COPD FOUNDATION

BRIDGE Patient to Investigator Training Key Lessons and Highlights

Module	Key Lessons	Highlights
Module 1: **What it Means to be a Patient/Caregiver Investigator**	Patient/caregiver investigators **are part of the research team from the beginning through all the phases** of the research study.	Patient/caregiver investigators are different from: • research advocates • patient advisors
Module 2: **Building Confidence**	• **Your perspective is important, unique and needed.** • Don't be afraid to speak up. • You are teaching your fellow research team members as much as they are teaching you!	**To *any research* team, you bring:** • experiential knowledge, • a unique perspective, • curiosity and • the ability to "fill in the gaps" to a research team There are several questions you can ask before joining a research team, that will help you understand expectations
Module 3: Types of Research	• **Different types of studies are used to answer different types of questions.** • Research studies can often be separated into **Observational** vs**. Experimental** Studies**.** • Research studies can also be separated into either **Quantitative, Qualitative** or **Mixed Methods** studies**.** • **Patient-Centered Outcomes Research** asks questions and studies topics that are **of most interest to patients and their caregivers.**	**Observational Studies:** Observe, measure, record, analyze—no changes **Experimental Studies:** Change, observe the effects of the change, compare, conclude—some type of change/intervention is done **Quantitative studies:** Data gathered and analyzed as numbers **Qualitative studies:** Information collected is often ideas, opinion, beliefs, attitudes, concerns (ideas) **Mixed Methods:** uses both quantitative and qualitative data/analysis

Module 4: Designing, Doing and Sharing a Research Study	**Before a study:** Identify a problem, plan a study, secure funding, get permission **During a study:** Recruit and consent participants, collect information, conduct analysis **After a study:** Evaluate impact, share results **During ALL phases of a study, there is an important needed role for patient/caregiver investigators**	Generally, research studies can be divided into different phases/stages: • **Designing and planning *(before study)*** • **Doing the research *(during study)*** • **Sharing the research *(after study)***
Module 5: Specific COPD-Related Research Information	**Past and current research studies on COPD have focused on all aspects of COPD—**from understanding it at the molecular/cellular level to diagnosing criteria to treatment to understanding its causes and risk factors **Future COPD research will likely focus on more understanding of all of these issues along with:** • better understanding whether COPD affects women differently; • expanding current criteria for diagnosing COPD; and • finding new treatments and ultimately, hopefully, a cure	***Research studies on COPD have focused on:*** • **Defining COPD** • **COPD at the Molecular/Cellular level** • **Trajectory of COPD** (what happens over time) • **COPD epidemiology** (patterns, frequency, causes, risk factors) • **Oxygen Issues and Therapies** • **Asthma and COPD** (the "overlap") • **COPD Phenotypes** (types, common traits) • **Screening for COPD** (identifying undiagnosed) • **Non-smoking Risk Factors** • **COPD Hospital Readmission Issues**

Module 6: Key Types of Study Documents	**As an active member of the research team you will be asked to review all of these different types of documents.** **Your feedback on these documents is important to help ensure the patient/caregiver point of view is considered**	**Most research studies will have these key documents:** • A research proposal • A study protocol • A statistical analysis plan • An informed consent document • Patient-facing documents These documents provide, respectively, a summary of the study, key details and step-by-step study plans, how the data will be analyzed, risks/benefits of the study and the many materials used directly with the study's participants.
Module 7: Protections for Research Participants	**Strong protections and federal regulations for people participating in research are in place today to avoid repeating past abuses.** These protections include: • institutional review boards • informed consent • extensive privacy and confidentiality protections through the Health Insurance Portability and Accountability Act (HIPAA)	**Today's research protections developed overtime because of these historical moments:** • Nazi experimentation (early 1940s) • Nuremberg "trial" and "Code" (1946-47) • Willowbrook Home for Children study (1963-1966) • Declaration of Helsinki (1964) • Tuskegee Syphilis study (1932-1972) • National Research Act (1974) • Belmont Report (1979)