

COPD Foundation Patient-Powered Research Network Registry Resource: PCORnet Research Entity with Patient Reported and Longitudinal Follow-up Data



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Project Aims

- Chronic obstructive pulmonary disease (COPD) affects 15–25 million individuals in the US and is a direct cause of >140,000 deaths, costs >\$50 billion, and leads to >700,000 hospitalizations annually.
- The COPD Foundation's expanding 12-year research infrastructure and sustaining partnerships can help accelerate PCORnet into the future.
- The Patient Powered Research Network (PPRN) uses nation-wide methods to enroll patients with COPD and those at risk into a patient-led registry for multi-mode survey research, electronic data capture, patient-reported outcomes (PRO) measurement, and multi-site and longitudinal study conduct.
- Using a technology platform that is flexible and scalable, we collect comprehensive longitudinal data.
- We aim to highlight COPD PPRN opportunities for partnership in patient-led research. The COPD PPRN has an access portal for any researcher to submit a proposal to partner with our patient/researcher team using PPRN resources/data.



Methods

- The COPD PPRN network uses a longitudinal patient reported registry and thus offers novel opportunities for scalable, efficient research.
- Eligible patients complete baseline and then ad hoc and longitudinal surveys at least annually.
- We have in collaboration with Kaiser Permanente/PORAL CDRN, DatStat, and Corepoint, developed an API technology to link EMR data using CDMv3 format into our COPD PPRN data platform.



Objectives

- A network of researchers affiliated with the COPD PPRN has developed and secured sustaining funding and project-focused external funding for studies that utilize the data platform and COPD PPRN resources.
- PRO collection includes general and disease specific domains gathering information on diagnosis, comorbidity, respiratory specific items, exacerbation history, smoking history, oxygen use, and core quality of life and symptom measures.
- Current analyses summarize the self-reported characteristics for enrollees of the COPD PPRN and describe initial baseline PRO data and subsequent longitudinal data.
- The COPD PPRN collects longitudinal data and is currently "research ready"
- We have 8 active studies open.

EMPOWERING PATIENTS



The COPD Patient-Powered Research Network

- The COPD Foundation is one of the original 18 organizations awarded money from the Patient Centered Outcomes Research Institute (PCORI) to create a Patient-Powered Research Network (PPRN) - the COPD PPRN.
- Community of COPD patients coming together to share information about their health and participate in research.
- Governed by a majority led patient Board working directly with researchers

Progress / Results

- The COPD PPRN has enrolled over 7,100 individuals through an on-line portal, AppleResearchKit app, or paper/phone processes.
- Of eligible participants, approximately 35% have completed longitudinal surveys to date.
- Our API technology to link EMR data has been validated and offers an efficient, scalable system for linking patient-reported data with EMR data to further expand the COPD PPRN research resource.
- As PCORnet, the COPD PPRN has a front-door mechanism for interested external stakeholders and researchers to propose collaborative research and engage with the COPD PPRN for work that includes the potential for cross-PCORnet studies. The COPD PPRN resources, as part of the PCORnet enterprise, expand the potential for (1) carrying out efficient, data-only retrospective and prospective population-based research, (2) refining identification and recruitment of eligible study patients, and (3) providing opportunities for prep-to-research or co-morbid assessments for cross-PCORnet entities and/or external-partnered research endeavors.
- A related social platform, COPD360social, with >36,000 participants, further expands the qualitative opportunities.
- COPD PPRN complements entities represented across PCORnet and are uniquely positioned to provide patient-driven research most needed to inform health care delivery in the current era.
- The existence of accessible large datasets and patient-engaged networks that integrate clinical data with their self-reported outcomes and preferences provides researchers with the ability to develop, test and implement more optimal, personalized treatment strategies.
- Please see our COPD PPRN intake form at <https://www.copdfoundation.org/Research/COPD-Patient-Powered-Research-Network/For-Researchers.aspx>
- Intake form is the pathway to open communication to COPD PPRN Research Review committee and our patient-led network.

FUNDING / ACKNOWLEDGEMENTS

The COPD PPRN is funded by PCORI (contract #PPRN-1306-04748) and the COPD Foundation; all statements in this poster, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee.

CONTACT INFORMATION

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