MODULE 1

WHAT IT MEANS TO BE A PATIENT/CAREGIVER INVESTIGATOR

Overview of Module 1: What It Means to Be a Patient/Caregiver Investigator

This section will include:

- **Information** about **what you will do**
- Details about **how you contribute** to the team
- **What you will NOT be expected to do**
- *Review questions to test your knowledge and understanding*

Estimated Time Commitment: *15-20 minutes*

Feel free to take breaks along the way – you can do this at your own pace!

Key Terms Used in this Module

- You will hear a lot of **new terms** during this module that you might not know

- We **do not expect you to know what these terms mean right away or memorize them** – just to familiarize yourself with the words

- Here is a **link to the key terms** used in this module that you can reference as you go through – click here

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What Does it Mean to be a Patient/Caregiver Investigator? What is Expected?

Patient/Caregiver Investigators: They are **participating members** of research teams that are **actively involved** throughout all steps of the research process.

As an investigator, you will:

- Join study team calls
- Be a **part of the study team from the beginning**—when the **research question** *(or "what do we want to study")* is being developed—
- **participate in all phases** of the research study *(you'll learn more about that soon)*
- Be there for **the end of the study** when **the results of the study are being evaluated and shared with others**. *(Yes! You could be an "author" on a published research study)*

What Does it Mean to be a Patient/Caregiver Investigator? What is Expected?

***As an investigator, you will*:**

- ***Share experience*** and ***perspective*—**You bring **real-world experience with COPD** and the related topics being studied.
- ***Review and edit materials*** that explain the study to people who may enroll (called informed consent) and the materials, like flyers, used to invite people to think about joining the study.
- ***Often see issues*** —Your patient viewpoint on this is important—you often see problems with the language or what is being asked of someone to do—as it directly relates to patients and their families—**that researchers will NOT see**. Your input is vital here.

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What a Patient/Caregiver Investigator is Not

Being a patient/caregiver **investigator** is *different* than being a research **advocate or** patient/caregiver **advisor** on a study.

Research Advocates: promote, often to other patients and their families, the need to participate—as "participants" in research. They have often been a research participant and promote others to become research participants as well. ***They are not involved in developing or actually doing the research studies.***

Patient Advisors: do just that— provide advice to researchers---but usually only when the researchers think to ask. They have a narrow role and researchers ask 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.***

What Does it Mean to be a Patient/Caregiver Investigator? What is NOT Expected?

As a patient/caregiver investigator, you will NOT:

- **Be expected to do the same work as a scientific investigator**
  - For example, you:
    - Do NOT need to know exactly how to design a study
    - Do NOT need to conduct the statistical analysis at the end *(HOWEVER, we will provide you with an optional introductory, basic overview of statistics in this training)*

Who are Other Members of the Research Team You will be Working With?

Joining you on a research study team will be several individuals with different roles and responsibilities who you will work with and you can ask questions of to help guide you:

Principal Investigator—responsible leader of the team, personally responsible for conducting and supervising the research study

Clinical Research Coordinator—manages and conducts the day-to-day study activities—following all protocols and regulations

Regulatory Coordinator—prepares and maintains all institutional review board (IRB) submissions

Data Coordinator—responsible for overall data management during the study

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Testimonials from Current and Previous Patient Investigators

John Linnell is a COPD patient diagnosed in 2005. His career was in retail, as a District Manager and troubleshooter and then, a Marketing Director. He left the workforce in 2011. After engaging in an internet film project and being asked to share his story at a pharmaceutical conference, John decided his efforts would be best spent doing advocacy work for the COPD community.

- **Watch his Patient Investigator Testimonial by clicking [here]**

Jean Rommes, PhD, is a COPD patient and advocate with intimate knowledge and experience with the challenges for the care and treatment of patients. She is a former smoker who quit in 1992 and was diagnosed with severe COPD in 2000. She "saw the light" in 2003 and through an aggressive exercise and diet program lost over 100 pounds and vastly improved her health. She is a great advocate for exercise and pulmonary rehabilitation and attends many conferences and meetings as a patient advocate.

- **Watch her Patient Investigator Testimonial by clicking [here]**

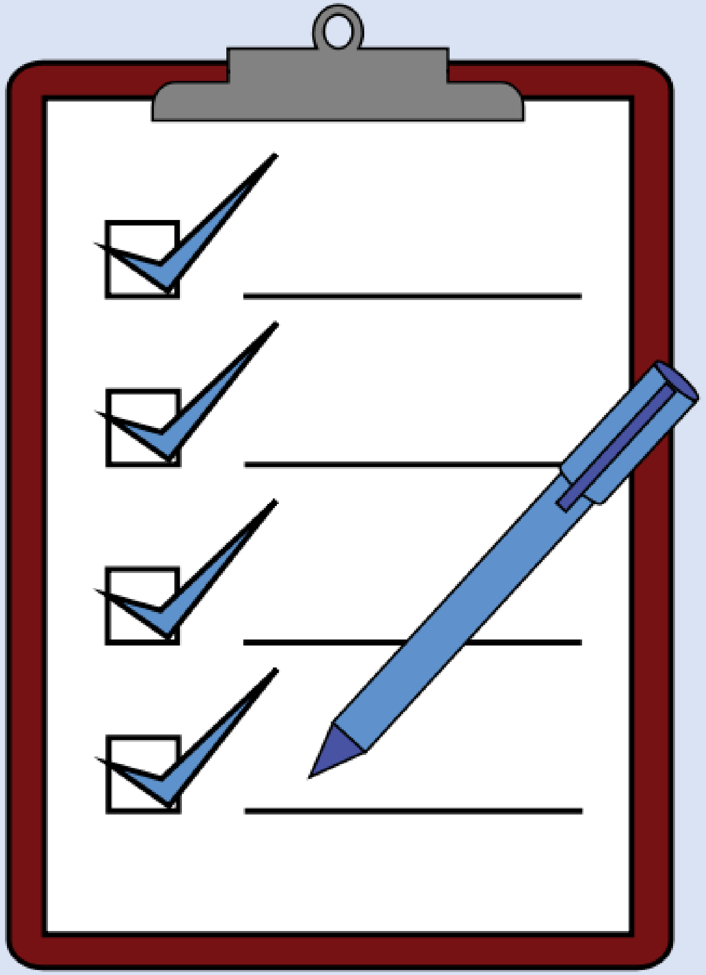
A Final Note on What it Means to be a Patient/Caregiver Investigator...

Remember, this is a process....just like the young scientific research investigators who are just starting out in their research careers:

- **you will not know everything your first time as a patient investigator**...
- **you will gain knowledge each time you do this**
- **you will definitely contribute a lot**
- you have a **perspective that is unlike anyone else's** on your research study team...
- your **input will be unique, valuable and appreciated**

MODULE 1: REVIEW QUESTIONS

- The next few slides have some **questions to help you review and remember** what we have presented in this Module.
- This is **not a graded test** and is **meant to only help you retain the information** from this Module. There is an answer key at the end.
- Here is a **link to the key terms** that might help as you go through the review questions – click here
- If you have any questions, please email BRIDGE@copdfoundation.org



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MODULE 1: REVIEW QUESTIONS

1.) Match the following words to the definition that makes the most sense:

_____ **Research Advocate**

_____ **Patient/Caregiver Investigator**

_____ **Patient Advisor**

a. Provide 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.

b. promote, often to other patients and their families, the need to participate—as “participants” in research. They have often been a research participant and promote others to become research participants as well. They are not involved in developing or actually doing the research studies.

c. They are participating members of research teams that are actively involved throughout all steps of the research process.

MODULE 1: REVIEW QUESTIONS CONTINUED...

2.) What will you **not** do as a patient/caregiver investigator? (choose the one answer that makes the most sense)

a. Join study team calls

b. Perform the statistical analysis

c. Review study materials

d. Share your perspective

3.) A patient/caregiver investigator and a research advocate are the same.

a. True

b. False

MODULE 1: REVIEW QUESTIONS ANSWER KEY

1.) __b___ Research Advocate

__c___ Patient/Caregiver Investigator

__a___ Patient Advisor

2.) b

Explanation: Patient/caregiver investigators are not expected to perform any statistical analysis of the study results. They will be part of understanding the study results overall from their perspective.

3.) b

Explanation: A patient investigator participates as part of a research team and the development of a study whereas a research advocate promotes the importance of research in general.

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LINKS TO KEY RESOURCES FOR MODULE 1

Below is a table with links to key resources and information that you might find useful

Takeaway Documents	• Module 1 Review Questions with Answer Key and Explanations: click here • Glossary of Key Terms: click here

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NEXT STEPS

Congratulations! You have completed Module 1!

When you are ready, please go on to ***Module 2 – Building Confidence***.

You don't have to do this right away – you can do it when you have time.

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