Respiratory Health

Findings

October 2024

healthwatch
Lincolnshire

Contents

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Please note that all quotes included in this report are presented verbatim unless otherwise indicated. Only filler words such as 'um' and 'you know' have been omitted for clarity and brevity.

Executive Summary

- Our second campaign of 2024 focused on respiratory health. In the UK, respiratory conditions are a significant concern due to their high prevalence and impact on those diagnosed and the healthcare system.

- In Lincolnshire, asthma and chronic obstructive pulmonary disease (COPD) are one of the top causes of years lived with disability for children and young people and those aged 65 and over, respectively. The prevalence of the two conditions is also higher in Lincolnshire compared to the national average. Both conditions are key areas of interest in the Lincolnshire Joint Strategic Needs Assessment (JSNA).

- Data on the prevalence of other respiratory conditions, including pulmonary fibrosis, bronchiectasis and long COVID in Lincolnshire is limited, as is information on people's experiences of accessing and receiving care for these conditions in the county.

- Therefore, we launched one survey for service users and another for professionals working in health and care services that support those with respiratory conditions to ensure we got a rounded understanding.

- In total 223 service users shared their views and seven professionals. Service users shared their views on the following:
    - Asthma - 38%
    - COPD - 20%
    - Asthma and COPD - 10%
    - Breathlessness - 7%
    - Bronchiectasis - 5%
    - Long COVID - 3%

- According to the data collected, experiences did not appear to differ based on the likes of whether the individual was, a carer or neurodiverse. There was inequality in experiences but they could not be explained by the data collected through this work.

- The information collected through this survey did show, at least for those that shared their views, experiences somewhat differed based on the respiratory condition they had. Also that there were inequalities in service provision.

Executive Summary

Key headlines include:

- Respondents with asthma tended to rate the different aspects of their care more highly than those with other respiratory conditions including bronchiectasis and breathlessness. However, we were unable to tell if these differences were statistically significant.

- Overall, the majority of respondents who shared their experiences of accessing and receiving care for asthma in the county rated their care as “good” across different domains such as “listening to you”, and “treating you with care and concern”. However, there were inequalities in their experiences of asthma care that could not be explained by the data collected.

Diagnosis

- 70% (153) were diagnosed correctly first time. Diagnosis times varied depending on the condition. For example, 63% (51) of those with asthma were diagnosed within three months or less. However, for other respiratory conditions such as COPD, long COVID and bronchiectasis diagnosis times were more varied and it tended to take longer to get a diagnosis.

Waiting Times

- 31% (68) were waiting for additional tests, treatments or diagnosis. COPD had the highest proportion of respondents (50% (21/42)) waiting for additional diagnostics or treatment. Regardless of the condition, respondents shared that they had often been waiting for months with appointments being cancelled, poor communication and little support in the meantime.

Treatment and Management

- Regardless of the specific condition, the majority (89% (195)) took medication for their condition. Overall, 41% (80) of people had faced challenges getting medications that worked for them. Challenges did not appear to be specifically related to certain conditions but instead were broader and covered issues such as medication shortages, especially inhalers, difficulties accessing specialist medication in the community and finding medications that effectively controlled symptoms.

- Respondents appreciated the ease and convenience of repeat prescriptions.

Executive Summary

- 24% (51) had been offered and or received treatment other than medication. COPD and Long Covid had the highest proportion of respondents being offered treatment other than medication. This included pulmonary rehabilitation, breathing exercises, support groups and mental health support.

When asked what works well and what could be improved both service users and professionals raised many of the same areas.

What works well?

- Specialist care including asthma and COPD nurses, Physiotherapists and community rehabilitation support
- Repeat prescriptions
- Monitoring and reviews
- Care from GP practices. However, this was not a universal experience.

What could be improved?

- Reduce inequality in the availability of services and support, both in terms of geographic location and specific conditions
- Introduce localised clinics with respiratory specialists
- Local support groups including those with lived experience
- Provision of more information around causes of conditions, prognosis and management. This included holistic support to complement medication
- Reduce waiting times for specialist support and provide support to help people "wait well"
- Better communication between services, especially with out-of-county services
- Increase staffing
- Free prescriptions for asthma

The findings of this work will support the review of respiratory services in Lincolnshire.

Background

Our second campaign of 2024 focused on respiratory health. Respiratory health includes various diseases and disorders affecting the lungs and other parts of the respiratory system. In the UK, respiratory conditions are a significant concern due to their high prevalence and impact on those diagnosed and the healthcare system.

The most common respiratory conditions in the UK include:

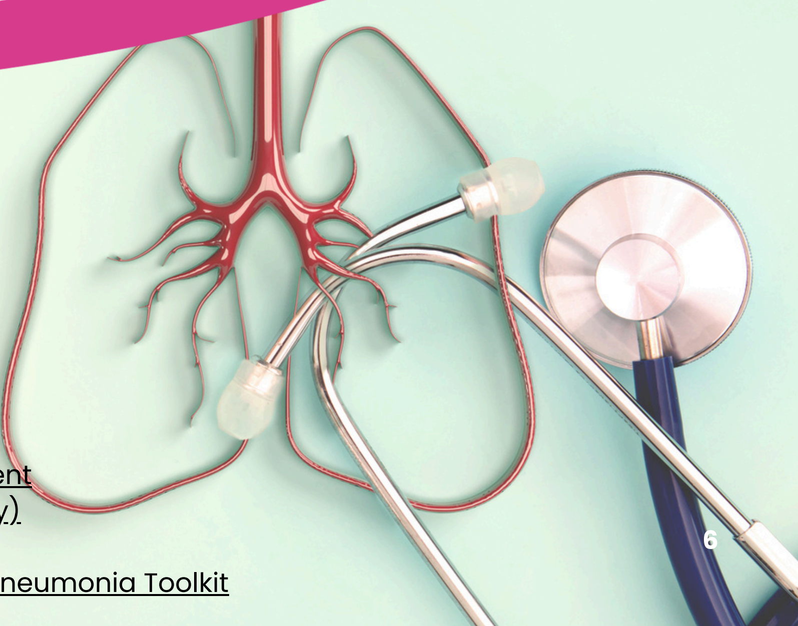
Asthma - More than 5.4 million people are currently receiving treatment for asthma in the UK.[1] The condition is a leading cause of emergency hospital admissions, especially among children and young adults.[2]

Chronic Obstructive Pulmonary Disease (COPD) - COPD affects about 1.2 million people in the UK. It is the second most common cause of emergency hospital admissions and[3] is associated with significant morbidity and mortality.[4]

Lung cancer - Around 47,000 new cases of lung cancer are diagnosed each year in the UK.[5] Lung cancer accounts for more than 21% of all cancer deaths in the UK, making it a leading cause of cancer mortality.[6]

Pneumonia - Pneumonia affects 220,000 people each year in the UK and it is a leading cause of hospital admissions and mortality among the elderly and people with a weakened immune system.[7]

Other respiratory conditions include breathlessness, bronchiectasis, interstitial lung disease and Long Covid.



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1. NHS England (2023) RightCare asthma scenario
2. RCPCH (2020) Asthma
3. Snell et al., (2016) Epidemiology of COPD in the UK
4. NICE (2018) COPD in over 16s: diagnosis and management
5. NHS Harrogate and District (2024) Lung cancer (primary)
6. Cancer Research (2023) Lung cancer statistics
7. NHS England (2022) RightCare Community - acquired Pneumonia Toolkit

The local picture

In Lincolnshire, asthma and COPD are one of the top causes of years lived with disability for children and young people and those aged 65 and over, respectively. Both conditions are key areas of interest in the Lincolnshire Joint Strategic Needs Assessment (JSNA).[8]

The charity Asthma + Lung UK produced a summary document outlining respiratory health in Lincolnshire as part of the Taskforce for Lung Health. In 21/22, according to the quality and outcomes framework (QOF) in Lincolnshire:[9]

7.3%
of people aged 6+
have asthma

England average = 6.5%

2.3%*
have COPD

England average = 1.9%

**This number is likely to be higher.*

In 2020/21, there were **5,695 emergency admissions** for respiratory conditions.

In August 2022, **3,841** people were on a waiting list for respiratory care.

This figure is **1.7x higher than the average for England.**

Also, in June 2022 there were 1,070 doctors in Trusts in **Lincolnshire**. Out of those, there were **3 respiratory specialists per 100,000** people, **compared to 5 per 100,000 across England**.

Data on the prevalence of other respiratory conditions in Lincolnshire is limited, as is information on people's experiences with accessing and receiving care for these conditions in the county. Therefore, we launched a survey for service users and another for professionals working in health and care services that support those with respiratory conditions to ensure we got a rounded understanding.

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8. Lincolnshire Health Intelligence Hub (2024) JSNA
9. Taskforce for Lung Health (2023) Respiratory Health in Lincolnshire

Engagement (Methodology)

We launched two surveys, one for service users and one for professionals. Individuals were also given the opportunity to share their experience over the phone, email or in another format that is easiest for them. The team and our amazing volunteers distributed paper copies of the survey to those who preferred to engage this way* and to local support and community groups. We also publicised the survey at the April YourVoice@Healthwatch event.

**The survey could be sent back to us using our Freepost address.*

Engagement (Methodology)

The surveys covered the following:

- Diagnosis
- Waiting times
- Treatment and management
- What works well
- What could be improved

Acknowledgments

We would like to thank:

- Everyone who took the time to share their views. Your experiences are invaluable.
- The HWLincs staff team including our amazing volunteers and local support groups for their support.

Disclaimer

We recognise and acknowledge that the experiences shared may not be fully representative of:

- All service users who have accessed health and care for their respiratory health and
- All professionals diagnosing and supporting those with respiratory conditions in Lincolnshire.

We do however believe that all individual experiences are important and should be reflected on. A strength of this data is that common themes persisted throughout responses from service users and professionals.

- According to the data collected, experiences did not appear to differ based on the likes of whether the individual was a carer or neurodiverse.

- The information collected through this survey showed that experiences somewhat differed based on the respiratory condition they had and where they lived in the county.

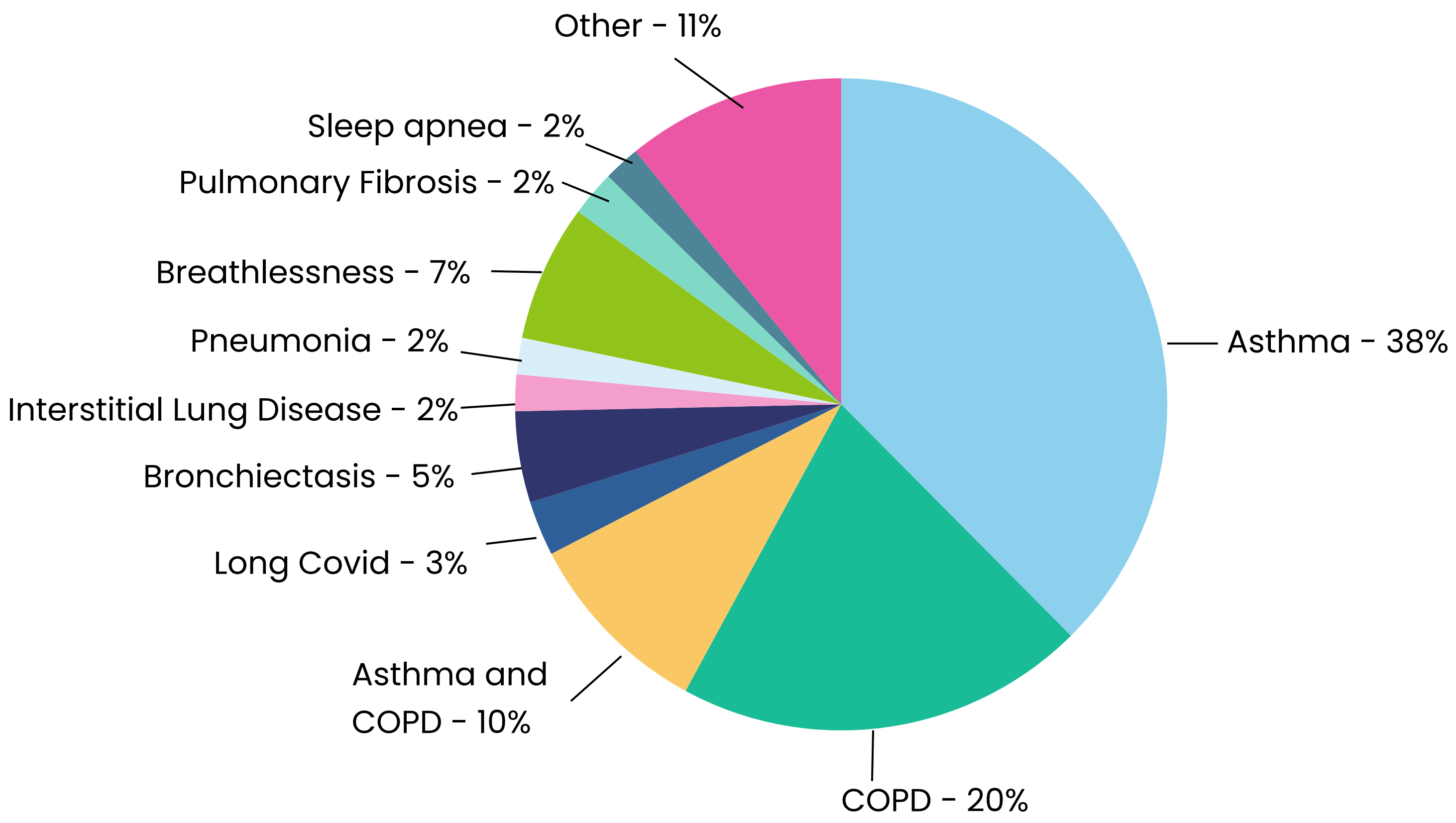
Findings - Who shared their views?

223

service users shared their views

7

professionals shared their views



- **7% (16) were veterans**
- **11% (25) worked in health and/or social care**
- **1% (2) worked in the farming/agricultural industry**
- **11% (23) were carers**
- **4% (9) belonged to the LGBTQ+ community**
- **5% (10) considered themselves neurodiverse**

A full breakdown of who shared their views can be seen in the demographics section of this report.

Overall

Overall, 223 people shared their views on accessing health and care services in Lincolnshire for various respiratory conditions. This section provides a brief overview of the findings. The findings for individual conditions are discussed separately and in greater detail in the following sections.

- 70% (153) were diagnosed correctly first time.
- Diagnosis times varied between less than one month and more than 18 months. 56% (109) were diagnosed within three months or less.
- 31% (68) were waiting for additional tests, treatments or diagnosis. Respondents shared that they had often been waiting for months and offered little support in the meantime.
- 90% (195) take medication for their condition.
- 41% (80) had faced challenges getting medications that worked for them. These challenges included medication shortages, especially inhalers, difficulties accessing specialist medication in the community and finding medications that effectively controlled symptoms.
- Respondents appreciated the ease and convenience of repeat prescriptions.
- 24% (51) had been offered and/or received treatment other than medication. This included pulmonary rehabilitation, breathing exercises, support groups and mental health support.
- 38% (82) had needed to access emergency or urgent care for their respiratory condition in the past year. Experiences of accessing such care were varied. Some were seen quickly and praised the care they received whereas others were faced with hour long waits to be seen.
- Respondents most commonly received care from the following: 90% (167) NHS GP and GP practice team, 37% (68) hospital services (in and outpatients) and 19% (36) NHS pharmacist.

Overall

Respondents were asked to think about the care they receive for their condition and rate them in a range of areas. Overall, the majority rated the following as:

Overall	**Very good**	**Good**	**Poor**	**Very poor**	**N/A or Prefer not to say**	**Overall**
Being able to access care for your condition when you need to	28% (53)	30% (57)	22% (41)	17% (32)	3% (5)	**GOOD 58% (110)**
Listening to you	27% (51)	30% (57)	21% (40)	18% (34)	3% (5)	**GOOD 57% (108)**
Explaining tests and treatment	24% (44)	35% (66)	18% (34)	17% (31)	6% (11)	**GOOD 59% (110)**
Involving you in decisions about your care	26% (48)	31% (58)	23% (44)	13% (25)	7% (13)	**GOOD 57% (106)**
Offering you different forms of treatment not just medication	11% (21)	17% (32)	28% (52)	23% (43)	21% (39)	**POOR 51% (92)**
Treating you with care and concern	28% (53)	38% (71)	21% (39)	12% (22)	2% (3)	**GOOD 66% (124)**
Addressing your needs or making plans to do so	20% (37)	32% (60)	28% (53)	15% (27)	5% (9)	**GOOD 52% (97)**

Overall

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	24% (45)	34% (64)	24% (46)	15% (29)	2% (4)	**GOOD 58% (109)**
Providing you with information about your condition, treatment and care	20% (37)	33% (61)	26% (48)	16% (30)	6% (11)	**GOOD 53% (98)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	14% (26)	20% (37)	30% (55)	18% (34)	18% (34)	**POOR 48% (89)**

Overall

What currently works well about how respiratory conditions are managed in Lincolnshire?

The following areas were highlighted as currently working well:

- Monitoring and reviews
- Once people accessed specialist care including asthma and COPD nurses, they praised its quality
- Repeat prescriptions
- There was some praise for GPs in terms of being able to access appointments and the quality of care provided. However, this was not a universal experience

“The practice nurse that specialises in respiratory health at our surgery is spot on, I trust her and she's open to listening to me rather than telling me what I must do. She's a shining example of great practice.”

“The continuing support from the nurses of the breathing team has been invaluable. They are so helpful.”

“Annual checks, asthma plan and care given if needed.”

“When I get to see the asthma nurse she is very caring. The problem is getting to see her!”

“Without the community rapid responce team I would have spent a lot more time in hospital. They are absolutely amazing. The people in the team run by Vicky Fisher are just exceptional in the service they deliver.”

“The community oxygen nurses are brilliant and are always good at explaining and communicating.”

Overall

What improvements or changes would respondents like to see in the care and management of respiratory conditions in Lincolnshire?

- Overall, when asked how care and management for respiratory conditions could be improved in Lincolnshire the following were highlighted:
    - Listening to patients
    - Reduce waiting times for specialist support and provide support to help people "wait well".
    - Provision of more information around causes of conditions, prognosis and management. This included holistic support to complement medication.
    - Local support groups including those with lived experience.
    - Localised clinics with respiratory specialists.
    - Better communication between services, especially with out-of-county services.
    - Free prescriptions for asthma.
    - Improve GP access.

"A support group, buddy system, would be helpful. Talking to someone who has expert lived experience would be very helpful."

"Free prescriptions for asthma, like people with diabetes get as asthma can kill without medication just as easily."

"Coordination between centres and information sharing when under multiple teams/hospitals. There is reliance on us sharing information or providing copies of letters."

- Respondents were asked if they knew of any factors that might have contributed to their respiratory condition. The following factors were highlighted:
    - Allergies
    - Family history
    - Worsened by respiratory infections, especially since covid
    - Active and passive smoking
    - Stress
    - Air pollution, bonfires and woodburners
    - Occupation - working in dusty conditions, farming, mining
    - Exposure to chemicals e.g. asbestos
    - Condition of home

Asthma

83 (38%) **people shared their experiences of asthma**

Diagnosis

- 88% (71) were diagnosed correctly first time with the remaining 12% (10) being initially diagnosed with something else.

- Diagnosis times varied from less than a month to more than 18 months. Most commonly, respondents were diagnosed in less than one month (36% (29)). 75% (61) were diagnosed within six months or less.

> “I was diagnosed quickly and have a blue sabutamol inhaler on prescription. After Covid I was also provided a brown clearing inhaler, and a guide, a flowmonitor plus exercises. Really quick diagnosis and very helpful.”
>
> “i went through over two years of them trying all different things to get put on the referral to see a specialist which took 10 months on the waiting list as I had to go to Newark hospital as Lincs don't have a service. Newark hospital was absolutely brilliant.”

- Just under half of those who waited more than 10 months to be diagnosed with asthma were initially diagnosed with something else.

- Delays in diagnosis were linked to a range of reasons including not being listened to, delays in referrals to respiratory services or suspected other conditions.

- It is important to note that some respondents could not remember their experience of being diagnosed as it occurred years, sometimes decades ago.

- Those who had been diagnosed years pr decades ago commented their experiences was relatively straightforward to a diagnosis appreciated being able to easily/quickly see a GP, “not like now”.

Asthma

Waiting Times

- 16% (13) were currently waiting for tests, treatment or additional diagnosis including referrals to specialist care.

- Some discussed their experience in more detail, sharing they had been waiting for months with no support in the meantime.

"I've been waiting for nine months. Not given any support."

"I am waiting for chest physiotherapy; I have been waiting since January and was told there was a nine-month waiting list. I am yet to hear any update or receive an appointment. have not received any support around this whilst waiting. When I have been in hospital the physios in the ward were not able to provide the support I need from a specialist chest physio."

Medication

- 99% (78) took medication for their asthma.

- 59% (46) had faced challenges getting medications that worked for them. Challenges faced included:
  - Medication shortages (specifically inhalers)
  - Medications not managing symptoms
  - Trialling medications to avoid exacerbating other health conditions

"The year before last Boots kept telling me that the steroid inhaled I was using was no longer being stocked by them and had to be ordered every time my prescription was sent to them, which delayed me getting it. It took me a year to persuade our surgery to change it as at the same time I was getting more attacks."

"My challenges are the times pharmacies are open. I work in education. I'm also an unpaid carer for family. Find it hard to order and collect repeats."

"I went through a few different types of medication before I found the ones that worked for me.
I was having asthma attacks on a regular basis, but have not had any for a very long time once I had the medication that was right for me."

Asthma

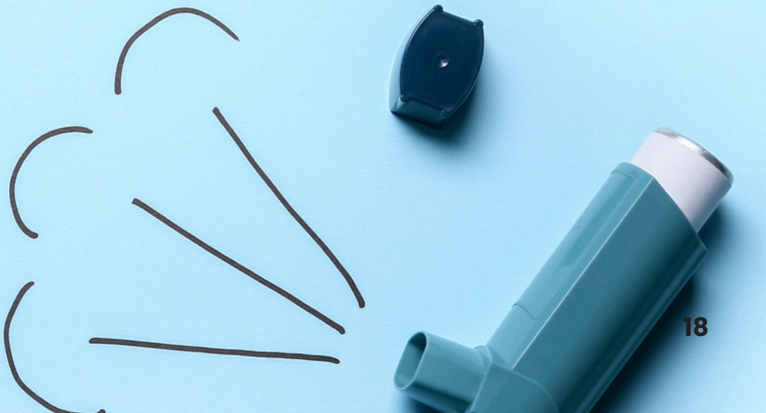
- People who had not faced any difficulties accessing medications were asked to share what works well about how they currently get their medications.
  Themes included:
    - Valued repeat prescriptions - quick and easy and prescriptions being delivered to home
    - Medication being available
    - No problems

“I lived in Nottinghamshire at the time, I was only allowed to order my Fostair inhaler when I had seven days left, the chemist did not always have it ready, having severe asthma this was very distressing, I asked for an extra inhaler but was told no. Since moving to Lincolnshire I have not had this problem, in fact having had an asthma attack shortly after moving, I was given two extra inhalers and told to increase my dosage until I had an asthma review. I was very relieved.”

“Get it online from my GP then sent to my chemist. Delivered by post, perfect.”

“Medications always available. Any questions are dealt with.”

“Medication regularly reviewed through checks with an asthma specialist nurse - medications easily accessed through the linked pharmacy
Always order repeat prescriptions online no problem.”



Asthma

Other treatment

- 6% (5) had been offered and/or received treatment for their respiratory condition. This included being seen by a specialist nurse in a hospital and for one individual psychological support.

- People who had not received any additional treatment outside of medication were asked if any/what additional support would be beneficial. Local support groups, breathing exercises and a better understanding into the causes of asthma and how to control it (outside of medication) were suggested.

Urgent and emergency care

- In the past year, 38% (30) have needed to access emergency or urgent care for their asthma. Some shared their experiences:

"Variable experience.
Speed of being seen in A&E was mixed.
When self-presenting I was left in the waiting room for over 40 minutes on two occasions despite the severity of my symptoms and ended up being rush to through to majors for urgent treatment.

When going in via ambulance I have been treated swiftly and my condition and severity of my asthma has been taken seriously."

"Varied each time. Majority of the time hard to get the care you need."

There was praise for the care received from urgent treatment centres (UTCs)

"I could not get to speak to a clinician at my surgery, so self referred to Louth UTC, where I got the medication I needed. I am no longer able to drive, so have no idea what I would be able to do now."

Fantastic thank you. I've been to Louth UTC regarding a challenging cough which needed antibiotics. I was treated very quickly and with patience and understanding, for which I'm very grateful for, thank you."

"Was 2am, dealt with within 20 mins in local UTC."

"Paramedics were amazing. Prompt response from UTC staff."

Asthma

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. (Good includes those who selected very good or good and poor includes those who selected very poor or poor.)

Good	**Poor**
• Being able to access care for your condition when you need to • Listening to you • Explaining tests and treatment • Involving you in decisions about your care • Treating you with care and concern • Communicating with you clearly about your care • Addressing your needs or making plans to do so • Providing you with information about your condition, treatment and care	• Offering you different forms of treatment not just medication • Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

Asthma

Respondents were then asked to rate aspects of their care from very good to very poor. **This is how respondents with asthma rated their care:**

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Being able to access care for your condition when you need to	30% (21)	48% (33)	16% (11)	6% (4)	0% (0)	**GOOD 78% (54)**
Listening to you	26% (18)	50% (34)	15% (10)	9% (6)	0% (0)	**GOOD 76% (52)**
Explaining tests and treatment	25% (17)	51% (34)	15% (10)	6% (4)	3% (2)	**GOOD 76% (51)**
Involving you in decisions about your care	32% (22)	42% (29)	17% (12)	6% (4)	3% (2)	**GOOD 74% (51)**
Offering you different forms of treatment not just medication	13% (9)	12% (8)	35% (24)	16% (11)	25% (17)	**POOR 51% (35)**
Treating you with care and concern	35% (24)	48% (33)	14% (10)	7% (5)	0% (0)	**GOOD 83% (57)**
Addressing your needs or making plans to do so	24% (16)	49% (33)	22% (15)	4% (3)	0% (0)	**GOOD 73% (49)**
Communicating with you clearly about your care	30% (21)	48% (33)	14% (10)	7% (5)	0% (0)	**GOOD 78% (54)**

Asthma

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Providing you with information about your condition, treatment and care	22% (15)	46% (32)	22% (15)	6% (4)	4% (3)	**GOOD** **68%** **(47)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	13% (9)	28% (19)	32% (22)	6% (4)	21% (4)	**GOOD** **41%** **(28)**

Asthma

Overall

- When asked overall what works well and what could be improved about the care they receive for their asthma, the following was highlighted:

What works well?	What could be improved?
• Annual reviews • Repeat prescriptions • Specialist asthma nurse	• Free prescriptions for asthma like other long term health conditions • Shorter waiting times to access specialist clinics • More frequent reviews particularly after flare ups and attacks • Local support groups

COPD

- 20% 45 people shared their experiences of accessing care for COPD.

Diagnosis

- 73% (33) diagnosed correctly first time with 59% (19) of these individuals being diagnosed within three months.

- 16% (7) diagnosed incorrectly to start with and it often took these individuals over 18 months to get a correct diagnosis.

- 11% (5) trying to get diagnosed. Three individuals had been trying to get diagnosed for three months or less. These individuals and another who has been trying for over 18 months to get a diagnosis were waiting for lung function tests.

Waiting Times

47%
(21)

were waiting for tests, treatment or additional diagnosis.

Lung function tests, rehabilitation courses and pulmonary therapy were what respondents were waiting for.

> “I was diagnosed with COPD in early 2023 and a referral was made to a respiratory specialist. Over a year later I am still waiting for the initial consultation.”

Medication

96%
(42)

take medication for their COPD.

48%
(20)

had struggled to access medications that worked for them.

- Struggles accessing medications included shortages and trying multiple inhalers to find one that works. These are the same difficulties faced by those trying to access medication for their asthma.
- Repeat prescriptions were again praised for their convenience.

COPD

Other treatment

- 36% (15) of respondents had been offered treatment other than medication including pulmonary rehabilitation and courses on breathing, exercise and eating.

> “Rehabilitation group but 10 miles away so declined as not easy to attend.”
>
> “I have attended a weekly therapy session, which has now finished. It was very informative and helpful.”

Urgent and emergency care

- 50% (12) of respondents had needed to access emergency care for their COPD and again, like with asthma, experiences were variable.

> “I have had a number of A&E/UCC visits into Grantham Hospital each and every time I have received very good care whilst in that hospital but follow up appointments are usually slow in being made. The downgrading of Grantham Hospital has not helped patients at all.”
>
> “Absolutely awful. Ambulance here immediately, taken to Lincoln County. Sat i waiting room for 15 hours. No nursing care no reaasurance, nothing.”
>
> “Used the 111 service. Response was excellent. I would not fault anything.”

COPD

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The responses were polarised, especially for the following:
    - Being able to access care for your condition when you need to
    - Listening to you
    - Explaining tests and treatment
    - Involving you in decisions about your care
    - Communicating with you clearly about your care
    - Addressing your needs or making plans to do so

- Overall, the following was rated more clearly as good and poor:

(Good includes those who selected very good or good and poor includes those who selected very poor or poor.)

Good	Poor
• Treating you with care and concern	• Providing you with information about your condition, treatment and care • Offering you different forms of treatment not just medication • Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

COPD

Overall

- When asked what works well about care for COPD, around half of the 26 people who responded to this question said something along the lines of "nothing".

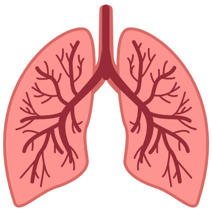
What works well?	What could be improved?
• "The respiratory team and paramedics have been very supportive, informative and caring." • "Good communication with the GP surgery and annual assessments. Prescriptions are always provided in a timely fashion from the surgery to the pharmacist. I have a consultant consultation every six months regarding my CPAP use and to identify any problems which I experience." • "The continuing support from the nurses of the breathing team has been invaluable. They are so helpful."	• "Earlier referral to information such as the training course so you are informed better at what support is available and what you may experience or need in the future." • "I have been treated at Lincoln, Boston and Skegness, it would be good to be seen at one location." • "Rather than just medication, guidance as the condition gets worse: what are the stages, any steps I could be taking, additional treatments available etc." • "Having someone to talk to who really understands the condition/symptoms, even if this was just once a year checking in - do you need anything, has anything changed etc."

Asthma and COPD

Overall

21 (10%)

people shared their experiences of having both asthma and COPD



Diagnosis

- All individuals had received an official diagnosis with 81% (17) being diagnosed correctly the first time.

- 72% (15) were diagnosed within three months or less. Diagnosis often came when presenting with other respiratory conditions and infections.

Waiting Times

- 14% (3) were currently waiting for additional tests, treatment or diagnosis. This included breathing tests and pulmonary therapy.

"I was invited to have pulmonary therapy three months ago, I was told after a consultation by phone that I qualified for it but there were 22 people ahead of me in the queue. This was three months ago."

Asthma and COPD

Medication

100% (20) **take medication for their asthma and COPD.**

35% (7) **had struggled to access medications that worked for them.**

- Difficulties accessing medications included being offered alternatives that were not as effective and difficulties finding medications that effectively controlled symptoms.

- When asked what worked well about accessing medications for their condition 11/13 shared sentiments along the lines of "My medications always on time, everyone is always very helpful".

Other treatment

- 48% (10) had been offered treatment other than medication. This included pulmonary rehabilitation, exercises and support groups.

Urgent and emergency care

- 29% (6) had needed to access emergency or urgent care for their respiratory condition in the past year.

Asthma and COPD

Overall

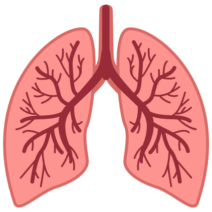
- Overall respondents rated different aspects of the care they receive for their asthma and COPD and again experiences were mixed. Across all the different aspects of care there is almost an even split between respondents rating it good and poor.

What works well?	**What could be improved?**
• "The GP is the person supporting me." • "Referrals and communication." • "Advice from respiratory nurse at GP practice is helpful." • "They help whenever I need it. They will offer advice if asked."	• "A three-monthly support group for respiratory." • "COPD clinics to help assess decline or stability a group therapy. To help with the mental and emotional state having COPD and asthma causes us." • "More specialist nurses in surgeries. I was surprised that not all doctors have specialist staff to support which means I have to be careful where I register if I move house."

Breathlessness

Overall

15 (7%) **people shared their experiences of having breathlessness**



Diagnosis

- 43% (6) had received a diagnosis.

> “My GP took me seriously when I explained the symptoms, and immediately prescribed treatment.”

- Breathlessness had the highest percentage of people trying to get a diagnosis with 50% (7) were trying to get a diagnosis. All of which had been trying for over 10 months.

> “Not very good. I’ve been saying for the last five years I've gone from doing 10,000 steps to not being able to walk far.”
>
> “Kept telling the doctor about the breathlessness. Went from walking 10,000 steps a day to struggling to get down the garden.”
>
> “Despite contacting PALS Im still waiting for a consulation now for nearly a year. My GP first referred me for breathlessness. I am a former miner with exposure to coal dust.”
>
> “Was told I had chest infection still ongoing since Sept 2023, numerous visits to doctors chest x-rays. Each visit I am told yes chest infection, then no chest infection, then yes chest infection, continuously. Nine months no diagnosis, no looking into symptoms other than chest x-rays. Still struggling to breathe when walking, wheezing, coughing, heavy legs, fatigue, lack of energy. No interest in my symptoms. No diagnosis. Appalling service.”

Breathlessness

Waiting times

- 33% (5) were currently waiting for additional tests, treatment or diagnosis, mainly breathing tests.

Medications

- 60% (9) took medication for their condition and three of these individuals faced challenges getting the medications that worked for them. These challenges included trialling medications to find a combination that effectively manged their symptoms and difficulties getting through to a GP.

Other treatment

- One individual had been offered treatment other than medication, which was counselling.

- Others respondents, who were not offered treatment, shared what they would find beneficial. The suggestions included:
    - Being able to get a diagnosis and access further investigations
    - Exercise and lifestyle support to compliment medicine

- 20% (3) had access urgent or emergency care in the past 12 months for their breathlessness.

Breathlessness

Urgent and emergency care

- In the past year, three of the respondents had needed to access urgent or emergency care for their breathlessness. Two went on to say that their experiences accessing this care was good but the primary care they received was poor.

> "Called 111. Sent paramedics, clinicians excellent, checked everything, breathing etc, where pain was etc. Wrote a report to give to doc, which the doctor threw it back on the desk and totally ignored it never even read it."

Overall

- Overall 12 of the respondents rated different aspects of the care they receive for their breathlessness. The majority rated the following aspects of their care as very poor.

Very poor
• Being able to access care for your condition when you need to • Listening to you • Explaining tests and treatment • Involving you in decisions about your care • Treating you with care and concern • Communicating with you clearly about your care • Providing you with information about your condition, treatment and care • Addressing your needs or making plans to do so • Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.

- When asked what worked well about the care they receive, one individual said "Integrated Care Systems. Supportive Practitioners". However, this positive comment was very much a minority (2/10 comments were positive).

- Communication between services and coordination of care were areas highlighted as needing improvements.

Due to limited responses for the following conditions, the findings have been summarised more concisely compared to conditions with more than 15 responses.

Long Covid

Six people shared their experiences of accessing health and care services for Long Covid. Two individuals were diagnosed correctly the first time and three were initially diagnosed with something else. One individual shared they are currently trying to get a diagnosis.

Diagnosis often took more than seven months, even for one of those who was diagnosed correctly first time. This delay in diagnosis had a negative effect on mental health and in some cases ability to work. Due to this one individual sought private care. For the individual that was trying to get a diagnosis, they had been trying for more than 18 months, saying, "It is dismissed every time. I keep having bloods taken, but that is it! No diagnosis apart from arthritis!"

"Due to the pandemic, it was difficult to see a doctor face to face. My employers (at that time) sent me to a private occupational health doctor and a private cardiologist to try to move things on. Though ill from Jan 22, I didn't speak to my GP regarding this until April 2022. As soon as he was aware of me, he and the rest of the practice have been brilliant, always going the extra mile."

"The wait for diagnosis on the NHS was interminable so I ended up paying privately for the respiratory assessments I needed to get my diagnosis. Initially my GP insisted I try several different antibiotics, inhalers and other medications and suggested I had a short-term virus."

"NHS waiting times were endless and my mental health was suffering due to lack of support and diagnosis."

Long Covid

Two people shared they are waiting for additional tests, treatment and diagnosis. One said they had "no support" and the other shared their experience in more detail:

"Very mixed. I have wide-ranging multi system symptoms and have seen multiple specialities. I was referred to the Long COVID (LC) rehab team in June 22 and started work with them in August 2022. I paid for a neurology appointment as I was advised that the NHS wait was significant. My GP supported me in this. Since being in hospital, appointments have been easier to get but this has still needed chasing by my partner. I have been referred for a nerve study (Dec 23) and not yet got an appointment. I have been referred on to Sheffield for neurology and have been advised in writing that there is a minimum of an 18 month wait. This is preventing me accessing my pension on grounds of ill health as all tests be to be completed."

Three of the respondents take medication for their conditions and two of these had struggled to get medication that works for them. One said, "I am only given pain relief and this is not monitored". The other explained "The inhalers I was prescribed made the problem worse and there was no sign of anyone properly seeing me to assess my condition. Most consultations were over the phone and as a result I was prescribed medication that did not work."

One individual shared their positive experience of accessing their medications, saying "My GP has been excellent, reading research, happy to trial different medications and communicating clearly re benefits and side effects."

Four out of the six respondents had been offered treatment other than medication. This included online support sessions, respiratory physiotherapy and cognitive behavioural therapy (CBT).

Four respondents had needed to access emergency or urgent care for their condition in the last 12 months and experiences were mixed. One respondent had a very positive experience saying "Very good they looked after me and could not understand the lack of care from GP." Others shared concerns about long waiting times.

Long Covid

Overall, when asked to rank the different aspects of their care, experiences varied.

"Adult social care have supported me in the home."

"I am reliant on occupational health and a private consultant for my support. My GP surgery have not been helpful and I keep being told I must just 'give it time' to improve and recover."

"Long Covid clinic and swift referral, no avoidance of condition by GP."

"I was treated in Grimsby as I live closer. There were issues regarding equipment and services at discharge as I have a Lincs postcode. I can not fault the support I get from my GP and from the LC team."

"If I did not have the Long Covid physiotherapist supporting me I would be in an even worse situation as I am now. He is the only professional to listen, look holistically and make referrals."

Pneumonia

Four people shared their experiences of accessing care for pneumonia, with all four being diagnosed correctly the first time and within three months. Three were diagnosed in an emergency setting. The individual who had to wait the longest to be diagnosed said: “Infection not taken seriously till after so many weeks to start with, treated as virus.”

One individual shared they were still waiting for a follow-up appointment: “Follow-up appointment after discharged from hospital in August 2023 after treatment for pneumonia, phoned in Nov 2023 and no appointment yet allocated.” Another said they “had lots of after effects and outpatients appointments often cancelled”.

Two took medication for their condition but neither had faced any difficulties in getting medications that worked for them. None of the individuals had been offered other treatment outside of medication but two individuals felt that physiotherapy would have been beneficial.

Interstitial Lung Disease

Four people shared their experiences of accessing care for interstitial lung disease (ILD). Two individuals had been diagnosed and the other two were trying to get diagnosed or had tried in the past. For the two that had been diagnosed, it took them both 4 - 6 months.

"Admitted to ITU end Dec'21/start Jan '22 with double pneumonia following Covid scarring on lungs I was unaware of. In May '22 readmitted to ITU with double pneumonia again, and subsequently have been admitted (est) 26 times in last 26 months, with referral to Nottingham City Hospital ILD team and have started various treatments, with possibility that a lung transplant could happen in near future."

"I started off with a chest infection but after been given three different courses of antibiotics I was advised to go to the local A&E where I was given intervenes antibiotics and also an x-ray. I was told that there was some shadowing in my lungs but because of my age it wasn't a concern. Around a week later I was worse than before so went back to my doctors who then sent me for a scan. Two days later I was contacted by my doctor and went for a meeting with him, I was told I had pulmonary fibrosis and needed to see a lung specialist but on the NHS it would take up to 80 weeks before I would be offered an appointment so I decided to go private. I was contacted two days later and had seen the specialist two days after."

The two individuals who are seeking a diagnosis had been trying for over 13 months.

"Referred by my Lincolnshire GP in December 2022 for respiratory medicine. During phone call received shortly after referral I said I was prepared to travel so was referred to Kings Lynn as I was told that would be fastest. Had first consultation at Kings Lynn in November 2023. Over next two months had blood tests, CT scan and lung function test. Appointment with consultant has since been cancelled twice. I have had a second CT scan and now have appointment for 20th June 2024. Comments by consultant during first meeting and subsequent phone call suggest pulmonary fibrosis is going to be the diagnosis at next consultation."

Interstitial Lung Disease

Three individuals were waiting for additional tests, treatment or diagnosis.

"Waiting for diagnosis following tests. Appointment with consultant has been cancelled twice. No support whilst waiting."

Three take medication for their condition. One had struggled to access medications that work for them.

"My specialist prescribed some medicine for me but my doctors refused to give it to me on prescription. I went back to my specialist who then sent a letter and the problem was resolved after around nice months."

Two of the respondents had been offered treatment other than medication which as with other respiratory conditions included respiratory physiotherapy and waiting to start a course on breathlessness.

One respondent shared they had needed to access emergency or urgent treatment in the past 12 months for their condition. The experiences shared were varied.

The needed for better communication between services especially those out of the county was again highlighted.

"Communication between Boston and Nottingham hospitals."

"Having been referred by Lincolnshire GP I subsequently discovered that my medical records in Lincolnshire cannot be seen by the respiratory consultant I am being seen by in Kings Lynn and the reverse is the same."

Pulmonary Fibrosis

Five individuals shared their experiences on accessing health and care services for pulmonary fibrosis. Four had been diagnosed, with one initially being diagnosed with something else. One individual was trying to get a diagnosis. Three were waiting for additional tests, diagnosis and/or treatment. One individual shared their difficulties getting medications that worked for them related to having to trial different medications to find ones that effectively controlled their symptoms. Two respondents shared they had pulmonary rehabilitation. One of which had chosen to access this privately.

Two had needed to access urgent or emergency care for their condition in the past 12 months and both had good experiences.

"Prior to getting a oxygen concentrator I has ambulatory oxygen and I ran out over a weekend in September 2023. I called the ambulance who came very swiftly and took me to Lincoln hospital. I was found to have pneumonia and Covid. I was so well treated for two weeks and recovered somewhat."

When asked what could be improved about the care and management of their condition two individuals shared:

"Being kept informed and knowing someone is there for you."

"Much more discussion about health condition and prognosis."

Sleep Apnea

Four respondents shared their experiences of accessing care for sleep apnea. There was an even split between those that were diagnosed correctly the first time within three months or less and those that were initially diagnosed with something else.

“I first got referred to ENT but they said I needed to go back to my GP to get referred to lung function / sleep apneoa clinic. Took about a year to be offered a Continuous Positive Airway Pressure (CPAP) machine.”

One individual shared they had struggled to get the support they needed for their CPAP machine “getting used to CPAP machine, need local support with this not a remote phone service”.

When asked what worked well about how health and social care services are supporting them, respondents shared:

“Quick diagnosis and provision of equipment to help manage the condition.”

“Received six monthly contact from Boston clinic for masks, hoses etc.”

“Inpatient sleep apnea test, direct contact with GP, GP has been excellent in following up abnormal blood tests and looking for answers.”

When asked what could be improved, one individual suggested:
“Help to educate people about this condition. I had no idea.”

Bronchiectasis

Ten respondents shared their experiences of bronchiectasis. Six individuals were initially diagnosed with something else and on average it took more than 10 months to be diagnosed correctly. The diagnosis often came when presenting with other health conditions or after repeatedly presenting at their GP.

“Long term recurrent chest infections misdiagnosed with multiple medications each time with little relief. Exhausting and fatiguing with little discussion or condition management from health professionals resulting in low mood, anxiety and stress.”

“Constantly told it was not anything serious, and then that it may be asthma, which it was not. My concerns were not taken seriously. It seems to have taken years before it was finally diagnosed after a CT scan following a broken shoulder!”

Nine took medication for their condition and three had struggled to get medications that worked for them. This included access issues and trialling medications.

“The respiratory team in the hospital told me about the medications I should be taking, but the surgery did not follow it up or told me on one occasion that it was expensive. Nearly a year later I have been prescribed it.”

Three respondents shared they had been offered treatment outside of medication which included physiotherapy, rehabilitation and a support group. For those that hadn’t been offered anything, they suggested that the latter could be beneficial.

Two had accessed urgent or emergency care for their condition in the past 12 months with one saying their experience was “very good” and the other had been prescribed a rescue pack of steroids antibiotics and an inhaler. However, they had to fight for replacements.

Bronchiectasis

Out of the ten individuals who shared their experiences of bronchiectasis, experiences were mixed. Overall just over half rated the following aspects of their care as:

Good	Poor
• Being able to access care for your condition when you need to • Listening to you • Explaining tests and treatment • Involving you in decisions about your care • Treating you with care and concern • Communicating with you clearly about your care • Providing you with information about your condition, treatment and care	• Offering you different forms of treatment not just medication • Addressing your needs or making plans to do so • Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

Respondents made several suggestions about how care for their condition could be improved in Lincolnshire, including:

- “More awareness of the condition and how limiting it can be.”
- “Better access to GP respiratory support.”

What did healthcare professionals say?

Five healthcare professionals shared their views on respiratory services in Lincolnshire covering current challenges, what working well and what could be improved. The professionals worked in the following services: primary care - GP, community health and hospital and provided care for a range of respiratory conditions.

What current challenges do services which support people with respiratory conditions in Lincolnshire face?

" - Delays due to staff shortages, availability of suitable clinics and changes imposed by NHS England on services.
- Geography.
- Access to pulmonary function testing.
- Lack of local patient support groups.
- Inequity of support available as based on diagnosis.
- High demand for acute respiratory support.
- Financial impact of respiratory disease particularly with drug budgets.
- No access to free inhalers for patients.
- Only nutritionists are in secondary care and needs GP referral."

"Staffing needs to improve. Pilgrim Hospital is short of Respiratory Consultant Physicians. There is no community support for patients using non-invasive ventilation (NIV), many of them cannot get to hospital for appointments. We do not have an interstitial lung disease (ILD) specialist nurse in Lincolnshire! Such a big county and no resource for ILD patients. We need community support for fibrosis patients which is not currently commissioned in Lincolnshire. These patients become severely ill very quickly and there is a huge gap in care."

"Specialist services for idiopathic pulmonary fibrosis (IPF) are not within the county. The only commissioned service for IPF in Lincs community setting is pulmonary rehab and home oxygen, no specialist case management or acute response service. The sickest of patients having to travel 1-2 hours is off putting, the unknown is frightening and many opt not to attend due to the travel. If the services were commissioned seamlessly for this group of patients, like they are with COPD this would remove a health inequality and allow this very vulnerable group of patients access to care and support in the community which they deserve."

"Inequality of services across the county. Eg the community respiratory team not commissioned for respiratory complex case management of COPD in the Welland area. Overwhelming demand for the pulmonary rehab service leading to long waiting lists."

What is working well currently in these services?

"Increased number of respiratory consultants in Pilgrim. Fantastic pulmonary rehabilitation service within LCHS. Community respiratory services. Community respiratory support for COPD patients."

"There is excellent provision of care for COPD patients in the community, this should be extended for ILD patients. LCHS have a gold standard community COPD team. The pulmonary rehabilitation in Lincolnshire is excellent. Patient satisfaction is excellent with the community respiratory services. A new respiratory virtual ward has opened in LCHS which is helping with patient flow in the hospitals but it needs proper decent resource so the staffing numbers are better to cover the whole county. GPs have a good relationship with the community respiratory team and work closely together which supports good patient outcomes."

"For COPD there is a community service encompassing acute, complex case management, pulmonary rehab (PR) and home oxygen. For those with IPF if they have attended the PR course they then don't receive any support in Lincs until they may end up on oxygen."

"Home oxygen service, acute respiratory assessment service, respiratory virtual ward."

What could be improved?

“Improved access to free clinic space in community. Local diagnostic hubs more accessible for patients nearer to home. Investment nationally in respiratory training for all relevant professions. A Lincolnshire wide career development pathway inclusive of all grades to help attract staff to respiratory and retain them. ICB supported local training days and community dietician or nutritionist.”

“ILD patients have to travel to Nottingham or Papworth for specialist care, and don’t have any ILD support from the nursing team in Lincolnshire unless they end up with oxygen. This needs to change because they become disabled and die quickly and have poor community nursing care. NIV services need support in the community they are too secondary care based. Many patients cannot get to their appointments and therefore do not get reviewed. Respiratory virtual ward needs better staffing for it be really effective.”

“Commissioning a service which encompasses ‘from diagnosis to death’ within the county, allowing these patients to be holistically managed rather than only their ‘lung disease’ to be managed. Better integrated specialist services to improve management of additional co-morbidities. A focus on areas of higher prevalence and mortality ie the East Coast and investment in the infrastructure of services to support, including access to transport or more community appointments/services within the areas of need.”

“Community support for patients with non invasive ventilation. More funding for pulmonary rehabilitation service.”

Contributing factors to respiratory conditions

“Smoking burden on disease management increases acute episodes and hospital admissions but easy access to One You Lincolnshire service. Nutritional needs high but cost of living affects access to good nutrition.”

“Patients using oxygen therapy at home have been really worried about their electricity bills over the winter with high energy costs. BOC healthcare had to use their hardship fund to support some patients in poverty who were rationing using their oxygen concentrators.”

“Poor transport / travel options, high unemployment, high retirement to the people moving away from their families/support network - creates a greater dependence on services and limited access to GP appts - some practices do not offer GP home visit options - again adds pressure to teams managing a complex case load.”

What works well?

Overall, when asked what works well about how health and social care services are supporting them for their respiratory condition(s), the following was highlighted:

Specialist care including asthma and COPD nurses, Physiotherapists, community rehabilitation support

Repeat prescriptions

Monitoring and reviews

Care from GP practice

However, this was not a universal experience

"The practice nurse that specialises in respiratory health at our surgery is spot on, I trust her and she's open to listening to me rather than telling me what I must do. She's a shining example of great practice."

"The continuing support from the nurses of the breathing team has been invaluable. They are so helpful."

"When I get to see the Asthma Nurse she is very caring. The problem is getting to see her!
Prescriptions are always provided in a timely fashion from the surgery to the pharmacist. I have a consultant consultation every six months regarding my CPAP use and to identify any problems which I experience."

"Without the community rapid responce team I would have spent a lot more time in hospital. They are absolutely amazing. The people in the team run by Vicky Fisher are just exceptional in the service they deliver."

What could be improved?

Some improvements and suggestions have been explored throughout the report. Overall, both service users and professionals highlighted many of the same areas in need of improvement. The most frequently suggested improvements are:

Reduce inequality in the availability of services and support, both in terms of geographic location and support for specific conditions such as interstitial lung disease and non-invasive ventilation

Listening to service users and taking them seriously

Localised clinics with respiratory specialists

Local support groups including those with lived experience

Provision of more information around causes of conditions, prognosis and management. This included holistic support to complement medication

Improve GP access

Reduce waiting times for specialist support and provide support to help people "wait well"

Better communication between services, especially with out-of-county services

Increase staffing

Free prescriptions for asthma

"A support group, buddy system, would be helpful. Talking to someone who has expert lived experience would be very helpful."

"It's an hour and a half to two hour journey to the regional clinic in Nottingham, and I find the journey very difficult."

"Local hospital dealing with respiratory illness."

"Better and shorter wait at respiratory clinic."

"Having someone to talk to who really understands the condition/symptoms, even if this was just once a year checking in - do you need anything, has anything changed etc."

"Rather than just medication, guidance as the condition gets worse: what are the stages, any steps I could be taking, additional treatments available etc."

Final Thoughts

We would again like to thank everyone who shared their views.

Some of the key issues raised were:

- The information collected through this survey showed that experiences somewhat differed based on respiratory condition. Also, there were inequalities in service provision.

- Respondents with asthma tended to rate the different aspects of their care more highly than those with other respiratory conditions including bronchiectasis and breathlessness. However, we were unable to tell if these differences were statistically significant.

- Overall, the majority of respondents who shared their experiences of accessing and receiving care for asthma in the county rated their care as “good” across different domains such as “listening to you”, and “treating you with care and concern”. However, there were inequalities in their experiences of asthma care that could not be explained by the data collected.

Diagnosis

- 70% (153) were diagnosed correctly first time. Diagnosis times varied depending on the condition. For example, 63% (51) of those with asthma were diagnosed within three months or less. However, for other respiratory conditions such as COPD, Long Covid and bronchiectasis diagnosis times were more varied and it tended to take longer to get a diagnosis.

Waiting Times

- 31% (68) were waiting for additional tests, treatments or diagnosis. COPD had the highest proportion of respondents (50% (21/42)) waiting for additional diagnostics or treatment. Regardless of the condition, respondents shared that they had often been waiting for months with appointments being cancelled, poor communication and little support in the meantime.

Treatment and Management

- Regardless of the specific condition, the majority (89% (195)) took medication for their condition. Overall, 41% of individuals had faced challenges getting medications that worked for them. Challenges did not appear to be specifically related to certain conditions but instead were broader and covered issues such a medication shortages, especially inhalers, difficulties accessing specialist medication in the community and finding medications that effectively controlled symptoms.

- Respondents appreciated the ease and convenience of repeat prescriptions.

Final Thoughts

- 24% (51) had been offered and or received treatment other than medication. COPD and Long Covid had the highest proportion of respondents being offered treatment other than medication. This included pulmonary rehabilitation, breathing exercises, support groups and mental health support.

When asked what works well and what could be improved both service users and professionals raised many of the same areas.

What works well?

- Specialist care including asthma and COPD nurses, physiotherapists and community (LCHS) rehabilitation support
- Repeat prescriptions
- Monitoring and reviews (for those that had them)
- Care from GP practices. However, this was not a universal experience

What could be improved?

- Reduce inequality in the availability of services and support, both in terms of geographic location and specific conditions
- Localised clinics with respiratory specialists
- Local support groups including those with lived or living experience
- Provision of more information around causes of conditions, prognosis and management. This included holistic support to complement medication
- Reduce waiting times for specialist support and provide support to help people “wait well”
- Better communication between services, especially with out-of-county services
- Increase staffing
- Free prescriptions for asthma

The findings of this work will support the review of respiratory services in Lincolnshire.

Workshop

To share the survey results, we held a workshop with health and care professionals and service users to foster a collaborative and co-production approach to enhancing respiratory health in our community. Attendees were invited to comment on our findings, as well as to share their insights and initiatives.
The first part of the workshop was a presentation of our findings and is available to watch on the HWLincs YouTube channel:

Click the picture to watch our presentation

Respiratory Health Research Workshop

In this presentation, we share the findings of the Healthwatch Lincolnshire research project on respiratory health as part of a workshop designed to improve the experiences of those accessing care for:

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Pulmonary Fibrosis
- Interstitial Lung Disease
- Other respiratory health conditions

Workshop attendees included professionals from our local hospital, community health trusts, primary and social care, and the voluntary and community sector. Service users were also present to share their experiences firsthand

healthwatch Lincolnshire

Respiratory Health Survey Findings Healthwatch Lincolnshire 2024

Workshop attendees included professionals from our local hospital, community health trusts, primary and social care, and the voluntary and community sector. Service users were also present to share their experiences first hand.

Below is an anonymised summary of what was discussed in the second part of the workshop. Three patients shared their experiences of respiratory care in the county.

Patient 1 - outside of medication they had not been offered any support at all. They highlighted the inequalities in signposting to additional support including rehabilitation. Their prognosis had never been discussed with them.

Patient 2 - shared their experience of inequalities in care in relation to access to respiratory nurses in primary care. They used to see a specialist every six months now its random, they have no consistency or knowing when their next appointment will be.

Patient 3 - raised concerns around the appropriateness of conducting asthma reviews over the phone and conflicting advice and management of asthma between boarding counties/areas.

Workshop

- Healthcare professionals shared their experiences around tourism pressures e.g. holidaymakers coming to the area who have forgotten medication/equipment needed to manage their condition and who as a result may need acute care. This puts pressure on the system.

- Everyone agreed (a mix of both patients and professionals) that they were unaware of what support was available and where to signpost people.

- A professional working in the community mentioned a feeling of still catching up from Covid. They did briefly mention successful virtual programs but much of what is available is COPD-centred.

- It was recognised that there needs to be a greater focus on other respiratory conditions, that often have smaller patient groups. Lots of work has been done to support COPD patients over the last decades which needs to be replicated for other conditions such as bronchiectasis, Long Covid and pulmonary fibrosis and other rarer conditions. People with these conditions are having to travel a long way for their care. There is only currently one ILD support group in Boston, which is run by a nurse in secondary care. Pulmonary rehabilitation with the support of the patients has set up patient support groups throughout the county so that once they have finished rehab they have somewhere else to go.

- Inequalities in access to support were discussed by many with a need to map out where the support is currently to identify where there are gaps or at least where there is need.

- Extend the use of every contact counts for example expand the ‘safe and well’ training of the fire service to include other professionals who come into contact with vulnerable individuals in the community. Support these professionals to provide signposting and create communication channels so they can raise any concerns to relevant organisations.

Workshop

A success story - access to pulmonary rehabilitation

- Initially only three places in Lincolnshire that offered pulmonary rehabilitation: Boston, Lincoln and Grantham, so access in highly deprived areas of the county such as the East Coast was very difficult. It has now been taken out of the hospital into the community with around 10 venues offering rehabilitation throughout the county. A virtual service has also been created as a result of the Covid pandemic and lockdowns. It is not right for everyone, as not everyone is suitable for a virtual programme and there are gaps in technical access and knowledge throughout the county. It has, however, allowed the service to open up for those who cannot tolerate the long drive or use public transport.

Recommendations

Key improvements that can be implemented in the short-term across all services for the benefit of residents.

1. Reduce inequality in service availability and access

- **Evidence from the report:**
    - **Geographic and condition-specific inequalities**: There are significant disparities in access to services across different geographic locations and specific respiratory conditions, such as interstitial lung disease and non-invasive ventilation. The report mentions the lack of localised clinics and support groups, which particularly affects patients with less common conditions (p. 44).
    - **Professional Feedback:** Healthcare professionals also pointed out inequities in service provision based on location, citing examples such as the absence of community support for patients using non-invasive ventilation and the lack of an interstitial lung disease specialist nurse in Lincolnshire (p. 31).

- **Potential solutions:**
    - As part of the Respiratory Services Review map current service provision against need, identify gaps and explore opportunities to collaborate with partners.
    - Consider the development or extension of more localised clinics and support groups to reach communities most in need.

2. Improve the support available to patients while they wait for tests or treatment, and ensure they are informed about these resources.

- **Evidence from the report:**
    - Impact on patient wellbeing: The report mentions that long waits often left patients without support or information on how to manage their conditions in the meantime, negatively impacting their overall wellbeing (p. 47).

- **Potential solutions:**
    - Review how patients are supported while waiting for tests or treatment to ensure they have sufficient resources to 'wait well.'
    - Ask those with lived or living experience to review resources available to patients while waiting and how they are communicated with during this time.
    - If needed, collaborate with people who have lived or current experience to co-produce materials that will better support patients during their wait for tests and treatment.

Considerations

These are to inform future planning, development and improvement of services for long-term benefits to be realised for residents.

1. Improve communication between services and patients

- **Evidence from the report:**
    - **Patient feedback:** Many patients reported poor coordination and lack of clear communication between primary care, specialists, and other services, often relying on patients themselves to share medical information (p. 33, p. 44).
    - **Professional's feedback:** In the focus groups, a need was highlighted to ensure that all individuals who may interact with patients (especially the most vulnerable.), such as those working in utility and housing services, are equipped to signpost individuals to support (p.56)

- **Potential solutions:**
    - Reinforce or extend the use of 'Every Contact Counts' and 'Safe and Well' visits conducted by the fire service. Non-health organisations, such as those in utility, housing or environmental services often come into contact with some of the most vulnerable patients/members of the community.
    - Provide these individuals with training, ensuring they are informed about the resources available and can effectively signpost individuals to the appropriate support.
    - Ensure there are appropriate channels to raise concerns around wellbeing to relevant health and care services.

Demographics

Demographic	**Percentage (number)**
Age	
18 – 24	1% (1)
25 – 49	14% (25)
50 – 64	35% (64)
65 – 79	47% (85)
80+	3% (5)
Prefer not to say	1% (2)
Gender	
Male	26% (48)
Female	74% (134)
Have you gone through any part of a process, or do you intend to bring your physical sex appearance, and/or your gender role, more in line with your gender identity?	
No	98% (171)
Prefer not to say	2% (4)
Ethnicity	
White: British/English/Northern Irish/Scottish/Welsh	91% (156)
White: Irish	1% (2)
White: Any other White background	5% (9)
Any other ethnic group	1% (1)
Prefer not to say	1% (2)
Not known	1% (1)

Demographics

Demographic	Percentage (number)
I am a veteran	7% (16)
I work in farming/agriculture	1% (2)
I work in health and/or social care	11% (25)
I am a new parent	0% (1)
I am a carer	10% (23)
I belong to the LGBTQ+ community	4% (9)
I have a long-term health condition	70% (154)
I consider myself to be neurodiverse	5% (10)
I have a disability	26% (57)

Contact Us

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If you require this report in an alternative format, please contact us at the address above.

We know that you want local services that work for you, your friends and your family.

That's why we want you to share your experiences of using health and care services with us – both good and bad. We use your voice to encourage those who run services to act on what matters to you.

Healthwatch Lincolnshire proudly delivered by HWLincs.

The Engagement to Insight People