

Engaging Patients and Stakeholders for Pulmonary Fibrosis Research: A Collaboration between the Pulmonary CRG and NIOSH



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Project Aims

- Bring together clinicians, researchers, and patients with NIOSH, a stakeholder organization with expertise in assessing exposures in a variety of settings
- Address research questions that matter to patients with pulmonary fibrosis

Pulmonary Fibrosis

- Complex disease characterized by lung scarring
- Often fatal within 3-5 years from diagnosis
- Most common form has no known cause

Role of the Pulmonary CRG

- In-person meeting allowed CRG members to share ideas and contribute their expertise
- Membership includes patients, stakeholder organizations, clinicians and researchers
- Stakeholders were invited to listen to the brainstorming
- Bringing stakeholders to the table early in the research process allowed them to contribute to the conceptualization and development of research projects
- Interstitial Lung Disease Research Interest Group (ILD RIG) had a breakout session to focus on research topics
- Facilitates formation of interdisciplinary teams

Methods

Assessing Topics of Interest

- PaTH IPF Working Group's Patient Partners and local PF Patient Support Groups shared questions that mattered to them
- ILD RIG members ranked top three research priorities during in-person meeting
- Engaged with the Pulmonary Fibrosis Foundation
- Interstitial Lung Disease Research Interest Group (ILD RIG) patients and researchers identified work history as a topic of interest
- NIOSH representatives at the meeting provided background on the available methods and tools they have developed

Role of PCORnet

- Access to "real-world" populations
- EHR provides rich data for assessing NIOSH's tools
 - Identification of patients for participation in research
 - Clinical notes with documentation of occupation/industry (for use with NLP)
 - Pulmonary function data to assess disease severity and progression

Role of Patient Partners

- Identification of research topics
- Input on patient perceptions :
 - Some patients are reluctant to share extent of mold or dampness in the home
 - Approach is essential
- Next step: Engage patients in adapting NIOSH's tool so it is accessible and easy to use in the home

Patient-Centered Research Questions

- Did my job cause my pulmonary fibrosis?
- My basement is moldy: is that making my pulmonary fibrosis worse?

Role of NIOSH

- Provides validated tools that enable researchers to assess exposure history
- Dampness and Mold Assessment Tool:**
 - Allows user to assess presence of dampness or mold in a building
 - Demonstrated association with respiratory outcomes in building occupants
- NIOSH Industry and Occupation Computerized Coding System (NIOCCS)**
 - Standardized encoding of occupation and industry

Progress

- 2 Letters of Intent submitted
- Ongoing discussions for additional funding

Take-home Messages

- Broad possibilities for collaborations
- PCORnet provides a platform to connect innovators to patients and researchers
- Interdisciplinary teams** are essential in addressing questions that matter to patients and stakeholders
- PCORnet investigators can **partner with external researchers and stakeholders** who are **incubating novel approaches** to solving problems of importance to patients

DISCLOSURES

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the National Institute for Occupational Safety and Health.

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The National Patient-Centered Clinical Research Network

Check if Nothing Found	Damage or Stains				Visible Mold				Wet or Damp				Flakey Paint	NOTES
(✓)	0	1	2	3	0	1	2	3	0	1	2	3	(✓)	
	⓪	①	②	③	⓪	①	②	③	⓪	①	②	③		Ceiling Tile Plaster Concrete Sheetrock

Figure 1: Excerpt from the Dampness and Mold Assessment Tool



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