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## **IMPROVING CARE FOR PEOPLE WITH CHRONIC RESPIRATORY DISEASES**



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## EXECUTIVE SUMMARY

**Chronic respiratory diseases (CRDs) are a collection of conditions that affect the airways and other structures of the lungs.**<sup>1</sup> Some of the most common CRDs are chronic obstructive pulmonary disease (COPD), asthma, occupational lung diseases and pulmonary hypertension.

**CRDs place a significant burden on individuals, societies and economies, but they are often overlooked.** In 2019, CRDs were the third leading cause of death globally, affecting an estimated 454 million people.<sup>2</sup> The prevalence of CRDs has been steadily rising,<sup>2</sup> and yet CRDs continue to be poorly prioritised in both research and policy.



**Risk factors for CRDs are broad and often have the biggest impact on the most vulnerable in society.** Smoking and exposure to indoor and outdoor air pollution are widely recognised as key risk factors for CRDs, along with work-related exposure,<sup>1</sup> a person's sex,<sup>34</sup> pre-term birth<sup>5</sup> and early life exposure to harmful substances.<sup>6</sup> Traditionally underserved communities are more likely to be exposed to these risk factors and also to die from CRDs.<sup>7</sup>

**CRDs have a detrimental impact on both individuals and society.** CRDs affect productivity and attendance in the workplace and schools,<sup>8</sup> and many people with CRDs experience social isolation and loneliness due to their symptoms.<sup>9</sup> Hospitalisation due to exacerbations of CRDs accounts for almost half the health system expenditure for these conditions,<sup>10</sup> but targeted interventions can significantly relieve pressures within the system.<sup>11</sup>

Addressing CRDs requires multi-sectoral collaboration. CRDs are not a health issue that can be tackled in isolation, because of their established links with climate change, health system sustainability and health inequalities. Strategies to address CRDs must consider these wider policy areas to achieve true impact.

This report identifies four major areas of focus within which tangible steps must be taken to help realise this approach. These are: primary prevention and population health; proactive detection and early diagnosis; improved access to high-quality care; and the need for strategic and supportive policies. The measures outlined within each of these areas will ensure that the burden of CRDs can be tackled today and in the future.

These priority recommendations have been developed by the authors of this report and, if implemented, would address key barriers in CRD care and ultimately improve the lives of people living with CRDs

#### The authors call on governments to take action in four key areas:





## CHRONIC RESPIRATORY DISEASES (CRDs): A GLOBAL PUBLIC HEALTH ISSUE

**Chronic respiratory diseases (CRDs) are a collection of conditions that affect the airways and other structures of the lungs.** Some of the most common CRDs are chronic obstructive pulmonary disease (COPD), asthma, occupational lung diseases and pulmonary hypertension.<sup>1</sup> CRDs are not curable; however, various forms of treatment, such as those that help open the air passages and alleviate shortness of breath, can help control symptoms and significantly improve daily life.<sup>12</sup>

# Despite affecting an estimated 500 million people in 2019 – and with this number increasing – CRDs remain overlooked by decision-makers.<sup>2</sup>

CRDs are one of the most common non-communicable diseases (NCDs) globally, largely due to ongoing tobacco use, rising rates of air pollution and other risk factors.<sup>13</sup> <sup>14</sup> However, compared to other chronic conditions, such as cardiovascular disease, cancer, stroke, diabetes and Alzheimer's disease, CRDs have thus far garnered limited public attention and research funding.<sup>15</sup> <sup>16</sup> For example, even though data show that CRDs are the most prevalent NCD in the US, they receive less public research funding than other NCDs.<sup>16</sup>

**CRDs sit at the crossroads of several major policy challenges.** These are growing health inequalities, the financial sustainability of health systems and the impact of climate change on lung health. Preventive approaches to CRDs are essential to addressing these challenges, but care for people with CRDs also needs to be optimised urgently. This is in light of evidence of substantial disparities in access to high-quality care,<sup>17</sup> the avoidable cost of emergency hospital admissions for exacerbations (flare-ups in symptoms),<sup>18</sup> and the effects of poor air quality on people living with CRDs.<sup>19</sup>

**CRDs should be a priority for all countries, regardless of income level.** Improving CRD care and outcomes will be instrumental for countries to achieve their commitments as part of the United Nations' Sustainable Development Goals to reduce mortality from NCDs by one third before 2030 (a goal that very few countries are currently on track to achieve).<sup>20 21</sup>



It is time to take the necessary steps towards better respiratory health and give it the recognition and investment it demands. In support of the Global Alliance against Chronic Respiratory Diseases' (GARD's) vision for 'a world in which all people breathe freely',<sup>1</sup> this report builds on promising case studies to highlight where action and progress to address CRDs can improve the lives of people who live with these conditions.



## UNDERSTANDING THE IMPACT OF CRDs

In 2019, CRDs were the third most common cause of mortality globally, causing **4 million deaths**.<sup>2</sup>

There were an estimated **454 million people** living with CRDs in 2019, with approximately **78 million new cases** worldwide – a rise of 49% from 1990.<sup>2</sup>

Without investment in effective interventions, **COPD alone** is predicted to cost the global economy **\$4.3 trillion** between 2020 and 2050.<sup>22</sup>

In the UK, the economic cost of CRDs was nearly **£80 billion** in 2019.<sup>23</sup>

### CRD symptoms and impact on quality of life

Symptoms of CRDs can affect people on a daily basis and significantly compromise their quality of life.

Symptoms can include wheezing, breathlessness, coughing and mucus production,<sup>14</sup> and their persistence can have a considerable impact on a person's quality of life. Many people with CRDs experience poor mental health, social and physical isolation, and lonelinesss.<sup>9 24</sup>

# Proper adherence to medical treatments is critical for effective symptom

**control.** Inhaled medications, such as bronchodilators and corticosteroids, can be used to treat symptoms and prevent exacerbations and attacks.<sup>1 25</sup> However, research estimates that between 22% and 78% of people with CRDs do not take their medication as advised.<sup>25</sup> There can be many explanations for low adherence – including unfamiliarity with proper use of inhaled medication (inhalers), or social and religious stigma around the need to use such medication – which may affect a person's willingness or ability to actively participate in their own care.<sup>25</sup>



### **Risk factors for CRDs**

Risk factors for CRDs vary around the world and disproportionately affect underserved communities.

Widely recognised risk factors include smoking, exposure to indoor and outdoor air pollution, living in areas of deprivation, and work-related exposure (Box 1).<sup>17</sup> Traditionally underserved population groups are more likely to be exposed to these risk factors.<sup>26</sup> For instance, people at the lowest socioeconomic levels are up to 14 times more likely to develop respiratory diseases than people at the highest levels.<sup>17</sup> The number of people who die from CRDs is also higher among underserved communities,<sup>17 27</sup> with data from England suggesting that CRDs are a major cause of the observed gap in life expectancy between the most affluent and most deprived communities.28

People with CRDs have a higher risk of developing another health condition that can further impact their quality of life. For example, COPD is associated with an increased risk of developing cardiovascular disease (CVD), osteoporosis or respiratory infections such as pneumonia, compared with people without COPD.<sup>29</sup> Having two or more long-term health conditions is associated with a lower quality of life and increased mortality.<sup>30</sup>

#### **BOX 1. Evolving risk factors for CRDs**

**Outdoor air pollution and climate change:** In 2019, around 4 million deaths were caused around the world by outdoor air pollution<sup>31</sup> including emissions from vehicles, burning waste and crops, and power stations.<sup>32</sup> Events related to climate change, such as storms and wildfires, also pose a direct threat to respiratory health.<sup>33</sup>

**Burning biomass fuels indoors:** Approximately 2.4 billion people are exposed to harmful fumes resulting from cooking indoors, with open fires, or heating homes with stoves that use biomass fuels, kerosene and coal. Most of these people live in low- and middle-income countries. Higher levels of exposure have been observed among women and children, as they tend to spend more time in domestic settings.<sup>34</sup>

**Tobacco and e-cigarettes:** In 2020, it was estimated that 1.3 billion people actively smoked.<sup>35</sup> The rise of new nicotine delivery systems, such as e-cigarettes (vapes), is also a growing concern, though more long-term data are needed to be able to determine whether there is a clear link with CRDs.<sup>26</sup>

**Work-related exposure:** Research suggests that around 13% of all COPD cases and 11% of all asthma cases are a result of occupational exposure to substances such as asbestos, silica and particulate matter.<sup>2 36</sup>

**Sex and gender:** Although mortality from pulmonary hypertension is higher among men, women are more likely to develop and die from asthma,<sup>3</sup> and experience worse outcomes from severe COPD than men in terms of hospitalisation and death.<sup>4</sup> Women are also less likely than men to receive a COPD diagnosis when they present with clinically relevant symptoms.<sup>4</sup>

**Socioeconomic status:** Lower socioeconomic status is a key risk factor for CRDs. For example, people with a lower household income have been found to be at an increased risk of developing asthma than those with a higher income.<sup>37</sup>

**Pre-term birth and exposure to harmful substances in early life:** Children who are born prematurely are at higher risk of developing a CRD in later life.<sup>5</sup> Prenatal exposure to tobacco can also affect lung development in unborn children.<sup>6</sup>



### The growing economic impact of CRDs

**The cost of CRDs, to both individuals and society, is significant.** CRDs can affect school attendance and productivity in the workplace, as people may need to take more time off or work fewer hours.<sup>8 38 39</sup> This could result in a reduced income for some individuals. In 2010, it was predicted that 16.4 million workdays were lost in the US due to COPD.<sup>40</sup> Another study from 2010 found that, on average, 1.5 days per month per person were missed in Spain due to asthma symptoms.<sup>41</sup>

CRDs also lead to considerable use of resources in health systems. For both asthma and COPD, attacks and exacerbations are the main cause of hospital admissions, accounting for a large proportion of the health system expenditure for these conditions.<sup>8 10</sup> In the UK, COPD alone causes approximately 130,000 emergency hospital admissions per year.42 The unexpected nature of these hospitalisations can disrupt other hospital services, leading to delays or cancellations of other planned procedures.43 Furthermore, there is a strong link between COPD and developing CVD,<sup>29</sup> and the healthcare utilisation in people living with both conditions is much higher than individuals living with COPD or CVD alone.<sup>44</sup> Experts have suggested that interventions to reduce exacerbations could significantly ease pressures on health systems<sup>11 45</sup> and help them to become more resilient and economically sustainable.



## ADDRESSING STRATEGIC ISSUES AROUND CRDs: WHAT ARE THE SOLUTIONS?

Addressing CRDs requires a multi-sectoral, holistic approach that combines long-term population health initiatives with health system changes to improve the equity and quality of care. To ensure sustained change and improvements in care, these actions must be supported by national strategic prioritisation of respiratory health within relevant health policy frameworks. Governments must also be mindful of how CRDs interact with wider policy areas such as climate change, health system sustainability and health inequalities.

**Tangible steps must be taken in four major areas to address the impact of CRDs both now and in the future** (*Figure 1*). Delivering comprehensive CRD care will require the coordination and alignment of these building blocks.







## Strengthen vaccination programmes against respiratory diseases

Effective vaccination programmes are needed to protect against respiratory infections. Contracting a respiratory tract infection is a known trigger for worsening symptoms of CRDs.<sup>46</sup> The Global Initiative for Chronic Obstructive Lung Disease (GOLD) and Global Initiative for Asthma (GINA) reports both recommend vaccination against influenza and COVID-19 for people with these conditions, with additional pneumococcus, pertussis and herpes zoster vaccines for people with COPD.<sup>47 48</sup> However, vaccination rates for people with CRDs remain low, with regional studies showing that vaccination rates in people with COPD can range from 11% to 33% for pneumococcus and from 24% to 40% for influenza.<sup>49-51</sup> Recently, immunisation programmes against RSV in early life have also been recommended;<sup>52 53</sup> studies have shown that experiencing an RSV infection before the age of three can impair lung function in later childhood and sometimes into adulthood.<sup>54</sup>

## Tackle indoor and outdoor air pollution

Indoor and outdoor air pollution can significantly impact health outcomes in people living with CRDs. In 2019, up to 99% of the world's population lived in areas that did not meet the standards for air quality recommended by the World Health Organization (WHO).<sup>31</sup> Additionally, the frequency and severity of wildfires is rising globally,<sup>55</sup> increasing the release of hazardous air pollutants known to aggravate asthma and trigger the development of lung disease.<sup>56</sup> Reducing the levels of these harmful pollutants is vital for better lung health. Efforts to tackle indoor air pollution are also important, particularly in low- and middle-income countries, where up to 23% of all COPD deaths are associated with exposure to household air pollution.<sup>34</sup>

> 'There isn't one climate-change-induced weather pattern that is not going to affect our respiratory health. Wildfires contribute a significant amount of exposure to fine particulate matter, while floods and changes to precipitation patterns can increase mould, which triggers asthma.'



**Strategies that seek to minimise the risk of indoor and outdoor pollution are integral for protecting lung health.** Policies that support cleaner technologies in transportation, urban planning and power generation, and improved access to clean household energy solutions, can play a key role in improving overall air quality (*Box 2*).<sup>31</sup>

## BOX 2. Intersectoral preventive approaches to reduce air pollution and improve air quality

Collaboration between different sectors is essential to effectively reduce air pollution and ultimately help to significantly decrease the burden of CRDs.<sup>57</sup> Such initiatives have already been introduced in a number of regions:

In **Bologna**, Italy, trials using an algorithm-based model of urban traffic light networks to improve and regulate traffic flow have been shown to significantly decrease vehicle emissions.<sup>58</sup>

In **Southern California**, a US region with historically high levels of air pollution, aggressive pollution-reduction policies to improve air quality have resulted in improvements in childhood lung function.<sup>59</sup> Policy measures include setting air quality standards<sup>60</sup> and providing support and incentives for greener cars and transportation.<sup>61</sup>

In **China**, action was taken to target air pollution levels by suspending the building of new coal power plants, mandating that existing plants reduce their emissions or utilise other renewable energy sources, and reducing the number of polluting vehicles on the roads. It was estimated that, if sustained between 2013 and 2020, these efforts could result in an increase in life expectancy of the average inhabitant of China by 2 years, rising to 4.6 years for people living in Beijing.<sup>62</sup>

### Implement smoking cessation strategies

**Initiatives to prevent smoking uptake and encourage people to stop smoking need to be strengthened worldwide.** Despite decreasing rates of smoking in most countries,<sup>35</sup> tobacco use still kills more than 8 million people every year.<sup>63</sup> Efforts have been made over the past 20 years to control the use of tobacco, for instance through initiatives such as the international WHO Framework Convention on Tobacco Control treaty.<sup>64</sup> However, as of 2023, only 74% of the 182 countries that signed up to the treaty have implemented national multi-sectoral strategies for tobacco control, indicating that there is still more to do.<sup>64</sup> Additionally, nearly 75% of the countries signed up to the treaty have since introduced new nicotine-delivery systems, such as e-cigarettes.<sup>64</sup> Consequently, there is likely to be a steady increase in the number of people exposed to the harmful, lung-damaging substances within e-cigarettes.<sup>65</sup> People who take up smoking e-cigarettes, particularly young people, are also more likely to smoke tobacco in the future,<sup>65</sup> but data on the long-term effects of using these devices will take time to emerge.<sup>26</sup>



## Facilitating the proactive detection and early diagnosis of CRDs

## Lung health checks

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Integration of lung health checks into lung cancer screening and general health checks could enable earlier detection of CRDs across the population. Screening for lung cancer in high-risk populations using lowdose computed tomography (LDCT) has been shown to reduce mortality.<sup>66</sup> As many risk factors for lung cancer and CRDs are similar, studies suggest that co-locating testing for both conditions within existing lung cancer screening programmes may help to identify more individuals with CRDs and there are examples of where this is starting to happen.<sup>67-70</sup> Lung function could also be assessed as part of more general, regular health checks that are already often conducted in primary care (Case study 1). This may be particularly relevant in low- and middle-income countries where certain risk factors are more prevalent, such as exposure to indoor household pollution and harmful substances at work.<sup>71</sup> Moreover, having regular health check-ups may help to monitor ongoing lung function, flag any changes in the severity of symptoms, and control disease progression in people with an existing diagnosis of a CRD who may no longer be receiving frequent check-ups for the management of their condition.

### Case study 1. Proactive health checks to detect chronic conditions

The Ministry of Health and Prevention and the High Council for Public Health in France have established an initiative called Prevention Reports to increase healthy life expectancy across the population. It takes the format of a regular health check targeting prevalent chronic conditions and is conducted four times between the ages of 18 and 75.

The programme includes targeted screening for CRDs in people over the age of 45. This is done by reviewing any symptoms that may indicate the development of respiratory conditions such as COPD (e.g. a long-standing cough or shortness of breath), with further confirmation obtained through spirometry testing. If a condition is identified and the person requires further care, the care pathway set out in this initiative provides recommendations for onward referral.<sup>72</sup>



The normalisation of lung function testing as part of general health checks could also play an important role in encouraging more people to proactively seek diagnosis for their symptoms. CRDs carry a level of shame and stigma related to breathlessness and respiratory symptoms;<sup>73</sup> normalising these tests could potentially facilitate more open discussions around the risk factors and impacts of CRDs between families and communities, and ultimately encourage more people to seek care for their symptoms. Dedicated programmes for the communities most at risk of CRDs can also be helpful, and could be run in collaboration with local schools, community centres, religious institutions or workplaces.

'Within some communities and cultures, having asthma is so taboo that people will deny they have it to avoid negative social consequences, such as being unable to get married and start a family.'

PROFESSOR EE MING KHOO, International Primary Care Respiratory Group

### Case-finding and proactive identification in primary care

Proactive identification in primary care can help identify people at risk of developing CRDs as well as people who already exhibit significant disease progression. An overwhelming 65–80% of people who have COPD remain undiagnosed,<sup>74</sup> and many people show significant disease progression at the time of diagnosis.<sup>75</sup> Proactive case-finding in primary care could help prevent late-stage presentation by identifying people at risk and those who require urgent specialist care, and ensuring their rapid referral for assessment and early intervention.<sup>76</sup> This could be done by systematically reviewing electronic health record (EHR) systems for family history and known exposure to risk factors. This approach has been used to identify people with a history of smoking in some parts of the UK.<sup>77</sup> However, the availability of EHRs and reliable health data systems varies considerably,<sup>78</sup> meaning this approach may be out of scope for countries with limited health data infrastructure.

### Timely access to effective diagnostics

Access to effective diagnostic tools is essential to ensure people with CRDs receive an accurate diagnosis. Peak flow tests and spirometry are typically recommended to accurately diagnose CRDs across care settings.<sup>79 80</sup> However, capacity to diagnose respiratory conditions can be hindered by



a lack of expertise and training on CRD diagnostic tests, or by a lack of access to diagnostic technologies such as spirometry testing.<sup>81</sup> This can be a particular issue in rural areas and in low- and middle-income countries.<sup>8182</sup> Dedicated training programmes are being rolled out in some countries to provide formal training (*Case study 2*), but greater efforts are needed.

#### Case study 2. Improving access to spirometry training

In Africa, the burden of respiratory disease is among the highest in the world,<sup>83</sup> yet access to spirometry testing is severely limited. Key challenges include low levels of training in spirometry, lack of access to necessary equipment, limited numbers of specialist respiratory physicians, generally low financial resources and insufficient research on the burden of disease in African populations. The Pan African Thoracic Society sought to address this by running a programme that provided free access to spirometry training and educational materials. The programme enabled healthcare professionals to qualify for certification to conduct testing.<sup>83</sup>

Where peak flow and spirometry testing are not available, other methods of diagnosis could be used. Symptom-based diagnosis is recommended by the WHO as an essential intervention in primary care for the management of NCDs.<sup>84</sup> In addition, self-screening tools (such as a questionnaire developed by the COPD Foundation) can be used by people who suspect they have a respiratory condition. This can help them initiate and guide discussions with a healthcare provider, who can advise whether further testing is appropriate.<sup>85</sup>

The ongoing development of novel diagnostic techniques will continue to improve the diagnosis of CRDs. Several promising methods that could serve as an alternative to spirometry are currently being researched, including forced oscillation techniques such as impulse oscillation systems. These non-invasive pulmonary function tests can be used to detect changes in the mechanics of the respiratory system.<sup>86 87</sup> They have been found to be easy for both patients and practitioners to use.<sup>86</sup> They may also be a better predictor of asthma control than spirometry and have greater sensitivity to COPD (meaning the condition could be identified at an earlier stage).<sup>86</sup> The development of novel portable oscillometry devices can enable point-of-care testing and could be a promising option for use in regular clinical practice;<sup>88</sup> ambulatory lung diagnosis systems (ALDS) are an example of such devices. Aside from this, ongoing research is examining the use of a variety of biomarkers that could help identify the presence and progression of CRDs.<sup>89-91</sup>





### Equitable access to effective treatments and care

**Targeted interventions are needed to ensure underserved communities are able to access high-quality respiratory care.** Regional studies have shown that people with CRDs who live in areas of deprivation have a higher risk of hospitalisation, unplanned emergency admissions and death.<sup>92 93</sup> Research also shows that they often have reduced access to the medicines they need to manage their conditions.<sup>17</sup> One study demonstrated that people with asthma from marginalised ethnic groups in the US, such as African-Americans, are less likely to receive specialist care than White people.<sup>94</sup> It is crucial to have a better understanding of such disparities, and the reasons behind them, to be able to develop targeted interventions for underserved communities and improve their access to care (*Case study 3*).

## Case study 3. Novel ways to use data: precision analytics to better understand unmet needs

The Atlas of Variation is a joint venture between the UK Health Security Agency, NHS RightCare, NHS Digital, the Office for National Statistics and other national UK organisations.<sup>95</sup> Its goal is to utilise data to identify the unmet needs of people living with chronic conditions across England. When looking at people with asthma, this tool can provide an overview of the variations in care delivery and outcomes, trend data, suggested actions to address these variations, and resources to support these actions.

### People living with CRDs must have adequate access to effective

**treatments and be able to use them properly.** The WHO NCD Global Action Plan's target is that 80% of essential NCD medicines (as defined by the WHO's List of Essential Medicines<sup>96</sup>) be made available in all countries; this includes those needed to manage CRDs.<sup>97</sup> However, these medicines remain largely unavailable or unaffordable in low- and middle-income countries.<sup>97</sup> <sup>98</sup> The lack of universal healthcare in many of these countries is a key contributor to the challenges around access to medicines.<sup>98</sup> Access to more innovative medicines for CRDs, such as guideline-recommended biologics,<sup>99</sup> also needs to be improved, and people who are eligible for and may benefit from them should be assessed for their use. However, even where CRD



medicines are available, up to 80% of people do not take them correctly.<sup>25</sup> This may be due to a number of reasons, including concerns about dependence on medication, their side effects and their cost.<sup>100</sup> For instance, spacers for inhalers are vital to enable the proper administration of some respiratory medicines,<sup>101</sup> yet experts have reported that spacers can often be too expensive for individuals to buy or for health systems to fund.<sup>101 102</sup>

> 'Many people in low- and middle-income countries do not have access to medications recommended for CRDs despite them featuring on the WHO's Essential List of Medicines. This is leading to inappropriate and long-term overuse of alternative medications, which can result in more adverse events.' PROFESSOR ARZU YORGANCIOGLU, GINA

### Strengthening CRD care in primary and community care settings

Increasing capacity within primary and community care is essential to reduce hospital admissions from CRDs. International guidelines recommend CRD management be led by primary care, and it is crucial that people with CRDs have access to integrated care from primary and community teams.<sup>48 103 104</sup> Strengthening the capacity of these settings to initiate effective CRD care relies on cooperation with specialists and the wider health system. This collaborative effort should enable primary care to provide high-quality, proactive management of CRDs closer to a person's home – including lung function testing, exacerbation management, smoking cessation support and initiation of treatments where appropriate.<sup>105-107</sup> In turn, a coordinated approach to managing CRDs across different levels of care could reduce hospital admissions and readmissions,<sup>44 108 109</sup> and subsequently alleviate pressures on already stretched health systems (Case study 4). Fully utilising community health workers is essential to this approach as, with appropriate training and resources, they can deliver primary care, support underserved communities and provide educational outreach - acting as a liaison between people with CRDs and the health system.<sup>110</sup>

### Case study 4. Integrated COPD management in primary care

Integrated disease management programmes are designed to combine the different components of care provided by a multidisciplinary team to deliver higher-quality, holistic care.<sup>111</sup> In Ontario, the Best Care COPD programme forms a proactive model of care for people with COPD by equipping primary care providers to work alongside a respiratory educator. Together they identify, diagnose and support people with guideline-directed care in the primary care setting.<sup>112</sup>

As part of the programme, a person's medical history, such as previous admissions for COPD and vaccine status, is examined and medication reviews are performed. The programme also includes education and self-management training, which covers exacerbation management, smoking cessation and inhaler technique; coordination of care with other healthcare professionals, including physiotherapists, social workers or mental health practitioners; and referral to specialist care where appropriate.<sup>112</sup>

Integrated disease management COPD programmes have demonstrated improvements in quality of life and adherence to respiratory medication, along with reduced frequency of severe exacerbations and hospitalisations.<sup>112-115</sup>

'Primary care is at the coal face of CRD management. It requires a system-wide approach to supporting healthcare professionals to manage these chronic conditions with limited resources.'

DR CHRISTINE JENKINS, University of New South Wales

# Building effective referral pathways and support systems to ensure timely access to specialist care

**Clear referral pathways and associated systems need to be designed to improve access to specialist, multidisciplinary respiratory care.** Respiratory referral pathways and training for healthcare professionals on 'red-flag' symptoms are crucial to ensure that people who present with suspected CRDs in primary care and emergency settings and require specialist, multidisciplinary care can be rapidly referred for assessment.<sup>116 117</sup>

**Introducing innovative models of care can help ensure respiratory clinical expertise is available across all care settings.** It is essential that people with CRDs receive the right treatment and care at the right time, and in the most appropriate clinical setting. Innovative models of respiratory care can



enable this, especially where there is limited clinical capacity. Hub-andspoke models that use telemedicine and digital tools to connect specialist expertise with primary care and community settings can help expand access.<sup>118</sup> <sup>119</sup> Other digital models of care, such as community virtual wards for CRDs, have been shown to improve management of symptoms and patientreported outcomes.<sup>120</sup> In China, artificial intelligence (AI) and digital solutions have been used to train and support healthcare professionals in small rural hospitals to deliver specialist care for CRDs (*Case study* 5).<sup>121</sup>

#### Case study 5. Utilising an application to widen patient access to specialist care

In China, healthcare resources in small rural hospitals can be limited; such hospitals often do not have access to specialist equipment, and doctors tend to have less clinical expertise.<sup>122</sup> This results in many people living in rural areas preferring to seek medical care in larger, regional hospitals in cities, where the influx of patients leads to added pressures on their services.<sup>122</sup> To tackle this, an application called the 'Medical Internet of Things' has been developed to allow doctors from large hospitals to connect with doctors in rural hospitals and support them with effective diagnosis and treatment.<sup>121</sup>

This approach has enabled people living with COPD to receive ongoing monitoring using a portable testing device that automatically uploads spirometry data to the cloud for review and interpretation by doctors.<sup>121</sup> People can also receive non-invasive positive pressure ventilation at home with parameters such as mask leaks, breaths per minute and tidal volume monitored in real time.<sup>123</sup> This type of intervention can help provide guideline-recommended care, improve health-related quality of life and potentially address disparities in access to quality respiratory care.<sup>121</sup>

# Supporting and empowering people living with CRDs to understand and manage their condition

#### People with CRDs must be empowered to self-manage their condition and

**symptoms.** Given the chronic, episodic nature of CRDs, it is vital to educate people to understand their risk factors, identify flare-ups and manage symptoms. Self-management may also encourage greater adherence to treatment.<sup>124</sup> Engagement and education are key for supporting people to self-manage, and patients require dedicated, regular check-ins with healthcare professionals (*Case study* 6).<sup>125</sup> Several resources have been developed with this in mind, including reflective self-assessment questionnaires assessing impact on quality of life,<sup>126</sup> innovative digital tools such as mobile applications to record symptoms and monitor lung function, and smart inhaler add-ons that can assess inhaler technique and track usage data (*Case study* 7).<sup>127</sup>



#### Case study 6. Self-management of CRDs supported by certified respiratory educators

The role of certified respiratory educator was established in Canada in 2007 with the aim of providing comprehensive, evidence-informed care to people living with CRDs. The educators come from a variety of multidisciplinary healthcare backgrounds such as nursing, physiotherapy, pharmacy, social work and medicine. They seek to teach people about preventive measures, avoidance of triggers, correct medication use, diet and lifestyle; they also help them develop action plans.<sup>125</sup>

This dedicated support has been found to reduce the number of emergency CRD hospitalisations and help people with CRDs manage their conditions effectively by themselves.<sup>103</sup>

#### Case study 7. Digitally supported asthma management

The myAsthma app, developed by My mHealth, was used by the Mid and South Essex Integrated Care System to support high-risk asthma patients remotely during the first national lockdown for COVID-19 in the UK. The app enabled people to more effectively self-manage their condition by:

- providing training in correct inhaler technique
- allowing access to their personalised asthma action plan
- equipping them to track their symptoms via the asthma control test and peak flow diary
- giving them access to educational resources.

The app was also used by the clinical team to virtually monitor and support people, and perform annual reviews.<sup>128</sup>



### Strengthening follow-up care and rehabilitation

**Ongoing monitoring and rehabilitation following hospital discharge are essential to support people with CRDs to maintain their lung health**. CRDs are evolving conditions that require long-term management of symptoms. Comprehensive discharge protocols, pulmonary rehabilitation, routine medical reviews and ongoing monitoring can help to reduce the risk of exacerbations, prevent loss of lung function, enhance quality of life and prevent hospital readmissions.<sup>129</sup> These touchpoints between a person with CRD and healthcare professionals also provide opportunities to optimise care and assess adherence to medications. Despite this, fewer than 10% of people with COPD in England, Scotland and Wales are referred for pulmonary rehabilitation after hospitalisation, and it is estimated that only 25% of people who have a known history of COPD exacerbations receive sufficient ongoing review and management.<sup>74 130 131</sup>

## A lack of ongoing care can significantly contribute to hospital readmissions, but measures can be taken to address this. Statistics from

Canada show that between 2015 and 2020, 35% of people with asthma were readmitted to hospital within 90 days of discharge.<sup>132</sup> There are several ways to support follow-up care; for example, by integrating lung function tests in regular general health checks, or by using telemedicine and digital tools (such as EHRs) to automatically flag when a person diagnosed with CRD is due for a follow-up. Promoting the uptake of regular immunisations against common respiratory illnesses, such as influenza and pneumococcal infections, can also help protect against hospitalisation and exacerbations.<sup>133</sup>





## Building strategic and supportive policies for tackling CRDs

## Developing national respiratory strategies to drive political prioritisation

Governments need to develop comprehensive strategies to address the burden of CRDs. Although much of the CRD burden is preventable or treatable with affordable interventions,<sup>134 135</sup> these diseases have received less attention from policymakers than other NCDs such as cardiovascular disease, diabetes and cancer.<sup>136</sup> There is a marked lack of comprehensive national and international strategies for CRDs, and this must be addressed.<sup>137</sup> As outlined by the International Respiratory Coalition in its manifesto for better respiratory health, for CRD strategies to truly make an impact they must outline clear areas for action on prevention, early detection and diagnosis, and access to effective treatments and care.<sup>137</sup> These must appear alongside wider recommendations that focus on strengthening the healthcare workforce, data collection, impact evaluation and investment in research. Finally, they must be supported with measurable goals that transect wider policy areas such as climate change, health inequalities and health system sustainability, all of which underscore many CRD risk factors and barriers to progress.

### Increasing investment in research

# Innovation in addressing CRDs has suffered from historic underinvestment, which must be rectified if we are to improve outcomes

**for patients.** Funding for research into innovative diagnostic tools and treatments, care management strategies and the changing epidemiology of CRDs is needed to guide effective public health strategies. In particular, climate change is shifting the established pattern of risk factors for CRDs, and research is needed to understand their short- and long-term impact on lung health – and how to mitigate that impact.<sup>138</sup> More studies would help to fully demonstrate the impact of alternatives to cigarette smoking, such as e-cigarettes and heated tobacco products.<sup>139 140</sup> Traditionally, lung health research has been centred on identifying disease causes and defining management; however, there is now a pressing need for studies evaluating the effectiveness of public health strategies and interventions designed to improve outcomes and maximise lung health.<sup>141</sup> It is also essential that



research findings be made universally available so international researchers and policymakers can use them to make improvements in care.

## Improving availability of reliable global health data

### There must be greater investment in the collection of reliable,

**observational data on CRDs.** Population-level data are needed to track the effectiveness of clinical or public health interventions and allocate resources to the areas of greatest need; but the accuracy of data for CRDs varies from country to country.<sup>142</sup> This can be addressed by establishing international and national disease registries. International disease registries currently exist for severe asthma;<sup>143</sup> however, registries for COPD<sup>144</sup> and rarer CRDs, such as interstitial lung disease<sup>145</sup> and bronchiectasis,<sup>146</sup> appear to have a more regional or national focus. Registries can help us understand what is driving increases in prevalence, hospitalisations and deaths from CRDs; they can also provide insights into clinical decision-making and health policy.<sup>147</sup> Data from national severe asthma registries, for example, have allowed researchers to study the economic cost of suboptimal care.<sup>148</sup> The considerable research made available through registries can also draw new researchers into the field and draw funding into the specific disease area.<sup>146</sup>



## HOW TO PROTECT LUNG HEALTH FOR LIFE: RECOMMENDED ACTIONS

CRDs affect the lives of millions of people, many of whom do not receive the high-quality care they require and deserve. This report outlines the system changes and actions necessary to improve the lives of people with CRDs and, in turn, alleviate the burden of disease currently facing economies and societies. To achieve long-term, sustained progress, these actions must be underpinned by tangible policy commitments.

#### We call on governments to take action in four key areas:

Refocus their approach to primary prevention and population <u>health by:</u>

- strengthening vaccination programmes to protect against respiratory infections throughout the life course
- adopting clean-air policies to reduce indoor and outdoor pollution and protect lung health
- bolstering programmes that prevent the uptake of smoking and support people to quit tobacco and e-cigarette use

Expand proactive detection and early diagnosis by:

- integrating lung health checks into lung cancer screening programmes to help detect CRDs
- integrating lung health checks into general health checks targeting high-risk populations
- proactively identifying people at risk of CRDs in primary care using electronic health records and data analytic tools
- increasing the availability of effective diagnostic tools such as spirometry, and providing training for healthcare professionals to use them

## Improve access to high-quality care by:

- investing in primary and community respiratory care capacity to enable people with CRDs to have faster access to diagnosis, treatment and support
- broadening and streamlining access to specialist respiratory care by investing in innovative models of care
- ensuring timely access to care, as recommended by the Global Initiative for Asthma (GINA) and Global Initiative for Chronic Obstructive Lung Disease (GOLD), for all people with CRDs
- supporting people living with CRDs to engage in their care through appropriate training and use of digital tools
- strengthening follow-up care and rehabilitation programmes to prevent hospital readmissions

### Build strategic and supportive policies for CRDs by:

- developing national and international lung health strategies to effectively tackle the burden of CRDs
- investing in research to better understand risk factors for CRDs and how they may be evolving
- ensuring local and national clinical practice guidelines are updated in line with the latest respiratory research and expert recommendations
- improving international data collection on CRDs to reveal what drives hospitalisations and mortality, and to create registries to track outcomes and direct changes in practice



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