

Experiences of accessing treatment and support for COPD and other respiratory & lung conditions amongst people in West Essex

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are encountering daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share difficult experiences such as the one's shared in this report.

1.2 Topic Background

The NHS Long Term Plan identifies Chronic Obstructive Pulmonary Disease (COPD) and other respiratory conditions as a priority area.

Between them, respiratory conditions put a significant strain across primary and secondary care in the NHS. Unchecked, these long-term conditions take a stronger hold, and we see significant morbidity and mortality.

In 2019, the BMJ reported there were 1.3 million people with a diagnosis of COPD, an increase from under 1 million in 2000.

In terms of diagnosed cases, COPD is the second most common lung disease in the UK, after asthma. Around 2% of the whole population and 4.5% of all people aged over 40 live with diagnosed COPD. 115,000 people are diagnosed with COPD each year, equivalent to a new diagnosis every 5 minutes.

However, with a purposeful, integrated approach there are a number of high value interventions that can increase the wellbeing and prognosis of patients, while decreasing the burden on longer-term NHS care including GP visits and hospital appointments and admissions.

1.3 Acknowledgements

Healthwatch Essex would like to thank the hundreds of people who engaged with us, participated in this project, and completed the survey.

Our thanks are also made to those individuals who took the time to speak with us and share their personal stories. By gathering lived experience of their journey through symptoms, accessing healthcare professionals, referrals, diagnosis and ongoing care, this report can help shape a co-produced system that offers the best available pathway.

We would also like to thank our many partners, contacts, and networks who worked with us to share the project and survey throughout West Essex and help generate such a strong level of interest and feedback.

1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

According to Asthma & Lung UK statistics, the UK is among the top 20 countries for COPD mortality worldwide, so there is a clear disparity between where we are, and where we want to be.

This report has been designed to draw out the lived experience of our local population to identify real world issues, successes, and challenges. It is designed to provide a platform to help identify what's working well, what lessons can be learnt, and where improvements can be made.

For the NHS Long Term Plan to be successfully delivered, the areas for investment and the services commissioned need to be identified and developed around these shared lived experiences. The HWE ICB has committed to engaging and consulting with its people and communities through this process.

2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website, through local West Essex based Facebook groups, the Healthwatch Essex newsletters, our own Facebook page, Instagram account and Tik-Tok. In-person outreach events and word of mouth also played an important role along with promotion of the project via our extensive networks.

Our partners, other organisations and working groups in West Essex, together with our volunteers and many individuals inside and outside of the NHS and ECC helped and supported our efforts to engage with and reach as many people throughout the area as possible.

They were engaged with in two ways:



Survey

A survey was created to gain perspective and insight from residents who have had experience of living with COPD and other respiratory conditions.



Interviews

Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during April and May 2023 and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

2.2 The survey

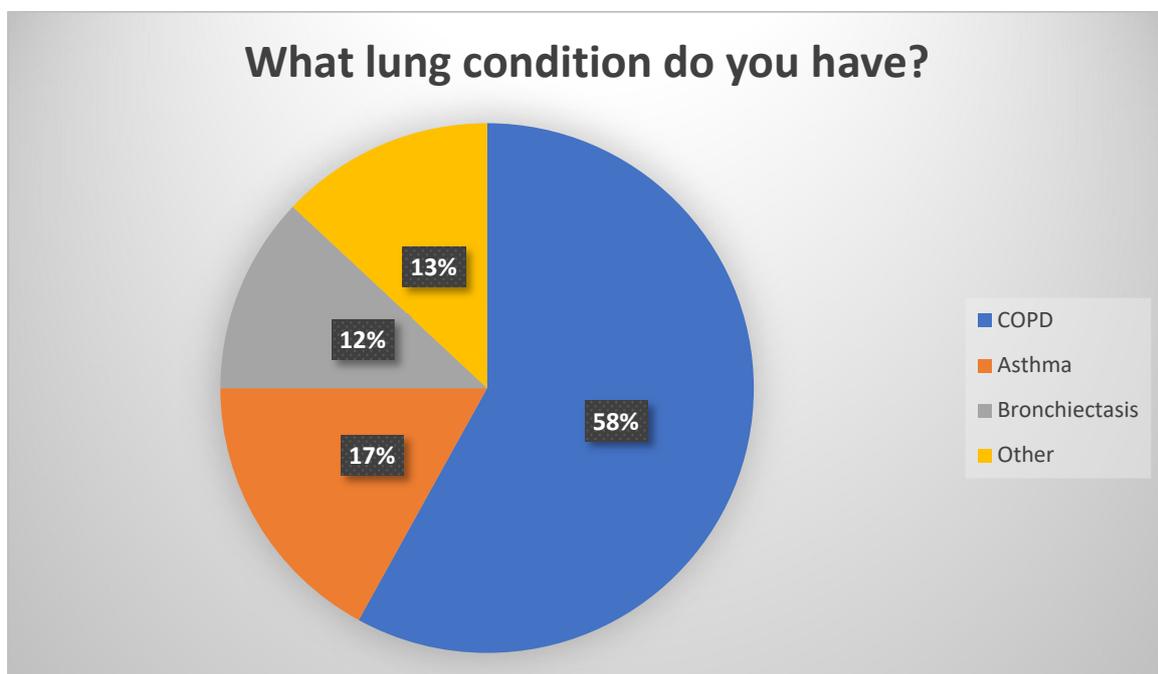
The survey consisted of ten core questions, mixing multiple choice questions and ‘free text’ information boxes enabling the participants to expand on their answers. There were an additional three demographic questions.

It was devised to encompass:

- The condition they have
- Their journey to diagnosis
- Ongoing reviews and treatments being offered
- Opportunities for self-management
- Impact on mental health

The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance (IAG) Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses received, are outline below.

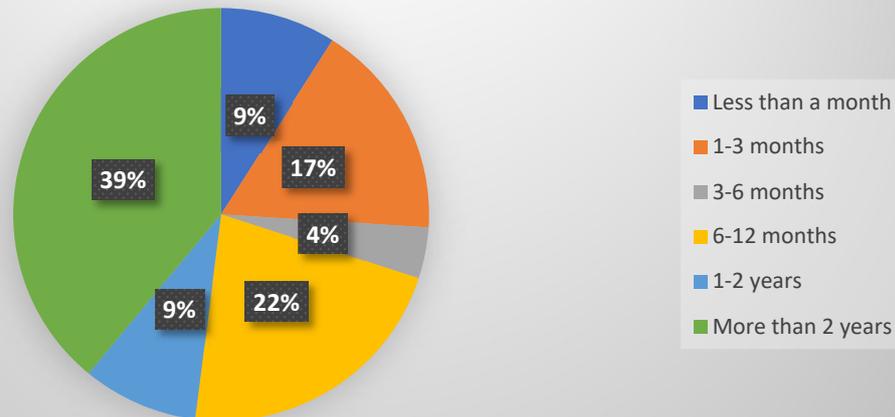
The starting point was to establish what disease or condition they have been diagnosed with:



The emphasis of the survey was placed on COPD, with 58% of respondents diagnosed with the condition. However, it's important to take into account the lived experience of those with other respiratory, lung related illness.

In the next section, we delved further into their pathway to diagnosis. Firstly, we asked about the timescales, and then we asked people to tell us about their experience and what they went through:

How long did it take from first visiting your GP, Nurse or other Healthcare professional, to getting a full diagnosis?



The percentage of people who waited over two years is worrying, but timescales are purely statistical - it's the experience of the process that provides the insight and context.

A number of people referred to finding out they had previously been diagnosed with COPD but were not aware of their diagnosis at the time. If this were one incident, it could be easily dismissed and ignored, but there were numerous reports, for example:

'It came out of the blue one day when being examined by paramedics after being admitted to hospital. Upon arrival it was a shock when told "it's your COPD" it was in my records, but I had never been told about COPD, didn't know what it was or what it meant. Don't know how long it had been on the medical records or who diagnosed it and wrote it on there.'

'I was not told about the condition or prognosis in a timely manner. Subsequently found out the condition had been diagnosed some years before the referral to a specialist was made.'

'I am answering this on behalf of my late mother. She had COPD but was not informed until one occasion when she was admitted to hospital the doctor referred to it from her records and she had had it for several years! It was on her records, but she hadn't been informed before then. It was a shock. We had never heard of it so had to research it to understand what it was.'

Many feel that their symptoms were recognised, and their pathway was well managed, such as:

‘I first noticed a slight shortage of breath about ten years ago. The doctor sent me for a chest x-ray, and I was seen by a specialist at hospital who diagnosed COPD. It has got gradually worse over the years.’

‘I felt breathless when I walked and felt sick quickly, so I complained to my GP. We have damp in the home, and it effects my daily life condition and I have breathing problems. Thank God he listened and prescribed inhalers.’

‘It was over 15 years ago, so my memory is hazy. I thought I might have lung cancer because of a persistent dry cough. An X-ray immediately diagnosed COPD and care by a practice nurse began soon after.’

There were a wide variety of other experiences of the diagnosis road, a sample of which are below:

‘It was discovered during abdominal surgery.’

‘I had a cough that did not go away. I was eventually referred to a specialist who conducted a bronchoscopy.’

‘I gave up on the NHS. I paid for a private consultation who then did a referral. Once diagnosed, I was transferred into the NHS to manage.’

‘I had pneumonia and pleurisy at 40 years of age...I am now 58 and have suffered with chest infections ever since.... it’s a struggle every day.’

‘I visited my doctor after being taken to hospital unable to breathe. Visited my GP shortly after feeling breathless and very unwell. I was dismissed on two appointments. Fortunately, a nurse practitioner listened to me, looked at an X-ray I’d had two years previously and asked why this hadn’t been addressed. I had no knowledge of this until that moment. She took this further by arranging a blood test

and speaking to my doctor. From this CT scans were arranged and a large nodule along with scarring on the other lung were discovered.'

'I had several years of being told I had asthma and then brittle asthma before I was referred to a consultant who scanned and diagnosed bronchiectasis. Also, there was a lack of access to medication when I needed it as I was not prescribed antibiotics or steroids until an infection really took hold.'

'I was experiencing breathlessness and was red faced. I visited my GP and was eventually diagnosed.'

'I was diagnosed nearly 20 years ago following a number of visits to the GP. However, in the last ten years my asthma medication was changed when I changed surgeries because I moved, and in the last five years it's got progressively worse. I've had seven medications reviews and changes in as many months and I'm now waiting for a GP referral to the hospital respiratory team. I have had a year's wait for a heart referral and been told that I have chronic heart failure due to severe asthma. Other factors are also at play; I'm overweight and I have mild heart disease, but the asthma is difficult to control now and I'm borderline COPD.'

'I went to hospital, and I had a lot of tests and they told me I have heart failure following a diagnosis of pulmonary hypertension.'

'Last December/January, I had a COPD flare up at my daughter's house. She consulted her own doctor, who asked to see me. He prescribed antibiotics and steroids. I stayed immobile on my daughter's couch for nearly two weeks. The steroids were wonderful. I was not charged for my prescription, since I'm 78 years old. I had a totally positive experience with the NHS. Thank you.'

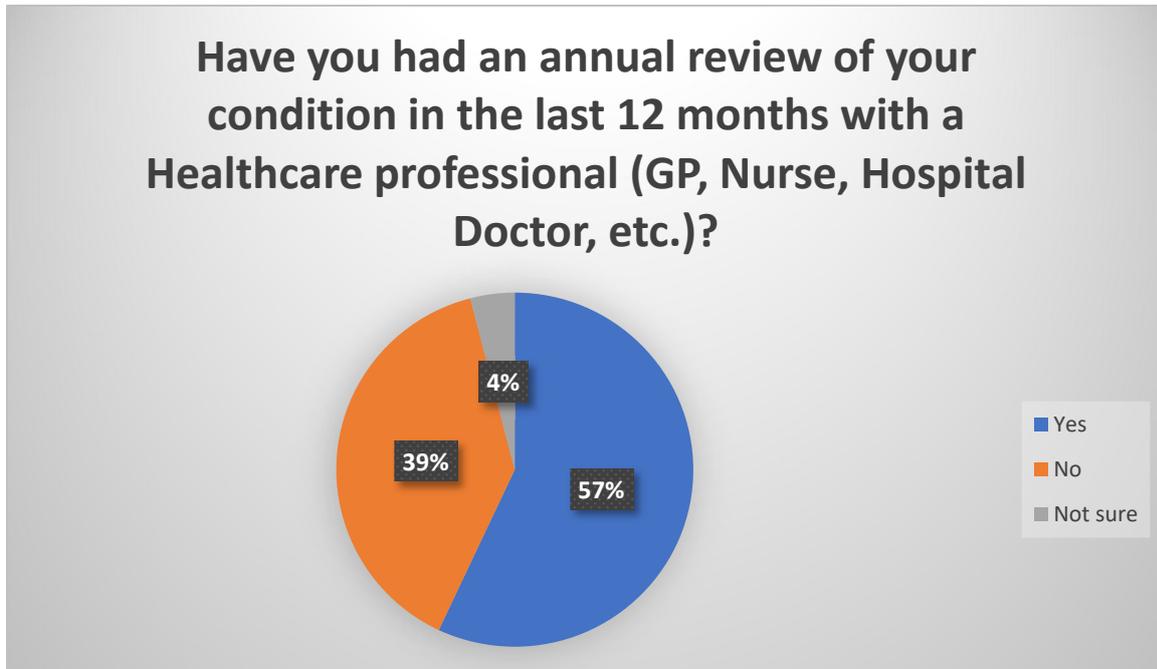
'I noticed I was getting short of breath when doing things.'

'I kept going to the GP with mucus plugs, but no infection showed.'

'I had chest infections and finally they decided further investigation was necessary. This happened very slowly, but I was eventually referred to hospital where I had a CT scan and a battery of tests from which the consultant diagnosed bronchiectasis.'

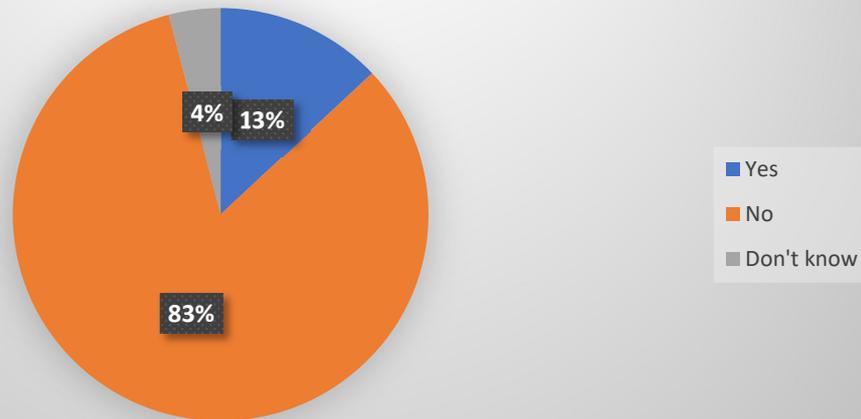
She referred my care to the Respiratory team, who gave me a Pulmonary Rehabilitation course to teach me self-management.'

The next section of the report looks into people's current and ongoing care:



Nearly four out of ten people have not had a review of their condition in the last twelve months. This is clearly well below where it needs to be.

Do you have a written self management plan that was put together with your healthcare professional?



An overwhelming majority of people do not have a written self-management plan. The benefits of patients having a clear understanding of how to manage their condition are well established, so there is a clear and significant gap in service provision here.

We asked participants to tell us more about how they manager their condition, and what ongoing support they receive. A mix of their experiences are below:

‘No ongoing support, I managed with Seretide and Salamol.’

‘My condition is not well managed. My meds work first thing in morning once I take them, but I am constantly extremely breathless wheezing and coughing on any exertion during the day, every day. My chest becomes tight and sometimes painful, and I cannot get breath into me. It can last up to an hour; I take my salbutamol blue inhaler but it’s taking longer each time to work.’

‘I take a Trimbrow inhaler, two puffs twice a day, this has enabled me to do without my Ventolin inhaler. I don’t appear to get any ongoing support.’

‘No support was provided.’

‘I always keep my inhalers with me and am taking my medicine, Montelukast and inhalers, on time.’

‘I received an inhaler.’

‘I take nebuliser fluids twice a day, Acapella twice a day, Carbocisteine three times a day plus Ventolin and Trimbrow inhalers. I also have an annual asthma check and consultant appointment, and a rescue pack of antibiotics and steroids.’

‘I have a CPAP machine. I get one phone call a year to check is still working ok.’

‘I have an annual review with a hospital consultant, I regularly have to request additional asthma medication which is an issue. I have had to pay privately for an operation to improve breathing due to NHS delays etc, etc.’

‘I was told to stop smoking.’

‘I manage my condition with knowing what my body can handle physically. I attend yearly CT scans.’

‘I monitor my peak flows, avoid spaces where there are lots of germs (I wear a mask if needed). I have a rescue pack which I take if I get an infection...it took a long time to get this, and the consultant had to write to the GP twice as they wanted to give different medicines than he suggested.’

‘My mother suffered many flare ups and was given emergency prescriptions for antibiotics as she was familiar with the early signs of an infection. We also bought her her own nebuliser which reduced her need to be admitted to hospital on occasions.’

‘Since the Covid pandemic my GP practice ceased annual reviews for COPD - I have not had a spirometry test since 2018. Two years ago, I began to struggle with breathing and was referred to the Community Respiratory Team (based 14 miles from my home). The nurse there attempted by phone to assess my lung condition by

asking me to stand & sit repeatedly. As I had a badly injured my back, that was not possible. She sent a package of about 20+ exercises which I found difficult to stick with. When I started (private) physio for my back the CRT discharged me to my GP practice once more - since when I've heard nothing. I shall be asking for a review from them very soon.'

'I have 2 inhalers taken twice a day, Seretide and Eklira, plus Ventolin if I get very puffed out.'

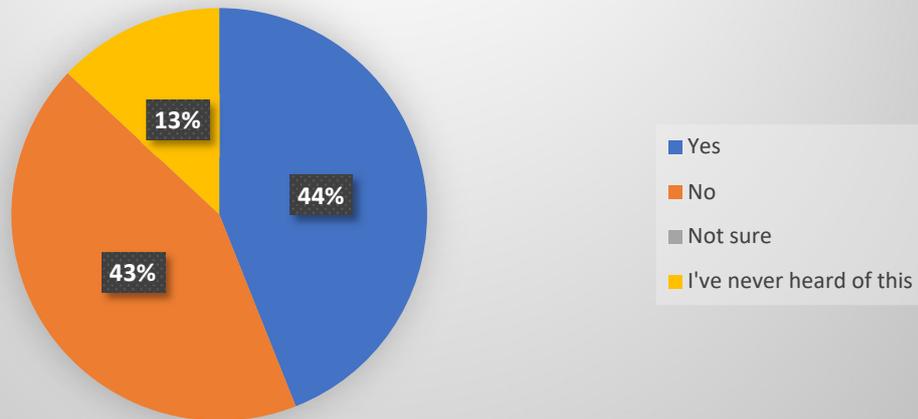
'I see a consultant yearly. I have also seen a respiratory physio recently for the first time. I had to pay privately to see a consultant when first diagnosed as it was in the pandemic. A GP is mostly unavailable or involves a long-standing queue which I can't manage when I'm ill.'

'I see my respiratory nurse annually and also can contact her if I have any problems.'

'I did have an asthma review recently at my GP surgery. I have been informed by one of the Respiratory team that my adult diagnosed asthma has in fact burnt out, but this news has evidently not reached the surgery. The reviewing nurse would not talk about bronchiectasis, but she did at least take my peak flow reading. I know the Respiratory Nurses are very busy, so I feel I should only contact them if I feel I have a real need. Bronchiectasis care involves a lot of self-management. At the moment I am coping and only deteriorating very slowly. I do daily breathing exercises, try to keep fit with Pilates and walking if the weather is suitable, and eat sensibly.'

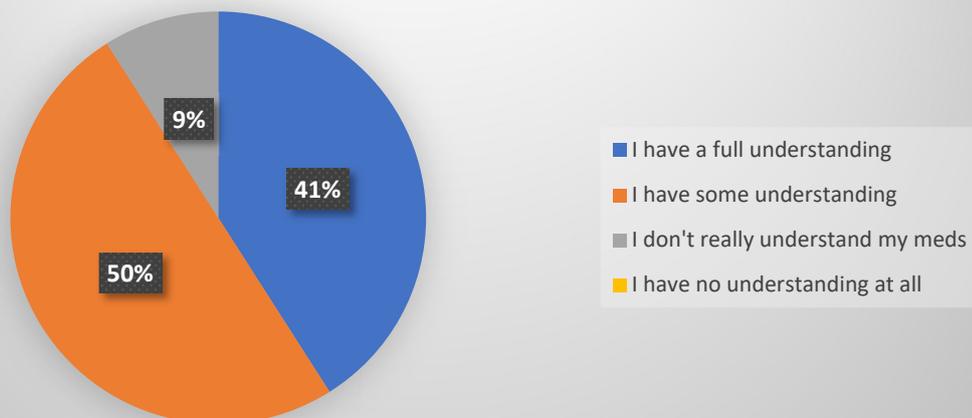
The survey continued with:

Have you had, or been offered, Pulmonary Rehabilitation Treatment (a program of exercise and education)?



PR Treatment has been clearly identified and widely accepted as a program with significant ongoing benefits, but 56% of our participants haven't been offered it or aren't even aware of it.

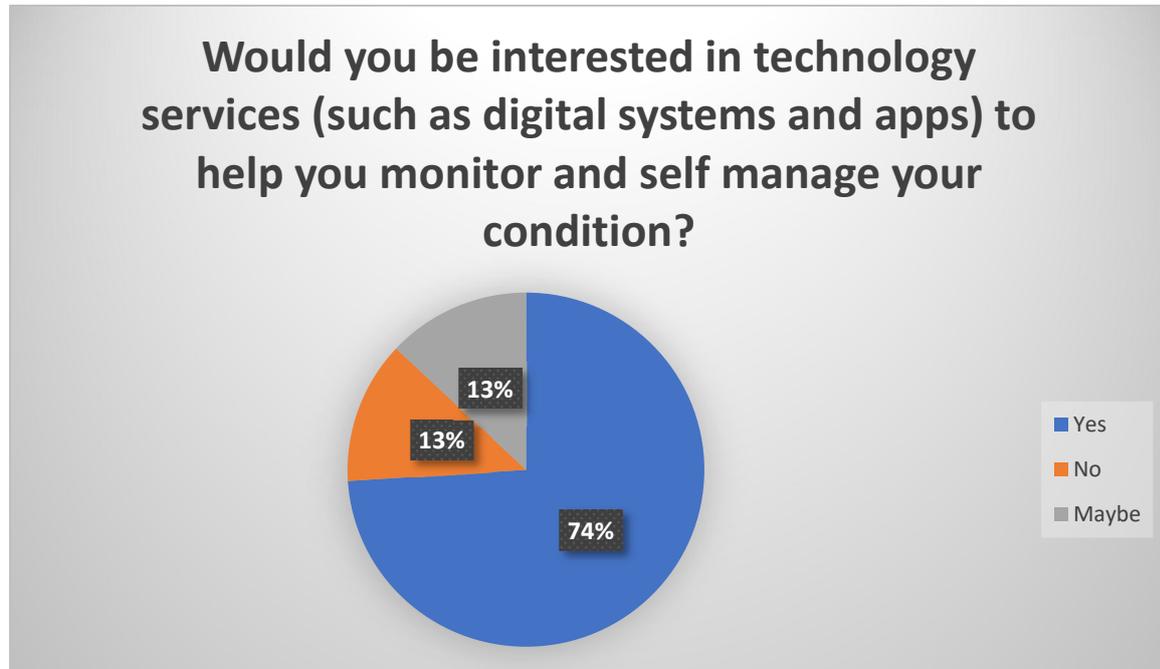
Do you have a clear understanding of your meds - what they are for, and why you have them?



To maintain and improve compliance, it's important that people are aware of the medications they are on, what they're for, and why they should take them. Over 90% of people have a full, or some understanding of what they're on. There's always

room for improvement to ensure as many people as possible are fully aware of what they're taking, but the statistics here are very positive.

We also asked about the possible use of technology.



Another very encouraging response that indicates significant opportunity as new technologies come on stream.

Finally, it was important to enquire about people's mental health, so we asked simply:

How would you say your mental health is impacted by your condition?

Here's some examples of what our respondents had to tell us:

'It has definitely impacted my mental health. I get anxious when I go out, not knowing whether I will be able to cope.'

'I have been slightly affected with unfounded fears. I also wake of a night and sometimes panic, and I have to sit up till I calm down and drift off to sleep again.'

'I am mostly ok but constant infections are wearing and depressing.'

'I am getting migraines too many times because of damp in my home. It triggers my asthma and I get lots of infection quickly. It's very depressing.'

'I spend too much time fretting.'

'I still experience very poor sleep so am exhausted and stressed.'

'I feel very low and depressed. There's just no way out and it's every day with no prospect of it ever getting better.'

'I'm in good spirits and my mental health is unaffected.'

'Mental health and physical health go hand in hand so not being able to do as much as I would like is depressing, so being aware at all times can be overwhelming.'

'I get down at times as it limits me.'

'Of course. Breathing difficulties and infections are very stressful/anxiety making.'

'I feel afraid of my future.'

'Okay, I'm tired mostly which can be quite upsetting.'

'Currently mobility problems and general ageing changes affect me more. I do find a couple of breathing exercises quite useful when breathing 'tightens up'.'

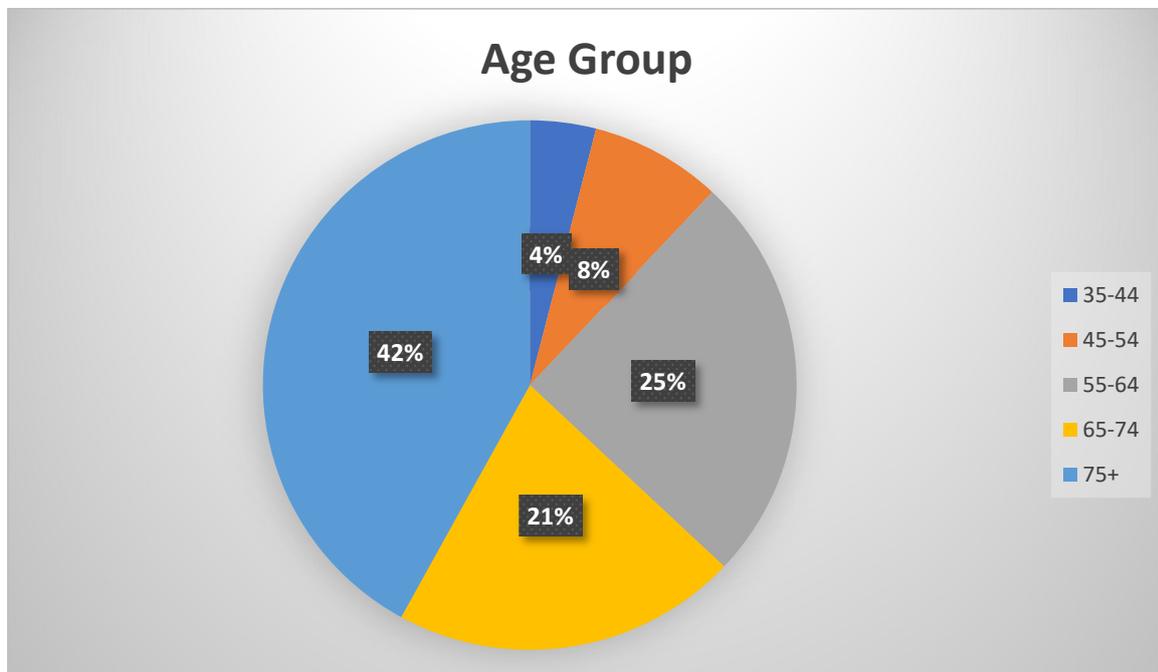
'Not a lot, I just get a bit fed up when I have to stop and rest.'

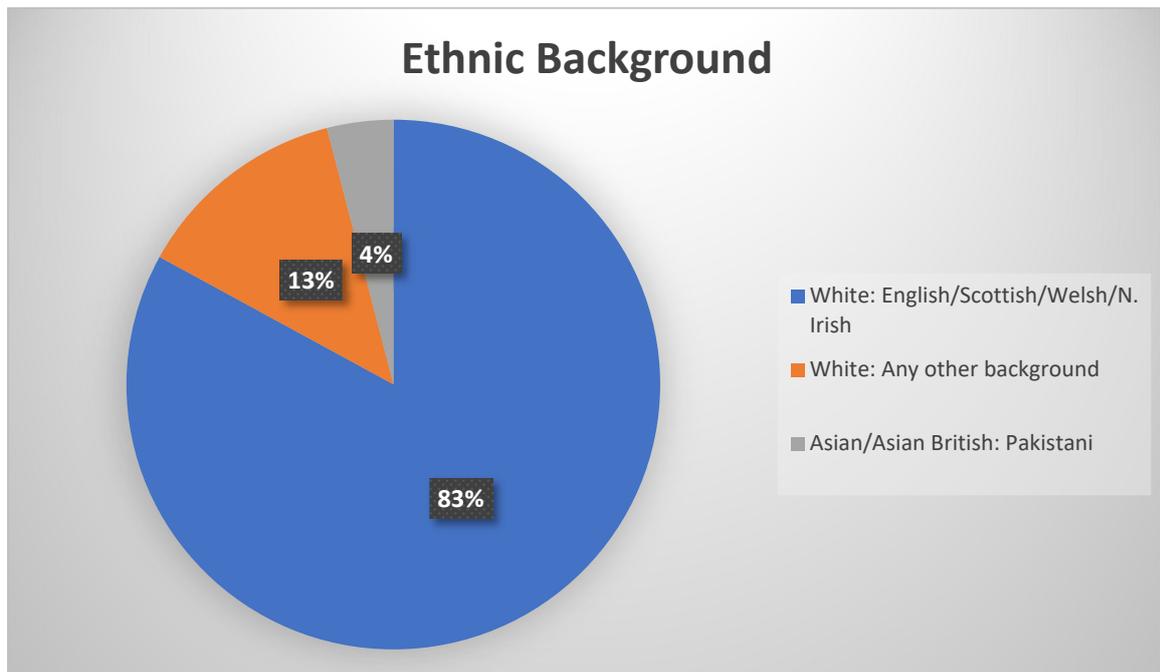
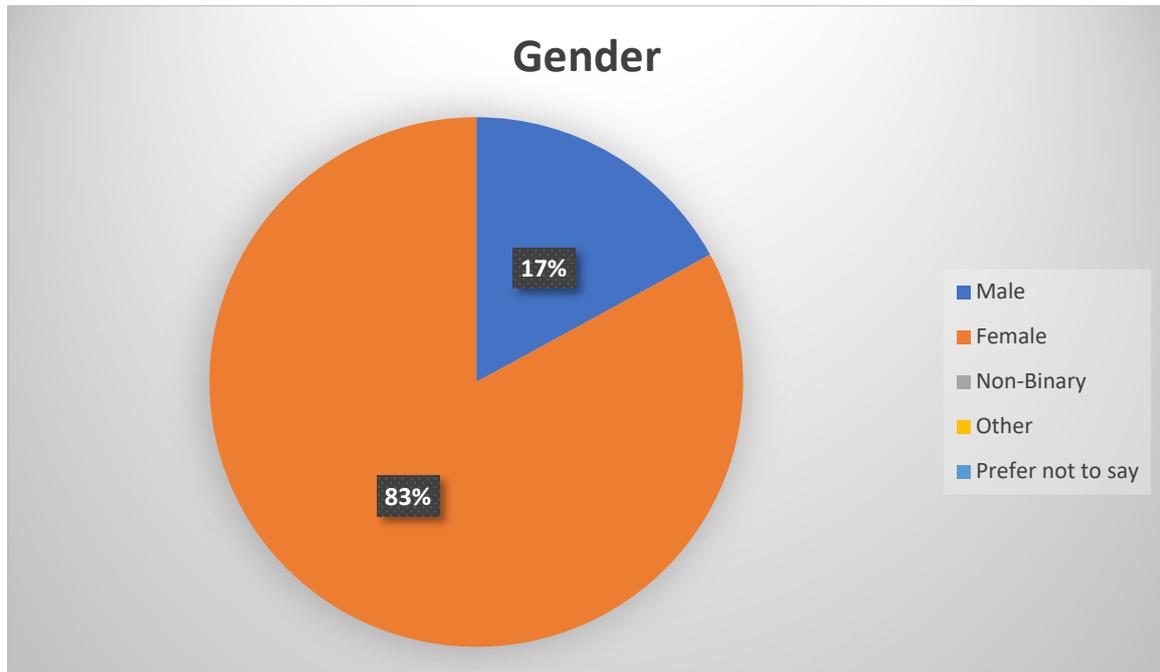
‘I feel like I have no quality of life anymore.’

‘Yes inevitably, I feel very low, and I can’t get away from it.’

Demographics:

We asked respondents three demographic questions, focussing upon age, gender and ethnicity.





2.3 Interviews

Many people offered to talk to us directly and tell us about their stories in depth. We would like to thank everyone who took the time to talk to us and share their experiences, helping us to produce this report. From those that we have spoken to,

we would like to highlight three case studies reflecting the lived experience of people locally.

Case Study 1

Shirly* was diagnosed with COPD about 10 years ago.

‘But it’s only fairly recently that it’s become a challenge. It’s something that I sort of lived with fairly easily before.’

She’s found the service from her GP has been significantly reduced since Covid.

‘That’s really been my main problems. With COVID, like everybody, they went over to telephone interviews. And the annual routine with the nurse, for people with COPD, asthma and possibly other conditions, that sort of broke down. And even when COVID was over, the GPs in West Essex stopped using spirometers, which means that there’s no... you haven’t got any exact sense of what’s going on. Which has been one of my gripes really. And the other thing is that the arrangements for an annual review seem to have broken down.’

Without her knowledge, Shirly was referred to the Community Pulmonary team in Harlow.

‘I had a phone call from them, a couple of phone calls. They tried to assess my lung capacity by asking me to stand and sit multiple times in a chair. Unfortunately, a couple of weeks before I’d had a bad fall, and I was physically in pain and not able to stand and sit with any sort of speed or repetition. So anyhow, they sent me sheets of papers with exercises. There are about 23 exercises, which just coming out of the blue and not very useful, quite frankly’ ‘this document, obviously somebody had worked very hard to compile it, but it wasn’t patient friendly at all.’

Shirly wasn’t sure if she was doing the exercises correctly, but despite this, on the follow-up call, the nurse from the Pulmonary team said, “*I’ll discharge you back to your GP*” and that was that.

The lack of face-to-face contact with anyone is also a significant worry for Shirly.

‘I can see the benefit of telephone and video consultations for quite a lot of younger and middle-aged people who perhaps have flu or something that they need some help with, but not when it’s complicated by other conditions.’

‘...people in my age group, most of my friends are still alive. They’re not even into mobile phones. I don’t like my smartphone. I quite like my laptop, but quite a lot of my friends and age group don’t even use computers. And yet the shift is so much over to digital.’

Following our conversation, Shirly was determined to contact her GP and insist on an appointment for an annual review, not only for her COPD, but for her general health. She monitors her blood pressure and oxygen levels at home but hasn't seen anyone in person since 2019.

'I shall get in touch with them and say, "Look, I'd like to come in person for a physical assessment."'

Case Study 2

Peter* has Bronchiectasis. He was diagnosed with asthma as a child, but then eight years ago he got a string of chest infections, and each time he was prescribed Amoxicillin, but it didn't work properly. Each infection just seemed to be worse.

'I had such a bad one, I think I could have died, quite honestly. I was absolutely full of phlegm and fever, not feeling very good at all. And my daughter insisted a doctor should come out, and the doctor who came out, he was one of the nice doctors at that surgery, and he told me I was very ill, gave me some antibiotics. I'm a bit surprised he didn't send me off to the hospital, but anyway, the antibiotics he gave me did the trick. It might well have been Doxycycline, which is sort of more or less the standard stronger one for people with that condition...'

At no point did any of the GPs talk to him about the possibility of any sort of other respiratory condition; it seems that they completely missed it. He was finally given a spirometry test, and subsequently referred to a respiratory consultant where he was finally diagnosed. This was 2019, four years after he started getting the chest infections.

It was still about five to six months before he was put on a pulmonary rehabilitation course though.

'It was extremely useful. There was a physiotherapist, and specialist respiratory nurses as well, and they were very good at informing you. It was to see how fit you were and to encourage you to believe that you could be more active if you weren't.'

Peter has had just one exacerbation since.

'One of the pulmonary nurses came out and she was really good and kind, this was during Covid, and she got the doctor to prescribe not only sort of an antibiotic to do with it then, but various things including an Aerobika, which worked absolutely wonderfully for me.'

However, at an asthma review, Peter had another bad experience and firmly believes there isn't enough knowledge about Bronchiectasis.

'In one of the asthma reviews, the man on the end of the telephone decided I'd be better off with a different inhaler. He changed me from the one I'd been taking for years to something new, which I believe is excellent for asthma, but it was

absolutely totally wrong for bronchiectasis, as I found out because it seemed to be worsened. The respiratory physiotherapist said, "No, that dries up the mucus, whereas in bronchiectasis, you need to cough it up." Totally the wrong thing. So, there is an awful lot of ignorance about bronchiectasis.'

He goes on to say:

'Well, I think really, more professionals need training in bronchiectasis. It is being, I think, more widely diagnosed because there are specialists who know it, but I feel that because I was palmed off by my surgery for several years, it has made my problems worse than they might have been.'

Although he's had a telephone review for his asthma, Peter hasn't had a review of his bronchiectasis since the end of Covid lockdowns.

'...not as regard to my bronchiectasis. And I'm beginning to wonder if I should phone the pulmonary rehab team and ask whether I should be getting a check. I think theoretically you get a check every year, but they're obviously very busy.'

Case Study 3

Like most people, Veronica's* journey to diagnosis started with her GP.

'I saw my GP loads, I kept going up there and saying, "Look, I'm coughing up these lumps of sticky sputum and, all the rest of it, sort of thing." And they said, "Oh yeah, it's nothing to worry about" or, "I can't hear anything with your breathing." But then of course, it obviously got progressively worse.'

Her first visit to hospital didn't go well.

'I had my day in hospital with all the tests, and then I was sent to respiratory where they did some more tests. I didn't see a consultant or anybody. There was just a letter to the GP saying, "You've got this and this, and this and this about breathing. I've told the GP to send you back if there's any more problems." So, I felt thoroughly dismissed. It was not okay.'

About six months later, following further flare-ups, Veronica finally saw a consultant and was diagnosed.

'The consultant was good, and answered all my questions'

She has an Oximeter at home, but has been offered little else, and was never told about a pulmonary rehabilitation course.

'Some days are horrible. Like yesterday was horrible. I coughed all day, couldn't stop. But today I'm quite good.'

'I do exercise. I go to yoga, et cetera, sort of thing, most weeks. So, if you like, I am exercising and I try and crawl. If it's a good day, I go, if it's a not very good day, I try and go, sort of thing, because there can be benefits.'

Veronica's life is complicated by the fact that she's a carer for her husband (although she doesn't see it that way), and her mental health and wellbeing is a struggle, something she's not getting any support for.

'My husband is ten years older than me. I'm not a carer for him, but put it like this, I do stuff. And you feel lousy, but you've always done it. Well not always done it but everything is the same. I worry. I do all that, particularly in the middle of the night when I'm sort of often awake and wondering about. Obviously, I'd say it's far worse in the middle of the night.'

'I don't like to think of myself as an ill person. It's limiting. And one of the worst things is planning, because you can't plan anything. Your plans maybe knocked out too. I was going to do Christmas, I hadn't done it for a while, but I was too ill, that sort of thing. But it can be much simpler than that, I will plan to go and do so and so, but then I'm not able to.'

However, when asked what one thing would help her with everything she's going through, the answer is incredibly simple.

'A good, reliable GP surgery where I can get an appointment when I need one and be seen.'

**names have been changed to protect participant anonymity.*

3.0 Key Findings and Recommendations

Key Findings

Diagnosis

- Respondents often have to make multiple presentations to their GP surgery before getting a referral and subsequent diagnosis.
- Many people were diagnosed by chance when being assessed for separate issues by medical staff.
- Only 30% are diagnosed within six months of seeing their GP.

Management

- Written self-management plans are not being offered to the vast majority.

- Many respondents have not had an annual review since the end of Covid restrictions.
- A large proportion of sufferers are not being offered Pulmonary Rehabilitation treatment.

Technology

- Patients are very open to having technology help them self-manage their condition.
- Activity trackers and apps would be very popular.

Mental Health

- The long-term nature of the conditions and the slow ‘inevitable’ decline in health is leaving people anxious and depressed.
- Many respondents feel anxious about their future.

Recommendations:

Diagnosis

- GP surgeries must find a way to book in face-to-face appointments for people who present with chest and lung related issues, and then be prepared to conduct spirometry tests at the earliest opportunity.
- Very careful consideration of a diagnosis of COPD or other complex conditions should be taken, rather than deferring to an asthma diagnosis or dismissing potential symptoms as just a propensity to chest infections.

Management

- There is a huge gap between accepted best practice and what is actually happening on the ground. This has to be urgently addressed.
- Pulmonary Rehabilitation programmes, self-management plans and annual reviews are woefully behind acceptable levels. These are absolutely vital elements of an integrated and holistic care approach that can directly reduce the burden on hospital and GP visits, as well as having a significant

and positive impact and patient health and wellbeing. Due process and clear pathways need to be established and reiterated.

- Management of respiratory conditions must be fluid and treatment should be continually re-assessed. Annual reviews are key to ensuring this happens efficiently and effectively.

Technology

- Technology can provide quick wins in terms of management and self-management.
- Activity apps can be developed to dovetail with Pulmonary Rehabilitation programmes to help with continued exercise and motivation. The same can be done regarding education and dietary advice.
- These apps can also be linked in with home spirometer equipment, CPAP machines, Oximeters, etc., to provide patients with a very clear understanding of their current health.

Mental Health and Wellbeing

- Annual reviews with Pulmonary specialists or GPs make a significant contribution to patients' emotional welfare - feeling included, listened to, and supported.
- Sufferers can feel abandoned, with their health steadily declining and few options. Streamlined and effective signposting to support groups, financial advice, charities and complimentary NHS services will help create a nurturing wellbeing environment.
- The great thing here is that the best treatments and management tools for respiratory conditions are closely aligned with good, positive mental health. Being active, taking exercise and having a good diet are core to successfully managing lung disease, and for most people, they make a significant contribution to good mental health. Implementing Pulmonary Rehabilitation programmes and the other recommendations above will have a direct and positive impact on people's mental health.

4.0 Conclusion

Many respiratory conditions develop over time, making early diagnosis difficult, but a proactive response from primary care can make significant gains. A safety first, inquisitive approach with early referral will increase detection rates, and diagnosis statistics will be greatly improved.

There are well established low cost, high gain interventions that are perfect examples of how effective holistic care directly reduces the burden on GP and secondary care resources and hospitalisations.

The statistics from a wide variety of legitimate sources show that across the country we lag behind where we should be. The lived experiences we have garnered also reflect that for West Essex. There are pockets of successful intervention and treatment that indicate the pathways that are in place can and do work, but too often the opportunities are missed.

West Essex has a chance now to stand out and become a centre of excellence and establish itself as an example of best practise for providing access to the best and most appropriate healthcare for those in its population with COPD and other respiratory conditions.

Easy wins, quick gains, positive impact.

5.0 Terminology and Acronyms

HWE ICB - Herts & West Essex Integrated Care Board.

ECC - Essex County Council.

GP - General Practice or General Practitioner.

IAG Team - Healthwatch Essex's Information & Guidance Team.

COPD - Chronic obstructive pulmonary disease.

BMJ - British Medical Journal.

Bronchoscopy - a procedure that lets doctors look at your lungs and air passages.

CPAP Machine - Continuous Positive Airway Pressure machine is a device for treating sleep apnea disorders.

Nebuliser - a machine that turns liquid medicine into a fine mist, breathed in through a mask or mouthpiece.

Spirometer - measures the amount of air you can breathe out in one second and the total volume of air you can exhale in one forced breath.

Aerobika - a handheld device you breathe into to help clear secretions (mucus) from your airways, making it easier to breathe.

Oximeter - a device to help you to check your blood oxygen saturation and your pulse rate at home.