



# Respiratory Disease and / or other Long Term Conditions in Local Area Partnership N4 Report



November 2023



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# Introduction and Background

West Northamptonshire Council and Healthwatch North and West Northamptonshire partnered up to conduct research within the community about the experience of individuals with respiratory conditions. The aim of this work was to address health inequalities and inequalities that surround respiratory care and outcomes. The aim of this project was also to better understand the experiences of those groups who are more vulnerable to health inequalities, respiratory conditions and other long term conditions such as cardiovascular disease in the local communities living in the N4 Local Area Partnership (LAP). The ambition of this work was to better understand the participants experiences of accessing support and wellbeing services, to hear the personal experiences of their respiratory conditions and from this, to be able to use the data to help shape the structure of care and support in the future.

Respiratory conditions are diseases that cause breathing difficulties<sup>1</sup>. For this project there was a wide range of respiratory conditions considered in the data collection and feedback. The signs and symptoms of respiratory disease may include shortness of breath, especially during physical activities, wheezing, chest tightness, frequent respiratory infections, and a chronic cough that may cause mucus (sputum). The common respiratory conditions include; asthma, chronic obstructive pulmonary disease (COPD) which includes emphysema and chronic bronchitis, lung cancer, infections such as pneumonia, flu, and long Covid, and less common diseases such as interstitial lung disease and mesothelioma. Some chronic smokers develop clinically apparent COPD. They may be misdiagnosed as having COPD until a more thorough medical evaluation is performed. Not all smokers develop COPD.

The aim of this project was to hear from individuals within the N4 Local Area Partnership (LAP), which covers the local areas of Northampton within the West Northamptonshire Council (WNC) including Electoral Wards of Castle, Abington & Phippsville, St George, and Dallington Spencer. This LAP area was selected because of West Northamptonshire Council's identification of this being an area which has respiratory disease as a community priority for action. The purpose was to connect with individuals within these areas who experience respiratory

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<sup>1</sup> West Northamptonshire Council, Respiratory disease and other long-term conditions in Local Area Partnership

conditions and also experience health inequalities due to living in deprived areas and may be from inclusion health groups.

Our organisation partnered with Northamptonshire Carers Breathing Space support group, and Change Grow Live's Substance to Solution service to facilitate this project. We completed 3 focus groups with a total of 35 participants, out of those participants 29 chose to provide demographics and completed our focus group paper questionnaires.

### Northamptonshire Carers Breathing Space Service

Northamptonshire Carers Breathing Space is a locally funded resource for people with COPD and other lung-related conditions. It welcomes anyone within the community to attend and allows also for their unpaid carers to come along to their meetings and events<sup>2</sup>. Breathing Space has a team of specialist respiratory nurses, Wellbeing Practitioners, General Practitioners (GPs) and guest speakers from within the community who provide a holistic support service which covers both lung-health and wider wellbeing for those who need additional support. Their aim is to enable those struggling with breathing difficulties to find helpful ways and develop skills to ensure individuals can have a full life and improve their wellbeing. Breathing Space offer frequent meetings for individuals across North and West Northamptonshire, with a meeting specific to Northampton. The Northampton Breathing Space support location was the one which was chosen for this research project.

### Change Grow Live's Substance Misuse Service

Change Grow Live is a locally funded resource for individuals experiencing drug and alcohol misuse, or those who are recovering from drug and alcohol misuse and are seeking support. CGL is an organisation that aspires and is committed to delivering services that make a real difference in people's lives and the communities they serve<sup>3</sup>. Their services focus on rehabilitation and support for those individuals who are struggling with substance dependency. CGL's services include programmes such as Substance to Solution, Drug and Alcohol Service, and a Resettlement Service. According to the National Library of Medicine, it is

<sup>2</sup> <https://www.northamptonshire-carers.org/pages/events/category/copd-breathing-space?locale=en>

<sup>3</sup> <https://www.changegrowlive.org/substance-to-solution-northamptonshire/northampton>

reported that many individuals who experience alcohol and drug misuse also find an increase in the instances of respiratory illness and a decline in lung health and immunity<sup>4</sup>. CGL has Substance to Solution services in multiple areas of North and West Northamptonshire, their Northampton support service location was the one which was chosen for this research project.

### The purpose of our partnerships

Our partnership with Northamptonshire Carers Breathing Space allowed our organisation to access older individuals, vulnerable individuals, and individuals living in deprived areas.

Our partnership and research with Change Grow Live allowed our organisation access to those who are experiencing drug and alcohol dependence, homelessness, vulnerable individuals and individuals living in deprived areas. Both locations have service users who reside within the selected N4 LAP area.

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4590617/>

### Methods

For this project, West Northamptonshire Council was the lead for the project design and research. WNC designed the questions, key themes and topics which would be used within the research. This was done based on their previous identification of COPD as a community priority for action. The aim of this project was to understand people's experiences of managing long term conditions and the support that they currently receive and to identify the types of support individuals would like to have available to them, to better manage their health and wellbeing.

The key themes that were asked to be included as part of the research questions were the following:

- What conditions do the participants experience?
- How do participants currently manage their conditions (including helpful support and current challenges experiences)?
- What support would participants like to see available in the future and why?
- What level of understanding do participants have regarding the risk factors for developing long term conditions?
- What currently works to support this group's conditions and overall health?
- What action needs to be taken to support them further and what organisations are responsible?

The research was carried out via facilitated focus groups which enabled a group discussion with the participants. This was a valuable method because it allowed us to connect with the participants on a personal level, allowing for reflection, group discussion and the collection of quantitative data. Individuals were able to provide their opinions in a safe and confidential environment supported by their peers.

The Healthwatch representative began each session by introducing and explaining the purpose for West Northamptonshire Council and Healthwatch North and West Northamptonshire's partnership and the intended impact of the project. Participants were provided with a set of demographics and the

questions which would be covered in the focus group, these questions were both quantitative and qualitative.

It was explained that all answers would be kept anonymous and that the focus group participation and demographic questions were voluntary, and they could choose not to answer a question if they wished. We found the approach of providing participants with the focus group questions prior to the group discussion beneficial, as not everyone participating in a group setting will always feel comfortable speaking out loud, so we were able to gather additional valuable data. Participants were given sufficient time to look over and respond to questions individually, and then the group came together to discuss the topics and questions, which allowed for group discussion, peer support and reflection.

# Key Findings Discussion

Our findings from the focus group's demographic data were insightful, as it helped us to better understand the cohort of individuals involved in the group discussion. Those attending the Northamptonshire Carers Breathing Space group were of an older demographic, and those attending the Change Grow Live group were of a middle-age demographic. The average demographic of the two Breathing Space focus groups was 73 years old, female, White in ethnicity, and non-working. With the majority of the participants being elderly, this highlighted their potential vulnerability, as these individuals reside within a deprived area and have a reduced income<sup>5</sup>. Also, these participants reported experiencing effects from their conditions such as mobility and breathing impairments, and these effects can attribute to potential vulnerability. The average demographic of the CGL focus group was 45 years old, female, equally diverse with participants being White, Asian and Asian British, and Black, African, Caribbean or Black British and unemployed. Our focus group with CGL reflects the voices of those individuals who have experienced substance misuse and who are working towards substance recovery, as well as those without stable housing.

The most common respiratory condition experienced by participants was COPD, followed by asthma and bronchiectasis. One of the aims of this project was to better understand how individuals are self-managing and supporting their condition, as well as how they are maintaining their overall wellbeing and health. From speaking with individuals within these focus groups, participants were able to express their views and discuss as a group the aspects of their conditions which they found challenging, and what could be improved with the services they accessed in the future.

Participants shared methods that they use to support and manage their condition which were:

- Attending breathing support groups
- Accessing doctors and respiratory nurses
- Using the internet for support, physical activity
- Receiving education about the condition
- Utilising medications

<sup>5</sup><https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3672844/>



- Through the support of family and friends
- Socialising
- Eating well and maintaining a healthy diet.
- Physical activity

Participants discussed the importance of staying active and ensuring they prioritise exercise for their conditions, they expressed that if they do not, their conditions worsen. Many felt they understood the risks of their long term conditions, some mentioned the importance of avoiding interactions with individuals who may currently be sick in order to avoid further sickness and infections. Participants noted that certain seasons and climates exacerbated their condition and stated that avoiding certain environmental elements, such as smoke was important, as it would aggravate their condition.

Participants expressed the positive impact attending support groups have had on their condition, having a place to meet with individuals experiencing the same conditions was important because they did not feel alone. They felt that the support groups such as Breathing Space helped improve their knowledge about their long term conditions and helped inform participants of new ways to cope with their condition and support their health and wellbeing.

Participants discussed the challenges they faced with their conditions and expressed frustration with trying to access support online, given the concern that there can be misinformation online and that it can be difficult when you don't know where to go for factually accurate information. A participant stated "It is difficult if you have to do it online". This may be correlated to the older demographic and possible instances of digital exclusion, however this highlights the need for increase guidance for digital health and wellness support. There was also concern over the ability to access doctors and GP services, but some participants expressed that once they were able to connect with a doctor, they felt they could gather helpful information and support. It was noted that those participants in the CGL group felt that information and support for respiratory conditions should be shared with places such as rehabilitation centres and support services for example dry houses<sup>6</sup>. One CGL participant said "Seeking and accessing the right services for my condition can be difficult".

<sup>6</sup> Dry houses are also known as 'halfway houses' these provide recovering drug or alcohol abusers with a place to have security and support as they adjust to their new life after addiction- typically dry houses are used after rehabilitation.

<https://www.uk-rehab.com/treatment-rehab/the-need-for-halfway-houses-following-rehab/>

Participants also discussed their need for more involvement from GP services and highlighted the inability to access adequate continuity of care. This is often due to the high volume of calls into practices and the inability to provide appointments without long wait times.

Participants discussed the difficulties they faced with certain daily tasks and actions, these challenges correlated with their reported conditions such as limited mobility and breathing. Many participants noted that they struggled with walking, daily activities of living such as household chores, gardening, and breathing troubles. These difficulties correlate with the majority of the participants having a disability. Participants expressed that there would be great benefit of being assisted with these tasks.

# Recommendations

Based on the feedback from the participants when expressing their needs and what they would like to see offered within the community, we have made the following recommendations.

1. Increase the number of respiratory support groups locally, specifically within the N4 LAP area
  - a. Ensure these support groups offer one-on-one support
  - b. No referral necessary to join the groups

One of the actions necessary to further the support for the participants would be to increase the number of respiratory support groups locally within the N4 LAP area. In addition to an increase of support group services, there would be great benefit in a service that offers one-on-one support. Some participants attributed their successful management of their condition to be because of their breathing support group attendance, stating that they are a large part of their wellbeing maintenance. Participants voiced their desire to be able to access services independently, without needing a GP or professional referral, a Breathing Space group participant said “We need self-accessible and self-referable services for people to use to support our conditions”.

2. Improve the available public transportation routes, to enable individuals to access more support

There are currently no respiratory condition support groups within the N4 LAP area, resulting in individuals needing to travel to access these groups. Public transport was raised as an issue for individuals as the lack of available transport stopped some from accessing health services and appointments. This could directly relate to the inability to attend current supports, therefore an increase in public transport routes would allow for better access to services.

3. Continue to fund the current available breathing condition supports, like Breathing Space and RESTART

It is important that support groups like Breathing Space and resources like RESTART (RESTART is an NHS Respiratory and Chest clinic offered at Northampton General Hospital which offers clinical care and support for patients with COPD)<sup>7</sup>

<sup>7</sup><https://www.northamptongeneral.nhs.uk/Services/Our-Clinical-Services-and-Departments/Medicine/Respiratory-Chest-Clinic/Respiratory-Chest-Clinic.aspx>

are continued to be funded, as they offer valuable care and support.

4. Encourage GPs and Respiratory care teams to increase their support of their patients with respiratory conditions
5. Increase the amount of available educational respiratory condition materials and increasing the guidance given for online support resources
6. Provide community support services like rehabilitations and dry houses with educational material to help support and manage their service users respiratory conditions

Participants expressed the need for better access to GP support, including increased GP appointments and regular reviews for their breathing conditions. A Breathing Space participant stated, "Doctors and GPs could be more involved with my condition". The frequency of information being shared from GPs and care teams to patients with respiratory conditions needs to be increased. It is recommended that local health services increase the information and education that they provide, as well as making it clear to patients where they can access accurate information online. It was discussed that many participants found the act of having to seek out information to support their condition difficult and often felt confused by the information available online, finding the information to be misleading or inaccurate. A piece of feedback received from the focus group at CGL was that rehabilitation centres and supports like dry houses, could benefit from offering breathing support and signposting to their service users, as they did not feel that any educational information or signposting was offered. We recommend that informational materials such as flyers and up to date guidance be distributed to substance misuse services and homeless services, so that service users can seek out additional support and help when needed.

7. Continue to campaign for healthy eating and healthy choices across the community to help support and guide individuals
8. Develop exercise groups tailored to those with respiratory conditions to encourage individuals with respiratory and other long term conditions to stay active.
9. Develop a service that could offer support for household and gardening chores to those with severe and diagnosed respiratory conditions
  - a. Provide this service at little to no cost for those who are low income

Participants emphasised the importance of healthy eating and drinking in moderation, stating that this was necessary for their health maintenance. It is encouraged that the Council's campaigns for healthy eating across the community continue, as these help to support and guide individuals.

Participants emphasised the importance that regular physical exercise and movement have on their conditions. Participants expressed that it would be beneficial to have community support offered for exercise, a Breathing Space focus group participant said "more exercise support locally in our community would be helpful". It is recommended to focus on increasing exercise and wellbeing support from within the area, so that those suffering with a respiratory condition can be offered more opportunities to stay active. This could be done through offering frequent low impact exercise groups specifically tailored to those suffering with respiratory and other long term conditions to be attended within the N4 LAP area, for example: a walking group or a group teaching seated exercises.

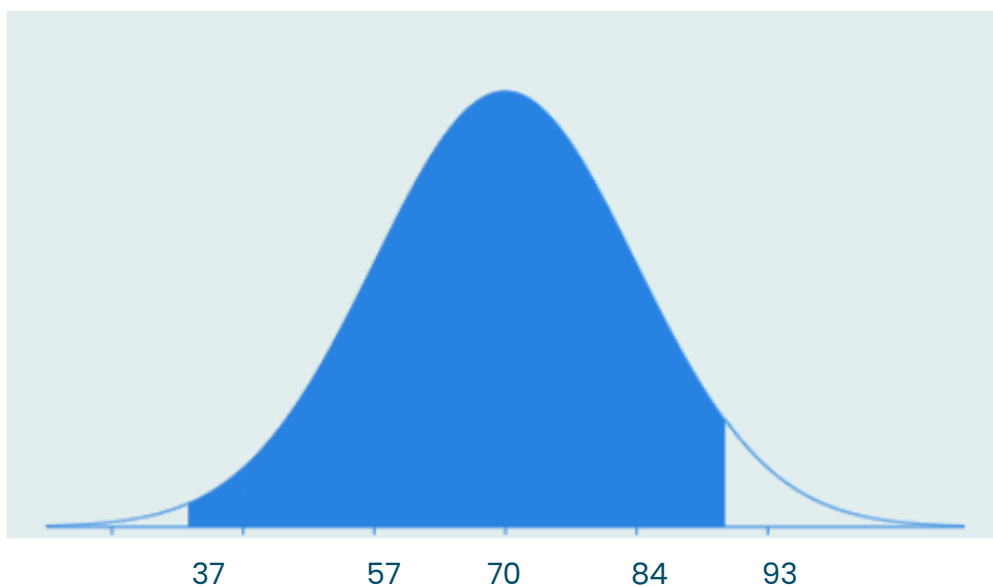
A challenge that participants faced was the inability to complete household chores and necessary daily living activities around their homes. Due to this need for daily living support, the development of a service that could offer a "helping hand" for household and gardening chores to those with severe and diagnosed respiratory conditions would be highly beneficial. The implementation of this service would also require that the service be offered at little to no cost, to those who would qualify if an individual was of a low income status.

## Key Data and Results

### Demographics

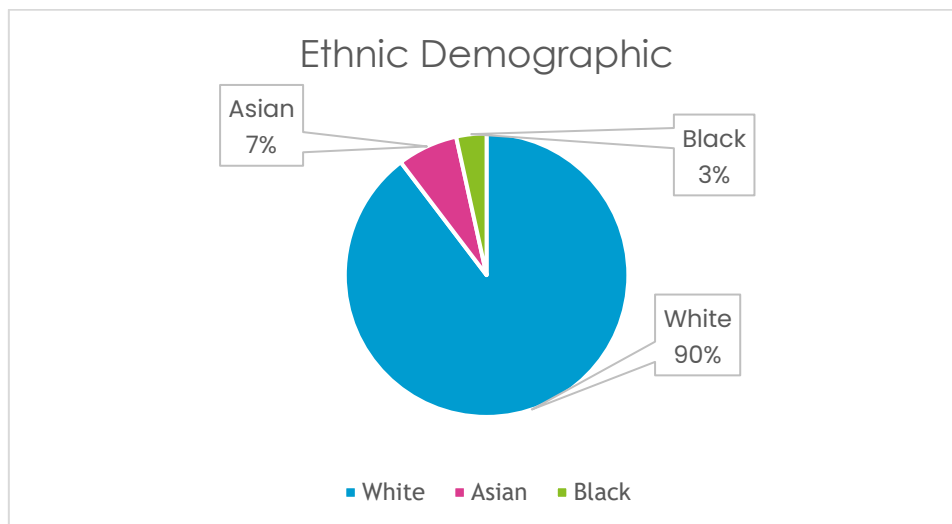
As part of the respiratory project, participants were asked to fill out a demographics survey, of the 35 participants 29 chose to answer demographics, this helped to give insight into participants. Participants were asked about their ages. The average age across the three focus groups was 70 years old, see the data spread in the Age Range Chart below.

Age Range Chart



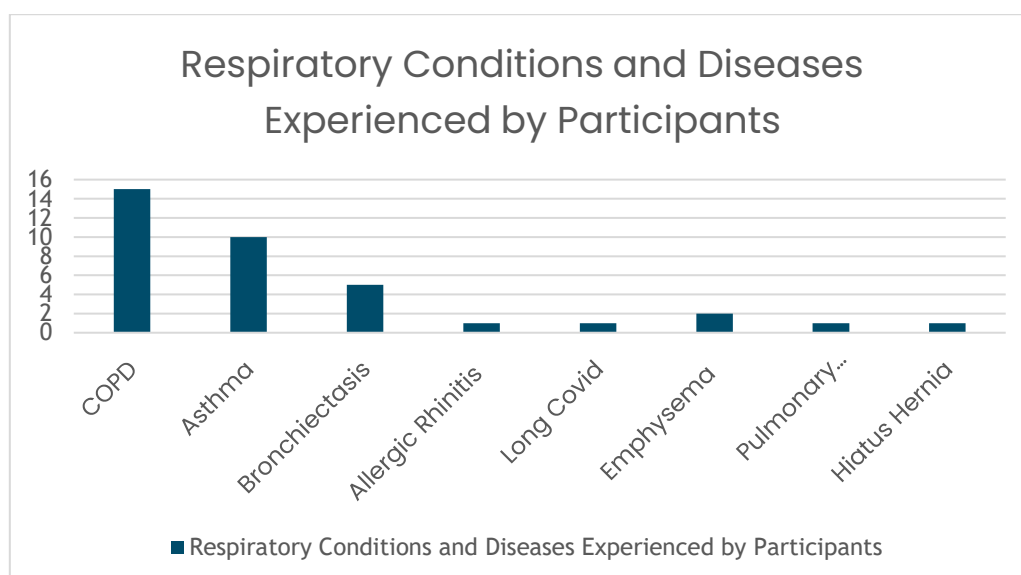
For the CGL focus group the average age of the participants was 45 years old. The average age of the participants in the Breathing Space group was 73 years old. This reflects an older cohort of individuals attending the Breathing Space group and a younger cohort of individuals attending the CGL group. Participants were asked about their current employment status, 48% were retired and 41% were unemployed, of the 11% that were currently working the average pay was £32,000 per year.

The majority of participants (83%) were female, with only 17% being male. The majority of participants (90%) were White in ethnicity, 7% were Asian and Asian British and 3% were Black, African, Caribbean, or Black British. The participants were asked to identify their sexuality: 85% of participants stated they were heterosexual or straight, 8% were bisexual, 4% were gay or lesbian, and 4% stated that they preferred not to say.



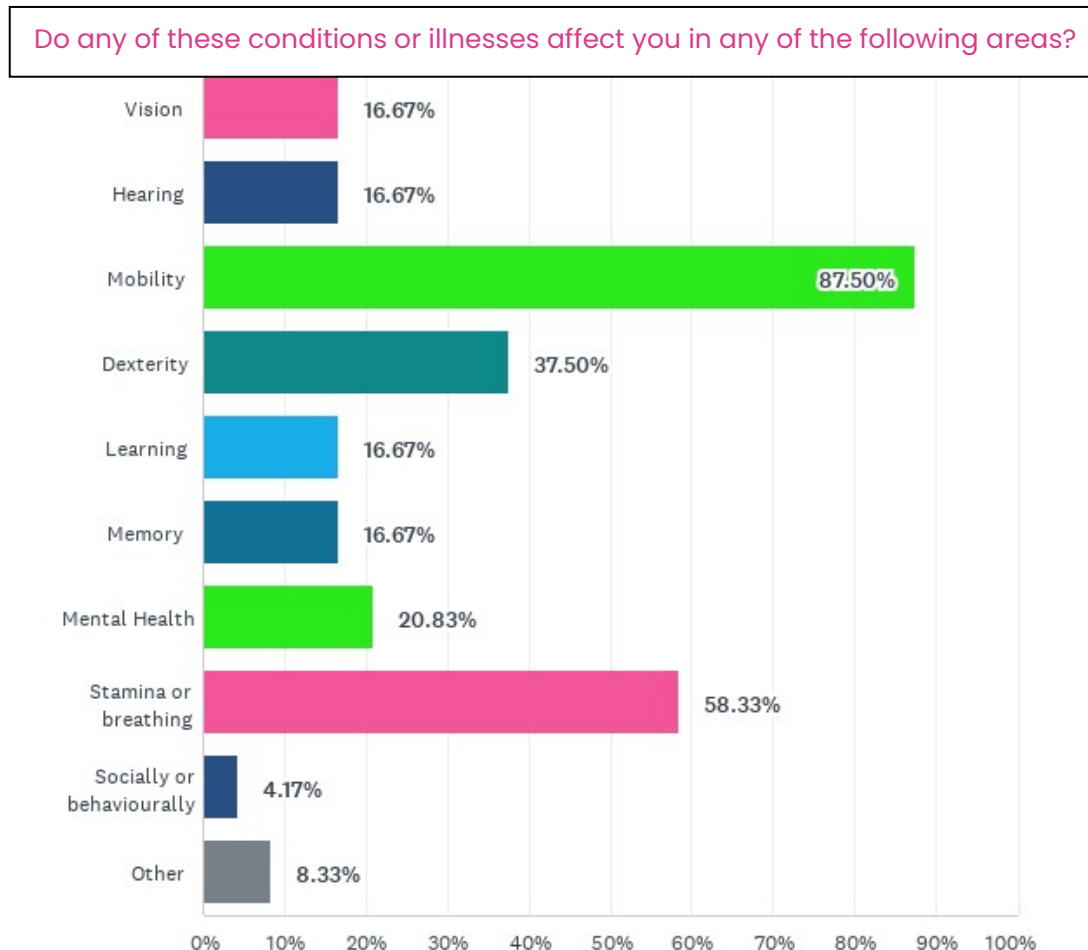
### Respiratory Conditions

Participants were asked about what conditions they experienced, both respiratory and other long term conditions. The predominant condition that participants experienced was COPD with 52% of participants being diagnosed with the condition. The second most common condition was asthma, which affected 35% of participants. The third most common condition was bronchiectasis which affected 17% of the participants. Other respiratory conditions experienced by participants were; allergic rhinitis, long COVID, pulmonary fibrosis(IPF), hiatus hernia and emphysema. All conditions were medically diagnosed.



Participants were also able to identify any other long term conditions, those which chose to included these conditions; mental health, atrial fibrillation, kidney failure, arthritis, and diabetes. We asked the participants if they considered themselves to have a disability. It was identified that the majority of

the respondents did consider themselves to also have a disability, with 78% saying that they did have a disability. We asked participants if their respiratory conditions or illnesses affected them in any other areas of physical health and mental health. The chart below details the findings.



It was found that the majority of individuals (88%) had mobility issues, these included walking short distances and/or climbing the stairs. 58% of individuals reported that they had stamina or breathing or fatigue. These issues reported with mobility and stamina and breathing difficulties is likely to be related to their breathing conditions, due to the limitations of their breathing conditions. 37% of participants reported experiencing dexterity problems, when completing actions such as lifting and carrying objects or using a keyboard. 21% of participants reported having mental health issues, this may be related to their condition and the struggles they experience from it's potential limitations. Less than 20% of participants stated that their respiratory conditions or illnesses affected them in these areas: vision including blindness or partial sight, hearing including deafness or partial hearing, learning or understanding or concentrating, and memory. Less than 10% of participants stated that their



respiratory conditions or illnesses affected them in these areas: Socially or behaviourally such as being associated with autism spectrum disorder, which includes Asperger's and attention deficit hyperactivity disorder and in other ways not listed.

### Management of Condition

The participants were asked a variety of questions concerning their respiratory condition/s, and how they have accessed support and managed their health and wellbeing, these responses were thematically analysed. Participants were asked if their conditions were currently being treated medically, the majority of participants said yes, however those who said no, detailed the reason being that there was currently nothing medically that could be done to support their condition. Participants were asked about the methods and helpful supports which they utilise to manage their respiratory conditions. From their responses, themes were identified these themes are detailed below:

- Education from resources like Restart and Breathing Space
- Support groups
- Keeping an active lifestyle ( ex: walking, swimming)
- Medications such as inhalers and nebulisers
- Easy access to a doctor or nursing team
- The help of family and friends

Participants were asked how they look after their health and wellbeing, participants discussed a variety of ways in which they were able to look after their wellbeing, and some expressed the ways in which they struggled to do so. Some of the methods which participants used were as follows:

- Through regular exercise such as walking
- By maintaining a good diet and drinking with moderation
- Staying hydrated
- Maintaining quality sleep
- Avoiding environmental toxins like fumes and smoke
- Attending support groups
- Socialising
- Avoiding interactions with sick and contagious individuals

In the focus group it was discussed their level of understanding of the risk factors of their long term conditions and possible worsening of their conditions,

participants emphasised the importance of staying active for their health and wellbeing. The importance of keeping moving ensures that their condition will not worsen. Ensuring that participants have access to the right information and medical advice ensures that they can continue to manage in the best ways possible. The importance of staying vigilant and away from those who may be sick or contagious ensures that they can avoid further sickness and any potential infections or complications.

Participants were asked about the challenges they faced when managing their respiratory condition, the themes that were identified are detailed below:

- Accessing support through their GP
- Lack of direct pathway for support when needed
- Environmental issues such as climate and seasons
- Environmental issues such as smoke
- Physical activities such as stairs, walking and household work
- Financial impacts from their conditions
- Chest infections or flare-ups from their conditions

In order to properly manage their respiratory conditions, participants were asked where they go to access information to help support their health and wellbeing. The resources discussed are detailed below:

- Online
- Online support groups
- Social media
- GP
- Respiratory Nurse
- Pharmacist
- Breathing Space
- Restart team
- Signposting through services
- Leaflets
- 111
- NICE guidelines

Participants were asked about how they found their experiences were of accessing information, advice and/or support for their health and wellbeing, there was a mix of positive and negative experiences. These responses were thematically analysed and separated between positive, neutral and negative

experiences. Participants who found their experience of accessing information advice or support to be positive stated that:

- Once referred it was fairly easy
- Generally good
- Support received through restart had been brilliant
- Support received through Breathing Space was effective
- GP had been helpful

Neutral experiences were as follows:

- Okay or Adequate
- Mixed, when able to see a GP the care and advice is good, but actually getting an appointment can be stressful
- NHS care can be “hit and miss”
- Dependent on the council and where you are living

Negative experiences were as follows:

- Encountering misinformation on the internet
- Not enough information on how to access support and advice
- Too many options can feel confusing
- Trouble accessing GP appointments to receive support
- A lack of continuity of care
- GPs not being helpful

Participants were asked what type of support would better help manage their conditions. The participants stated that they would benefit from the following:

- Increased reviews and regular contact from doctors and nurses
- More one-on-one support
- More community support groups like Breathing Space
- Better access to GP support, including access to doctors and appointments
- Better community/public transport
- More exercise
- Support with strenuous activities and home chores/tasks

Participants were asked about what type of service, delivery model and location would best fit their needs and who could best deliver this type of support/service, as well as how it could be delivered. The participants suggested:

- More one-on-one services
- More involvement from the GP and doctors services
- More community groups like Breathing Space
- Continuing to support services like Breathing Space, which is beneficial to providing support and a community of individuals who experience similar issues.
- Increased bus services for accessing services
- A service easily accessible without having to go to the GP or without the need for a professional referral
- Exercise support

# Acknowledgements

Healthwatch North and West Northamptonshire is grateful for the time and efforts of Breathing Space run by Northamptonshire Carers, and from Change Grow Live. Both organisations kindly donated their time for assistance in planning our research and allowed us access to their service users for these respiratory focus groups. Thank you for your support.

We would also like to thank the West Northamptonshire Council for the opportunity to carry out this research within our community. This project has given us the ability to better understand the experience of individuals within the Northampton N4 LAP who experience respiratory issues.

## About Healthwatch North and West Northamptonshire

Healthwatch North and West the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch North and West Northamptonshire and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at [www.healthwatchnorthamptonshire.co.uk](http://www.healthwatchnorthamptonshire.co.uk)

**healthwatch**  
North Northamptonshire  
West Northamptonshire

## About Connected Together

**Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch North and West Northamptonshire.**

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

**Find out more at [www.connectedtogether.co.uk](http://www.connectedtogether.co.uk)**



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