

Defining and Promoting Pediatric Pulmonary Health: Equitable Family and Community Partnerships

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abstract

Optimizing pulmonary health across the lifespan begins from the earliest stages of childhood and requires a partnership between the family, pulmonologist, and pediatrician to achieve equitable outcomes. The Community Pediatrics session of the Defining and Promoting Pediatric Pulmonary Health workshop weaved together 4 community-based pillars with 4 research principles to set an agenda for future pediatric pulmonary research in optimizing lung and sleep health for children and adolescents. To address diversity, equity, and inclusion, both research proposals and workforce must purposefully include a diverse set of participants that reflects the community served, in addition to embracing nontraditional, community-based sites of care and social determinants of health. To foster inclusive, exploratory, and innovative research, studies must be centered on community priorities, with findings applied to all members of the community, particularly those in historically marginalized and minoritized groups. Research teams should also foster meaningful partnerships with community primary care and family members from study conceptualization. To achieve these goals, implementation and dissemination science should be expanded in pediatric pulmonary research, along with the development of rapid mechanisms to disseminate best practices to community-based clinicians. To build cross-disciplinary collaboration and training, community-academic partnerships, family research partnerships, and integrated research networks are necessary. With research supported by community pillars built on authentic partnerships and guided by inclusive principles, pediatric lung and sleep health can be optimized for all children and adolescents across the full lifespan in the community in which they live and thrive.



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The optimization of pediatric pulmonary health across the lifespan begins in childhood. More than 10 000 infants are born premature with bronchopulmonary dysplasia each year and need multidisciplinary care coordinated by their primary care pediatrician.¹ An estimated 8000 children, who are ventilator-dependent at home, rely on their primary care doctors for home care needs.² Six-million children currently living with asthma need routine follow-ups to reduce triggers and optimize medication dosage and delivery.³ Greater than 30 000 individuals currently living with cystic fibrosis already received or will require transitions support as they move from adolescence to young adulthood.⁴ For those children and the many more with other lung and sleep disorders, optimization of pediatric pulmonary health requires a partnership between the family, pulmonologist, and pediatrician. Despite recent advances and calls for pediatric health equity, there remains great opportunity to close gaps in pulmonary health research and practice for children in the United States.⁵ A community partnership approach with equity at the center has the potential to transform pediatric pulmonary research and optimize health.

Many children with pulmonary disorders require long-term management from pediatric pulmonology specialists. Yet, given the immense number of children affected, partnership with general pediatricians and primary care clinicians in the child's community is essential to fully address the needs of children with pulmonary disorders, both in research and in practice. Each year, >150 million office visits are completed by children aged <18 years, with 2.5 million of those being for asthma alone.^{6,7} To provide quality and equitable care at those visits in the community, considerations for practice must begin at the bench and research institutions. For example, the discovery of new therapeutics must be paired with novel mechanisms for the delivery of inhalers to children, because only 40% to 70% of children use their prescribed asthma controller medications at any given time.⁸ Understanding the challenges of primary care practice, health care delivery, and home health provides invaluable insights at the discovery phase of research, transforming the process to be one centered on the patient and family in their community.

There is an opportunity to optimize pediatric pulmonary health throughout the life course by fostering partnership between families, pulmonologists, and primary care providers, both in research and in practice. As part of the Defining and Promoting Pediatric Pulmonary Health workshop, the Community Pediatrics session was organized to challenge assumptions about:

1. what community means to patients and clinicians;
2. how the field of pediatric pulmonology can work outside of traditional health care silos;

3. how experts in pediatrics and pediatric pulmonology can partner to synergistically improve pulmonary health for all children throughout the life course; and

4. how principles of equity and inclusion can contribute to current and future research priorities.

Community primary care sites including community health centers, racial and ethnically minoritized communities including Indigenous and Native American populations, nontraditional care settings including school health and home care, and family partnerships in research and health care were identified as central pillars.

DISCUSSION

To understand the current state and future needs for optimizing pediatric pulmonary health in the community, we developed a framework of 4 research principles grounded in the current best-practice evidence: (1) address diversity, equity, and inclusion, (2) foster inclusive and innovative research, (3) expand implementation and dissemination science, and (4) build cross-disciplinary collaboration and training. As shown in Fig 1, the framework weaves together our 4 research principles along with central community pillars to set an agenda for future pediatric pulmonary research in optimizing lung and sleep health.

Address Diversity, Equity, and Inclusion

Diversifying pulmonary research for lung and sleep disorders is needed to ensure best practices for all pediatric patients. The same populations that were historically exploited in studies (eg, children, people with mental and physical [dis]abilities, incarcerated individuals, and those from minoritized communities) must be further represented in research populations. Unfortunately, the historic impact of research atrocities in the United States, such as the painful gynecologic experiments performed on enslaved women and the public health experiment about syphilis in Tuskegee, Alabama, often limits the desire for marginalized and minoritized patients to participate in research.⁹ Greater investments and attention to recruitment are needed to ensure research cohorts and protocols represent a diversity of participants, who are partners from the earliest stages of study design.

Beyond diversifying participation in research, greater attention to the community and their specific needs outside of the walls of a hospital will help to address principles of diversity, equity, and inclusion. Perhaps 1 of the biggest barriers to progress is the fact that health care is delivered in silos. These health care silos are further complicated in the home and community setting, where children learn and play, and additional people and systems like education (who likely also operate in silos) are introduced. Although families are the only "caregivers" who communicate, coordinate, and work across all silos

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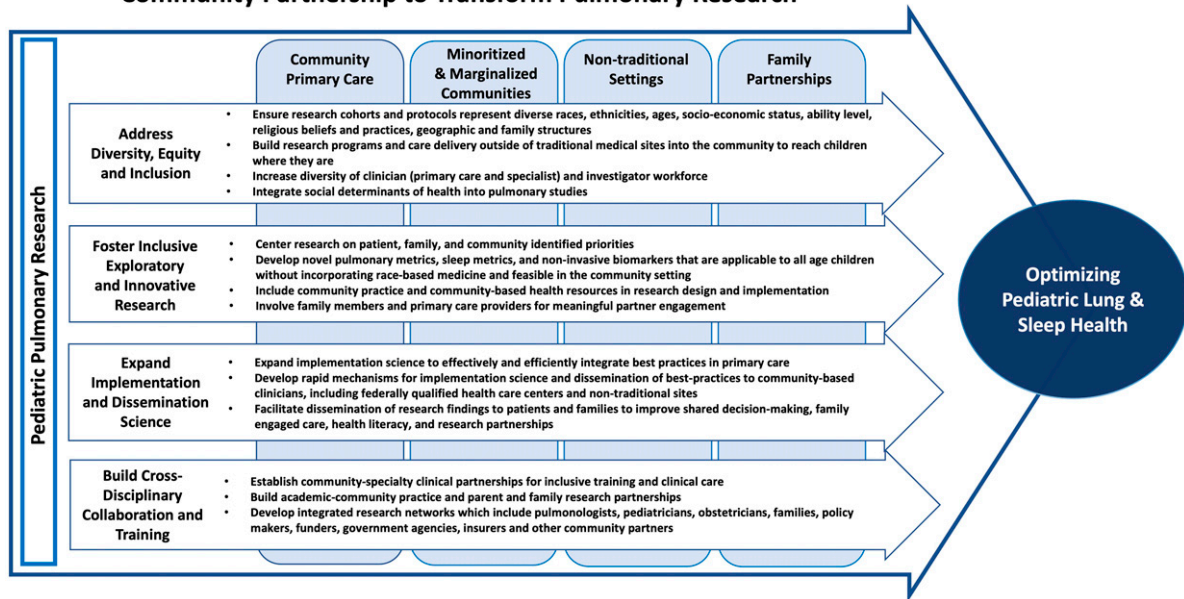


FIGURE 1

Framework to address integration of patients and families, pediatric primary care clinicians, and pediatric pulmonologists in research and practice to optimize lung and sleep health.

of care for a child, they are often left out as equal partners on care teams. Shared decision-making, shared plans of care, and models to integrate care, such as the medical home model, have been in various stages of use for decades.¹⁰ However, universal and standard implementation is lagging and often mired in processes that are inequitable (ableist, racist), not family centered, and not financially sustainable.¹¹

Stronger research programs rooted in the community, responsive to community needs, and fully inclusive of patient and family voices are needed. For example, school-based health centers (SBHCs) provide primary and preventive health care services in the school setting and are associated with improved delivery of preventive services.¹² In particular, SBHCs have demonstrated a profound impact for students with asthma, including decreased overall asthma morbidity and decreased asthma-specific emergency department utilization.^{12,13} SBHCs offer the opportunity to directly provide guideline-based asthma care, removing access barriers related to transportation, school and work schedules, and competing priorities for families.¹³⁻¹⁵ In addition, care in the community can be tailored to the specific needs of patients and families, driven through innovative research programs. For example, individualized care plans that account for social determinants of health (SDOH) may have greater impacts on pulmonary health outcomes for children living in medically underserved communities or those with low income, such

as American Indian and Alaskan Native (AI/AN) reservation communities.

To achieve the principles of diversity, equity, and inclusion in research, the diversity of clinician and investigator workforce must also be addressed.^{16,17} Our patients and families, who participate in and benefit from the research, must see themselves represented in the staff and clinics that serve them. Purposeful hiring and staff building may help to diversify research teams.¹⁸ Cultural and linguistic competency training, now extensive in the health professions training, may be beneficial for research staff who interact with participants.¹⁸ Recruitment pathway programs; partnerships with Hispanic-serving, tribal, and historically Black colleges and universities; and school loan repayment programs are just a few examples of initiatives that can help to bring the research workforce and medical practice closer to the appearance of the community of individuals with whom they work.^{19,20}

Finally, health inequities are well documented in the diagnosis, treatment, and management of pulmonary disorders, including asthma, for marginalized and minoritized children and adolescents.²¹ For example, mortality rates for influenza and pneumonia are 3 times greater for AI/AN children compared with the general US population, and for infants aged <1 year, the rate is 5 times higher.²² Asthma prevalence is highest in Black and Caribbean Hispanic populations, with significant neighborhood contribution to disparities across racial and ethnic groups.²³

These persistent disparities stem from the historical impact of SDOH in the United States.²⁴⁻²⁷ Pulmonary health research must take into account other drivers of health, particularly SDOH. Household crowding and insecurity, local and community pollution, and inadequate public infrastructure are just some of the SDOH that impact multiple marginalized communities in the United States, including AI/AN children, those living in rural communities, and those living with lower incomes.²⁸⁻³⁰

Recommendations

1. Ensure research cohorts and protocols represent diverse races, ethnicities, ages, socioeconomic status, ability level, religious beliefs and practices, and geographic and family structures.
2. Build research programs and care delivery outside of traditional medical sites into the community to reach children where they are (eg, home and school).
3. Increase diversity of clinician (primary care and specialist) and investigator workforce.
4. Integrate SDOH into pulmonary studies (eg, environmental health, cash transfers, home improvements).

Foster Inclusive Exploratory and Innovative Research

To drive advancements in pulmonary health for children and adolescents, emphasis on new exploratory and innovative research methods are needed that reflect the need for diversity and equity.

Meaningful and authentic partnerships with youth and families are critical to ensuring lived experiences enrich an inclusive research process, from planning to implementation to dissemination. For example, longitudinal patient cohorts have the benefit of identifying risk factors for disease, following changes over time for individuals and the population, while at the same time reducing bias seen in retrospective studies that rely on patient reports.³¹ Given previously described concerns for diversity in clinical and research arenas, any future cohort studies must thoughtfully gain trust and fully engage patients in racial and ethnic minority groups. Patients and their families must be included as active partners of the research team, with appropriate compensation, particularly those who have been historically marginalized and minoritized. Innovative approaches in community-based participatory research can enhance and transform the field of pediatric pulmonary research to be responsive to the most pressing questions by the patients and families themselves.^{32,33}

Additionally, innovative research to develop novel metrics and biomarkers for pulmonary health, among other cutting-edge research, must consider the end users through usability and feasibility testing. Without a full consideration of the realities of general pediatrics practices, such as care delivered through community health centers, pulmonary research will not extend into the community and have the reach to address longstanding disparities in pulmonary

health. In fact, without specific consideration for all end users, new advanced methods for diagnosis will leave some patients and families behind and perpetuate existing inequities in access and care. Additionally, adequate funding is needed for the implementation of any initiatives based in community practices to support practice integration and potential clinical revenue loss, as well as research, researchers, and community partners.

Community-based health resources, such as school-based health and home nursing, should also be considered in the design and implementation of exploratory and innovative methods. Despite the well-established benefits of school nursing and SBHCs, more than 20% of US schools do not have a school nurse and only 10% of US schools have access to an SBHC.^{15,34,35} At the same time, the vast potential of school health to improve health and educational outcomes for students is dampened by a lack of large-scale implementation and evaluation of evidence-based interventions.³⁶ Further, there is a lack of data to evaluate access to home health care, which remains largely anecdotal.³⁷ As such, splintering occurs between what is ordered during office visits and provided at home, necessary accommodations for school or adaptive activities, and accountability between a child's team in the broadest sense (clinic, home, school, community). Data obtained in a longitudinal cohort study could provide valuable insights into the biologic and environmental influences of disease and support families in much-needed intervention supports in the home setting.

Finally, partnership, family-centered care, shared decision-making, and multidisciplinary care are not new concepts to the field of pediatrics and research. Yet, to ensure that they are active approaches in an inclusive and innovative environment (not simply adjectives), family must be promoted as faculty and research partners.³⁸ Engagement of patients and families in research teams is increasingly common practice.^{5,39} For example, youth and family partners can be involved as compensated partners in quality improvement projects for care coordination between clinic, home health care, and school, lending their expertise in developing outcome measures that include quality of care and quality of life. Importantly, patient and family partners should serve in a partner role for the work, and not only consultants who act on an intermittent basis providing feedback and advice.³⁸ Similar inclusion of clinicians, such as general pediatricians, on research teams may enhance innovation and promote further inclusivity of community members.

Recommendations

1. Center research on patient-, family-, and community-identified priorities (eg, family, patient, and community advisory boards, as well as community needs assessments).

2. Develop novel pulmonary metrics, sleep metrics, and noninvasive biomarkers that are applicable to children of all ages without incorporating race-based medicine and feasible in the primary care offices, home, and other community settings.
3. Include community practice and community-based health resources in research design and implementation (eg, home nursing, school-based health centers).
4. Involve family members and primary care providers for meaningful partner engagement.

Expand Implementation and Dissemination Science

The future of ensuring more rich and balanced lives of children with pulmonary disorders requires a balance of biomedical research and improved implementation science. Principles of implementation and dissemination should be considered at even the earliest stages of exploratory research.

Translating academic research into community practice necessitates understanding of the feasibility of implementing the work into primary care practices and community-based care.⁴⁰ This requires an assessment of current operations and determining how proposed services or research initiatives could be incorporated into the local context, often the clinical flow of a busy, medical office. For example, there are >1300 federally qualified health centers (FQHCs) delivering care to almost 8 million children in the United States.⁴¹ For FQHCs serving marginalized communities, the standard of care for treatment and management of asthma and other pulmonary disorders is the same as other sites of care, like major academic centers. However, the availability of support services and clinical resources varies widely and impacts delivery of care. Medical organizations affiliated with academic institutions may have increased funding to support respiratory therapists, pulmonary function tests, and distribution of asthma supplies to patients (ie, nebulizer machines, aerochambers). Community practices and FQHCs often rely on grants, philanthropic donations, and other funding sources to provide similar care for their patients. To ultimately achieve equity and improved outcomes in pediatric pulmonary health, primary care practices in the community must be considered as part of implementation science frameworks.

After successful incorporation of implementation science frameworks into pulmonary research, the dissemination of results and subsequent best practices must be adopted. There is a need to develop mechanisms to disseminate information more rapidly to the end users in the community, including primary care practices. Dissemination of best practices and research findings is challenged by the number of information sources, limited protected time for continuing education outside of clinical responsibilities, and insufficient resources to implement findings in real time. For example, recent asthma

guidelines from multiple agencies do not align on management recommendations across all age groups or with insurance coverage.⁴² Integration of multidisciplinary teams and research networks could expand the scope and reach of results, allowing for quicker adoption and implementation of findings. The inclusion of study participants, patients, families, and primary care providers during all stages of the research may also benefit the dissemination of information. As results are discovered, participants should be pulled in early to learn how their own care, care of their family members, or care of their patients may be optimized.

Recommendations

1. Expand implementation science to effectively and efficiently integrate pediatric pulmonary health best practices in primary care including: lung and sleep health screenings, biomarkers for early disease detection, genetic testing and interpretation, pulmonary function, and sleep testing in home and community settings.
2. Develop rapid mechanisms for implementation science and dissemination of best practices to community-based clinicians, including FQHCs and nontraditional sites (ie, schools, day cares, and community sites such as libraries, churches, barber shops, community centers, home care).
3. Facilitate dissemination of research findings to patients and families to improve shared decision-making, family engaged care, health literacy, and research partnerships.

Build Cross-Disciplinary Collaboration and Training

To fully improve pulmonary health and achieve equitable outcomes, the clinical and research practice workforce must collaborate across disciplines and roles.

Partnerships between community-based primary care providers and specialists can support both training and clinical care. For example, home health nurses play a vital role in the lives of children with medical complexity, many of whom have lung or sleep disorders. Yet, home health nurses and personal care aides, who often move through life at school and community with a child, are not typically included in clinical and research teams; omitting a very important perspective. There is opportunity to standardize training for home health nurses in pediatric care and pulmonary care, which may be best supported through community–specialist partnerships.⁴³ In yet another example, there are myriad evidence-based interventions that can be implemented in schools, including those targeting asthma management.^{44–47} However, real or perceived barriers to communication between school personnel, school health staff, community-based primary care providers, and specialists based on federal

and state privacy regulations including the Health Insurance Portability and Accountability Act and Family Educational Rights and Privacy Act can limit care coordination opportunities in day-to-day practice.^{36,48} They can also require complex data-sharing agreements for evaluation.⁴⁹ Investments and investigations in cross-disciplinary community partnerships, for both training and clinical care, are needed.

The patient and family must also be equal partners in clinical care and research. Although clinicians often refer to a patient or family as an expert, this reference often comes with preconceived footnotes or limitations that, in practice, can lead to miscommunication, mistrust, missed opportunity, and, ultimately, poor health. The same is true in research partnerships. Patients and families can serve as equal partners in research teams, and when they do, should be compensated in a way that respects their time, expertise, and equal role on the team.⁵⁰ The inclusion of patients and families in the research process, from ideas to dissemination, allows for greater success at each step and in final results.³⁸

Finally, cross-disciplinary collaboration and training are best exemplified through integrated research networks, such as networks that include not just researchers and clinicians, but also patients and families, community primary care providers, maternal child health experts, multidisciplinary staff, and public and private agencies. Integrated networks allow for multiple perspectives, promote shared understanding, and efficiently move research ideas to practice. They allow for improved diversity and inclusion, foster inclusive and innovative research ideas, and expand the implementation and dissemination of research results, all the while integrating the central pillars of pediatric pulmonary health and keeping community at the center.

Recommendations

1. Establish community–specialty clinical partnerships for inclusive training and clinical care.
2. Build academic–community practice and patient and family research partnerships.
3. Develop integrated research networks, which include pulmonologists, pediatricians, obstetricians, families, policymakers, funders, government agencies, insurers, and other community partners.

CONCLUSIONS

For the millions of children diagnosed with a lung or sleep disorder each year in the United States, optimizing their pulmonary health begins in the community where they live out their daily lives with their families. In this workshop summary, we outlined 4 principles to guide future pediatric pulmonary research centered on 4 community pillars: community primary care, marginalized and minoritized communities, nontraditional health care settings, and family partnerships. To improve pediatric lung and sleep health, investigators, clinicians, and policymakers should use this framework to guide study designs, clinical protocols, and guideline and policy development. Across all efforts, partnerships between patients, parents, pulmonologists, and pediatricians are vital to centering actions on community needs, enriching clinical care, and transforming pulmonary research to achieve equitable lung and sleep health for children and adolescents.

ABBREVIATIONS

AI/AN: American Indian and Alaskan Native
FQHC: federally qualified health center
SBHC: school-based health center
SDOH: social determinants of health

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