Module 9

Conclusion

COPD FOUNDATION

Overview of Module 9: Conclusion

This section will include:

- Key Lessons & Highlights
- Next Steps

Estimated Time Commitment*: 15-30 minutes*

COPD FOUNDATION

Key Lessons and Highlights

We hope you have enjoyed progressing through the **BRIDGE: Patient to Investigator** training modules.

We hope the information presented has been helpful and encouraging for you as you move towards participating in a future COPD-related research project.

Let’s take just a moment to review what we’ve discussed and learned through this training.

COPD FOUNDATION

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

Key Lessons and Highlights

Module	Key Lessons	Highlights
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)***

Key Lessons and Highlights

Module	Key Lessons	Highlights
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**

Key Lessons and Highlights

Module	Key Lessons	Highlights
***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.

Key Lessons and Highlights

Module	Key Lessons	Highlights
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)

Research Team Liaisons

As we noted in Module 2, we urge you to ask, before the study begins, which team member will be **designated as your personal liaison**.

This liaison should be available to answer your questions one-on-one, providing you with further clarification on topics, outside of the team's regular meetings and phone calls.

Having a research team liaison doesn't mean you should not ask questions during team meetings.

Having a liaison simply means you have someone available to you as questions arise and who can give you more in-depth information and explanations that may not always be possible during a team meeting.

Having a research team liaison is one way to make you feel more comfortable during the study—particularly during your first study as a co-investigator

Links to Instructional Videos and Documents

Many research teams meet via video conferencing. The following document contains links to instructions on how to use some of the common meeting programs you might encounter as a patient/caregiver research investigator.

- Instructions for online meetings: click here

Research teams often share documents online. The following document contains links to instructions on how to use editing tools on some of the common types of documents you might encounter as a patient/caregiver research investigator.

- Instructions for editing documents: click here

Next Steps

Now that you have completed the training:

- Please complete the feedback survey at the end of this training
- A COPD Foundation staff member will reach out to you to discuss your interest in participating on research teams
- You can join the **COPD Foundation BRIDGE Research Partners** group
- Remember, you can come back and review these modules at any time to refresh your knowledge

COPD Foundation Contact

Questions about training:

- Email BRIDGE@copdfoundation.org

COPD FOUNDATION

LINKS TO KEY RESOURCES FOR MODULE 9

Take Away Documents	• Links to Instructions for Online Meetings: click here • Links to Instructions for Editing Documents: click here • BRIDGE Key Lessons and Highlights: click here

NEXT STEPS

Congratulations! You have completed Module 9 and the BRIDGE: Patient to Investigator training!

We hope you will consider joining the COPD Foundation BRIDGE Research Partners Group

Please remember to complete the post training survey on the BRIDGE Patient to Investigator Training Page – once completed you will receive your certificate of completion

COPD FOUNDATION