# Roadmap for Advancing a New Subspecialty in Pulmonary Medicine Devoted to Chronic Respiratory Failure

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Exponential expansion of medical knowledge since the mid-1950s has driven progressive subspecialization of medicine, thereby enabling physicians to achieve and maintain mastery across the scope of their individual practices (1). We contend that the time has come to formalize a new subspecialty devoted to the care of people with chronic respiratory failure.

Beginning with the polio epidemic of the early 1950s and accelerating to the present, extraordinary advances in technology for long-term mechanically assisted ventilation have improved the quality of life and extended the lives of hundreds of thousands of people afflicted by chronic diseases that impair the function of the respiratory pump (2–7). Regrettably, most pulmonologists in North America have not kept abreast of these advances. The rapid growth of technology for home assisted ventilation is outpacing the education of clinicians in the long-term management of chronic respiratory failure, resulting in practice gaps across North America. Filling the deficiencies will require an organized effort to train and certify physicians in the care of people with chronic respiratory failure (8).

## What Do We Mean by "Chronic Respiratory Failure"?

Since 2016, the International Classification of Diseases has included codes for chronic respiratory failure without otherwise defining the term. To our knowledge, no consensus publication has standardized criteria for differentiating chronic from acute respiratory failure or defining the severity inclusion threshold for chronic respiratory failure. In current practice, the term chronic respiratory failure is commonly used to identify children and adults who benefit from long-term assisted ventilation to manage persistent hypercapnia.

Chronic respiratory failure conditions are distinctly characterized by ventilatory impairment with hypercapnia initially during sleep and often progressing to diurnal hypoventilation (Table 1). People with chronic respiratory failure benefit from long-term mechanically assisted ventilation spanning the spectrum from nocturnal to continuous support.

## The Emerging Subspecialty

Specialization in chronic respiratory failure combines knowledge of the diseases that cause chronic hypercapnia with expertise in management of devices used to support respiratory pump failure. Practitioners combine physiologic assessment of chronic hypoventilation with continuity management of assisted ventilation and remote patient monitoring. Taking a comprehensive care approach, specialists in chronic respiratory failure also assess and guide management of other care needs, including mobility devices, assisted communication, supplemental nutrition, and end-of-life care planning.

The sophistication of mechanical devices available to treat chronic respiratory failure has expanded considerably over the past 30 years. At the foundation of treatment, ventilatory support devices augment or replace insufficient patient inspiratory effort by applying positive pressure to the airways through a facial mask interface or tracheostomy. Bilevel positive airway pressure devices are designed to support ventilation during sleep (respiratory assist devices [RADs]). Home mechanical ventilators derived from critical care ventilators are adapted to support people who need a higher, more secure form of home ventilatory support often extending into the day. Cough assist and multifunction airway clearance devices lead an armamentarium of tools designed to help clear the airways of people who can no longer cough productively.

Home care monitoring technology has advanced dramatically. Advanced RADs and home ventilators are configured to transmit ventilatory performance parameters, including breath-by-breath measures of

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**Table 1.** Causes of chronic respiratory failure

| Condition | Examples |
|---|---|
| Congenital neuromuscular diseases | Spinal muscular atrophy, muscular dystrophies |
| Brain disorders | Cerebral palsy, congenital central hypoventilation syndrome |
| Adult-onset motor neuron diseases | Amyotrophic lateral sclerosis, multifocal motor neuropathy |
| Metabolic myopathies | Mitochondrial disorders, Pompe disease |
| Autoimmune neuromuscular diseases | Myasthenia gravis, chronic immune demyelinating polyneuropathy |
| Diaphragm paralysis | Amyotrophic neuralgia, traumatic or surgical phrenic nerve injury |
| Obesity hypoventilation syndrome | — |
| Chronic obstructive pulmonary disease | — |
| Spinal cord injury | — |
| Other conditions leading to chronic respiratory failure | Post–COVID-19 acute respiratory failure, chronic critical illness/prolonged mechanical ventilation |

*Definition of abbreviation*: COVID-19 = coronavirus disease.

pressure and tidal volume, thereby allowing clinicians to assess and optimize device function in the patient's home. Noninvasive monitoring of carbon dioxide partial pressure and oxygen saturation as measured by pulse oximetry is available, allowing assessment and normalization of respiratory gas exchange (9). The availability and impressive technology of noninvasive respiratory devices have provided patients the opportunity to live at home instead of in long-term care facilities and avoid emergency room visits or hospital admissions.

## Current Gaps

The number of individuals who might benefit from a physician specialist in chronic respiratory failure is unknown but, by all indications, growing rapidly. With the benefit of home assisted ventilation and emerging disease-modifying therapy, children with congenital neuromuscular diseases or severe thoracic cage anomalies who previously died before the age of 18 years are surviving well into their 40 s. In the United States, an estimated 500,000 children and adults are living with a neuromuscular disease (10). In the United States, the estimated prevalence for amyotrophic lateral sclerosis (ALS) is 9.9 per 100,000 (11). The obesity epidemic is driving a sharp increase in obesity hypoventilation consequences. Home ventilation is now recommended for a substantial fraction of adults with advanced chronic obstructive pulmonary disease (COPD).

Reflecting these trends, the number of home ventilators in use in the United States has grown dramatically. Figure 1 highlights the substantial increase in beneficiaries and noninvasive home ventilator claims from 2009 to 2017, as reported by the Office of Inspector General (12). In 2021, 106,635 beneficiaries submitted a claim to Medicare for an RAD or home ventilator, a dramatic increase from 46,704 claims in 2017 (13). If the noninvasive ventilation (NIV)/RAD payer mix for PromptCare, a multistate respiratory durable medical equipment (DME) company with service locations in 18 states, is representative nationwide (53% Medicare; Christopher Lange, R.R.T. and Katie Allen, personal communication, August 2023), more than 200,000 adults in the United States are currently supported by an advanced RAD or home ventilator.

The number of physicians who specialize in continuity management of chronic respiratory failure in the United States is likewise unknown but manifestly inadequate to meet the current needs. The authors estimate that fewer than 300 U.S. adult pulmonologists welcome referrals for continuity care of people dependent on home assisted ventilation. By default, neurologists, hospitalists, and intensivists are initiating home assisted ventilation in hospitals for people who have no subsequent outpatient access to expert physician management. Readmissions are common, especially for COPD respiratory failure (14).

## Call to Action

Gaps in education and competency, coupled with lack of specialized respiratory centers and poor financial compensation for high-intensity coordination of home respiratory care stand in the way of expanding the cadre of physicians and clinical specialists in chronic respiratory failure (15). Addressing those gaps will require a multifaceted approach.

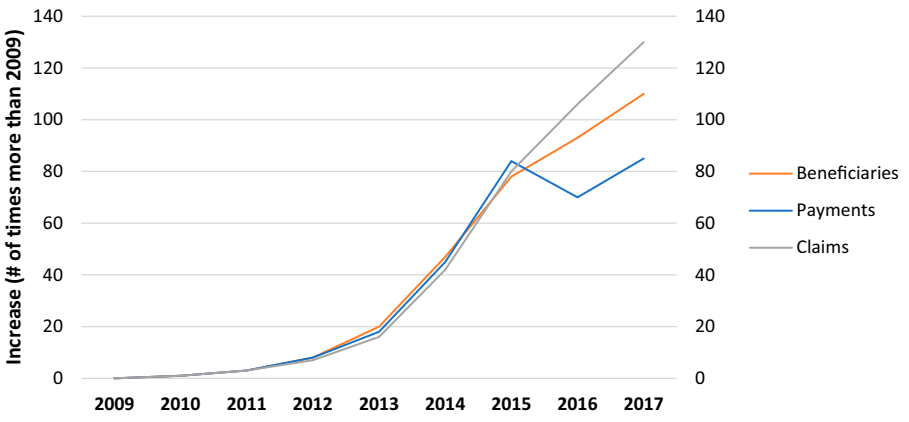


**Figure 1.** During 2009 to 2017, the number of beneficiaries with noninvasive home ventilator claims increased from 418 to 46,704, and the number of noninvasive home ventilator claims increased from 2,670 to 344,867. In 2016, Medicare reduced the reimbursement rate for noninvasive home ventilators (12).

### Education and Training

A recently published 35-page practical guide to home assisted ventilation hints at the breadth of knowledge needed to master continuity care for people with chronic respiratory failure (16). A new online ALS Respiratory Care course serves as an example of the educational material needed in chronic respiratory failure management (https://alsrespcare.com/). Much of this knowledge is so new that little has penetrated the curricula of medical schools or graduate medical education programs. Thus, a critical early step in narrowing the gap between knowledge and practice must be to develop education and training programs for physicians and clinical providers desiring to enter the field.

The knowledge base for management of chronic respiratory failure overlaps with pulmonary medicine and two established specialties: critical care medicine and sleep medicine. The breadth and depth of knowledge needed to master this subspecialty is more than what can be incorporated in the current pulmonary and critical care medicine (PCCM) curriculum. We argue that dedicated training is required, and advanced training pathways should be offered in these three subspecialties.

We particularly welcome North American trainees enrolled in PCCM fellowships to consider specializing in chronic respiratory failure. PCCM fellowships comprehensively cover cardiopulmonary pathophysiology and coordinated multisystem management of respiratory failure. Pulmonologists are well prepared to manage the acute and chronic lung diseases that often accompany chronic chest pump failure. Pulmonologists work closely with hospital- and outpatient-based respiratory therapists (RTs), who are essential for setting up and maintaining home respiratory care devices. For those who work in intensive care unit (ICU) settings, this specialty offers an outpatient practice portfolio that complements their inpatient management of acute respiratory failure.

A proposed pathway for training future leaders in the field arises from the Accreditation Council for Graduate Medical Education initiative known as Advancing Innovation in Residency and Education (AIRE). AIRE waives conventional graduate medical education requirements to enable exploration of novel training pathways, specifically exploring competency-based training models (17). An AIRE pilot program sponsored by the American Academy of Sleep Medicine was approved to blend formal sleep medicine fellowship with concurrent PCCM fellowship. In this AIRE model, theoretically, the second and third years of training can be customized to combine formal training in chronic respiratory failure with sleep medicine to qualify fellows for additional board eligibility in sleep medicine. Physicians thus trained would have the benefit of formally recognized advanced training without the need to complete a fourth full year.

### Implementation of a Home Assisted Ventilation Program in the United States

Caring for patients across the spectrum of chronic respiratory failure calls for an interdisciplinary and multifaceted model. This program provides a continuum of ambulatory care and facilitates smooth transition of care between inpatient/ICU as well as between pediatric and adult pulmonology programs (18). Core providers include the pulmonologist (and allied healthcare provider), RT, and clinical coordinator. This infrastructural model is not unique and can be borrowed from widely recognized pulmonary subspecialties, including cystic fibrosis, lung transplant, pulmonary hypertension, and interventional pulmonology, that incorporate interprofessional team members. Unfortunately, a program for adult patients living with long-term home mechanical ventilation is a foreign concept for most U.S. healthcare systems.

### Incorporating Interprofessional Team Members

Borrowing from successful inpatient models for COPD, the qualified RT is a key individual in implementation of care delivery (19). This individual serves a critical role in providing expert care, including initiation and titration of mechanical ventilation, patient/caregiver education and training, remote monitoring, and navigating respiratory DME services. The U.S. medical structure lacks dedicated funding for RTs who care for patients on long-term home assisted ventilation. It is currently a piecemeal approach; DME companies employ RTs on set-up of home ventilators but lack financial incentive to provide continuity of care beyond technical support, and very few academic institutions are successful at implementing a home assisted ventilation program with dedicated full-time RTs. The American Association of Respiratory Care urges physician support in their advocacy for federal policy modifications to extend the role of RTs in clinics and patient homes under general supervision of a prescribing clinician (https://www.aarc.org/advocacy). A cultural shift and financial structural change are needed to implement specialized centers and support employment of interprofessional team members to care for this population.

## Addressing Deficiencies in Financial Incentives

Physicians and medical systems are dissuaded from management of chronic respiratory failure out of concern that they are not adequately reimbursed for the intense coordination of care effort required to manage outpatient respiratory failure. Recent additions to the Procedural Terminology coding system for prolonged and complex care partially address this concern, some of which are under the Medicare Chronic Care Management program (20). Others are dissuaded by lack of access at their institutions for staff support. In most places, the sole responsibility of the RT is to perform spirometry. Unlike lung transplantation or interventional pulmonology, chronic respiratory failure management generates little direct or downstream revenue for hospitals to support ancillary personnel. Part of this problem is the lack of robust data to show insurance payors and hospital systems the benefits of a specialized home assisted ventilation program. We believe, however, that effective programs can reduce hospitalizations and ICU days, facilitate hospital discharges, and reduce COPD readmissions, thereby potentially covering the cost of ancillary staff allocation.
The Medicare Hospital Readmissions Reductions Program was created to incentivize healthcare systems to reduce readmissions among high-cost conditions (COPD, heart failure, myocardial infarction). This incentive should be extended to patients with chronic respiratory failure. It is also important to remind

ourselves that a specialized program may exist to improve the quality of medical care, not principally for financial gains.

## Summary

Chronic respiratory failure is an increasingly recognized and growing subspecialty within pulmonology. Technological advances in NIV, airway clearance modalities, and remote patient monitoring have paved a new pathway that requires combined expertise in pulmonary physiology, critical care management, and sleep medicine from the acute care setting to ambulatory care. The gaps in education, competency, research, and funding on chronic respiratory failure, combined with rapid advances in NIV technology, have resulted in an unmet need for pulmonologists and clinician specialists who can master this arena. A national call for change and implementation is necessary to address this unmet need. Finally, by implementing an advanced subspecialty fellowship training pathway in chronic respiratory failure, we can leverage and build a new generation of pulmonologists who are ready to close this gap, provide state-of-the art care, set up centers of excellence, and promote research. ■

**Author disclosures** are available with the text of this article at www.atsjournals.org.

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