

CO-CREATING THE PATHWAY:

A Report for Connected Respiratory Care

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We would like to thank the members of the Respiratory Health Initiative's (RHI) Advisory Board, who contribute their time and knowledge helping to shape the content and direction of the RHI's work.

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Foreword

from José Luis Castro

In 2025, our governments committed to more than most of us expected. In May of 2025, the World Health Assembly adopted Resolution WHA78.5, the first in its history to treat lung health as one integrated issue rather than a scattered collection of separate diseases. Later that year, member states adopted the UN Political Declaration on noncommunicable diseases and mental health, with specific targets to meet.

Two of those targets were designed with the health clinic in mind. By 2030, at least 80% of primary health care facilities should have affordable, WHO-recommended essential medicines and basic technologies, and at least 60% of countries should have financial protection policies, so that a terrible diagnosis does not also become a bankruptcy.

WHA78.5 does not ask for a separate strategy for each condition. It asks for something harder: one integrated approach to lung health, inside primary care, on the road to universal coverage, and adapted to each country's own context and priorities rather than imposed from outside it.

Two further things have to hold. Tobacco control remains the most proven lever we have, and one in five adults worldwide still smoke; our commitment to the Framework Convention on Tobacco Control must remain absolute. Yet millions of people living with severe lung disease may have never smoked a single day. They fall ill because of the air they breathe in their homes, workplaces and neighbourhoods. Clean air, indoors and out, is lung health.

There is no easy answer to how this is sustained while public health funding is being cut, but each of us has a role to play. Clinicians can keep saying what their patients need, loud enough to reach the people who control the budget. Those who run primary care can insist that integration arrives with support rather than as more work. Patient advocates can ask directly whether a report for action gives patients meaningful authority or only a mention. Parliamentarians hold tools nobody else holds, in legislation, budget and oversight, and can use them on tobacco control, clean air, primary care funding and the essential medicines list.

Science discovers what is possible; policy decides who should receive it, clinicians have to deliver it. This Report will be measured by whether a woman in an underfunded urban clinic can get an affordable inhaler before her airway is irreversibly obstructed, by whether a factory worker exposed to silica or grain dust receives timely diagnosis and protection, and by whether a parent can sleep through the night without fearing that their child's next asthma attack will bankrupt the household.

Let us turn these global resolutions into domestic action. Let us walk the pathway together.

JOSÉ LUIS CASTRO

WHO Director-General's Special Envoy for Chronic Respiratory Diseases



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Executive summary

Chronic respiratory diseases remain a major global health challenge. The 2025 World Health Assembly resolution on lung health and the UN Political Declaration on noncommunicable diseases and mental health have strengthened commitments to integrated lung health. Within that agenda, this report focuses on chronic obstructive pulmonary disease (COPD) and asthma. COPD attracts far less research funding than its burden would suggest.[1] Despite effective treatments and established clinical guidelines, many people living with these conditions are diagnosed late, fall through gaps between services and receive care only when their condition becomes acute.

Co-creating the Pathway: A Report for Connected Respiratory Care builds on the Respiratory Health Initiative's Roadmap *From Policy to Practice: A Roadmap for Advancing Respiratory Health by 2030*. It draws on a workshop held alongside the European Respiratory Society Congress in Barcelona in September 2026, bringing together primary care professionals, respiratory specialists, patient advocates and policymakers. Using country case studies from Spain, France, China and Mexico, participants examined where respiratory care breaks down and identified practical actions for 2027 and longer-term ambitions towards 2035.

The discussions examined the first strategic direction from the Roadmap, expanding access to diagnosis, treatment and care, through four priority areas: diagnosing earlier, connecting primary and specialist care, shifting from reactive treatment to proactive management, and making patients partners in care. Participants stressed that improving respiratory care requires strengthening the whole care pathway.

The Report sets out eight actions for countries: public awareness, lung function assessment, shared care protocols, regular patient reviews, equitable access to medicines, correct inhaler technique, patient access to their own health record and prevention. For patients whose disease remains uncontrolled despite optimised treatment, it also calls for timely specialist assessment and access to advanced therapies. Work on most actions can begin by 2027, with longer-term recommendations extending towards 2035. Alongside improvements in care, countries need to sustain efforts on tobacco and nicotine control, vaccination and reducing air pollution.

These actions are grouped within the Respiratory Action Framework *(Figure 3)*, written for policymakers and adaptable to each country's capacity, with a role for clinicians and patient organisations. The RHI's COPD and Severe Asthma Indices and forthcoming country policy briefs provide evidence for national prioritisation and benchmarking.

The Report offers a practical starting point for turning global commitments into national action. Stronger respiratory care depends on connecting the services, professionals and patients along the pathway, with sustained political commitment and clear accountability.

Why respiratory care pathways need to change

Chronic respiratory diseases were the fourth leading cause of death worldwide in 2023, responsible for 4.2 million deaths, and affected an estimated 569.2 million people.[2] Effective treatments exist for most of these conditions, yet people living with them move through health systems that were not organised around their needs, and there are gaps in their care at several stages.

The first gap comes before care begins. Most people with COPD have never been diagnosed, and many who are diagnosed reach that point only once respiratory damage is well established. The Lancet Commission on COPD argued in 2022 that the disease is recognised too late and called for earlier detection and for wider attention to other causes as well as smoking, from early-life events to environmental exposures.[3]

Further gaps appear between levels of care and after acute episodes. The UK National Review of Asthma Deaths, the largest study of its kind, found potentially preventable factors in two-thirds of the asthma deaths it examined, and judged overall asthma management to be good in less than one in five of the people who died.[4] COPD shows the same pattern after exacerbations. Guidelines recommend pulmonary rehabilitation after a hospital stay, yet of more than 220,000 Medicare beneficiaries in the United States hospitalised for COPD in 2012, only 1.9% received it within six months, and people from lower socioeconomic groups were less likely to be included.[5] In both cases, care tends to focus on managing crises and becomes less intensive once the crisis has passed.

The last gap concerns the patient's own role. Managing a long-term condition and taking part in decisions about treatment both depend on people being able to find, understand and act on health information. The HLS19 survey, conducted in 17 countries across the WHO European Region, found that between 25% and nearly 75% of residents, depending on the country, had limited general health literacy. Health literacy followed a social gradient, with financial circumstances showing the strongest association, and was also lower among people with long-term health problems. This matters particularly for respiratory care, where disadvantaged groups already experience poorer outcomes.[6] Those with the greatest need are among the least supported to participate in treatment decisions. For those living with several long-term conditions, navigating care becomes even more demanding as they have to manage appointments and treatments across different services and platforms.[7]

These gaps are usually tackled separately, but they are linked: a late diagnosis brings a patient into the system with more advanced disease; weak links between primary and disease specialist care leave exacerbations to be managed in hospital rather than prevented; and a patient who has not been involved in their own care is less able to act on early warning signs.

Chronic respiratory disease now has a firmer place on the global health agenda. In the 2025 UN Political Declaration on noncommunicable diseases and mental health, governments committed to promoting national policies for an integrated approach to lung health within primary health care, covering both noncommunicable and communicable diseases, and to scaling up the prevention, early diagnosis and treatment of asthma and COPD through better access to effective treatment, stronger diagnostic services and structured programmes for long-term management.[8]

The starting point of this Report

The Respiratory Health Initiative (RHI) has built a shared evidence base on respiratory health. Its COPD Index and Severe Asthma Index compare how 45 countries prevent, diagnose and manage these conditions. This Report draws on that work and the previously published 'From Policy to Practice: A Roadmap for Advancing Respiratory Health by 2030', developed by CIFS with the RHI. The Roadmap identified three strategic directions for countries to advance in parallel: expanding access to diagnosis, treatment and care; comprehensive tobacco and nicotine control; and reducing air pollution and environmental risk factors *(Figure 1)*. This Report addresses the first strategic direction and asks what its measures look like where care is delivered: at the first point of contact, between primary and specialist care, in the months after an exacerbation, and in the consultation room.



Figure 1: The three strategic directions of the Roadmap to 2030.

Three years remain before 2030, which turns the Roadmap's 2030 vision into a short-term agenda. This Report holds two horizons in parallel: what should be in place by the end of 2027 to improve care now, and what should be true by 2035.

How the Report was developed

This Report draws on the event held in Barcelona on 5 September 2026, *Pathways to Policy: Co-creating Stronger Chronic Respiratory Care*, a roundtable workshop held as a side event to the European Respiratory Society Congress. José Luis Castro, WHO Director-General's Special Envoy for Chronic Respiratory Diseases, gave the keynote, describing the task as building the operational bridge between global political commitments and the everyday reality of clinical practice. Lord Nick Herbert of the Global Health Caucus drew on the experience of the Global TB Caucus to argue that parliamentarians are often the missing link between global commitments and domestic action. Four experts then each gave a short presentation introducing one stage of the pathway: Professor Richard van Zyl-Smit on earlier diagnosis, Siân Williams on connected care, Professor David Halpin on proactive management and Riley Sanders on patient involvement. Participants subsequently discussed these stages in groups, with each expert joining the relevant group to help get the discussion started.

Participants were selected to bring perspectives from across the whole pathway, including family doctors, respiratory specialists and pulmonologists, patient representatives and organisations, and policy representatives. They were split into four groups of eight to ten participants. Each group took one stage of the pathway and the corresponding RHI country policy brief, which was available in preliminary form. These briefs are one-page summaries that turn each country's results in the COPD and Severe Asthma Indices into national priorities and recommendations for respiratory care. Each group's discussion forms one of the four priority areas that follow: earlier diagnosis at the first point of contact (Spain); shared care between primary care and respiratory specialists (France); the shift from reactive treatment to proactive long-term monitoring (China); and health literacy and patient involvement in shared decision-making (Mexico).

Every group followed the same three-step structure of Assess, Envision and Act. In Assess, participants reviewed the case study, tested its data against their own experience, and agreed on one priority issue, the single point where the pathway fails most often. In Envision, they described in one sentence an ambitious but plausible picture of 2035 and named one minimum standard every country should meet. In Act, they worked back from that vision to one short-term action to take by 2027 and one longer-term recommendation towards 2035. A spokesperson for each group then presented a summary to the plenary. The chapters that follow keep the same logic: the challenge, what participants discussed, the 2035 ambition, the minimum standard, the priority action, the longer-term recommendation and the policy implications.

The country profiles were used as discussion anchors, not as assessments, so that participants could test real local data against the systems they know. Working from one concrete system helped the groups locate problems that participants recognised across very different contexts.

The aim of this report

This Report is written primarily for policymakers, while also addressing clinicians, patient organisations and other advocates, since no single stakeholder group can close these gaps alone. Its aim is to help policymakers turn global commitments on respiratory health into practical action along the health care pathway, in ways that suit each country's starting point and capacity. To support that aim, the Report follows the respiratory care pathway through four priority areas, each discussed by experts at one of the workshop's four groups. Eight actions for countries, grouped as the Respiratory Action Framework *(Figure 3)*, were developed after the event, drawing on those discussions, and are set out after the four priorities of each group.

The ambitions, minimum standards and actions in this Report reflect the roundtable discussions and CIFS's subsequent analysis. Campaigns, platforms and tools mentioned in this Report are included as illustrative examples that other countries can learn from.

The Report is organised in two parts. **Part 1** presents the findings of the four roundtables held in Barcelona, one for each stage of the pathway. **Part 2** draws on those findings to set out eight actions for countries, grouped as the Respiratory Action Framework.

Building on the Roadmap

Each group discussed one stage of the respiratory care pathway, which are presented as the four priority areas in this Report *(Figure 2)*:

1. **Diagnosing earlier:** helping people recognise symptoms and seek care, with screening and diagnostics available in primary care.

2. **Connecting care:** timely referral, shared treatment plans and interoperable records, so that patients move between primary care, specialists, hospital and rehabilitation without losing continuity.

3. **Shifting to proactive management:** a trained and confident workforce, essential medicines, preventive care such as vaccination and smoking cessation, and clear priority for high-risk patients.

4. **Making patients partners in care:** giving patients the knowledge and confidence to manage their condition.

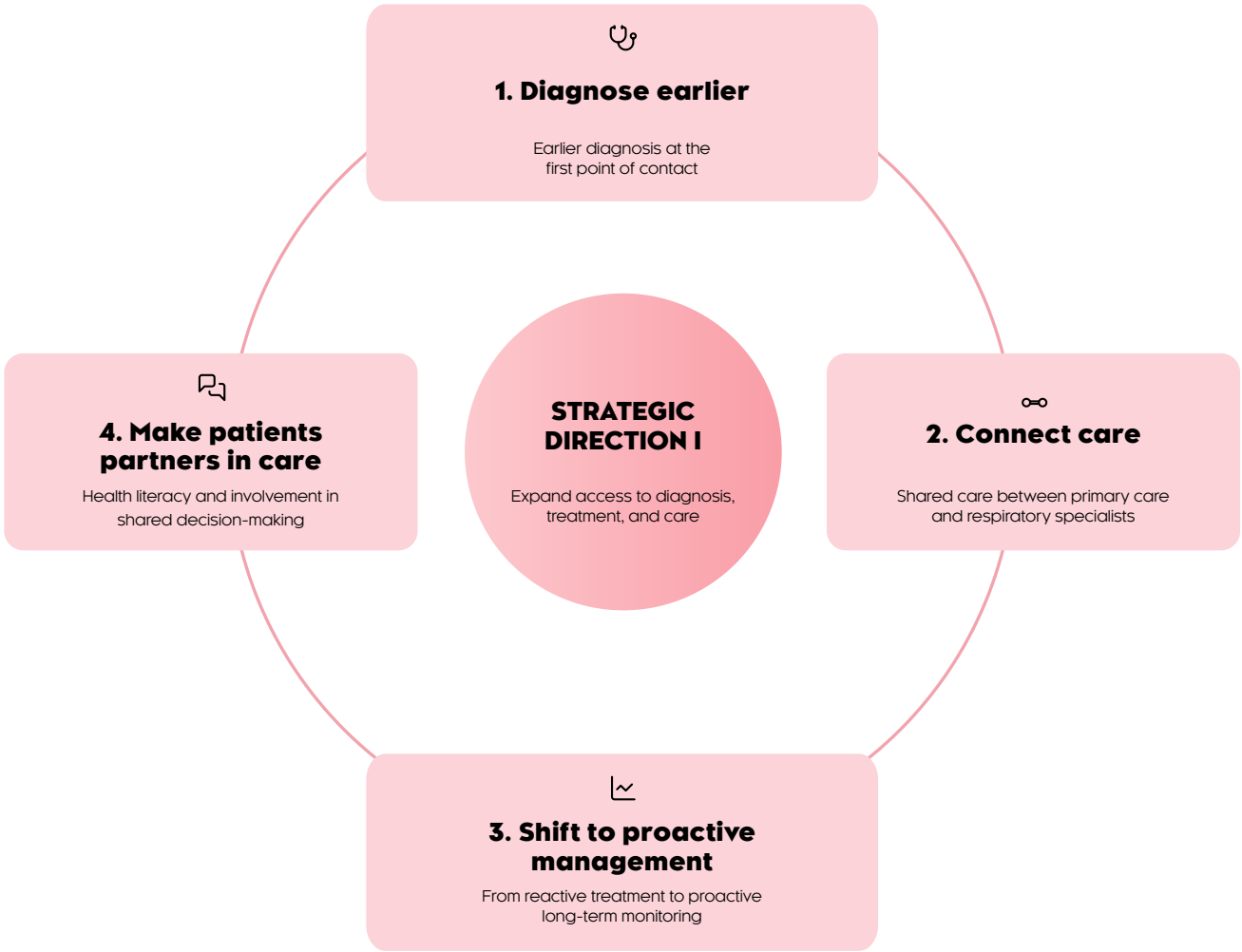


Figure 2: The four priority areas of the Report, set within Strategic Direction I of the Roadmap.

Using the RHI evidence base

The COPD Index and Severe Asthma Index compare countries across disease burden, care capacity, risk factors and policy. Findings from the indices can help users identify gaps relevant to each part of the pathway and compare respiratory health performance with peers.

The country policy briefs, which will be published towards the end of 2026, will translate index findings into a country-specific picture of which gaps matter most, where policies or implementation fall short, and which actions are most relevant.

This part follows the respiratory care pathway one stage at a time. Each chapter presents the discussion at one of the four roundtables: the challenge, what participants said, the 2035 ambition, the minimum standard, the priority action, the longer-term recommendation and the policy implications.

Part 1:

INSIGHTS FROM THE BARCELONA ROUNDTABLES

Priority 1: Diagnose earlier

This chapter draws on the roundtable discussion that examined earlier diagnosis at the first point of contact, with Spain as its case study country and Professor Richard van Zyl-Smit starting the discussion. The group started from the call in the UN Political Declaration for access to early diagnosis and asked what it would take to turn that call into routine practice.

THE CHALLENGE

Chronic obstructive pulmonary disease (COPD) alone caused 3.4 million deaths in 2023, and nearly 90% of COPD deaths in people under 70 occur in low-and middle-income countries.[9] Yet most people living with it do not know they have it. Population surveys covering 44 sites in 27 countries found that 81.4% of COPD cases identified by spirometry had never been diagnosed.[10] The consequences compound over time. People reach advanced stages of the disease before treatment starts, receive therapy for a condition they do not have, or miss out on the support they need.

Richard van Zyl-Smit's opening presentation turned this into a question of how health systems use the tools they already have. Chronic respiratory disease, he noted, is often missed or mistaken for something else; in many low-and middle-income countries, other chronic respiratory conditions and lung cancer are frequently treated first as tuberculosis. This points to the need for a more integrated approach to lung health, with services equipped to assess symptoms and distinguish between possible causes at each level of care. Even where medicines are unavailable, a correct diagnosis can help patients understand their condition and what they can do to manage it.

The Spanish case study showed that the gap persists even in a well-resourced health system. According to the EPISCAN II national survey, three in every four COPD cases in Spain are undiagnosed and around 2.3 million of the country's 3.1 million patients receive no COPD-specific care. The figure has barely moved in two decades, and underdiagnosis among Spanish women, at 80.6%, is higher.[11] Spain has no national COPD referral pathway, and access to pulmonary rehabilitation varies between regions.[12] Nicotine replacement therapy is available but not funded by the national health system.[13]

Participants identified the failure to recognise early symptoms as the biggest challenge before people seek care. Symptoms are rarely recognised as respiratory disease, so testing is often not considered. The group therefore prioritised strengthening public awareness and health literacy.

WHAT PARTICIPANTS SAID

Participants from very different health systems described the same pattern. A clinician from Belgium reported that few people know what COPD is. Patients often react to the diagnosis with relief, showing how rarely chronic respiratory disease is understood as life-threatening.

Vildana Mujkic of the Global Allergy and Airways Patient Platform (GAAPP) described how, in Sarajevo, many deaths are linked to air pollution among people with chronic respiratory disease. She pointed out that when COPD occurs alongside other conditions, such as heart disease, it often goes unrecorded and the burden is hidden.

The group argued that opportunities to identify respiratory disease should extend beyond the clinic. Jean Wright, CEO of the COPD Foundation, questioned whether primary care alone could close the diagnosis gap, and called for "making lung health measurement ubiquitous in society". She pointed to blood pressure as an example, where checks offered in everyday settings have helped raise awareness on cardiovascular health.

Participants stressed that awareness work need not wait for wider access to spirometry, which remains important but requires trained staff and is not yet available in every setting. They highlighted that simple local campaigns could help people recognise persistent respiratory symptoms and understand when to seek assessment. These efforts can begin through existing community networks and patient organisations.

THE 2035 AMBITION

By 2035, respiratory health is part of everyday public knowledge: people know what healthy breathing looks like, recognise the symptoms of chronic respiratory disease, use its medical names, and ask for a diagnosis when something is wrong.

The group set the bar deliberately high and measured it against the public understanding of HIV (Human Immunodeficiency Virus) and of cardiovascular health. The ambition includes giving people the markers that separate ordinary breathlessness from a symptom worth taking to a doctor. To be able to make a diagnosis, the individual needs to first recognise they might be sick and then seek help.

Knowing what healthy breathing looks like and understanding how the lungs work is the starting point. The International Primary Care Respiratory Group (IPCRG) has produced an animated film, *How We Breathe*, designed to improve "breathing literacy"; it is one resource clinicians can use to build that understanding.[14]

MINIMUM STANDARD

Everyone who presents at a first point of contact, in primary care or a community pharmacy, with persistent breathlessness, cough or sputum is asked about their breathing and their exposures at home and at work,

has an initial assessment with the tool appropriate to that level of care, and is offered quality-assured spirometry, or referred for it, when that assessment indicates a need.

The standard applies Professor Richard van Zyl-Smit's recommendation of the right test at the right level, in two steps. The first step is case finding, identifying people who need further testing. A peak flow meter is a small, low-cost handheld device. It can help detect asthma and flag reduced airflow; a low reading signals that lung function should be checked further. A structured symptom questionnaire can capture breathlessness, cough, sputum and exposures such as smoking, household fuel smoke and dust or fumes at work. A validated questionnaire can provide a score to guide referral for testing. The second step is diagnostic assessment using spirometry. Spirometry is the standard lung function test: it measures how much air a person can breathe out after a full breath and how much of it is exhaled in the first second, to assess whether airflow is obstructed. Spirometry is required to confirm COPD[7] and supports the diagnosis of asthma. Where spirometry is unavailable locally, people identified through case finding should have a clear referral route to a service that provides it.

PRIORITY ACTION BY 2027

By 2027, every country should launch a national respiratory health awareness campaign that gives citizens a few simple messages about the symptoms that should prompt a check.

One participant described a public campaign now running on buses, on the subway and in Times Square in New York City. It uses an open question, three symptoms and a QR code that leads to further information on COPD.[15] A linked symptom questionnaire gives people a record to discuss with their doctor, while providing the organisation leading it with evidence for policymakers. Participants considered similar approaches feasible in low- and middle-income countries, where local television and radio could feature people living with COPD or asthma. They noted that asthma can be harder to characterise in awareness campaigns because symptoms vary over time and differ between individuals, making it difficult to convey a readily recognisable picture of the condition.

LONGER-TERM RECOMMENDATION TOWARDS 2035

Towards 2035, countries should turn the campaign into a sustained movement for respiratory health, with a standing national coalition, public champions from outside medicine, and primary care resourced to meet the demand that awareness creates.

Participants drew on the HIV and tuberculosis (TB) experience, where social movements carried awareness into schools, the arts and national politics within a few years. Respiratory disease can follow the same playbook if the message reaches everyday settings: television and film, workplaces, schools and consumer spaces, with open spirometry in shopping centres wherever its quality can be assured.

POLICY IMPLICATION

For decision-makers, the group's message is that early diagnosis should start before the clinic. Ministries of health should treat public respiratory health literacy as part of the diagnostic pathway and fund it accordingly and should give primary care and community pharmacies the tools and training to assess lung function at the level appropriate to their setting. Participants highlighted that patient organisations are ready partners and should belong in the conversation from the start. Actions 1 and 2 in Part 2 take this forward.

Priority 2: Connect care

This chapter draws on the roundtable discussion on shared care between primary care and respiratory specialists, with France as its case study country and Siân Williams, Chief Executive of the International Primary Care Respiratory Group (IPCRG), starting the discussion. The participants were asked where the transitions between the two levels of care break down, in either direction, and how to strengthen them.

THE CHALLENGE

Primary care needs to recognise when a patient's needs are too complex to manage locally and refer them to a specialist team for further assessment and care. When a patient is admitted to hospital, secondary care should plan discharge in coordination with primary care, ensuring that the information needed for follow-up is shared to reduce the risk of readmission. The French case study illustrated that solid foundations in primary care do not necessarily guarantee a connected pathway. France has comprehensive national data, strong guidelines from the Haute Autorité de Santé and an organised primary care system. Yet in a study of 48,638 patients admitted with a COPD exacerbation in 2017, only 8.6% received pulmonary rehabilitation within 90 days of discharge,[16] and access to it is uneven between regions and overseas departments.

Participants identified the pressures facing primary care as the main barrier, with delayed diagnosis as one of the clearest consequences. They described a service adapting to changes in its gatekeeping role while working with limited time and varying levels of capacity. Short consultations leave little room to investigate respiratory symptoms, particularly where clear tools for recognising disease and guiding referral are lacking. Local circumstances further shape what services can realistically provide.

WHAT PARTICIPANTS SAID

Siân Williams explained that the IPCRG works towards a world in which the whole population can breathe well. She argued that universal access to respiratory care can only be achieved through primary care, and that the data tell only part of the story of each patient; her advice to policymakers and policy administrators was to ask primary care professionals to explain the narrative behind the numbers, since they know why and how the pathway breaks down and the competing pressures of other pathways and patient need.

Other participants strongly agreed, and the group saw this as one of the main takeaways of the discussion. Change depends in large part on understanding the lived realities of patients navigating these systems and of the professionals working within them, particularly between primary and secondary care. That calls for qualitative work on the ground to capture the narrative around each care pathway, alongside the quantitative data.

She framed the problem in terms of the COM-B behaviour change model.[17] If we want the 5Cs of primary care (first contact, comprehensive, continuous, coordinating and person-centred), then we need to support the right capabilities, opportunities and motivation. Capability means confidence and competence in respiratory health, backed up by a system that gives primary care professionals the agency and the rights to make decisions with patients. Opportunity means that the system makes the pathway to primary care easy for patients and is financed sufficiently that it can be trusted to provide the 5Cs of care, including electronic health records and access to essential diagnostic tools and medicines. Motivation, in addition to the intrinsic motivation of primary care to provide holistic person-centred care over time, includes the right financing and performance incentives linked to patient outcomes, as laid out in the six building blocks of a health system defined by the World Health Organization.[18]

Participants added that referral is a skill as well as a decision, and many primary care professionals may not have been trained in it. In France, since the 2004 health insurance reform, patients register with a primary care physician who now has a gatekeeping role and coordinates their care. However, the gatekeeping role works only where the primary care team is supported by the system to manage patients whose disease is hard to manage. It takes time for patients to build trust in a different system, and for primary care and secondary care specialist teams to build trusting relationships.

Participants argued that, to improve continuity of care, if relational continuity was not possible, informational continuity could be achieved if patients owned their records. Systems should share information automatically, and patients should be able to see and use it. France's *Mon espace santé*,[19] the national digital health system, supports this by giving people access to their shared medical record and control over who can view it. Other schemes include Patients Know Best, which is used by over 1 million patients in the UK.[20]

THE 2035 AMBITION

By 2035, every person with chronic respiratory disease experiences primary and specialist care as one continuous, interdisciplinary pathway without gaps, centred on them, in which clinicians listen to the patient, agree treatment goals with them and reach those goals in the patient's local setting, with specialist input available without delay when it is needed.

This ambition centres coordination on the patient's needs. Where specialists are scarce or unevenly distributed, their time should focus on advising primary care teams and managing complex cases. Patients returning to primary care should have a clear plan for ongoing treatment and follow-up.

MINIMUM STANDARD

Every person with COPD should have several structured medical reviews each year, for example four, each with protected minimum consultation time. Every patient returns to primary care from any specialist or hospital care with an updated written care plan.

The standard starts from the group's concern with time. Scheduled reviews and a written plan can work on paper where digital systems are not yet in place and can become part of the shared record where they are.

PRIORITY ACTION BY 2027

By 2027, every country should improve communication between health professionals across levels of care by defining and piloting a shared care protocol for people with the most unstable respiratory disease that sets out when and how primary care refers, how specialists give advice and return patients, and what happens at hospital discharge, backed by training in referral for primary care professionals, including nurses, and community pharmacists.

Clinicians should lead the protocol through their national primary care and respiratory societies. Pilots can test simple tools such as structured assessment templates, referral guides, advice lines when primary care needs urgent specialist advice, and a standard discharge process for patients admitted with an exacerbation, including referral to pulmonary rehabilitation and smoking cessation services if appropriate.

LONGER-TERM RECOMMENDATION TOWARDS 2035

Towards 2035, countries should build better patient data records: a single respiratory record, owned by the patient, that primary care, specialists, hospitals and pharmacies can all read and update.

A shared record would allow information to follow patients between services, while enabling them to view their records and contribute information relevant to their care.

POLICY IMPLICATION

For decision-makers, the group's message is that shared care often fails at the handovers. Ministries of health should ensure that healthcare professionals have the proper training, the confidence and a clear route to refer, and require a written plan whenever a patient comes back from specialist care or hospital. Health systems should invest in shared records that are easy to use, with financing that supports coordination and clear responsibility for patients' transitions between levels of care. Actions 3 and 7 in Part 2 take this forward.

Priority 3: Shift to proactive management

This chapter draws on the roundtable discussion that examined the shift from reactive treatment to proactive long-term management, with China as its case study country and Professor David Halpin joining the table to start the discussion. The participants were asked what it would take to move from a system that treats single episodes to one that manages care over time.

THE CHALLENGE

Proactive management rests on a simple sequence: a person is diagnosed, starts maintenance treatment, and is reviewed regularly so that treatment can be adjusted before a flare-up turns into an emergency. Where any link in that sequence is missing, care defaults to the acute episode.

Professor Halpin argued that widespread exposure to COPD risk factors means that health systems must prepare for more cases. Reactive care, he stressed, does not work for noncommunicable diseases; even high-income health systems often manage emergencies more effectively than long-term ongoing care. What is needed is a management programme with clear objectives for the system, in the same way that the GOLD strategy sets treatment targets for the individual patient. He highlighted examples, such as China's investment in training health professionals and providing regular follow-up, alongside patient-held records in South Africa that support continuity of care.

Yet long-term management depends on identifying patients in the first place. Underdiagnosis is where the sequence most often breaks, and China, the group's case study country, illustrates the scale of this challenge. The China Pulmonary Health study estimated that 8.6% of adults aged 20 and over live with COPD, close to 100 million people.[21]

Participants therefore identified access to diagnosis as the starting point for proactive care. Once diagnosed, patients need affordable essential medicines and primary care services equipped to support them over time. Widespread underdiagnosis means many patients never reach that stage.

WHAT PARTICIPANTS SAID

Respiratory specialists tend to be concentrated in hospitals, with limited reach into local communities. Where primary care does not act as a gatekeeper or provide continuity of care, patients may miss regular reviews. One participant described crowded hospital clinics where staff have little time to explain treatment, making it harder for patients to follow treatment plans.

Access to medicines is a problem. Primary care professionals find it hard to provide medicines that have to be ordered and imported. Nicotine replacement products are scarce but needed.

The group also saw assets that many countries can build on. Where respiratory physicians have a strong working relationship with primary care, as they do in China, they can train primary care physicians to take the lead. Participants also described clear political will in China to tackle chronic respiratory disease. One participant argued that if the burden stays hidden, politicians treat it as a small problem and allocate little money to it. Better diagnosis will make recorded prevalence rise before it falls, and participants see that rise as a sign of progress.

THE 2035 AMBITION

By 2035, every country is meeting measurable targets to reduce smoking and other exposures, most people diagnosed with COPD are in active maintenance treatment, and a primary care workforce trained in respiratory disease manages it proactively, supported by digital, monitored self-management.

The ambition has three parts that apply in any country: a target for reducing exposure, a target for bringing diagnosed patients into treatment, and the system that delivers both. A number gives a government something to be held to.

MINIMUM STANDARD

Every country provides accessible, affordable diagnosis, including spirometry, essential medicines and a primary care workforce equipped to provide continuity of care instead of one-off acute visits, so that patients are identified and treated before deterioration becomes a crisis.

Diagnosis and medicines must be affordable for the patient, and patients who know that good COPD or asthma care means regular review and adjustment of treatment are more likely to ask for it.

PRIORITY ACTION BY 2027

By 2027, governments should reduce exposure to the main risk factors, with stronger tobacco control, including enforcing bans on smoking in public places, free smoking-cessation medicines, and continued action on indoor and outdoor air pollution.

Earlier diagnosis and better treatment must be accompanied by prevention to reduce future cases. Diagnosing and treating more people matters, but first the influx of new patients must be stopped. National and local governments should drive tobacco control policy, while primary care should provide practical cessation support to help people stop smoking.

LONGER-TERM RECOMMENDATION TOWARDS 2035

Towards 2035, countries should expand access to essential

medicines and structured treatment pathways, and strengthen patient self-management, including digital, monitored self-management plans, building on primary care physicians trained to lead the ongoing management of respiratory disease.

With training and support from respiratory specialists, primary care physicians should lead routine management and identify patients at greatest risk of severe flare-ups for closer follow-up. Individual self-management plans should help patients manage their condition between appointments, with clear guidance on when to seek help. Health ministries should lead this work in partnership with primary care leaders, backed by government commitment and resources.

POLICY IMPLICATION

For decision-makers, proactive management starts with finding patients and making treatment affordable. Ministries of health should fund diagnosis and essential medicines at the primary care level, organise primary care to provide continuity instead of one-off visits, with the highest-risk patients identified and followed most closely, and invest in medical records that follow the patient between providers. Governments should treat tobacco control and clean air as part of the same agenda. Actions 4, 5 and 8 in Part 2 take this forward.

Priority 4: Make patients partners in care

This chapter draws on the roundtable discussion that examined health literacy and patient involvement in shared decision-making, with Mexico as its case study country and Riley Sanders joining the table to start the discussion. The group discussed strengthening health literacy for shared decision-making.

THE CHALLENGE

A systematic review covering more than 54,000 people with asthma or COPD found that only 31% of the patients used the inhaler correctly.[22] A separate review found that health professionals performed the technique correctly only 15.5% of the time.[23] Since patients often learn inhaler technique from health professionals, improving staff training is a practical starting point for helping patients use their treatment correctly.

Riley Sanders' opening presentation argued that translating new global commitments into better care depends on patients being able to participate meaningfully. Many patient advocates had themselves experienced misdiagnosis. He called for countries to work with patient organisations and families to strengthen involvement in care, supported by multidisciplinary services and policies with sustained funding and clear accountability. He highlighted the limited opportunities for patients to participate in treatment decisions in many low- and middle-income countries.

The group was asked to name the point in the patient's journey where understanding and involvement decline most. Participants placed it at two points: before diagnosis, where low awareness leaves many people undiagnosed, and soon after, when a patient starts first-line treatment with no follow-up or action plan, does not know when to return, and stays at the first step until an exacerbation forces a change.

WHAT PARTICIPANTS SAID

Awareness among people not yet diagnosed is low, and the condition is stigmatised: changes in breathing are put down to ageing or changes in body weight, and COPD is not seen as a condition people can manage. Access to support also varies significantly across settings.

After diagnosis, limited health literacy can make treatment harder to understand and follow. Participants returned several times to inhaler technique, linking it to adherence and to checking how patients take their medicines as well as whether they take them. Asthma needs to be properly explained so that people can recognise it, name it to another clinician and understand why it needs regular treatment.

Participants also discussed air quality. A participant from the United Kingdom argued for simple messages on days of high pollution and pointed to a website in England showing an 18-year gap in life expectancy between postcodes, promoted with blunt marketing modelled on a supermarket price label.[24] A respiratory physician from the United Arab Emirates warned that vaping is the next emerging threat to lung health. Raising awareness means building literacy about the social determinants of lung health and about inequities in exposure, and reducing those inequities supports prevention, diagnosis and long-term care alike.

Respiratory health must stay on the political agenda. A parliamentarian in the group described the work as constant replenishment: commitments need to survive changes of political leadership, and advocates need a wider network that includes the permanent civil service, since plans already in place can be reversed.

THE 2035 AMBITION

By 2035, people understand their lung health as well as their heart health, know their lung function numbers and what they mean, and every patient is empowered by their own accessible respiratory health record.

The ambition joins two kinds of literacy: public recognition of respiratory disease, and each patient's understanding of the information about their own respiratory health.

MINIMUM STANDARD

The right respiratory tests, including spirometry, are available as a standard part of assessment in primary care, within a patient-centred pathway that coordinates primary care professionals, specialists and prevention, including smoking cessation and vaccination, and every patient has an accessible personal record of their respiratory health.

The standard starts from what the patient needs and looks for inequalities. Prevention needs a pathway, as diagnosis does, and stopping smoking should be seen as treatment. Spirometry is not the only tool: asthma results can look

normal on a good day, so the standard is the right test for the condition, explained to the patient.

PRIORITY ACTION BY 2027

By 2027, respiratory health advocates should secure representation in front of parliamentarians to make the case for a patient-held lung health file, paired with awareness efforts that help patients and general practitioners understand lung function numbers and why they matter.

Pharmacies can take a larger role in prevention, digital tools can help patients improve their inhaler technique and take their medicines as prescribed, and self-management plans tailored to the individual can do much. Participants also called for renewed national vaccination campaigns.

LONGER-TERM RECOMMENDATION TOWARDS 2035

Towards 2035, every patient should have an individual, accessible respiratory health record, in a booklet or an app, covering lung function results, action plan, medicines, vaccinations, and any smoking cessation or pulmonary rehabilitation.

France's shared medical record, the *dossier médical partagé*, is an example of a single file that follows the patient and is open to the patient as well as to clinicians, through the national digital health space Mon espace santé.[19] It is designed to help patients understand and take part in managing their own condition.

The goal of the recommendation is explicit: a measurable reduction in premature mortality from respiratory disease.

POLICY IMPLICATION

A patient becomes a partner in care only once they have a diagnosis they understand and the information to act on it. Ministries of health should make the right respiratory tests, including spirometry, a standard part of assessment in primary care, make sure patients are told what their results mean, and give community pharmacies a defined role in prevention. Health systems should start planning now for a personal respiratory health record that patients can access and carry across levels of care. Patient organisations and civil society belong in the design of these measures from the start. Actions 6 and 7 in Part 2 take this forward.

Part 1 followed the pathway one stage at a time. Part 2 looks across the four stages: it identifies the lessons the groups shared and turns them into eight actions that countries can begin by 2027 and build on towards 2035.

Part 2:

FROM INSIGHT TO ACTION: The Respiratory Action Framework

What the four priorities show together

The four groups examined different points along the pathway, and their findings suggest five areas that need attention when putting the recommendations into practice.

Improvement needs to be planned across the whole pathway. Earlier diagnosis emerged as the strongest common thread across the roundtables. Participants named access to diagnosis, essential medicines and functioning primary care as the priority bottleneck and stressed that tackling smoking and indoor and outdoor air pollution is part of proactive care. These discussions point to a broader principle: improvements in diagnosis, referral, and follow-up need to be planned together, so that progress in one area does not simply expose gaps elsewhere.

The whole pathway also includes people whose asthma or COPD remains uncontrolled despite treatment. For them, international guidelines describe a stepwise approach.[25,7] People who have frequent exacerbations or poor symptom control should be referred promptly for specialist assessment, where biomarkers can help identify the type of inflammation driving the disease: blood eosinophil counts in both asthma and COPD, and fractional exhaled nitric oxide (FeNO), mainly in asthma. These results are interpreted alongside clinical assessment and spirometry. For eligible patients, guidelines recommend advanced therapies, including biologics, with regular monitoring of the response. Access should follow national approvals and health technology assessment and should not depend on where a patient lives or is treated.

Primary care needs the capacity to deliver. Stronger connections are needed between primary care, specialist services and the rest of the health system. Primary care professionals often lack the time, training, equipment or support to meet expectations, so new standards and responsibilities need to be matched by investment in primary care capacity. Patients need to be active partners in care. Health literacy matters here, including misinformation, vaccine hesitancy and confusion around respiratory terminology. Shared decision-making, accessible information, and tools such as personal respiratory health records can help patients take a more active role. Actions need to reflect local needs and inequalities. While similar challenges arise across countries, the barriers differ. Countries should identify their main gaps and adapt actions accordingly, paying particular attention to underserved populations and unequal access.

A final cross-cutting topic is the difference between having policies, guidelines or services in place and patients and providers being able to use them. Progress

needs to be measured in practice. Monitoring should measure whether access and outcomes differ between population groups, and whether patients understand their condition, feel involved in decisions and know where to seek help.

Together, these lessons inform the eight actions that follow, providing a basis for practical improvements by 2027 and longer-term changes towards 2035.

EIGHT ACTIONS TO STRENGTHEN THE PATHWAY: THE RESPIRATORY ACTION FRAMEWORK

The actions apply to any country but need adapting to where each one starts. Each action ends with recommended indicators for tracking progress.

1. Make lung health part of public knowledge

Many people living with COPD have not been diagnosed, and the groups traced much of the delay to the period before a person seeks care. Countries should run a national respiratory health awareness campaign built on a few simple messages about the symptoms that should prompt a check, written simply enough for everyone to understand and carried by patient organisations, schools, pharmacies and popular media. A campaign of this kind needs no equipment and can start by 2027 in any setting.

Indicators: symptom recognition for patient; adequate follow-up; gain of skills and knowledge.

2. Assess lung function at the first point of contact

Primary care and community pharmacies should ask people with frequent breathlessness, cough or sputum about their breathing and their exposures at home and at work, use a case-finding tool suited to that level of care, such as a peak flow meter or a validated symptom questionnaire, to identify who needs further testing, and confirm the diagnosis with quality-assured spirometry, either on site or through a clear referral route. Testing needs trained staff, since poorly performed spirometry leads to overdiagnosis and underdiagnosis, and staff should explain the results so that people know their lung function numbers as they know their blood pressure.

Indicators: availability of spirometry in clinics; trained staff to perform spirometry; percentage of asthma and COPD diagnoses made using objective testing.

3. Agree how primary and specialist care communicate about specific care

Care for patients who need both primary and secondary care most often fails at the handover between levels, even in well-resourced systems with strong guidelines. Countries should define and pilot a protocol for chronic respiratory disease that sets out the situations in which primary care might refer, how specialists give advice and how the written care plan is updated and what happens at hospital discharge, including referral to smoking cessation services where appropriate and to pulmonary rehabilitation, a supervised programme of exercise and education. A protocol can be piloted by 2027 and scaled once tested, including in underserved areas.

Indicators: existence and implementation of standardised discharge protocols;

percentage of patients referred to, participating in or completing post-admission pulmonary rehabilitation; average waiting time for a respiratory specialist, especially in rural or underserved regions; hospital readmissions after discharge.

4. Schedule regular reviews and make a shared plan with every patient

Proactive management depends on seeing the same patient again before a flare-up becomes an emergency. Many patients start first-line treatment with no follow-up or action plan, in consultations as short as one to two minutes. Countries should set a schedule of structured reviews with protected consultation time, such as four a year for people with COPD and more often for severe disease or after an exacerbation, in line with national guidelines,[26] and if there is no universal health coverage (UHC), keep reviews affordable so that charges do not deter people on lower incomes.

Indicators: use of individualised treatment or action plans; percentage of patients reporting continuity with a regular care provider.

5. Ensure equitable access to medicines

A medicine that is not stocked locally cannot become part of routine care. Countries should check that essential medicines for chronic respiratory diseases and smoking cessation medicines are on the national essential medicines list, covered by public payers and stocked in pharmacies, applying the Declaration's 80% target to respiratory disease. Ministries of health can set a baseline by 2027 and report against it each year to 2030. For people whose disease remains uncontrolled despite optimised treatment, countries should also ensure timely specialist referral, access to guideline-recommended biomarker testing and, for eligible patients, equitable access to advanced therapies in line with national approvals.

Indicators: stock-out rates for relevant medicines in the public sector; public payer coverage for relevant drugs and treatments; maximum annual costs of treatment per patient; time from identification of uncontrolled disease to specialist assessment; availability of blood eosinophil testing in primary care and FeNO testing in specialist care; share of eligible patients with access to recommended advanced therapies.

6. Check that treatment reaches the lungs

With many prescribed inhalers, an inadequate amount of the medication reaches the lungs because they are not used correctly. A systematic review found that fewer than a third of people with asthma or COPD use their inhaler correctly, and that this has not improved over four decades.[22] Inhaler technique should be checked at every review and whenever a device is changed, by whoever sees the patient, including community pharmacists. Free, independent resources on inhaler technique, such as those from national guideline bodies, professional societies or platforms, can help, alongside digital tools that guide each step of inhaler use and paper self-management plans for people without a smartphone.

Indicators: gain of skills and knowledge; behavioural change following learning activities; prevention of exacerbations.

7. Give patients access to their own health record across the pathway

A shared decision depends on the patient having the same information as the clinician. Countries should work towards a single and comprehensive health record that follows the person across every stage of the care pathway and covers all their conditions, not only respiratory health. For people with chronic respiratory disease, it should include lung function results, action plans, medicines, vaccinations, smoking cessation and pulmonary rehabilitation. It should sit in interoperable systems that primary care, specialists, hospitals and pharmacies can read and update. Patients should be able to open it through an app, a portal or a printed booklet. Most countries will need until 2035 to build it, but every patient can be given a copy of their lung function results, with an explanation, now.

Indicators: use of individualised treatment or action plans; duplication of tests and imaging.

8. Include prevention as part of care

However well a pathway is organised, the number of patients will keep rising while tobacco use and polluted air add new cases. Within the pathway, smoking cessation should be offered as treatment, with free cessation medicines and support in primary care and pharmacies. People with chronic respiratory disease should be a priority group for influenza, pneumococcal and respiratory syncytial virus (RSV) vaccination. Outside the clinic, smoke-free public places, regulation of vaping products and action on air quality should advance alongside action on care.

Indicators: influenza and RSV vaccination rates for people with CRD; prevalence of tobacco and nicotine use.

FROM EIGHT ACTIONS TO A RESPIRATORY ACTION FRAMEWORK:

The eight actions are written for policymakers, to help them turn global commitments on respiratory health into practical action along the care pathway. Together they form the **Respiratory Action Framework** *(Figure 3)*: one set of actions that follows the four priority areas, separates what can start by 2027 from the system changes needing implementation towards a 2035 goal, and can be adapted by any country to its own starting point and capacity. Clinicians, patient organisations and other advocates have a part in each action, because policymakers cannot close these gaps alone.

The actions were developed after the Barcelona workshop, drawing on the discussions in the four groups. A practical way to begin is to identify the priority where the gap appears greatest in each setting. For each priority, it is worth asking who may be missing out and whether access and outcomes differ between population groups. It is also worth agreeing early who is responsible for each action and how progress will be tracked through the indicators attached to it, with the 2035 direction kept in view.

THE RESPIRATORY ACTION FRAMEWORK

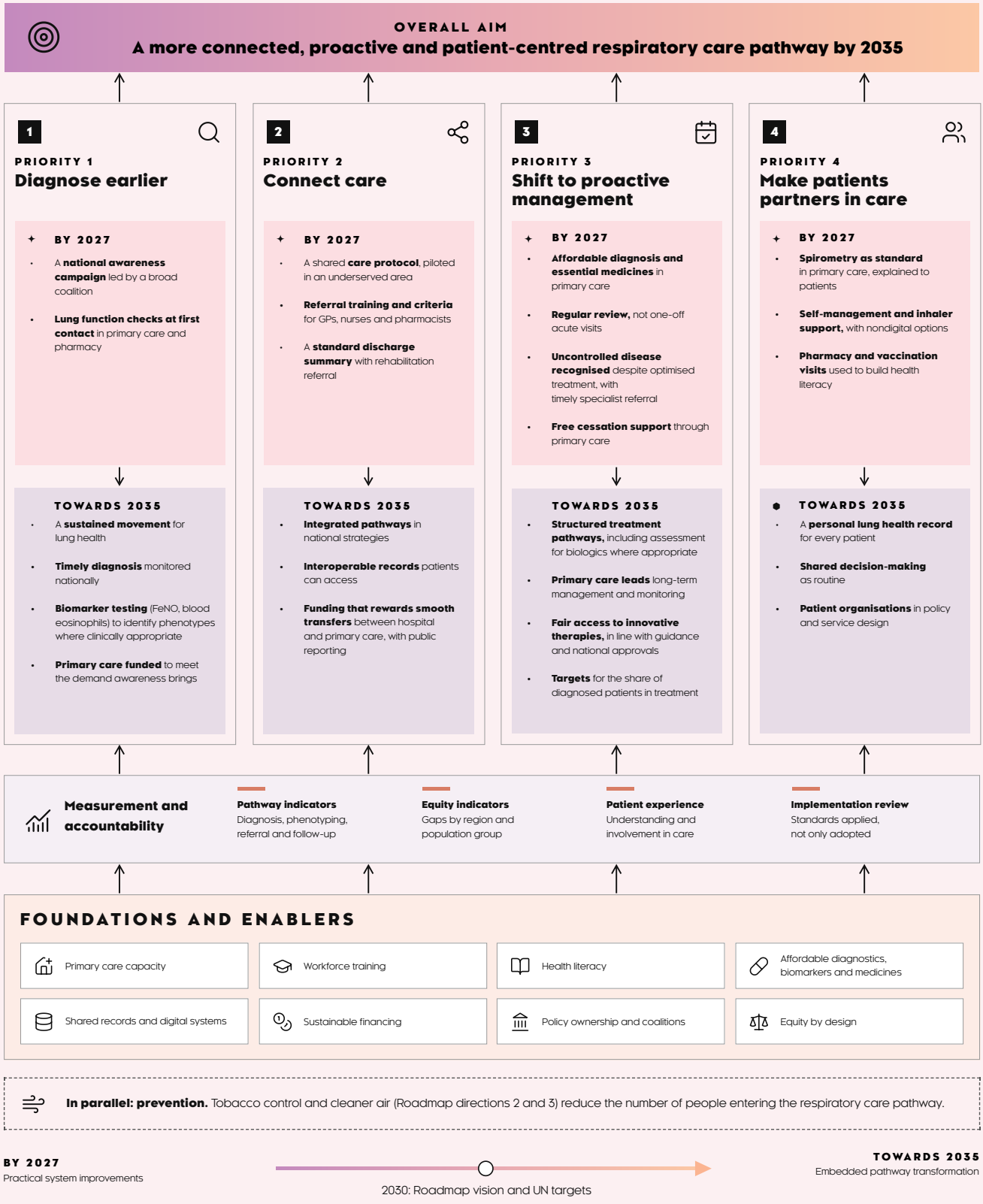


Figure 3: The Respiratory Action Framework.

Conclusion

The global commitments are now in place. Governments have recognised chronic respiratory disease as a public health priority and set targets for improving access to diagnosis, treatment and care. The challenge is to turn these commitments into improvements that patients experience in practice.

The four roundtable discussions showed that earlier diagnosis, connected care, proactive management and patient involvement cannot be addressed in isolation. Progress depends on stronger primary care, clear responsibilities between services, affordable treatment and patients who have the information and support to manage their condition.

This Report sets out eight actions that countries can begin taking by 2027, alongside longer-term ambitions towards 2035. The eight actions, with their indicators, give clinicians, policymakers and patient organisations a practical basis for agreeing priorities and tracking progress. Actions will need to reflect national and local contexts, with particular attention to populations facing the greatest barriers to care.

As José Luis Castro and Lord Nick Herbert emphasised at the roundtable, progress requires both practical implementation and sustained political commitment. The task now is to bring these together, with clear responsibilities and accountability for whether care is improving. This Report offers a shared starting point for that work.

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