



# Moving Asthma & Allergy Science Forward

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Director, Research & Evaluation

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A black and white photograph of a hand holding a pen over a document. A dark grey text box is overlaid on the left side of the image, containing the mission statement of the Allergy & Asthma Network.

The mission of  
**ALLERGY & ASTHMA  
NETWORK**  
Is to end the needless  
death and suffering due to  
asthma, allergies and  
related conditions through  
outreach, education,  
advocacy and research.

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## Meet Our Speaker



De De Gardner, DrPH, RRT, RRT-NPS, FAARC, FCCP

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**POLL  
QUESTION**


We'd like to know who is with us today!

What category best describes you? (we have a limited number of answers or would offer more!)


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# Learning Objectives

-  Explain the types of Patient / Caregiver research.
-  Describe the reasons to be involved in Patient / Caregiver research
-  Discuss the research opportunities for Patient / Caregiver

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**POLL  
QUESTION**

Have you participated in research?

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## Why Should We Be Involved in Research?



Make a difference



Improve the study design



Select relevant outcomes



Share a specific patient story



Increase participants diversity



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## Patient/Caregiver Involvement in Research

- PARTNERS in all stages of the research process
- Research is carried out “WITH” or “BY” patients VS. “to, about or for” patients.
- Have a right to provide input to research on condition
- Hold a lived experience perspective
  - improve the efficiency and value of research
  - Increases relevance
  - Improves patient participation and retention
  - Improves sharing of findings beyond academic audience
- Increase the accountability and transparency of research



Greenhalgh T. et. al. 2019 Health Expectations  
Forsythe L. et. al. 2018. Quality of Life Research

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# BENEFITS of Patient/Caregiver Involvement in Research



- Quality and relevance of results are stronger
- Influence the choice of the research topic
- The project design and methods are appropriate
- Recruit diverse population
- Strong data analysis
- Distribution of results
- Positively affects the researchers and the research process



Greenhalgh T. et. al. 2019 Health Expectations  
Forsythe L. et. al. 2018. Quality of Life Research

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**POLL  
QUESTION**

True or False?

Patient/ Caregiver participation increases the accountability & transparency of a study.

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## Types of Patient / Caregiver Research

-  Expert opinion
-  Advisory board
-  Focus group
-  Surveys
-  Develop questions
-  Patient Centered Outcomes Research (PCOR)
-  Comparative Effectiveness Research (CER)
-  Clinical Trials or Interventions



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What is Patient  
Centered-  
Outcomes  
Research  
(PCOR)?



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## What is different about PCOR?



Focuses on research topics, questions, and **outcomes most important to patients** and those who care for them.



Works closely with a **range of healthcare stakeholders**—including patients, caregivers, scientists, clinicians, health systems, and insurers—to guide our research funding.



Requires that **patients be engaged** in the research we fund, not as subjects but as partners who help determine what to study and how.

By C. Clayatt, PCORI

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## Patient Centered-Outcomes Research (PCOR)

- Considers patients' needs and preferences, and the outcomes most important to them
- Investigates what works, for whom, under what circumstances
- Helps patients and other healthcare stakeholders make better-informed decisions about health and healthcare options
- Pays attention to
  - Conditions that heavily burden patients, families, and/or the healthcare system
  - Chronic or multiple conditions
  - Rare and understudied conditions
  - Conditions with varied outcomes across subpopulations



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# PCOR

## Engagement: Ensuring Patient/Stakeholder Partnership

- Patients and stakeholders from across the entire healthcare enterprise are actively and meaningfully involved in the entire research process—from the development of research priorities to the dissemination and uptake of research findings.
- Patients are treated as partners in research, not just “subjects.”
- To achieve critical goals:
  - To influence research to be patient-centered, relevant, and useful
  - To establish trust and a sense of legitimacy in research findings
  - To encourage successful uptake and use of research results



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## PCORI Ambassador Program



### About the PCORI Ambassador Program

Learn what the Ambassador program is and how it supports PCORI's overall mission and vision.



### Get Involved

Complete the program interest form to get started. New Ambassadors can learn about ways to get involved.

C. Clayatt, PCORI


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## Research Fundamentals Structure

pcori

### Learning Need Navigation Tool




Interactive PDF




Video Based Module


Developing Research Questions




Designing the Research Study




Planning Patient-Centered Consent and Study Protocols



Sampling, Recruiting, and Retaining Study Participants



Understanding and Sharing Research Findings




### Five Interactive Learning Modules

C. Clayatt, PCORI

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## Timeline and Time Commitment

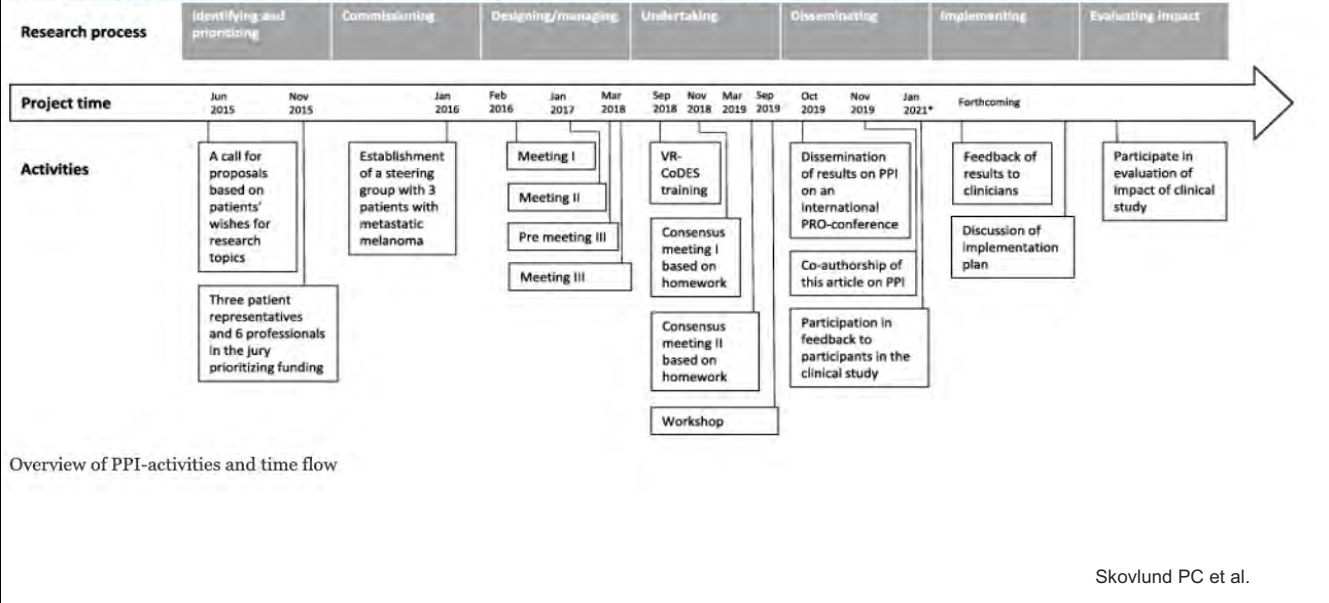
- Depends on study type
- May vary from 3 – 20 minutes for survey research
- 1 – 2 hours for expert opinion
- Commitment for 1 year for 2 hours a month for advisory board
- Clinical trials vary



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**Fig. 2**

From: The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, controlled trial



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## What are the Expectations of Person who participates in any form of Research?

- ✓ Be committed
- ✓ Be honest
- ✓ Be present when present

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## Are people compensated for their time participating in any form of Research?

- IDEALLY YES
- \$5 - \$100 for Surveys completion depending on need
- Standard rate is \$80- \$100 per hour for expert opinion, interview, focus group or advisory board
- Clinical trials have varying compensation
- \$5 - \$100 for Surveys completion depending on need

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## What Opportunities Exist at AAN?



- ✓ Research Partner
- ✓ Asthma360 registry (<https://asthma360.datstat.com/portal#!/>)
- ✓ Covid Registry (<https://allergyasthmanetwork.org/research/covid-19-registry/>)

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## What Opportunities Exist at AAN?



- Join the Research Newsletter subscription to learn about research opportunities bimonthly (<https://allergyasthmanetwork.org/research/get-involved-with-research-for-allergy-asthma/>)

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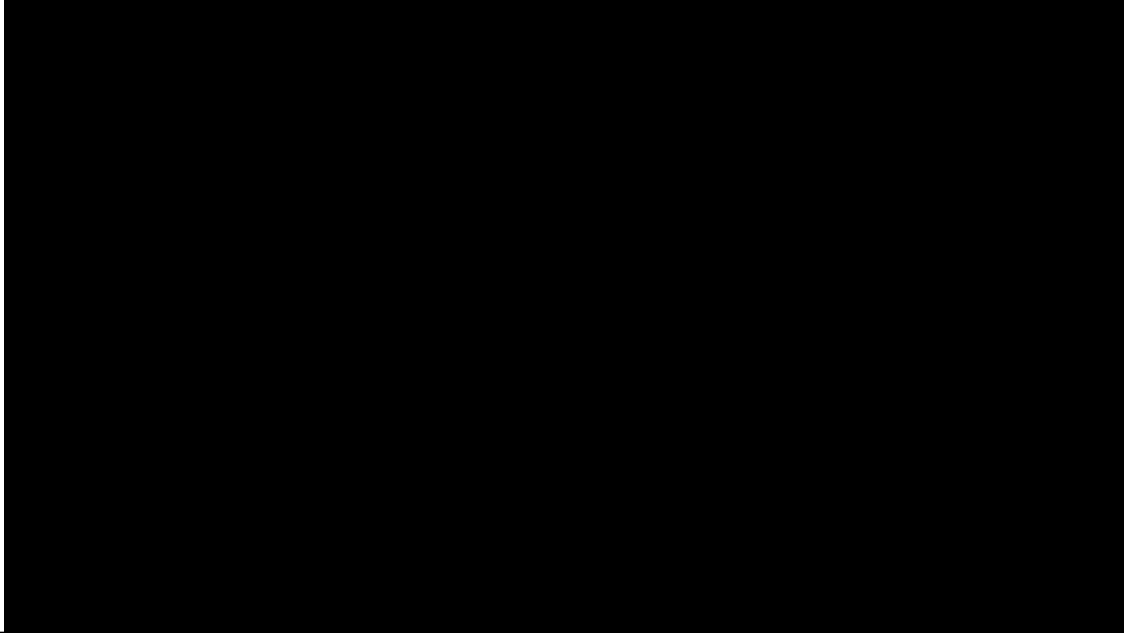
## What Opportunities Exist at AAN?



New opportunities are posted on the Current Opportunities page bimonthly (<https://allergyasthmanetwork.org/research/get-involved-with-research-for-allergy-asthma/>)

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## A Great Experience!



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**POLL  
QUESTION**

After hearing about the different types of research opportunities,  
Which opportunity is of interest to you?

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## QUESTIONS



We'll get to as many questions as we can!

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## Next Webinar



## Asthma & COVID\_19: Care & Education at Appropriate Literacy Levels

June 16, 2022

4:00 PM ET

Register at [allergyasthmanetwork.org](https://allergyasthmanetwork.org)

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Breathe Better Together



Please stay online for 2-3 minutes to complete the evaluation survey – we use this information to plan future webinars!

[allergyasthmanetwork.org](http://allergyasthmanetwork.org)