

BRIDGE Patient to Investigator Training GLOSSARY	
Abstract	An abstract is a short summary of the research that highlights why the study needs to be done, how it will be done, who and how many will be invited to the study and how the information will be analyzed.
Access to care	Access to care means having the timely use of personal health services to achieve the best health outcomes.
Adaptive Study	findings. For example, a research team might learn early on that a treatment has harsh side effects, and many people getting that treatment are uncomfortable continuing in the study. So, the research team may reassign people who were getting that treatment to one of the other treatments.
Adherence	Adherence, or taking medications correctly, is generally defined as the extent to which patients take medication as prescribed by their doctors. This involves factors such as getting prescriptions filled, remembering to take medication on time, and understanding the directions.
Adverse Event (AE)	An unfavorable change in the health of a participant, including abnormal laboratory findings, that happens during a clinical study or within a certain amount of time after the study has ended. This change may or may not be caused by the intervention/treatment being studied.
Agency for Healthcare Research and Quality (AHRQ)	The Agency for Healthcare Research and Quality's mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.
Air sacs	Air sacs, also called alveoli, are a part of the lung that form at the end of the bronchioles. When air reaches the air sacs, oxygen passes through the air sac walls into the blood in the capillaries. The airways and air sacs are elastic (stretchy). When you breathe in, each air sac fills up with air like a small balloon. When you breathe out, the air sacs deflate and the air goes out. There are about 300 million alveoli in a normal lung.
Algorithm	A step-by-step set of operations (mathematical equations) that are used to perform reasoning, or a set of rules that defines a sequence of operations.
Alpha-1 antitrypsin (AAT) deficiency	Alpha-1 antitrypsin (AAT) deficiency is an inherited condition that raises the risk for lung and liver disease. AAT is a protein produced by the liver that protects the lungs. If the AAT proteins are not the correct shape, they get stuck in the liver cells and cannot reach the lungs.
Analysis of Variance (ANOVA)	Analysis of variance is used to determine whether there are any statistically significant differences between the means of three or more independent (unrelated) groups.
Animal Research	Animal Research is the use of non-human animals in experiments that seek to control the variables that affect the behavior or biological system under study.
Anticholinergics	These medications work to relax the muscles in airways through the parasympathetic pathway, by relaxing the tense state of muscles. These are available as controllers.
Applied Research	A methodology used to solve a specific, practical problem of an individual or group.
Area Under the Curve	A measure of how much drug reaches a person's bloodstream in a given period of time after a dose is given. The information is useful for determining dosing and for identifying potential drug interactions.
Arterial blood gas test	Arterial blood gas tests measure how much oxygen and carbon dioxide are in the blood. They also determine the pH, or how acidic or basic, the blood is.
Attrition	When people stop participating in a study. For example, people might drop out of a study because of a change in their health status, or they might lose interest or move away.
Belmont Report (1979)	The Belmont Report summarizes ethical principles and guidelines for research involving human subjects. Three core principles are identified: respect for persons, beneficence (doing good, not harm), and justice.
Beneficence	A principle of research ethics that suggests studies should be designed for the least risk to individual participants and most benefits to the individual and society.
Beta-agonists	These medicines work to relax the muscles in your airways through the sympathetic pathway. These are available as rescue relievers and controllers.

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Bias	In research, bias occurs when systematic error is introduced into sampling or testing by selecting or encouraging one outcome or answer over others. Bias can occur at any phase of research, including study design or data collection, as well as in the process of data analysis and publication.
Biomarker	A biomarker refers to a broad subcategory of medical signs — that is, objective indications of medical states observed from outside the patient — which can be measured accurately and reproducibly. Medical signs stand in contrast to medical symptoms, which are limited to those indications of health or illness perceived by patients themselves.
Blinded Study	A study done in such a way that the study participants do not know whether they are getting a placebo (an inactive substance) or a drug, but the study team does know. If the study is comparing two different doses or two different medications, then the human participants do not know which they are getting. In a “double-blinded study”, neither the study participant nor the investigator know which treatment any one study participant is getting. That information is revealed only once the treatment is over.
Bronchial tubes	The bronchial tubes, or bronchi, are two tubes that branch off the trachea, or windpipe. Bronchial tubes carry air to the lungs. The most common problem with the bronchi is bronchitis, an inflammation of the tubes.
Bronchiectasis	Bronchiectasis is a chronic lung disease that affects hundreds of thousands of people in the U.S. It is characterized by the widening of the small airways, which allows for the collection of mucus in the airways, and in turn causes recurring lung infections. Nontuberculous Mycobacterial (NTM) lung disease is common in individuals with Bronchiectasis. NTM are naturally occurring bacteria, some of which cause lung infections.
Bronchitis	Bronchitis is an inflammation of the bronchial tubes. It causes a cough that often brings up mucus and can also cause shortness of breath, wheezing, a low fever, and chest tightness. There are two main types of bronchitis: acute and chronic.
Bronchodilators	A medicine used for relaxing muscles around the lungs' airways allowing the airways to open up and expand. These include anticholinergics and Beta-agonists.
CAPTURE Study	A multi-center study to validate a unique COPD case finding tool in primary care.
Case-Control Study	A type of observational study that looks backwards to determine what might be associated with a certain result. Compares individuals with the result (or disease) to those without—looking for reasons, behaviors, situations that caused the one group to have the result or disease. May use interviews or a review of medical records to identify cases and controls.
Causation	Causation means one variable or event is directly responsible for another event or variable.
Centers for Disease Control and Prevention (CDC)	The Centers for Disease Control and Prevention (CDC) is the nation's health protection agency. The CDC conducts critical science and provides health information that protects the U.S. against expensive and dangerous health threats, and responds when these arise.
Centers for Medicare & Medicaid Services (CMS)	The Centers for Medicare & Medicaid Services is part of the Department of Health and Human Services. Its programs include Medicare, Medicaid, the Children's Health Insurance Program, and the Health Insurance Marketplace.
Certificates of Confidentiality	Issued by National Institutes of Health; they prevent researchers from being forced to reveal private information about human subjects.
Chi-Square Tests	Chi-square tests tell you how significant the differences between groups are when using proportions; in other words, it lets you know if those differences comparing proportions (two thirds compared to one half) could have happened by chance.
Chronic Bronchitis	Chronic bronchitis is long-term inflammation of the bronchi. It is common among smokers. People with chronic bronchitis tend to get lung infections more easily. They also have episodes of acute bronchitis, when symptoms are worse.
Chronic Obstructive Pulmonary Disease (COPD)	Chronic Obstructive Pulmonary Disease is an umbrella term used to describe progressive lung diseases including emphysema, chronic bronchitis, and refractory (non-reversible) asthma. This disease is characterized by increasing breathlessness.

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Clinical Practice Guidelines	Systematically developed statements or recommendations to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. They present indications for performing a test, procedure, or intervention, or the proper management for specific clinical problems. Guidelines may be developed by government agencies, institutions, organizations such as professional societies or governing boards, or by convening expert panels.
Clinical Research Coordinator	The person who manages and conducts the day-to-day study activities; following all protocols and regulations.
Clinical Significance	If a study has clinical significance, its results or findings will be of practical use to health care providers and patients.
Clinical Trial	Any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes.
Cluster Randomized Trial	A study design in which the research team randomly assigns a treatment to a group of people with something in common, such as patients who all go to one clinic or students who all go to one school, rather than randomly assigning the treatment to individuals.
Coercion	Motivating people to join a study because of a real or imagined threat. For example, students might fear getting a lower grade in class if they don't participate in their professor's study. Prisoners might believe they will be released sooner only if they join a study. Research ethics require that people can join studies freely without fear of negative consequences.
Cohort Study	A type of observational study which studies and compares a cohort (group of people who share a defining characteristic) over a period of time.
Co-Investigator (Co-I)	An individual recognized by the prime institution and the principal investigator (PI) as someone making a significant contribution to a project. The Co-I is an individual who the PI relies on to assume responsibilities related to the execution of the project and to commit a specified percentage of time to the project. A Co-I is considered "key personnel" and may be employed by or formally affiliated (through written agreement) with the prime institution or a collaborating institution. The patient and/or stakeholder partner may be listed as a Co-I. The designation of a Co-I does not affect the PI's roles and responsibilities nor does it imply a Dual PI Award.
Common Data Element	Standardized pieces of data that are expected to be collected and are then used across networks.
Common Data Model	Standardizes the definition, content, and format of data across networks to enable a single standardized view that can be used for querying.
Common Rule	The Common Rule is the short name for the Federal Policy for the Protection of Human Subjects that was published in 1991, recently updated in 2019 and is based on the 1979 Belmont Report. The Common Rule is the minimum standard of ethics that all government funded research in the United States is held to and is codified in the Health and Human Services (HHS) regulations, 45 CFR part 46.
Comorbidity	Comorbidity describes two or more disorders or illnesses occurring in the same person. They can occur at the same time or one after the other. Comorbidity also implies interactions between the illnesses that can worsen the course of both.
Comparative Effectiveness Research (CER)	The direct comparison of two or more existing healthcare interventions to determine which interventions work best for which patients and which interventions pose the greatest benefits and harms. The core question of a Comparative Effectiveness Trial is which treatment works best, for whom, and under what circumstances.
Comparators	Two or more options for diagnosis, prevention, treatment, or healthcare delivery that would be available to the patients, caregivers, providers, and/or health systems facing the actual healthcare decision.
Confidence Interval	A range of values so defined that there is a specified probability that the value of a parameter lies within it.
Confidentiality	Involves a person's identifiable information and the security and procedures in place to ensure that only authorized individuals see this information.

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Conflict of Interest (COI)	A Conflict of Interest is any “association, including a financial or personal association, that has the potential to bias or has the appearance of biasing an individual’s decisions in matters related to the Institute or the conduct of activities” [Patient Protection and Affordable Care Act, Pub L No. 111-148, 124 Stat 727, §6301(a)(3)]. Conflicts of Interest will be considered and managed throughout every step of the review and selection process, including, but not limited to, the technical and programmatic reviews, the selection and assignment of scientific and stakeholder reviewers, Board of Governors deliberations, and post-award negotiations and monitoring.
Confounding	When the results of a study could be muddied by other unplanned factors that might provide an alternative explanation for the outcomes. Confounding can occur from any factor that was not planned to be part of the study. For example, a study might compare two ways to reduce obesity in children and test those two ways in different cities. If one city also started a youth sports program at the same time, and the study did not account for it, the study results in that city might be affected by both the obesity program and the sports program, making it difficult to know how well the obesity program worked.
Consent Participants	To consent participants means to tell the patients about the potential benefits of a study without promising too much, the potential risks of participating in the study in language that is clear but not frightening, and the rights of the patient in understandable, clear terms.
Consultant	Typically an individual who is not involved with the management of the project, but instead provides general services or subject matter expertise for an hourly fee. Applicants must include a letter of support from the consultant detailing their work and rate of compensation per hour. The patient and/or stakeholder partner may be listed as a consultant.
Continuing Medical Education (CME)	Continuing medical education is the process by which primary physicians and other health professionals engage in activities designed to support their continuing professional development. Activities are derived from multiple instructional domains, are learner centered, and support the ability of those professionals to provide high quality, comprehensive, and continuous patient care and services to the
Control Group	The group of participants who resemble the experimental group, (for example, they are in the same age range) but who do not receive the experimental treatment. Changes are measured in both the treatment group and this group, to compare the effect of the new drug, medical device, procedure, or prevention.
COPD and Pneumonia Study (CAP Study)	The purpose of the COPD and Pneumonia Study was to look at and measure the impact of pneumonia on COPD patients through a series of online surveys.
COPD Biomarkers Qualification Consortium (CBQC)	The COPD Biomarkers Qualification Consortium is a public-private partnership formed in 2010 with a goal of qualifying biomarkers and clinical assessment tools for use in clinical or nonclinical decision-making and particularly within the regulatory context.
COPD CONNECT	The CONNECT team developed a dissemination framework to address specific needs of the COPD community. CONNECT Framework focuses on dissemination of research to three priority audiences; patients and caregivers, primary care professionals, and advocacy organizations.
COPD Invest Study	Observational, Non-Interventional, Direct-to-Patient Study to Assess Patient Experience Using a Biometric Shirt to Collect Activity, Cardiac, Respiratory, and Sleep Data in a Non-Randomized, Unblinded Sample of Subjects with Chronic Obstructive Pulmonary Disease.
COPD Patient Powered Research Network (COPD PPRN)	The COPD Patient-Powered Research Network (COPD PPRN) is an opportunity to join a community of individuals who want to revolutionize COPD research. The COPD PPRN will be the largest network of patients affected by Chronic Obstructive Pulmonary Disease ever assembled.
COPD Phenotypes	Research focused on the different types of COPD and the groups of patients who share common characteristics and similar disease progression.
COPD PPRN BRIDGE Project	Bridging the gap between Patients/Caregivers and COPD Research - the ultimate goal of the project is to increase people with COPD and their caregivers’ voice in research and ensure participation at the highest level.
COPD Readmissions	COPD patients being re-admitted to the hospital within 30 days of a previous hospital stay.

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COPDGene	COPDGene is a multicenter observational study designed to identify genetic factors associated with COPD.
Co-Principal Investigator (Co-PI)	An individual recognized by the prime institution and the principal investigator (PI) as someone who shares scientific and administrative leadership responsibilities for a project with the PI. The Co-PI is an individual who the PI relies on to contribute substantively to the scientific development and direction of the project in addition to the execution of the project. The Co-PI shares responsibility with the PI for ensuring that milestones are achieved and contracted deliverables are completed on time. The Co-PI is considered “key personnel” and may be employed by or formally affiliated (through a written agreement) with the prime institution or a collaborating institution. The patient and/or stakeholder partner may be listed as a Co-PI. The designation of a Co-PI does not affect the PI’s roles and responsibilities nor does it imply a Dual PI Award.
Correlation	A statistical calculation of if and how much two paired variables are related.
Cross-Sectional Study	A type of observational study that uses a survey/interview to gather facts (and sometimes opinions) from a selected group of people for a specific topic and usually for a limited time period.
Data and Safety Monitoring Board (DSMB)	An independent committee of experts responsible for reviewing research study data on an ongoing basis to ensure the safety of study subjects and validity and integrity of the data.
Data Coordinator	The person who is responsible for overall data management during the study.
Declaration of Helsinki (1964)	The World Medical Association, meeting in Helsinki, Finland, approved principles for ethical research. Important principles are: <ul style="list-style-type: none"> • Research plans should be reviewed by an independent committee, such as an Institutional Review Board (IRB). • Research participants must give their "informed consent" to be in a study. • Risks of being in a study should not outweigh benefits.
Deductive Research	A deductive approach is concerned with developing a hypothesis (or hypotheses) based on existing
De-identified information	Demographic information must have all direct and indirect identifiers removed, to eliminate (or at least make highly improbable) re-identification using statistical techniques.
Demographics	Demographics are statistical data relating to a study’s participants, such as age, race, sex, income, education, etc.
Descriptive Research	A research method that describes the characteristics of the population or phenomenon that is being studied. This methodology focuses more on the “what” of the research subject rather than the “why” of the research subject.
Dissemination (active)	The intentional, active process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of evidence, and to motivate its use in policy, practice, and individual choices. The purpose of dissemination is to spread and sustain knowledge and the associated evidence-based interventions.
Dissemination (passive)	Sometimes called research diffusion, is an untargeted dissemination process whereby new evidence is absorbed and acted upon by a small body of highly motivated recipients.
Domains	Areas of thought resulting from analyzing and summarizing information which is recorded in words.
Dyad	In sociology, a dyad is group of two people, the smallest possible social group.
Dyspnea	Dyspnea is shortness of breath, breathlessness, or difficulty breathing.
Effectiveness/Efficacy	Whether a new drug or treatment works. An effective drug or prevention will improve health or successfully prevent a disease.
Electronic Health Record (EHR)/Electronic Medical Record (EMR)	An electronic health record is a repository of electronic information about an individual’s health status and health care. EHRs contain much of the same information that is found in a patient’s (paper) medical chart, but because the records are digitized, the data can be viewed, and providers (eg, primary care physicians and specialists) can capture far more extensive information. EHRs may contain administrative and billing data, patient demographics, progress notes, vital signs, medical histories, diagnoses, medications, immunization records, allergies, radiology images, laboratory and other test results, and much more.

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Emphysema	Emphysema is a type of COPD involving damage to the air sacs (alveoli) in the lungs. As a result, the body does not get the oxygen it needs. Emphysema makes it hard for an individual to catch his or her breath. It may also cause chronic coughing and trouble breathing during exercise.
Empirical evidence	Information acquired by observation or experimentation. This data is recorded and analyzed by scientists and is a central process as part of the scientific method.
Eosinophils	A type of disease-fighting white blood cell.
Epidemiology	Epidemiology is the study of the distribution (frequency, pattern) and causes and risk factors of health-related states and events (not just diseases) in specified populations, including neighborhoods, schools, cities, states, countries, and global.
Epidemiology of COPD	Research focused on the distribution, frequency, patterns, causes and risk factors of COPD.
Epidemiology Study	A type of observational study which uses new observations or existing information, such as information in medical records, to better define a condition and who is likely to have that condition in a population of people.
Etiology	Etiology is the cause or origin of disease.
Evaluation Research	Evaluation research is a type of applied research, and so it is intended to have some real-world effect. Many methods like surveys and experiments can be used to do evaluation research.
Evidence-based practices (EBP)	Evidence-based practices are the conscientious, explicit, and judicious use of current best evidence when making decisions about the care of the individual patient. This involves integrating individual clinical expertise with the best available external clinical evidence from systematic research.
Exacerbations	Exacerbations refer to a worsening (flare-ups) of COPD. About half of COPD exacerbations are caused or triggered by bacterial and viral infections (colds, especially from rhinovirus), but air pollution can also contribute to the beginning of an exacerbation.
Exclusion Criteria	Exclusion criteria are those characteristics that disqualify prospective subjects from inclusion in a study.
Experiential Knowledge	Experiential Knowledge is knowledge or wisdom gained through life experiences, rather than formal training or education.
Experimental Research	Studies that require something new or include some type of action or change. Researchers initiate the change, observe the effects of the change, make comparisons and draw conclusions from the data generated.
Explanatory Research	Explanatory Research is conducted for a problem which was not well researched before, demands priorities, generates operational definitions and provides a better-researched model. It is actually a type of research design which focuses on explaining the aspects of your study in a detailed manner.
Exploratory Research	Exploratory research is defined as a research used to investigate a problem which is not clearly defined. For such a research, a researcher starts with a general idea and uses this research as a medium to identify issues, that can be the focus for future research.
False Negative	A test result that incorrectly shows a negative finding. For example, a lab tests shows no infection, but the patient does have strep throat.
False Positive	A test result that incorrectly shows a positive finding. For example, a mammogram report identifies a cancer, but it turns out to be a cyst.
Field Research	Field research is a qualitative method of data collection that aims to observe, interact and understand people while they are in a natural environment.
Fixed Ratio	The global initiative for obstructive lung disease recommends a <i>fixed ratio</i> between forced expiratory volume in one-second (FEV1) and forced vital capacity (FVC) of <0.7 (FR) for the diagnosis of COPD.
Focus Group	A qualitative research method in which people participate in a group discussion. A researcher asks open questions about their experiences or perspective on a subject. The responses of the people participating in the group discussion are analyzed for common themes and experiences.
Forced Expiratory Volume (FEV)	Forced expiratory volume (FEV) measures how much air a person can exhale during a forced breath. The amount of air exhaled may be measured during the first (FEV1), second (FEV2), and/or third seconds (FEV3) of the forced breath.

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Forced Vital Capacity (FVC)	Forced vital capacity is the total amount of air exhaled during the FEV test.
Funder	A funder is a person or organization that provides money for a particular purpose.
Generalizability	How well the outcomes of a study for those participating in the study reasonably apply to all other people with the same condition or circumstances.
Genomics	Genomics is the study of genes and their functions, and related techniques.
Genotype	The inherited genetic instructions of an organism.
Global Initiative for Chronic Obstructive Lung Disease (GOLD)	The Global Initiative for Chronic Obstructive Lung Disease is an initiative that works with health care professionals and public health officials around the world to raise awareness of COPD and to improve prevention and treatment of the disease.
Health Conditions	These are the broad terms used to categorize funded research studies; specific diseases or conditions are included within the appropriate larger category. Note: not all funded projects focus on a single disease or condition; some touch on multiple diseases or conditions, research methods, or broader health system interventions. Such projects won't be listed by a primary disease/condition and won't appear if this filter tool is used to find them.
Health Insurance Portability and Accountability Act (HIPPA)	The act which provides the ability to transfer and continue health insurance coverage for American workers and their families when they change or lose their jobs, and reduces health care fraud and abuse. HIPPA mandates industry-wide standards for health care information on electronic billing and other processes, and requires the protection and confidential handling of protected health information.
Health Resources and Services Administration (HRSA)	The Health Resources and Services Administration (HRSA) is an agency of the U.S. Department of Health and Human Services (HHS) and is the primary federal agency for improving health and achieving health equity through access to quality services, a skilled health workforce and innovative programs. HRSA's programs provide health care to people who are geographically isolated and economically or medically vulnerable.
Heterogeneity	Heterogeneity refers to something made up of elements or ingredients that are not alike.
Human Subjects Research	Studies of living individuals about whom an investigator (whether professional or student) conducting research obtains data through intervention or interaction with the individuals or obtains identifiable private information.
Hypoxia	Too little oxygen in the body.
Idiopathic	Relating to or denoting any disease or condition which arises spontaneously or for which the cause is unknown.
Implementation Research	Research focused on determining how to take what has been learned in studies and trials and use this information to help diagnose, treat and support patients in primary care and pulmonary practices.
Incidence	The rate of occurrence of something, especially of something unwanted. For example: The rate of new cases (the incidence) of diabetes in 2012 was 1.7 million new diagnoses.
Inclusion Criteria	Inclusion criteria are characteristics that the prospective subjects must have if they are to be included in a study.
Inductive Research	An inductive approach is where the researcher begins with as few preconceptions as possible, allowing theory to emerge from the data.
Informed Consent Document	A document that outlines what people who are thinking about joining a study are agreeing to if they decide to join the study.
Inhaler	An inhaler (also known as a puffer, pump or allergy spray) is a medical device used for delivering medication into the body via the lungs.
Institutional Review Board (IRB)	A group that follows federal regulations, state laws, and institutional policy to review, monitor, and approve research in order to protect the ethical rights and privacy of the participants involved.

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Intent to Treat	An assessment of the people taking part in a trial, based on the group they were initially (and randomly) allocated to. This is regardless of whether or not they dropped out, fully adhered to the treatment or switched to an alternative treatment. Intention To Treat (ITT) analyses are often used to assess clinical effectiveness because they mirror actual practice, when not everyone adheres to the treatment, and the treatment people have may be changed according to how their condition responds to it.
Interquartile Range	A measurement of dispersion or spread; the Interquartile Range (IQR) describes the middle 50% of values when ordered from lowest to highest.
Intervention	A process or action that is the focus of a clinical study. This can include giving participants drugs, medical devices, procedures, vaccines, and other products that are either investigational or already available. Interventions can also include noninvasive approaches such as surveys, education, and interviews.
Interventional Study	A clinical study in which participants are assigned to receive one or more interventions (or no intervention) so that researchers can evaluate the effects of the interventions on biomedical or health-related outcomes. The assignments are determined by the study protocol. Participants may receive diagnostic, therapeutic, or other types of interventions.
Justice	In research ethics, the idea that the benefits and burdens of research should be fair. For example, it would be unfair to conduct research in a poor neighborhood for a treatment that would be expensive and available only to those with more money or private health insurance. It also would be unfair to exclude people who could benefit from a treatment from a study of it.
Key Personnel	Individuals who contribute to the scientific development or execution of the project in a substantive and measurable way. The contribution is independent of financial compensation.
Landscape Analysis	Landscape analysis is a type of organizational analysis. The concept focused on finding a cohesive and consistent view of the main organizations and initiatives in some analysed area of operations and analysing chosen key aspects of them.
Letter of Intent or Letter of Inquiry (LOI)	A notification that an organization intends to apply. Submission of an LOI is a prerequisite to submitting an application. The Letter of Intent or Letter of Inquiry also includes information describing the proposed project.
Letters of Collaboration	Signed letters from each collaborating individual or organization that will demonstrate that the Principal Investigator has the support or resources necessary for the proposed work. Letters of support from patient and stakeholder partners should clearly describe the origin of the study topic and the role of the patient partners in defining the question, outcomes, comparators, goals and outcomes, etc. Letters from the partners or partnering organizations affirming support to disseminate and implement research findings that are germane and warranted for implementation are also highly encouraged.
Literature Review	A literature review is a survey of scholarly sources (such as books, journal articles, and theses) to discover what other studies have been completed on the topic and what is already known on the topic.
Long-Acting Beta Agonists (LABA)	Long-Acting Beta Agonists are inhaled medications that are used in the treatment of asthma and chronic obstructive pulmonary disease. Eg: Foradil, Serevent, Brovana & Perforomist
Long-Acting Muscarinic Antagonist (LAMA)	LAMAs (long acting muscarinic antagonist), for example tiotropium. LAMAs are mainly prescribed for people with chronic obstructive pulmonary disease but are sometimes helpful for people with asthma too. Eg: Genuair, Breezhaler, HandiHaler, Respimat & Ellipta
Longitudinal Study	A longitudinal study is an observational research method in which data is gathered for the same subjects repeatedly over a period of time. Longitudinal research projects can extend over years or even decades. In a longitudinal cohort study, the same individuals are observed over the study period.
Lower Limit of Normal (LLN)	For spirometry, only low values are considered to be abnormal, so the lower limit of normal is taken to be equal to the 5th percentile of a healthy, non-smoking population.

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Lung function tests (PFTs)	Lung function tests, or pulmonary function tests (PFTs), measure how well the lungs work. They include tests that measure lung size and air flow, such as spirometry and lung volume tests. Other tests measure how well gases, such as oxygen, get in and out of the blood. These tests include pulse oximetry and arterial blood gas tests. Another pulmonary function test, called fractional exhaled nitric oxide (FeNO), measures nitric oxide, which is a marker for inflammation in the lungs. One or more of these tests may be used to diagnose lung and airway diseases, compare lung function to expected levels of function, monitor if a patient's disease is stable or worsening, and see if a treatment is working.
Mean	The mean is the average of a set of numbers.
Median	The middle of a sorted list of numbers is the median. To find the median, place the numbers in value order and find the middle number. When there are two middle numbers, the average of those two numbers is the median.
Memorandum of Agreement/Understanding (MoA/MOU)	A written document between parties to cooperate on an agreed upon project or objective.
Meta-Analysis	Examination of data from a number of independent studies of the same subject, in order to determine overall trends.
Mixed Methods Study	A study using both qualitative and quantitative methods of measurement.
Mode	The mode is the number which occurs most often in a set of numbers.
Molecular Research	Molecular Research studies the composition, structure and interactions of cellular molecules – such as nucleic acids and proteins – that carry out the biological processes essential for the cell's functions and maintenance.
Morbidity	Refers to having a disease or a symptom of disease, or to the amount of disease within a population. Morbidity also refers to medical problems caused by a treatment.
Mortality	In medicine, this term refers to the death rate, or the number of deaths in a certain group of people in a certain period of time. Mortality may be reported for people who have a certain disease, live in one area of the country, or who are of a certain gender, age, or ethnic group.
n	Number of participants. In a research study n=100 means that 100 individuals participated in the research study.
National Heart, Lung, and Blood Institute (NHLBI)	The National Heart, Lung, and Blood Institute, part of the National Institutes of Health, plans, conducts, and supports research related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases; and sleep disorders. The Institute also administers national health education campaigns on women and heart disease, COPD, and other topics.
National Institutes of Health (NIH)	The National Institutes of Health is an important U.S. health agency. It is devoted to medical research. Administratively under the Department of Health and Human Services (HHS), the NIH consists of 20-some separate Institutes and Centers.
National Organization for Rare Disorders (NORD)	The National Organization for Rare Disorders is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them.
National Research Act (1974)	The National Research Act required the U.S. government to create rules to protect people in research studies and created a national committee to develop guidelines for ethical research. These guidelines are in the Belmont Report.
Nontuberculous mycobacteria (NTM)	Nontuberculous mycobacteria (NTM) are naturally-occurring organisms found in water and soil. NTM lung infection occurs when a person inhales the organism from their environment. Most people do not become ill but for some susceptible individuals, a slowly progressive and destructive disease can occur. NTM lung disease is common in individuals with Bronchiectasis.

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Nuremberg Code (1947)	In 1946-1947, a U.S. military court in Nuremberg, Germany charged 23 Nazi doctors and officials with war crimes, including unethical medical experiments on concentration camp prisoners. After the Nuremberg Trials, the judges listed important principles of acceptable medical experiments. These principles became known as the Nuremberg Code. Important principles are: <ul style="list-style-type: none"> • Research participation must be voluntary. • Research participation cannot put people at high risk for disability or death. • Participants can quit a study at any time.
O2VERLAP Study	Study comparing effectiveness of proactive care versus reactive care in patients with COPD and Obstructive Sleep Apnea (OSA)
Observational Research	Studies that use existing information or new information by watching without interfering. Researchers observe, measure, record and analyze the data generated.
Onboarding	The action or process of integrating a new employee into an organization or familiarizing a new customer or client with one's products or services.
Outlier	In statistics, an outlier is a data point that differs significantly from other observations. An outlier may be due to variability in the measurement or it may indicate experimental error; the latter are sometimes excluded from the data set.
P Value	<i>P</i> value is the way significance is reported statistically. <i>P</i> value measures how likely the results could have just occurred from chance. The lower a <i>p</i> value, the more “real” the results (not a result of coincidence). The results of a study are statistically significant when <i>p</i> value is ≤ 0.05 ; In other words, there is a 5 percent or less likelihood that the results are due to chance.
Palliative care (PC)	The goal of palliative care is to help people with serious illnesses feel better. It prevents or treats symptoms and side effects of the disease and treatment. Palliative care also treats emotional, social, practical, and spiritual problems that illnesses can bring up. When the person feels better in these areas, they have an improved quality of life. Palliative care can be given at the same time as treatments meant to cure or treat the disease.
Pathogenesis	The pathogenesis of a disease describes the mechanisms by which it develops, progresses, and either persists or is resolved.
Patient Advisor	A patient advisor provides advice, often limited, to researchers. These individuals have a narrow role—researchers approach them to review a specific part of the research—they do not have a voice at all phases of the research study and they are not a member of the research team.
Patient Engagement	Involvement of patients and other stakeholders throughout the planning, conduct, and dissemination of the proposed projects.
PATient Navigator to rEduce Readmissions (PARtNER)	PATient Navigator to rEduce Readmissions (PARtNER) is a transitional care model for Minority-Serving Institutions (MSIs) that aims to increase support to patients and caregivers at the hospital through their transition home.
Patient Partners	Patients who are representative of the population of interest in a study, as well as their family members, caregivers, and the organizations that represent them. Patient partners are not to be confused with patient subjects; patient partners are members of the research team and involved in the planning, conduct, and dissemination of the research, whereas patient subjects are those individuals enrolled in the study as participants.
Patient Reported Outcomes (PRO)	A PRO is a measurement based on a report that comes from the patient (i.e., study subject) about the status of a patient’s health condition without amendment or interpretation of the patient’s report by a clinician or anyone else. A PRO can be measured by self-report or by interview, provided that the interviewer records only the patient’s response. Symptoms or other unobservable concepts known only to the patient (e.g., pain severity or nausea) can only be measured by PRO measures. PROs can also assess the patient perspective on functioning or activities that may also be observable by others.
Patient/Caregiver Investigator	Patients or caregivers who are participating members of research teams that are actively involved throughout all steps of the research process.
Patient-Centered Outcomes Research (PCOR)	Research that helps people and their caregivers communicate and make informed healthcare decisions, while allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions.

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Patient-Centered Outcomes Research Institute (PCORI)	The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit research organization created to help patients and those who care for them make better informed health decisions.
Patient-Facing Materials	These are any materials that participants in a study will see, as in recruitment materials such as emails, flyers, posters, surveys used in the study, instructional documents, etc.
Patient-Powered Research Networks (PPRN)	Patient-Powered Research Networks are operated and governed by patient groups and their partners, and are focused on particular conditions or populations.
Patients	Individuals who have or have had the condition under study; it may include patient surrogates or caregivers as well. It does not necessarily mean, but does not exclude, patient advocates or patient navigators.
Patients and Public Stakeholders	The patient and public stakeholders involved as the intended user of the tool and/or resource, as applicable.
Payers	Those who function as financial intermediaries in the health system, including private insurers and public insurers, and organizations representing insurers, such as America’s Health Insurance Plans.
Peak Expiratory Flow (PEF)	The peak expiratory flow (PEF), also called peak expiratory flow rate (PEFR), is a person’s maximum speed of expiration, as measured with a peak flow meter, a small, hand-held device used to monitor a person’s ability to breathe out air.
Peer Review	The goal of peer review is to ensure that the primary research studies funded by PCORI are held to the highest standards of scientific integrity, methodological rigor, and relevance and usefulness to patients, caregivers, clinicians, and other healthcare stakeholders. The process may include review of study proposals, methods or results by content experts, methodologists, patients, and other healthcare stakeholders with experience related to the study.
PEer-Led oxygen Infoline for patients and CAregivers (PELICAN)	The PELICAN study tested whether an O2 infoline for patients and caregivers would increase supplemental oxygen adherence and improve health in people with COPD.
Per Protocol	The per protocol population is all patients completing the study without major protocol deviations – that is, those who followed the rules of the study.
Pharma	Abbreviation for the pharmaceutical industry
Pharmacogenetics	Pharmaceutical treatments that are personalized through genetic information.
Phenotype	A phenotype is an individual’s observable trait, such as height, eye color, and blood type. The genetic contribution to the phenotype is called the genotype. Some traits are largely determined by the genotype, while other traits are largely determined by environmental factors.
PICO Approach	A useful way to decide if a proposed research project will provide new evidence related to a decision that is important to patients and caregivers is to break the research question down into four major categories. This is called the PICO Approach. PICO stands for the first letter in each category. 1. P: The population of patients/research participants and relevant subgroups of patients; 2. I: The intervention(s) relevant to the patients in the target population; 3. C: The comparator(s) relevant to the patients in the target population; 4. O: The outcomes that are meaningful to the patients in the target population.
PICOTS	A brief overview of the essential characteristics of a study: Participants, Interventions and Comparators (the treatments), Outcomes (what is measured), Timeframe, and Setting.
Pilot Project	Pilot Projects are smaller studies done to explore how to conduct and use patient-centered outcomes research in ways that can better serve patients and the healthcare community.
Placebo	An inactive substance or treatment that looks the same as, and is given in the same way as, an active drug or intervention/treatment being studied.
Populations	The group that is studied or represented by those enrolled in the study.
PORTAL Network	Patient Outcomes Research To Advance Learning is a new network that brings together four leading healthcare delivery systems: Kaiser Permanente, Group Health Cooperative, HealthPartners, and Denver Health.

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Power Calculation	Using statistics to determine sample size, or how many people need to be in a study for the study to detect a difference between two treatments, if a difference exists.
Pragmatic Clinical Trial (PCT)	Pragmatic clinical trials are usually considered large simple trials, or large-scale studies that compare two or more alternatives for prevention, diagnosis, treatment, or management of a disease or symptom; improving healthcare system-level approaches to managing care; or eliminating health or healthcare disparities.
PRAXIS	The mission of the COPD Foundation’s PRAXIS is to Prevent and Reduce COPD Admissions through eXpertise and Innovation Sharing. The initiative aims to reduce the heavy burden of COPD exacerbations and hospital readmissions currently weighing on patients, families and providers through alignment with CMS Hospital Readmissions Reduction Program (HRRP) goals and the sharing of expertise and resources in ways which enable the proactive identification and elimination of gaps in COPD care.
Prevalence	The proportion of individuals in a population having a disease or characteristic. Prevalence is a statistical concept referring to the number of cases of a disease that are present in a particular population at a given time, whereas incidence refers to the number of new cases that develop in a given period of time. For instance, as of 2012, 29.1 million Americans, or 9.3% of the population had diabetes (prevalence).
Primary Outcome	The primary outcome is the main measure of the study on which the statistics is built – ensuring enough participants to reasonably detect an important difference.
Principal Investigator (PI)	The lead researcher and primary contact for the project. The person responsible for conducting and supervising the research study.
Privacy	An understanding that information an individual provides will not be shared with others without their permission and that the methods and setting used to collect information will ensure the information remains private and patients’ wishes are respected.
Probability Value (P Value)	<i>P</i> value is the way significance is reported statistically. <i>P</i> value measures how likely the results could have just occurred from chance. The lower a <i>p</i> value, the more “real” the results (not a result of coincidence). The results of a study are statistically significant when <i>p</i> value is ≤ 0.05 ; In other words, there is a 5 percent or less likelihood that the results are due to chance.
Prognosis	The prognosis of a genetic condition includes its likely course, duration, and outcome. When health professionals refer to the prognosis of a disease, they may also mean the chance of recovery; however, most genetic conditions are lifelong and are managed rather than cured. COPD is measured in stages with Stage 1 being very mild and Stage 4 being very severe.
Prospective Observational Study	A type of study in which a research team collects data for people who happen to be getting a certain treatment. The study covers a specific period of time going forward. For example, it might track all emergency room visits for the next six months, or patients’ health for several years after they get a treatment.
Protected Health Information (PHI)	Any information held by a covered entity which concerns health status, the provision of health care, or payment for health care that can be linked to an individual.
Protocol	A written plan for carrying out a clinical study. A protocol includes what will be done, when and how.
Public Abstract	A summary of the research plan or research findings that is written for, and accessible to, a general lay audience.
Pulmonary Function Tests (PFTs)	Pulmonary function tests measure how well the lungs work. They include tests that measure lung size and air flow, such as spirometry and lung volume tests.
Pulmonary Rehabilitation (PR)	Pulmonary rehabilitation, also called pulmonary rehab or PR, is a broad program that helps improve the well-being of people who have chronic (ongoing) breathing problems. For example, PR may benefit people who have COPD, sarcoidosis, idiopathic pulmonary fibrosis, or cystic fibrosis.

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Pulse Oximetry	This test measures how much oxygen is in your blood. The test is easy, and the result is a percentage. The doctor will put a sensor on your finger or ear and a light will be used to measure the oxygen content in your blood. The result of this test may show if you need oxygen therapy.
Purchasers	Those who purchase health benefits for employees and their dependents, including individual businesses as well as local, state, regional, and national business groups, coalitions that represent businesses, and health coalitions.
Pure Research	Basic research, also called pure research or fundamental research, has the scientific research aim to improve scientific theories for improved understanding or prediction of natural or other phenomena.
Qualitative Data	Data which is based on opinions, preferences or observations; what is told or said via interviews or open-ended questions.
Qualitative Study	A study in which the information collected is often ideas, opinions, beliefs, attitudes or concerns. Focus groups, interviews or oral histories are used to gather information which is recorded in words and not translated into numbers. Analysis of the information tries to summarize the ideas into areas of thought often called domains.
Quantitative Data	Data which can be measured and given a numeric value and shown in tables and graphs.
Quantitative Study	A quantitative study is the most common type of medical research. It uses tests, questionnaires or surveys to collect information or data which is recorded as numbers. Analysis of the data uses the numbers to give results.
Query	The mechanism for getting information from a database. They are questions that are asked of the database in a predefined format, written in a language that the computer understands in order to produce.
Randomization	A type of allocation strategy in which participants are assigned to the arms of a clinical trial by chance.
Randomized Controlled/Clinical Trial (RCT)	A type of experimental study in which participants are randomly allocated to receive one of two (or more) diagnostic, preventive, therapeutic, or palliative interventions and are then followed to determine the effects of the intervention.
Range	A measurement of dispersion or spread; the range is calculated by subtracting the lowest data point from the highest data point. This gives the amount of spread between the lowest and highest data points.
Regression Analysis	Regression analysis is used to find trends in data. It provides an equation that can be used to graph the data, which can often show predictions that can be made from the data.
Regulatory Coordinator	The person who prepares and maintains all Institutional Review Board submissions.
RELIANCE Study	The COPD Foundation is partnering with top pulmonary doctors and researchers at more than 30 institutions across the country to conduct the RELIANCE study. RELIANCE is a clinical trial that compares two medicines currently used for COPD, azithromycin and roflumilast.
Request for Proposal (RFP)	A request for proposal is a document that describes a project's needs and asks for proposed solutions from qualified vendors.
Research Advocate	A research advocate promotes, often to other patients and their families, the need to participate as participants in research.
Research Proposal	A research proposal is a summary of a research project that is written to explain the research idea and how the research is to be done.
Research Team	A group of people organized to function cooperatively to design and conduct research. Should include patients and other stakeholders as key contributors to the research process.
Respect for Persons	In research ethics, the idea of respecting and protecting the rights of individuals to make choices. Includes the right of a person to know the risks and benefits of a study and to decide voluntarily whether to participate. For example, people need to have all the information they need to choose whether to participate in a study and make that choice freely.

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Resubmission	An unfunded application that has been modified following initial review and resubmitted for new consideration.
Retention	Keeping participants involved to fulfill each step of a study.
Retrospective Observational Study	A type of study in which a research team looks at data collected in the past, such as people’s medical records, to identify and compare the results of different treatments. For example, a study may look at blood pressure readings documented in medical records over the past five years for two groups of people – one group that took Medicine A and another that took Medicine B – to see if there was a difference in how each medicine reduced blood pressure.
Secondary Outcome(s)	Secondary outcomes are other outcomes that matter and will be measured – some may not occur frequently enough to determine a difference (statistically significant) but researchers should measure, e.g., in a study that targets preventing going to hospital (primary) other outcomes like death, patient satisfaction, cost might also be measured.
Sham-Controlled	A treatment or procedure (sham surgery) that is performed as a control and that is similar to, but omits a key therapeutic element of the treatment or procedure under investigation. In clinical trials of surgical interventions, sham surgery is an important scientific control.
Shared Decision Making	An intervention or approach that draws on and presents available evidence to inform patients of available treatment options and their risks and benefits, and either engages patients in a decision-making process with their clinician or promotes their ability to engage in such a process.
SHERLOCK	The SHERLOCK Consortium is a multi-stakeholder group established following the publication of the COPD National Action Plan in 2017. The SHERLOCK Consortium suggests a chain of care involving 9 steps to ensure that patients are successfully initiated on home oxygen therapy during transitions from hospital to home.
Short-Acting Beta Agonist (SABA)	Short-acting beta agonists (SABA) are a type of bronchodilator used for the acute relief of asthma symptoms. The most common one being albuterol; they help with symptoms such as wheezing.
Soft Skills	Soft skills are the traits that make you a good team member, such as etiquette, communication, listening and getting along with other people.
Spirometry	Spirometry measures the rate of air flow and estimates lung size. For this test, a person breathes multiple times, with regular and maximal effort, through a tube that is connected to a computer. Some people feel lightheaded or tired from the required breathing effort.
Stakeholder Engagement	Meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. Healthcare stakeholders include a broad range of communities have a stake in the effectiveness of our healthcare system (Examples include: patients, clinicians, researchers, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions).
Stakeholder Partner	Members of constituencies based on professional, rather than personal, experience. These can include clinicians, healthcare purchasers, payers, industry, hospitals and other health systems, policy makers, training institutions, and researchers. Some individuals may fit into several categories.
Stakeholders	Stakeholder partners may include members of constituencies based on professional, rather than personal, experience. For example, these constituencies can include: clinicians, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions. Some individuals may fit into several categories.
Standard Deviation	A measurement of dispersion or spread; standard deviation measures the spread of a data distribution. The more spread out a data distribution is, the greater its standard deviation.
Statistical Analysis	Statistical analysis is the technique used to make sense of and draw some inferences from data collected.

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Statistical Analysis Plan (SAP)	A statistical analysis plan may be a separate document or may be included in the protocol. The plan describes how the data will be analyzed, including the tables used to describe the results of the study. It may include a description of the types of tests or statistical techniques to be used during analysis of the study information.
Statistical Significance	Statistical significance is the measurement of how confident we are that a difference or relationship exists between two variables and is not just a result of chance.
Statistics	Statistics is a branch of math focused on the collection, analysis, interpretation and presentation of numerical data or information.
Stepped Wedge Trial	A type of experimental design that involves rolling out a treatment at different times in different places. For example, a one-year study involving three clinics might have each clinic start using a treatment at different times throughout the year. Clinic A starts giving patients the treatment on the first day of the study. After three months, Clinic B also starts giving patients the treatment. At six months, Clinic C does the same. The research team can compare patients' health at each clinic at different points in time to determine if the treatment made a difference to patients within that clinic or across different settings. A stepped wedge design may be a practical choice for studies with multiple sites and a large number of participants.
Study Advisory Committee (SAC)	A broad spectrum of patients and other stakeholders that advise and assist the research team with refining the study questions, outcomes, and protocols of a study.
Study Protocol	A written plan for carrying out a clinical study. A protocol includes what will be done, when and how.
Study Registration	Federally-funded studies are required to register in ClinicalTrials.gov (NCT) or the National Library of Medicine's Health Services Research Projects in Progress (HSRP) database. Study registration information includes study aims, patient population eligibility, interventions and comparators, outcomes measures, and, as required, participant recruitment status.
Summary Statement	For applications that are discussed at the in-person merit review meeting, the summary statement includes a final overall average application score, a summary of the application discussion at the in-person merit review meeting, and preliminary online reviewer critiques. For applications that are not discussed at the in-person merit review meeting, the summary statement includes only the preliminary online reviewer critiques. Summary statements no longer include any preliminary review scores.
Systematic Review	A synthesis and critique of existing literature, which can identify evidence gaps and inform decisions regarding how to address these gaps.
Technical Abstract	A summary of the research plan that is written for scientists and researchers.
Trajectory of COPD	Research focused on how and why COPD progresses, over time, from moderate to severe.
Translational Research	Translational research – a term often used interchangeably with translational medicine or translational science or bench to bedside – is an effort to build on basic scientific research to create new therapies, medical procedures, or diagnostics.
Trough FEV1	Trough FEV1 is the mean volume of air that can be forced out in one second after taking a deep breath approximately 24 hours after the last administration of study drug.
T-Tests	T-tests tell you how significant the differences between groups are; In other words it lets you know if those differences (measured in means/averages) could have happened by chance.
U.S. Food and Drug Administration (FDA or USFDA)	The U. S. Food and Drug Administration (FDA) is a federal agency of the United States Department of Health and Human Services. The FDA is responsible for protecting and promoting public health through the control and supervision of food safety, tobacco products, dietary supplements, prescription and over-the-counter pharmaceutical drugs (medications), vaccines, biopharmaceuticals, blood transfusions, medical devices, electromagnetic radiation emitting devices (ERED), cosmetics, animal foods & feed and veterinary products.