introduce Local Peer Led Support Groups**

Challenge:

The dissolution of the Asthma & Lung Breathe Easy group and the St. Helena Breathlessness group means that there is no accessible peer-to-peer support group that acts as an easily accessible space where people with COPD can access different kinds of practical support. While there is a clear clinical pathway for medical support, there is a clear compartmentalisation of practical support which means that patients are often not aware of what support they can access. Support is often accessed through ad hoc referrals from clinicians or nurses.

Opportunities:

Create integrated working spaces in St. Anne's & St. Johns that can be accessed easily with all information. Doing so will centralise all forms of practical support in one place. It will also help overcome the digital challenges of online psychological support by re-establishing community-based peer-support. There are significant challenges to overcome in terms of participation, funding, and facilitation. Healthcare professionals, local authorities, and community organisations must work together to provide the infrastructure and resources needed to encourage and sustain these local groups. One key obstacle to establishing more support groups is the lack of facilitators and long-term resources to maintain the groups. Training volunteers to facilitate sessions could ease the burden on respiratory nurses and professionals. As such, we need to collaborate with local healthcare providers and community centres to set up regular peer-led support groups in areas like Colchester and Clacton. Consider involving former patients who have successfully managed their condition as facilitators. COPD patients who are housebound or isolated due to mental health struggles are often the ones who could benefit the most from these support groups but are currently under-represented. Work with community teams to identify and directly reach out to these individuals, offering home-based visits, phone calls, or even smaller support networks more suitable to their needs. Highlight success stories and demonstrate the tangible benefits of joining, like improved mental health and practical advice-sharing to encourage more people to join.

15. **Address Increase in Digital Exclusion**

Challenge:

People who are older or from less economically advantaged backgrounds often lack digital skills. As a result, this means that a lot of patients with COPD experience health inequalities in the form of digital exclusionary barriers to accessing the wealth of online information support that may be available to help them manage their condition - leading to worse health outcomes. In some cases, patients may also experience challenges accessing some phone-based assets, such as Therapy For You or EWS Smoking Cessation, as their condition means that they struggle to talk on or hold a phone for prolonged periods of time. If they cannot access these assets, then it leads to worse health outcomes, as patients may continue smoking - thereby worsening their condition - or experience mental health conditions as a result of their condition, such as anxiety or depression, which has been documented to negatively affect respiratory conditions.

"There is the MyCOPD app but there are people that wouldn't know what to do with a computer, don't have a smartphone and can't use apps."
- Community Respiratory Nurse

Opportunities:
Data Literacy Training: Local authorities, healthcare providers, and community organisations should collaborate to provide targeted digital literacy training tailored specifically for the elderly with chronic health conditions. Programs could focus on basic skills like booking GP appointments, applying for benefits, or accessing healthcare services online.

Offline Support: Ensure that essential services like healthcare appointments, Blue Badge applications, and benefit claims remain accessible through non-digital channels, such as phone or in-person services. Frontline staff at GP surgeries and local council offices should be trained to support those unable to use digital platforms. Work closely with third-sector organisations like Age Well East and Citizens Advice to provide structured digital support services. These organisations could be given additional funding to handle the increased demand for assistance with online services.

Develop a physical COPD Information pack for newly diagnosed patients, which can include contact information for local support services. [See Recommendation 10]

16. **Community Transport Provisions**
    Challenge:
    Participants highlighted the importance of reliable transportation for maintaining independence and accessing care, especially in underserved areas. Without access to a car, patients living with COPD in St. Anne's & St. John's or Jaywick & West Clacton may struggle to reach local assets, as most of these journeys would require extended periods of walking. In Jaywick & West Clacton, buses are often reported as unreliable and subject to cancellations, while taxis remain a costly alternative.

    "It would be a different story if we didn't have the car. I can get to it, sit down and go out. If I had to go use the public transport, I'd be stuck. The bus stop is just up the road there, but I wouldn't be able to get to it. I couldn't do it. I'd be housebound all the time and it would drive me potty."
    - *Tendring Participant*

    Opportunities:
    Local authorities must work with transport operators to improve reliability and frequency of bus services, particularly in rural areas like Jaywick & West Clacton.
    Install digital signage at key bus stops to provide real-time bus information.
    Offer free digital training sessions and resources to help older and digitally illiterate residents use transport apps, ensuring they can access accurate bus information.
    Expand Community Transport provision in Colchester and Jaywick to ensure that people with COPD can travel to appointments and assets significantly easier.
    Increase awareness of existing local Community Transport and Dial-A-Ride services through COPD information packs and online resources [See Recommendation 10].
    Additionally create a local and easily accessible space which integrates work across allied health professions to eliminate the need for transport to health assets all together [See Recommendation 14].

Healthwatch Essex
49 High Street
Earls Colne
Colchester
Essex
CO6 2PB

www.healthwatchessex.co.uk
☎ 0300 500 1895
✉ enquiries@healthwatchessex.co.uk
@HWEssex
/healthwatchessex
@HWEssex
/healthwatch-essex
@hiddenvoiceshwe