

Supplemental Material 1.

PCORI Training Modules

Research¹

- The Navigator
<https://www.pcori.org/engagement/research-fundamentals/navigator>
- The PCORI Approach to Patient-Centered Outcomes Research
<https://www.pcori.org/engagement/research-fundamentals/pcori-approach-pcor>
- Engaging in Stakeholder-Driven Research,
<https://www.pcori.org/engagement/research-fundamentals/engaging-stakeholder-driven-research>
- Module 1: Developing Research Questions
<https://www.pcori.org/engagement/research-fundamentals/developing-research-questions>
- Module 2: Designing the Research Study
<https://www.pcori.org/engagement/research-fundamentals/developing-research-questions>
- Module 3: Planning Patient-Centered Consent and Study Protocols
<https://www.pcori.org/engagement/research-fundamentals/planning-patient-centered-consent-study-protocols>
- Module 4: Sampling, Recruiting, and Retaining Study Participants
<https://www.pcori.org/engagement/research-fundamentals/sampling-recruiting-retaining-study-participants>
- Module 5: Understanding and Sharing Research Findings
<https://www.pcori.org/engagement/research-fundamentals/understanding-sharing-research-findings>

Teams²

- Building Effective Multi-Stakeholder Teams: Engaging Stakeholders
<https://research-teams.pcori.org/engaging-stakeholders>
- Building Effective Multi-Stakeholder Teams: Working as a Team
<https://research-teams.pcori.org/working-as-a-team>

Supplemental Material 2.

Mastering Dry Eye. Study Guide, Table of Contents.

Table of Content from Mastering Dry Eye: A learning experience presented in conjunction with Your Dry Eye Mystery Solved: Reversing Meibomian Gland Dysfunction, Restoring Hope.³

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Supplemental Material 3.

Mastering Dry Eye, Sample Challenge Questions. Modules B, C, and D.



MASTERING DRY EYE

MODULE B – CHAPTER 1

DISCUSSION SESSION CHALLENGE ITEMS: Each item provides you with a challenge to solve. For your assigned items, discuss your proposed solution and record your response in the field on the right. Be prepared to present your decisions.

CHALLENGE ITEM	NOTES ON YOUR RESPONSE
Challenge 1-1: RABBIT AND HUMAN MEIBOMIAN GLANDS Review the photos of rabbit and human Meibomian glands shown in Fig. 1.1 (p. 40) and discuss your responses to the questions below. • What similarities do you notice between rabbit Meibomian glands and human Meibomian glands? • What differences do you notice between rabbit Meibomian glands and human Meibomian glands?	Similarities: Differences:
Challenge 1-2: COMPARING POSTERIOR BLEPHARITIS TO EVAPORATIVE DRY EYE Review the definitions and descriptions of <i>Posterior Blepharitis</i> and <i>Evaporative Dry Eye</i> and discuss your responses to the following questions. • Do the terms <i>Posterior Blepharitis</i> and <i>Evaporative Dry Eye</i> mean the same thing? Can the terms be used interchangeably? • What issues might be associated with using the terms interchangeably? • What clarifications would you provide to someone who is getting the two terms confused?	
Challenge 1-3: DISCUSSING THE MYTHS ABOUT MGD Review the eight myths that were introduced at the end of Chapter 1. Collectively, identify the top two myths that most apply to you (or to someone you know). For each myth you select, discuss your responses to the following questions. • Since this myth applied to you (or to someone you know), did you believe this myth? If so, what contributed to your belief in it? • Now that you know that the myth is untrue, how do you (or someone you know) benefit?	



MASTERING DRY EYE

MODULE C – CHAPTER 3

DISCUSSION SESSION CHALLENGE ITEMS: Each item provides you with a challenge to solve. For your assigned items, discuss your proposed solution and record your response in the field on the right. Be prepared to present your decisions.

CHALLENGE ITEM	NOTES ON YOUR RESPONSE
Challenge 3-3: MEIBUM'S PATH TO THE NOSE Describe the path that meibum takes to eventually arrive in the nose, using the key terms listed below. • Junction of central duct and acinar-ductular unit • Acinus • Ductule • Central duct • Excretory duct • Orifice • Lid margin • Tear film • Tear outflow duct	
Challenge 3-4: MEIBOMIAN GLANDS ARE SEBACEOUS, HOLOCRINE, AND EXOCRINE Discuss your responses to the statement and the associated questions that follow. Meibomian glands are sebaceous, holocrine, and exocrine. • How can knowing this influence a clinician treating a patient? • How can knowing this influence a researcher designing a study about Meibomian glands?	
Challenge 3-5: THE STRUCTURE OF A MEIBOMIAN GLAND The parts that make up the structure of a Meibomian gland are the acini, ductules, central ducts, excretory ducts, and orifices. • How can knowing the structure of a Meibomian gland influence a clinician treating a patient with MGD? • How can knowing the structure of a Meibomian gland influence a researcher studying a treatment for MGD?	
Challenge 3-6: THE PROCESS OF MEIBUM SYNTHESIS AND SECRETION The process of meibum synthesis and secretion are described in Challenges 3-1 and 3-2. • How can knowing the process of meibum synthesis and secretion influence a clinician treating a patient with MGD? • How can knowing the process of meibum synthesis and secretion influence a researcher studying a treatment for MGD?	



MASTERING DRY EYE

MODULE D – CHAPTER 5

DISCUSSION SESSION CHALLENGE ITEMS: Each item provides you with a challenge to solve. For your assigned items, discuss your proposed solution and record your response in the field on the right. Be prepared to present your decisions.

CHALLENGE ITEM	NOTES ON YOUR RESPONSE
Challenge 5-1: COMORBIDITIES AND THEIR ROLE IN MGD Select three and describe the roles they play in MGD. Chapter 5 of <i>Your Dry Eye Mystery Solved</i> examines comorbidities – diseases of the eye that occur at the same time as other diseases. Identify three comorbidities and describe how each one plays a role in MGD.	
Challenge 5-2: CATEGORIES OF COFACTORS THAT CAN CONTRIBUTE TO MGD Follow the instructions and prepare your response. Chapter 5 of <i>Your Dry Eye Mystery Solved</i> identifies four categories of cofactors that can contribute to MGD. Identify the four categories of cofactors and describe each one.	
Challenge 5-3: EXPLAINING THE COMPLEXITY Review the statement and discuss your responses to the following questions. Keeping in mind the comorbidities that can coexist with MGD and the factors that can contribute to disease: - Will studying MGD in a research setting be a relatively simple undertaking or relatively complex? Why so? - How about treating a patient with MGD, simple or complex? Why so? - How about for a patient managing the disease at home, simple or complex? Why so?	

Supplemental Material 4.

Judges' Scoring Rubric

Score Card

Research Study Title _____

Criteria	Excellent (4)	Good (3)	Fair (2)	Poor (1)	Score
Clarity of research question	Clearly defined and well-articulated	Mostly clear with minor ambiguities	Somewhat clear but lacks detail	Unclear or poorly defined	
Literature review	Comprehensive and up-to-date	Adequate but could be more thorough	Limited and outdated	Inadequate or missing	
Hypothesis/Research Objective	Specific, testable, and relevant	Generally clear but could be more specific	Vague or not clearly stated	Not testable or irrelevant	
Methodology	Detailed, appropriate, and well-explained	Generally appropriate but lacks detail	Incomplete or poorly explained	Inappropriate or missing	
Sampling	Well-justified and appropriate	Adequate but could be better justified	Poorly justified	Not justified or inappropriate	
Data collection methods	Rigorous, systematic, and well-described	Generally systematic but lacks rigor	Inconsistent or poorly described	Unsystematic or missing	
Data analysis plan	Comprehensive and appropriate	Adequate but could be more detailed	Limited or vague	Inadequate or missing	
Ethical considerations	Fully addressed	Generally addressed but could be more thorough	Partially addressed	Not addressed	
Feasibility	Highly feasible with clear plan	Feasible but with some concerns	Somewhat feasible	Not feasible	
Potential impact	High potential to contribute to the field	Moderate potential	Low potential	No potential	
Responses to judges' questions	<i>No questions were asked</i> or	Generally addressed but	Partially addressed	Not addressed	

	questions were fully addressed	could be more thorough			
				Total Score	

Qualitative Assessment and Questions for Teams

Research Study Title _____

Strengths of Research Study

- 1.
- 2.
- 3.

Opportunities for Improvement

- 1.
- 2.
- 3.

Questions for Team

- 1.
- 2.
- 3.
- 4.

Supplemental Material 5

Interviewer Guide

I. Introduction

In this interview we are interested in hearing about your perceptions of the three phases of Dry Eye Patient Council training

- PCORI online modules
- Mastering Dry Eye
- Dry Eye Patient Council Practicum
- Overall experience

II. 2. PCORI online modules

Considering your experience with the PCORI online modules on patient-centered research and comparative effectiveness research...

1. What did you learn from this experience that was valuable to you?
2. How valuable was it (very valuable, somewhat valuable?)
3. And why was it valuable?
4. What surprised you about this experience
5. Of the listed methods (videos, quizzes, PowerPoint slides), which were *effective* in contributing to your learning?
 - a. How effective were they (very effective, somewhat effective?)
 - b. And why?
6. Of the listed methods (videos, quizzes, PowerPoint slides), which were *not effective* in contributing to your learning?
 - a. How ineffective were they (very ineffective, somewhat ineffective?)
 - b. And why?
7. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of patient-centered comparative effectiveness research *before* the PCORI modules?
 - a. And why?
8. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of patient-centered comparative effectiveness research *after* the PCORI modules?
 - a. And why?

III. Mastering Dry Eye

Considering your experience with the Mastering Dry Eye training...

1. What did you learn from this experience that was valuable to you?
2. How valuable was it (very valuable, somewhat valuable?)
3. And why was it valuable?
4. What surprised you about this experience
5. Of the listed methods (text book, study guide, quizzes, discussion sessions, final exam), which were *effective* in contributing to your learning?
 - a. How effective were they (very effective, somewhat effective?)
 - b. And why?
6. Of the listed methods (videos, quizzes, PowerPoint slides), which were *not effective* in contributing to your learning?
 - a. How ineffective were they (very ineffective, somewhat ineffective?)
 - b. And why?
7. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of dry eye *before* this experience?
 - a. And why?
8. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of dry eye *after* this experience?
 - a. And why?
9. On a scale of 1 to 5 (1= poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent) how would you rate:
 - a. The quality of Mastering Dry Eye training?
 - b. The quality of questions asked in the quizzes?
 - c. The quality of the discussion sessions?
 - d. The quality of the study guide?
 - e. The quality of the learning management system software?
 - f. The quality of the book *Your Dry Eye Mystery Solved: Reversing Meibomian Gland Dysfunction, Restoring Hope*?
10. On a scale of 1 to 5 (1 = very disengaged, 2 = disengaged, 3 = somewhat engaged, somewhat disengaged, 4 = engaged, 5 = very engaged), overall, how would you rate your engagement or disengagement in Mastering Dry Eye training?
11. Are there any other comments you would like to make about Mastering Dry Eye training?

IV. Dry Eye Patient Council Practicum

Considering your experience with the Dry Eye Patient Council practicum...

1. What did you learn from this experience that was valuable to you?
2. How valuable was it (very valuable, somewhat valuable?)
3. And why was it valuable?
4. What surprised you about this experience
5. Of the listed methods (study guide; virtual instruction; team contract; team project assignments: written study, study presentation, addendum), which were *effective* in contributing to your learning?
 - a. How effective were they (very effective, somewhat effective?)
 - b. And why?
6. Of the listed methods (study guide; virtual instruction; team contract; team project assignments: written study, study presentation, addendum), which were *not effective* in contributing to your learning?
 - a. How ineffective were they (very ineffective, somewhat ineffective?)
 - b. And why?
7. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of designing a research study *before* this experience?
 - a. And why?
8. On a scale of 1 to 5 (1= no knowledge, 2 = minimal knowledge, 3 = moderate knowledge, 4 = good knowledge, 5 = expert knowledge) how would you rate your knowledge of designing a research study *after* this experience?
 - a. And why?
9. On a scale of 1 to 5 (1= poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent) how would you rate:
 - a. The quality of the Dry Eye Patient Council practicum?
 - b. The effectiveness of your team contract in setting expectations for your team's collaboration?
 - c. The quality of the materials provided in the training packet and via email?
10. (*For patients only*) On a scale of 1 to 5 (1= poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent), overall, how would you rate the effectiveness of the practicum in preparing you for membership in a Dry Eye Patient Council?
11. On a scale of 1 to 5 (1 = very disengaged, 2 = disengaged, 3 = somewhat engaged, somewhat disengaged, 4 = engaged, 5 = very engaged), overall, how would you rate your engagement or disengagement in the six Zoom sessions?
12. Are there any other comments you would like to make about the practicum?

V. Overall Experience

Considering all three phases of this experience...

1. What motivated you to participate in this training experience? In other words, what were you hoping to learn or take away from the experience?
 - a. Feel free to include personal, professional or other reasons that mattered to you.
2. On a scale of 1 to 5 (1 = not met at all, 2 = met minimally, 3 = moderately met, 4 = fully met, 5 = clearly exceeded) how much would you say your objectives were met?
 - a. And why?
3. How satisfied or unsatisfied are you with the level of compensation you received? (1 = very unsatisfied, 2 = unsatisfied, 3 = neither satisfied nor unsatisfied, 4 = satisfied, 5 = very satisfied).
 - a. Please elaborate
4. How like or unlikely are you to recommend this experience (PCORI online modules, Mastering Dry Eye, Patient Council practicum) to others? (1 = very unlikely, 2 = somewhat unlikely, 3 = neither likely nor unlikely, 4 = somewhat likely, 5 = very likely).
 - a. And why?
5. (*For patients only*) How long have you had dry eye? How did this experience change the way you manage or cope with this disease?
6. Are there any other comments you would like to make about the overall experience?

Supplemental Material 6.

Sample Interviewer PowerPoint Slides

Mastering Dry Eye

- Of these listed methods, which were effective in contributing to your learning?
- How effective were they (very effective, somewhat effective)?
- And why?

Text book
Study Guide
Quizzes
Discussion sessions
Final exam

Mastering Dry Eye

- Of these listed methods, which were not effective in contributing to your learning?
- How ineffective were they (very ineffective, somewhat ineffective)?
- And why?

Text book
Study Guide
Quizzes
Discussion sessions
Final exam

Mastering Dry Eye

- On a scale of 1 to 5, how would you rate your knowledge of Dry Eye **before this experience**?
- And why?

1	2	3	4	5
no knowledge	minimal knowledge	moderate knowledge	good knowledge	expert knowledge

Mastering Dry Eye

- On a scale of 1 to 5, how would you rate your knowledge of Dry Eye **after this experience**?
- And why?

1	2	3	4	5
no knowledge	minimal knowledge	moderate knowledge	good knowledge	expert knowledge

Table 1*Phase 1: Themes, Codes, and Representative Quotes*

Theme/method and codes	Representative quotes
Perceptions of value, surprise, knowledge, other (Items 1-4, 7-9)	
Explanation of the research process	
Research process	"I learned how a research topic was born and what kind of method to fit the research, how they conclude the research and come up with the conclusion." [P4, p/c]
Learned about PCORI	"A very comprehensive review of studies and how to design studies." [P1, p/c]
	"I learned what... PCORI supports." [P8, r]
Awareness of patient-centered CER	
Non-professional contribution	"Seeing people who are not research professionals talking about how they felt they were able to contribute in the research process was helpful." [P7, p/c]
Stakeholders	"I like the way they break it into small sections with different people talking. That gives me the perspective of different stakeholders involved in the study." [P4, p/c]
Collaboration	"The thing I found most valuable is learning about the collaboration between all the different personnel." [P6, r]
Barriers to engagement	
Confusion	"I'm still not sure how the rubber meets the road. I'm still not sure exactly how it works." [P7, p/c]
No interest	"It was like...18 months before we actually did the study... design. So, at that time, I really didn't understand really the whole setup of the thing... it was just confusing for me to understand what we were doing." [P1, p/c]
	"I thought it was going to be more so learning, about dry eye. And that was not what this was." [P9, p/c]
Perceptions of effectiveness of training methods (items 5-6)	
Slide presentations	
Positive	
Supports learning	"I like having written work... because I can refer to them during the quizzes. Most effective to assist with the quizzes." [P6, r]

"Power Point was effective. Easier to understand. I'm more a reader, not necessarily a video person." [P1, p/c]

Negative

Length/tedium

"I remember them being kind of long." [P6, r]

No interest

"Same as videos" [P9, p/c]

Lost focus

"Reading them, my mind would sometimes wander." [P5, p/c]

Videos

Positive

Modeled process

"Seeing videos of patients who had worked with researchers through that PCORI training was valuable." [P6, r]

Explained impact

Memorable

"Rather than it being theoretical or bullets, it was a person talking about their experiences being a patient and how they felt they were able to make a difference." [P7, p/c]

Kept attention

"The videos are what stick in my mind... particularly impactful... very effective because they were memorable, relatable." [P7, p/c]

" They kept my attention more." [P5, p/c]

Negative

Redundant

"They were just a little bit redundant and stretched out too long." [P6, r]

No interest

"None of them were effective for me learning, because it wasn't what I was looking to learn, so it didn't catch my interest." [P9, p/c]

Quizzes

Positive

Supports learning

"Because you see the video, then you have the PowerPoint, but once the information impressed on my mind, it's the quizzes. Because if I don't know the answer I have to go back. Or if the answer is not very clear, I still have to go back and relearn. So, the quizzes work the best." [P4, p/c]

"I think I would have mastered the information anyway, but it's always helpful to know that you're going to be quizzed because you pay attention a little bit closer if you know you're going to have to recall the information." [P7, p/c]

"It validated my understanding." [P8, r]

Negative

Did not explain adequately	"I don't know if they fully explained if you got the answer wrong."
No interest	[P1, p/c] "Same as videos." [P9, p/c]

Note. Because items 5-6 asked participants to evaluate specific training methods, responses were organized by method rather than coded into emergent themes. Positive and negative explanations were grouped to reflect participants' ratings.

PCORI = Patient-Centered Outcomes Research Institute, P = participant, p/c = patient/caregiver, r = researcher, CER = comparative effectiveness research.

Table 2*Phase 2: Themes, Codes, and Representative Quotes*

Theme/method and codes	Representative quotes
Perceptions of value, surprise, knowledge, other (items 10-13, 16-17, 20)	
Expanded dry eye knowledge	
Dry Eye	"I learned anatomy, more of the technical side of dry eye disease, terminology. I think that was certainly valuable to the extent that I'm going to be working with the researchers on that topic, I would need to have that information." [P7, p/c]
Physiology	
Pathophysiology	
Comorbidities	"It just really gave us a good understanding of how the pathophysiology of dry eye." [P1, p/c]
Treatments	
Symptoms	"More knowledge on dry eye, symptoms, diagnosis." [P3, r]
Causes	"Learning the general physiology of eye health was the new information for me." [P6, r]
Diagnosis	
Terminology	"I actually learned a lot more than I had previously known as far as vocabulary words, the scientific field of it, different comorbidities that cause the inflammation that causes dry eye disease, and overall, more knowledge and experience than I had prior." [p5, p/c]
Protocols	
Value of structured and collaborative learning	
Structured learning	" I was mostly surprised about how much I did not know, that I didn't pick up from reading the book on my own. And that was my biggest surprise, because I thought I was knowledgeable, but I didn't realize how much I was lacking in the knowledge of dry eye." [P9, p/c]
Group discussions	
Depth of content	
Length of process	"Because we have to learn, because we have to answer questions, it's forced me to read." [P4, p/c]
Accessibility	
Professional delivery	" The discussion sessions I found very effective. ... I think when you're talking to other people, and seeing their perspective, and understanding, and all of us discussing things together, it really helps you understand the problem better." [P10, p/c]
	"How in depth it was, the long process, the quizzes." [P5, p/c]
	"That was what I was after, and that was an unbelievably professionally done... It was well done, it was, it was very informative, it taught us a lot, I believe it was an excellently prepared course." [P9, p/c]
Application of knowledge to professional or volunteer roles	
Supports work	"It was valuable because I am currently working in an ophthalmology office. That makes it more valuable to care for the patients or their
Supports volunteer work	

Research opportunities	symptoms and make them more at ease with what they're going through." [P3, r]
	"Because I am a patient advocate. I talk to people that are in the infancy stage of this disease from all over the world. And, I was able to become a better patient advocate to give them more technical information about how this disease works." [P9, p/c]
	"I learned about what research projects could be undertaken in this area and I learned a lot about dry eye." [P8, r]
Personal confidence and accomplishment	
Enjoyed learning	"Even though it was challenging to my eyes and to my brain. I feel like a lot was accomplished." [P2, p/c]
Sense of accomplishment	"In the end, I actually enjoyed this experience for what I learned. This is a great experience. [P4, p/c]
Barriers to engagement	
Confusion/frustration	"There were times when nobody really knew why we were doing what we were doing, and we probably should have." [P7, p/c]
More instruction	"You know, this is the overview and here's where we are on the continuum, and this is the eye, and this is what we're learning about today. And that would have made it more effective for me. " [P7, p/c]
Explain purpose	
Perceptions of effectiveness of training methods (items 14-15)	
Text Book	
Positive	
Supports learning	"It was in a format that was really easy for me to comprehend. It was very straightforward." [P1, pc]
Well written	
In-depth	
	"It gave all the information that we needed." [P6, r]
	"It's a very well-written book. And so it was... it was a great way to learn." [P10, p/c]
	"The book was very easy to understand and comprehend, and that translated to really pretty easily taking the quizzes." [P1, p/c]
	"It provides details. Because of the way it is written in detail." [P8, r]
Negative	No negative comments were reported.
Study Guide	
Positive	

Supports learning	"You are able to take notes. It makes it easier to answer questions when you write things down." [P3, r] "I found those places I need to go. It leads me to the main points, what I should spend time on." [P4, p/c] "...was effective as a nice summary." [P7, p/c]
Negative	
Lacked graphics	"I would like more pictures and more of just graphics." [P7, p/c]
Did not use/used textbook more	"I did not use the study very much during the process. It helped prepare just a little bit to know what you're going into for the meeting, but I never used it to jot down thoughts prior to the meeting." [P6, r]
Quizzes	
Positive	
Supports learning	"You think you know something until you're asked the question and you have to pick the right answer. And after the quizzes I learned also what I didn't know. And so that was very helpful in me going back and re-reading and figuring out and learning from the quizzes." [P9, p/c] "The quizzes were very effective because that made me focus in on what I was reading in the textbook more, and trying to get understanding." [P10, p/c]
Directed focus	
Negative	
Frustration	"They were a little bit frustrating but it was like I'm gonna get this no matter what." [P5, p/c] "The questions were worded and created a little confusion." [P3, r]
Confusion	
Discussion sessions	
Positive	
Other perspectives	"The discussion sessions I found very effective. Just like I said before, I think when you're talking to other people, and seeing their perspective, and understanding, and all of us discussing things together, it really helps you understand the problem better." [P10, p/c] "It gave me a chance to go over the materials that we were supposed to learn every few weeks." [P5, p/c]
Supports learning	
Negative	

Digressed	" Somewhat effective because it's digressing sometimes." [P4, p/c]
More instruction	"The discussion sessions might have been given a little bit more emphasis when you are reading through such difficult and challenging material." [P2, p/c] "I think that the discussion sessions could have been more effective if we had started with kind of a summary of what we learned, an overview." [P7, p/c]
Final exam	
Positive	
Supports learning	"At that point in time I felt very comfortable with the information. I knew the information very well because of those other four topics. So the final exam just solidified to me that my... what my knowledge base was." [P9, p/c] "It put together everything that we learned throughout, the process of Mastering Dry Eye." [P5, p/c]
Negative	
Stressful	"Oh, it's just nerve-wracking." [P10, p/c]

Note. Because items 14- 15 asked participants to evaluate specific training methods, responses were organized by method rather than coded into emergent themes. Positive and negative explanations were grouped to reflect participants' ratings.

P = participant, p/c = patient/caregiver, r = researcher.

Table 3*Phase 3: Themes, Codes, and Representative Quotes*

Theme/method and codes	Representative quotes
Perceptions of value, surprise, other (Items 20-23, 26-27, 31)	
Experiencing the research process	
Research process	"It made you really think about everything from ethical considerations with research to the various problems with research with regard to confounding variables and everything else." [P10, p/c]
Complexity of conducting research	
Patient perspective in research	
	"How you come up with the hypotheses and how you conduct the study, how finalize the study. The whole process is just fascinating to me. [P4, p/c]
	"What surprised me is hearing from the patient perspective, what they want to have studied." [P6, r]
Value of structured and collaborative learning	
Other perspectives	"Working as a team and using both everyone's strengths and weaknesses to accomplish a goal was valuable." [P1, p/c]
Collaboration	
Structured learning	"Development of a research study from start to finish and having a collaboration, was the most valuable to me." [P6, r].
Personal confidence and accomplishment	
Sense of accomplishment	"I felt better equipped to be talking to researchers about a research project" [P7, p/c]
Pushed out of comfort zone	
Skill-building	"It pushed me to do something I was actually very uncomfortable doing." [P5, p/c]
Improved knowledge	I think that was valuable for teamwork skills. I think it was good for my learning skills just to broaden those skills of working with the team, communicating with them. [P1, p/c]
Barriers to engagement	
Personal limitations	"I learned that I cannot be involved in any future research that involves an enormous amount of study... I know my skill set and it's not in this." [P2, p/c]
Difficulty of assignment/too challenging	
Poor team support/frustration	"I did not expect it to be this challenging. Had I known, I would have not participated" [P2, p/c]
Stressful	"We did not get all the support we needed from our team to do what had to be done." [P2, p/c]
Did not enjoy	"Because it was very stressful, it's not that valuable. [P5, p/c]
Tedious/time consuming	

Confusing	"I did not enjoy that part of it at all. It was tedious. I did learn from it."
Feeling of not knowing	[P9, p/c]
	We were confused at times, like, what were we supposed to do?" [P9, p/c]
	"I just feel like there's a lot more that I would have to learn about it. I have a better understanding than I had before, but I feel like I still have a long ways to go." [P7, p/c]
	"Even though I went through this whole patient council, I still don't feel like I'm a researcher." [P5, p/c]
Perceptions of effectiveness of training methods (items 24-25)	
Written study	
Positive	
Supported learning	"We had to put what we learned down on paper, and we knew that was going to be going to the higher ups for judging." [P1, p/c]
Expert feedback/Judging	
Thought-invoking	"I found the feedback you got from people, the, you know, the experts who were, engaged as well, was very useful, and the questions they asked were very useful and made you even think more about the study that you were working on." [P10, p/c]
Collating information	
	"It showed all the work put together, putting everybody's work, all the information we gathered into one study." [P3, p/c]
Negative	
Frustrating	"It was frustrating. I felt like it was the blind leading the blind." [P7, p/c]
Blind leading the blind	
Virtual instruction	
Positive	
Face-to-face	"It clarified questions" [P1, p/c]
Clarified	"The virtual instruction was good, that's what I found most effective...I'm a face-to-face [person]." [P9, p/c]
Negative	

Missed live sessions	"I missed a few." [P4, p/c]
Team contract	
Positive	
Initiated teamwork	"We kind of threw that together and it gave us a good start." [P1, p/c]
Negative	
Did not contribute to learning	"I don't know how it contributes to learning." [P8, r]
Terms changed	"It was hard deciding on who was going to do what part. We thought we knew at the beginning then we ended up changing it around, trying to put things in order." [P2, p/c]
Not useful	"If we had not had it, it wouldn't have made any difference." [P7, p/c]
Study guide	
Positive	
Provided guidance/format	"To give us some format or to lead us through what we were supposed to be doing. To walk us through the steps." [P7, p/c]
Described research process	"It helped us start thinking about how to set up... a research, study." [P10, p/c]
Negative	
Did not use	"It was out of my wheelhouse of what I know and what I learned... the study guide was difficult to follow, but for me. For our researcher in our group, it was simple."
No prior experience/difficult to follow	
Presentation	
Positive	
Supported learning	" Good to have everyone openly discuss and really consider all, any kind of holes in the study once we were speaking about it. And then also get feedback from the study, because that was included in the presentation." [P6, r]
Expert feedback, questions/Judging	
Thought invoking	"You can put your thoughts in order. What is important, what is not important." [P4, p/c]
Forced preparation	
Teamwork	"We had to prepare to present and talk." [P1, p/c]

"It showed teamwork and what everybody brought to the study, and all the information and experiences." [P3, r]

Negative

Frustrating	"Same as for written study." [P7, p/c]
Blind leading the blind	

Addendum

Positive

Supported learning	"It made us go back and re-evaluate and either change or validate our original thinking or methods." [P4, p/c]
Thought-invoking	

Negative

Frustrating	"Same as for written study." [P7, p/c]
Blind leading the blind	

Note. Because Items 24-25 asked participants to evaluate specific training methods, responses were organized by method rather than coded into emergent themes. Positive and negative explanations were grouped to reflect participants' ratings.

P = participant, p/c = patient/caregiver, r = researcher.

Table 4*Overall Impressions: Themes, Codes, and Representative Quotes*

Themes and codes	Representative quotes
Motivations for participation (item 32)	
To learn about dry eye	"I wanted to learn more about dry eye disease, how to research and take away more knowledge of something that was really unknown to me prior." [P5, p/c]
To advocate for patients	
To provide better care to patients	"More ability to advocate for dry eye patients." [P2, p/c]
To increase awareness of dry eye	"To learn more about the patient experience and learning what patients go through," [P3, r]
To advance dry eye research	"To increase the understanding and awareness that young people can also have... problems with dry eye disease. It's not just all about old people." [P7, p/c]
The reason evolved	"You want more research, you want to understand it better, and you want to... and by understanding it better, then that gives you the ability to discuss." [P10, p/c]
	"Initially it was the professional experience. I wanted to share what I could as a researcher.... But as we go through this training, it became more personal, as I heard all the patients' personal stories, and how this disease has impacted them, and how research can really make a difference, and hearing them motivated me." [P6, r]
Objectives met (Item 33)	
Positive	
Learned about dry eye	"We clearly exceeded our objectives here. like I said, it really helped me focus more on understanding, the problem and the anatomy and everything more than I'd ever bothered before, with regard to the eye and the problems with the eye." [P10, p/c]
Learned about patient experience	
Improved ability to advocate for patients	"I learned about the disease. I got down into the weeds on the disease, and I learned all different facets of the disease, and that was what I thought I was going in for, and that is what I expected. [P9, p/c]
New information	"I learned a lot more about patients and what they know and what they'd like to learn." [P6, R]
Developed contacts	
Surrendered to the process	"We are...equipped with knowledge and the learning experience helped us to expand our horizon to help others." [P4, p/c]
	"a lot of knowledge that I had no idea." [P1, p/c]
	"I got to know people. I got to know about the problem and the solutions." [P8, r]

"I trusted the process." [P5, p/c]

Negative

Remains to be seen

Lack confidence

"This training is preparing to make that change, right? It's not actually making the change. I mean I haven't communicated with any ophthalmologists, or participated in any research." [P7, p/c]

"A little bit of a lack of confidence I may have on being able to explain the technical aspect of dry eye in a comprehensive way for patients to understand." [P2, p/c]

Satisfaction with compensation (item 34)

Positive

Not necessary

Reflected work accurately

Validated effort

Good use of time

"I would have participated with this completely voluntarily." [p10, p/c]

"It reflected the amount of effort that was put into these modules and experience." [P6, r]

"It just feels like your work is valid." [P4, p/c]

"It was good use of my time, I did not expect, any compensation." [P8, r]

Negative

Not an incentive

"It was such a minimal amount...it was no incentive at all." [P2, p/c]

Likelihood of recommending PCORI modules (item 35)

Positive

Learned about patient-centered research

Learned about the research process

Well done

"Anybody who's interested in research, especially wanting the patient-centered aspect...should go through that training." [P10, p/c]

"It's the basis of the information we get from doing the research...very scientific methodology...lay the foundation." [P4, p/c]

"I think it was well done." [P7, p/c]

Negative

Tedious

No interest

"I felt them to be tedious and long." [P6, p/c]

"It just didn't interest me." [P9, p/c]

Difficulty with slide-based learning	"I just have a hard time learning from a slide design... hard for me to learn in that format." [P1, p/c]
No recall	"I don't remember the modules too well." [P3, r]
Likelihood of recommending Mastering Dry Eye (item 35)	
Positive	
Learned about dry eye	'If you're a patient or caregiver, you learn a lot about this dry eye disease." [P5, p/c]
Supports patient advocacy	"It was the backbone of every advocacy's dream. We learned so much about the disease." [P9, p/c]
Important foundation for overall training	"The background knowledge learned in Mastering Dry Eye is very important for this experience." [P6, r]
Informative and easy to understand	"It's a very informative book. It's well written and easy to comprehend." [P1, p/c]
Negative	
Needs more visual/anatomical graphics	'I'm a visual learner, so I was seeking out photographs of the eye anatomy and trying to keep all the information in one place." [P7, p/c]
Recommendation depends on patient's dry eye status	"Some would struggle, others would benefit. It depends on who I'm talking to." [P2, p/c]
Likelihood of recommending the practicum (item 35)	
Positive	
Contribute to research	"It gives patients a chance to put together research questions and projects that could be worked on in the real world." [P10, p/c]
Learned about dry eye	"You learned from it, and you could take away learning more about the disease from the research portion of it." [P9, p/c]
Supports patient advocacy	"Spreading the knowledge of dry eye is very important." [P8, r]
Learned about the research process	"I have a better understanding of the research process as a result." [P7, p/c]
Applied, hands-on learning	"Hands-on experience is the best kind of experience, and this gets people motivated and involved." [P6, r]
Negative	
Emotionally demanding/high burden	"It's very intense... it could be stressful for someone who doesn't know what they're getting into." [P5, p/c]
Recommendation depends on interest	"Some people wouldn't be interested, but if they want to expand their skills, then yes, I'd recommend it." [P1, p/c]

Patients: effect on disease management (item 36)	
No change	"It hasn't changed how I manage or cope because I've been coping and managing for 15 years." [P5, p/c]
Learned about options	"The way I change the way I manage or cope with my disease has been through [my doctor]." [P2, p/c]
	" It gave me more avenues of being able to try different things, knowing the disease better." [P9, p/c]
Other comments (item 37)	
Awesome experience	"It was an awesome experience. I met a lot of good people, made a lot of good bonds and friendships." [Participant 9]
Interest in future research	"It's certainly made me want to do more research and push for more research on dry eye." [Participant 10]

Note. Because item 35 asked participants about recommending the phases of training, responses were organized by phase. Positive and negative explanations were grouped to reflect participants' ratings.

P = participant, p/c = patient/caregiver, r = researcher.

References

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2. PCORI. Building effective multi-stakeholder research teams. (<https://research-teams.pcori.org/>).
3. Maskin SL, Warren NA. Your dry eye mystery solved: Reversing Meibomian gland dysfunction, restoring hope. New Haven and London: Yale University Press, 2022.