Protecting and Promoting Respiratory Health in Northern Ireland

NICHS Respiratory Manifesto 2023

MAKING IT EASIER FOR ALL OF US TO BREATHE

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Northern Ireland has been without a Services Framework for Respiratory Health and Wellbeing since 2018. The previous framework had 56 standards to improve respiratory services in NI. Sadly, this was not delivered, and services did not improve due to a lack of political and health service leadership and investment. As a result, Northern Ireland Chest Heart and Stroke (NICHS) is now calling on the Department of Health and policy makers to make respiratory health and services a priority area for action.

Thank you to the over 300 people living with lung conditions who took the time to respond to our recent survey.Their views have informed our asks in this manifesto.

NICHS and our respiratory community want to see reforms across a number of areas to improve lung health for the people of NI.

These are:

- **Prevention, early detection and awareness**
- **Air quality**
- **Smoking prevention and cessation**
- **Asthma**
- **Chronic Obstructive Pulmonary Disease (COPD)**
- **Bronchiectasis**
- **Interstitial Lung Disease (ILD)**
- **Sleep Apnoea**

Our Family Support Service is here to provide practical advice and support to anyone living with a respiratory condition and their family.

Our Inspire Choir is offered to those with chest conditions as singing helps to significantly improve breathing and general lung function.

Our Respiratory Manifesto

Northern Ireland Chest Heart and Stroke is calling for:

1. **Improve air quality.** NICHS supports the creation of a Clean Air Strategy for Northern Ireland.

2. **A new Lung Health Strategy** which integrates and transforms respiratory services in primary, community and secondary care.

3. **Detect and diagnose respiratory problems earlier.** Identify and record people living with undiagnosed lung conditions such as COPD,Sleep Apnoea, Asthma and Interstitial Lung Diseases to ensure they receive information, support and treatment.

4. **Ensure patients have equal and appropriate access to the best medications** in Northern Ireland for their conditions, similar to other parts of the UK. Initiatives should be put in place to try to improve medicine adherence.

We campaign for the introduction of health policies and changes in legislation that will lead to improvements in the care and treatment of chest illnesses.

5. **Reduce tobacco use and support smokers who wish to quit.** We are calling for a new, ambitious Tobacco Control Strategy focusing on addressing health inequalities and use of E-cigarettes, which would aim for less than 5% of people smoking by the mid-2030s. A consistent policy decision is also required to ensure smokers with COPD or severe asthma can access oxygen therapy if eligible. Unfortunately, there is currently inconsistent practice around this issue across NI which is unfair and inequitable.

6. **Integrated respiratory care units, hubs and services.** We need to provide excellent, specialised, safe and high-quality early detection, treatment, rehabilitation and care services for children, young people and adults.

7. **Evidence-based and patient-focused integrated pathways** for Asthma, COPD, Bronchiectasis, Interstitial Lung Disease and Sleep Apnoea.

8. **The right to rehabilitation.** Everyone should have access to high quality, personalised community rehabilitation – when they need it.

9. **Investment in, and development of, the respiratory workforce.** To meet the need, we need to increase the number of community-based respiratory specialist nurses, respiratory physiologists, and other allied healthcare professionals.

10. **Reform the GP contract in the absence of QOF.** We must ensure GP services conduct annual reviews and spirometry tests for people with asthma and COPD. They need to allow adequate time for first appointments with newly diagnosed patients, so they can check the patient can use their medication correctly, such as asthma inhalers.

11. **Make asthma a priority.** We need to take action to ensure the basics of asthma care and treatment are in place so that deaths from asthma, particularly deaths of children, become increasingly uncommon in Northern Ireland. All relevant healthcare professionals must be trained in inhaler use and technique.

The Burden of Respiratory Conditions

174,706 people

or **9.2%** of the population have been diagnosed with a respiratory condition.

9%

Deaths due to Respiratory Conditions: 4 per day

1,555 deaths due to respiratory conditions in 2021.

COPD

Almost 43,000 people have been diagnosed with Chronic Obstructive Pulmonary Disease (COPD) in Northern Ireland. As many as 24,000 people could be living with COPD undiagnosed.

The majority of these people have mild or moderate COPD but if they were diagnosed early they could take the necessary steps to improve the outcome of their disease. COPD is progressive and cannot be cured, however, timely and accurate diagnosis, with supportive ongoing management can help modify the impact of the disease, helping people to self-manage more effectively and thereby reducing the need for hospital admission. NICHS is proud that our Breathing Better programme (which is entirely funded by NICHS) can help some of these people but unfortunately only reaches a tiny percentage of those who could benefit.

It is therefore vital that patients receive a quality-assured diagnosis at the earliest opportunity to commence appropriate treatment and to slow the progression of the disease for the individual. This can also reduce the impact on carers and on the burden of long-term management and its related costs.

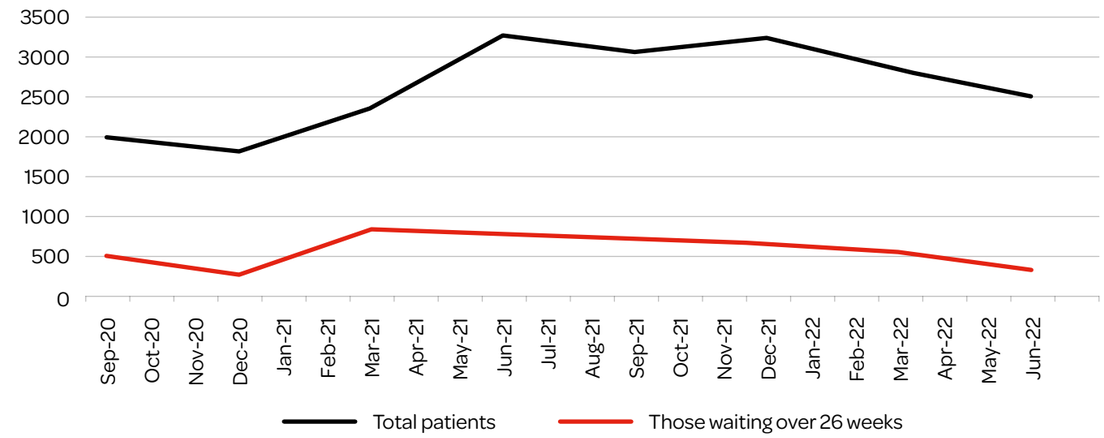
It is essential that the care received is also enhanced. Across the UK, over three quarters (75.5%) of patients did not receive the five fundamentals of COPD care as set out in NICE clinical guidelines, according to the Asthma + Lung UK report 'Failing on the Fundamentals'[2].

According to the report the situation is even worse in the devolved nations. In Northern Ireland only 13.5% of people received the five fundamentals of care. (In Scotland the figure is 17.2% and in Wales 17.4%).

Spirometry Waiting Lists

In addition, the capacity to diagnose patients with lung conditions using the necessary objective tests remained low throughout 2021. Spirometry remains a core tool in diagnosing lung conditions early. Unfortunately, as with the rest of the health service in Northern Ireland, there are now significant waiting lists. The graph shows a 76% rise in the number of people waiting between December 2020 and December 2021. More encouragingly the total number of patients waiting as well as those waiting over 26 weeks is now declining.

Figure 1: Spirometry waiting lists in NI, Sept 2020 - June 2022

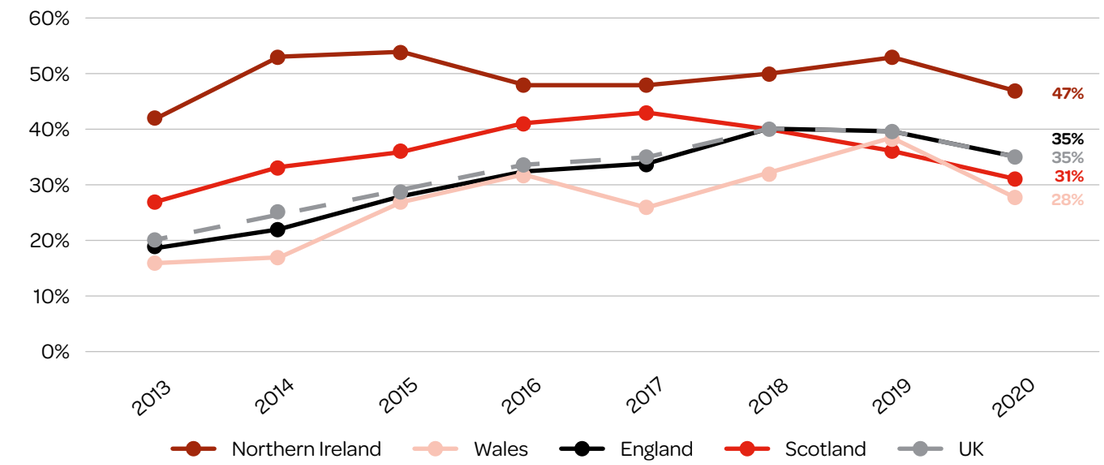


Asthma

Almost 132,000 people in NI are diagnosed with asthma and another 20,000 may be living with the condition undiagnosed. NICHS is collaborating with clinicians to improve awareness of issues surrounding asthma and the knowledge of healthcare professionals, parents, children and young people about the basics of asthma management including proper inhaler technique.

The annual Asthma + Lung UK survey continually shows that Northern Ireland has better asthma care than other parts of the UK. It has, however, declined in recent times and the overall figure hides considerable geographic disparities.

Figure 2: Basic care trends across the UK, 2013-2020



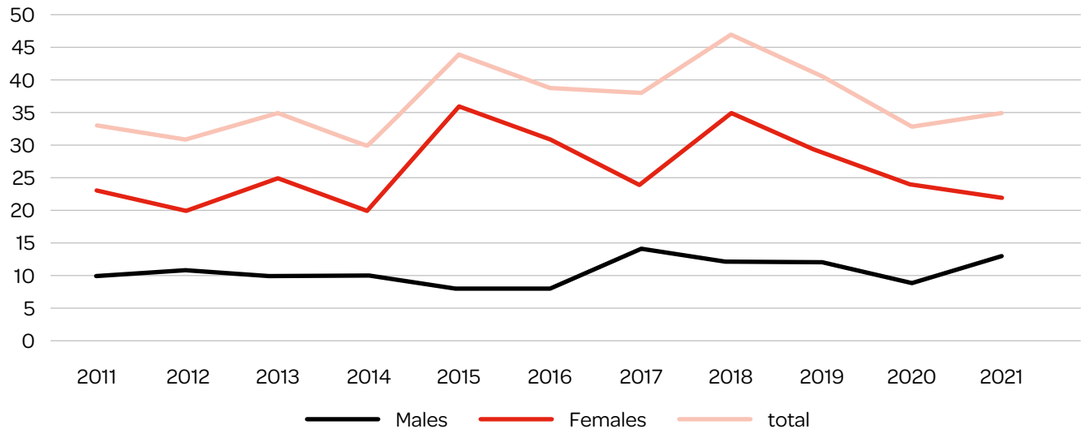
Overall, the UK performs very poorly in asthma management and has one of the worst asthma death rates in Europe.[3] Experts suggest the poor UK ranking could be due to patients missing basic asthma care, and a lack of awareness about the seriousness of asthma.

[1] an Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England, Department of Health, July 2011

[2] https://cdn.shopify.com/s/files/1/0221/4446/files/COPD_survey.pdf?v=1636977618&_ga=2.256772104.2002291521.1657278101-110646046.1627990829

[3] https://www.asthma.org.uk/about/media/news/press-release-uk-asthma-death-rates-among-worst-in-europe/

Figure 3: Asthma related deaths in NI, 2011-2021



We need the Department of Health, the Trusts, the Public Health Agency, and the Department of Education to make asthma a greater priority.

Obstructive Sleep Apnoea

Obstructive Sleep Apnoea (OSA) presents a major healthcare challenge. Asthma + Lung UK estimate that at least 13% of adult men and 6% of adult women are living with Obstructive Sleep Apnoea in NI. Promoting awareness and improving access to diagnostics are fundamental in ensuring cases are not missed in order to prevent the recognised complications associated with untreated OSA. Diagnosis usually occurs in secondary care however there may be long wait times to undertake tests, reach a diagnosis and start treatment.

In 2014 an Office for Health Economics study commissioned by the British Lung Foundation estimated that 18,000 adults in NI had moderate to severe OSA and that 9,000 were being treated. In fact, NICHS discovered via a Freedom of Information Act request that in 2014 and in the five previous years less than 1,000 people per year were being treated for sleep apnoea. Undiagnosed OSA is strongly associated with serious health problems, including hypertension, diabetes, stroke and heart disease. More action needs to be taken to quantify the scale of the problem, to increase diagnoses, and to put in place treatment on a consistent basis across Northern Ireland.

Bronchiectasis

Bronchiectasis is a condition characterised by chronic sputum production and frequent lung infections, often requiring hospital admission affecting 1 in every 1000 people in Northern Ireland. Physiotherapy has a significant role in Bronchiectasis management, helping to reduce infections and hospital admissions.

Interstitial Lung Diseases

Idiopathic Pulmonary Fibrosis (IPF), the most common Interstitial Lung Disease (ILD), has increased in prevalence over the past 20 years affecting over 1,200 people in Northern Ireland, the highest IPF prevalence rate in the UK. Whilst the cause of some ILDs is unknown, some are caused by cigarette smoke, and others are linked to a reaction to medication, asbestosis, and farmer's lung.

What Should NI Be Doing?

Improving Air Quality

NICHS is concerned about the current and future impact of poor air quality and air pollution on our health. We are calling for further action to limit these effects. Air pollution can exacerbate existing conditions, including respiratory diseases.

NICHS supports the creation of a Clean Air Strategy for Northern Ireland and a broad range of measures to tackle air pollution including:

- Increased investment in public transport and the promotion of electric vehicles, cycling and walking.
- Measures to improve the insulation of homes, measures to discourage the burning of solid fuel and increased awareness and enforcement of Smoke Control Areas.
- More extensive monitoring, more planning of concerted action and better communication regarding air quality.

Developing a New Lung Health Strategy

The above actions must form part of a new Lung Health Strategy. In 2015 the Department of Health published the Services Framework for Respiratory Health and Wellbeing, outlining 56 standards to improve respiratory services over a three-year period. Sadly, very little progress was made regarding many of these.

Evidence-based and patient-focused integrated pathways for lung conditions must form an essential part of a Lung Health Strategy.

Detecting and Diagnosing Respiratory Problems Earlier

Currently around one third of people with a first hospital admission for a COPD exacerbation have not been previously diagnosed[4]. Primary care needs to be enhanced to support the diagnosis of respiratory conditions – including improved access to spirometry. More staff in primary care need to be trained and accredited to provide the specialist input required to interpret results.

More Education and More Support

We need to do more to increase awareness, prevention, treatment and care for people living with lung conditions amongst the public, health professionals and policy makers, in order to improve lung health and reduce health inequalities.

We also need to support those with respiratory disease to receive and use the right medication. In many parts of the country 90% of NHS spend on asthma goes on medicines[5], but incorrect use of medication can also contribute to poorer health outcomes and increased risk of exacerbations, or even admission to hospital. Prescribing pharmacists need to be facilitated to undertake a range of medicine reviews, and to work with other healthcare professionals to educate patients on the correct use of inhalers and compliance with the medication prescribed for their condition.

[4] Bastin, AJ., Starling, L., Ahmed, R., Dinham, A., Hill, N., Stern, M. & Restrick, LJ. (2010) High prevalence of undiagnosed and severe chronic obstructive pulmonary disease at first hospital admission with acute exacerbation. Chronic Respiratory Disease. 7(2) 91–97. Available from: https://doi.org/10.1177/1479972310364587

[5] NHS Networks. (2013) 2012-13 programme budgeting PCT benchmarking tool (Data File). Available from: https://www.networks.nhs.uk/nhs-networks/health-investment-network/news/2012-13-programmebudgeting-data-is-now-available

Chest Heart & Stroke

Improving Tobacco Control and Support

NICHS has been at the forefront of campaigns for stricter controls on tobacco for many years and welcomes the many measures introduced to date including the ban of smoking in cars with children. There has been a welcome drop in the numbers of people smoking but too many continue to smoke, particularly in deprived areas. Smoking accounts for as many as 8 out of 10 COPD deaths. Smoking is both a cause and outcome of health inequalities. The rate of Respiratory Mortality among under 75's in the most deprived areas of Northern Ireland is over 3.5 times that in the least deprived areas. NICHS is also concerned about the potential harm from vaping. Vaping may assist some to quit smoking and lower their cancer risk, but it may lead to increased respiratory health issues and possibly cardiac issues too.

- NICHS is calling for a new, ambitious Tobacco Control Strategy with a focus on addressing health inequalities that aims for less than 5% of people smoking by the mid-2030s.
- In line with the precautionary principle, we believe the age for sale of tobacco and vaping products should be raised to 21.
- A regional policy decision must be made about whether smokers living with COPD or severe asthma can access oxygen therapy if eligible.

Providing Integrated Respiratory Care Units, Hubs and Services

We need to provide excellent, specialised, safe and high-quality early detection, treatment, rehabilitation and care services for children, young people and adults.

In England the NHS announced in October 2020 that it was developing Community Diagnostic Hubs or 'one stop shops' across the country, away from hospitals, so that patients can receive life-saving checks close to their homes[6]. This was based on the premise of having 3 hubs per million of population and these would be based away from acute hospitals.

Professor Sir Mike Richards was commissioned by NHS Chief Executive Sir Simon Stevens to review diagnostic services as part of the NHS Long Term Plan.

The Taskforce for Lung Health, a large collaboration of organisations and individuals, produced a report in 2018 and continues to monitor and press for improvements. Its key recommendations included:

- Establish a new pathway with a diagnostic hub in every local health system to improve access to the right assessment for people with complex cases of breathlessness and cough.
- Collect and publish data to establish a baseline for how long it takes people with respiratory symptoms to get a diagnosis and start treatment for different conditions.

Increasing Availability of Rehabilitation

We need to increase access to all forms of rehabilitation. Pulmonary rehabilitation offers a structured exercise and education programme designed for those with lung disease or breathlessness. 90% of patients who complete the programme experience improved exercise capacity or increased quality of life[7]. By expanding pulmonary rehabilitation services exacerbations can be prevented and admissions avoided. To increase access to pulmonary rehabilitation, a population-management approach could be used in primary care to find eligible patients from existing COPD registers who have not previously been referred to rehabilitation. Those with mild COPD should be offered self-management support.

Investing in and Developing the Respiratory Workforce

To meet the need, we must increase the number of community-based respiratory specialist nurses, respiratory physiologists, and other allied healthcare professionals.

Improving Primary Care Support

We must ensure GP services conduct annual reviews and spirometry tests for people with asthma and COPD. They need to allow adequate time for first appointments with newly diagnosed patients, so they can ensure patients can use their medication correctly, such as asthma inhalers.

All relevant healthcare professionals must be trained in inhaler use and technique to ensure that basic asthma care is provided to reduce its burden in NI.

Our Breathing Better Walking Groups support people with chest conditions to exercise in a safe environment, at their own pace.

[6] https://www.england.nhs.uk/wp-content/uploads/2020/11/diagnostics-recovery-and-renewal-independent-review-of-diagnostic-services-for-nhs-england-2.pdf

[7] Royal College of Physicians (2017) National Asthma and COPD Audit Programme (NACAP). Available from: https://www.rcplondon.ac.uk/projects/national-asthma-and-copd-audit-programme-nacap

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Find out more and join our campaign to improve lung health for people in NI by emailing your details to **campaigns@nichs.org.uk**

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