

# Include Everyone – Partnering with Patients and the Public to Improve Research and Evaluation

American Evaluation Association  
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# Financial Support



HEALTH SCIENCES CENTER AT  
PRISMA HEALTH – UPSTATE



UNIVERSITY OF SOUTH  
CAROLINA SCHOOL OF  
MEDICINE GREENVILLE



PATIENT CENTERED OUTCOMES  
RESEARCH INSTITUTE (PCORI)

# Acknowledgements

Peggy Wagner,  
Founding Director  
of the PES

Engagement  
Champions  
Windsor Sherrill  
and Matt Hudson

Priscilla Kendrick  
and Kimbell  
Dobbins

Patient Expert  
Steering  
Committee  
Members

Patient Experts  
from the  
Condition  
Specific Panels

Students: Ross  
Lordo, Dan Strat,  
Kurestin Miller,  
and Anne Kirby

Patient experts for  
special topics

Research, clinical,  
and patient  
experience  
partners

# Benefits of Patient Perspectives in Research



Establishing credibility



Anticipating controversy



Ensuring transparency and accountability



Improving relevance



Enhancing quality



Increasing dissemination and uptake of findings



Patient-Centered Outcomes Research Institute

BLOG

NEWSROOM

HELP CENTER

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ABOUT US

RESEARCH & RESULTS

TOPICS

ENGAGEMENT

FUNDING OPPORTUNITIES

MEETINGS & EVENTS



ABOUT US

## Research Done Differently

PCORI was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information.

[Find out more](#)

and clinical staff, and they contributed actively to discussions about the results and interpretation.

and strengthening exercise might slow cognitive impairment in dementia has gained widespread popularity. Many studies describe plausible mechanisms using mammalian models, but there are fewer studies using human participants.<sup>2,3</sup>

The results of recent systematic reviews of trials



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## Patient Engagement Panels

Patient as Partners

“Co-Investigators”

“Patient Experts”

- Patient involvement includes:
  - Planning
  - Conducting
  - Disseminating
- Can be diagnostic/disease specific
- Patient represents all patient opinions

## Focus Groups

Patients as Subjects

“Data Sources”

- Patient involvement includes:
  - Data and opinions: focus groups, surveys, social media
- Study specific
- Patient represents personal opinion

## Patient Advisory Councils

Patients and Community Members

- Patient Involvement: Political, financial and community expertise
- Health system operations; patient experience of care measures
- Members express community perspectives on system initiatives

# Differences Explained

# LEVELS of PATIENT and RESEARCHER ENGAGEMENT in HEALTH RESEARCH

	GOALS LEARN / INFORM	PARTICIPATE	CONSULT	INVOLVE	COLLABORATE	LEAD SUPPORT
PATIENT	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researchers in all aspects of research	To make decisions and lead research activities
RESEARCHER	To provide information, listen, and answer questions honestly	To act ethically and respectfully in the conduct of research	To seek your input on an ad hoc basis	To include you as standing members of an advisory group	To partner equally with you as team members	To follow your lead and support your decisions
HOW CAN THIS BE DONE	Through orientation and information sessions, and media campaigns in an open atmosphere for sharing)	Through quantitative, qualitative, or mixed methods research	Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels	Patients as members of standing working groups and research advisory committees	Patients as co-investigators and research partners, and as members of research steering committees	Through patient or community steering committees and patients as principle investigators

Manafò E, Petermann L, Vandall-Walker V, Mason-Lai P (2018) Patient and public engagement in priority setting: A systematic rapid review of the literature. PLOS ONE 13(3): e0193579. <https://doi.org/10.1371/journal.pone.0193579> <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0193579>

# The Patient Engagement Studio at Work

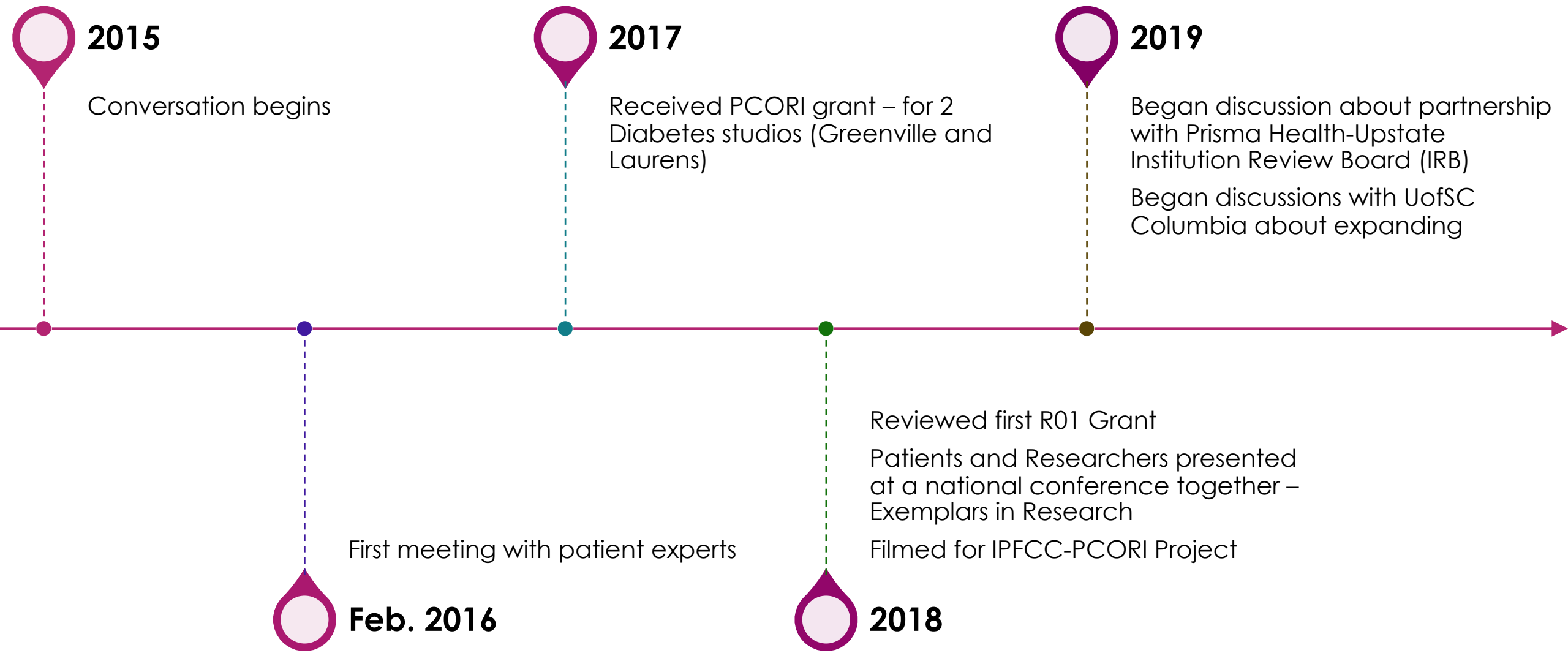
- First
  - Investigator presents project
  - Investigator prepares list of questions for patients to discuss
- Then
  - We listen . . . .
  - We discuss . . . .
  - We give ideas . . . .







# Studio Evaluation



# Patient Engagement Studio Timeline

# Patient Engagement Studio Steering Committee

11 Patient Experts

4 Clinicians

2 additional researchers

Studio Director

Support staff

## Condition/Population Specific Studios

Breast Cancer Studio – Clemson Dissertation

Rheumatoid Arthritis Studio - Pfizer Corporation and Institute for Healthcare Improvement

2 Diabetes Studios (Greenville and Laurens County) – PCORI Grant

### Future Condition / Population Specific Studios

- Adolescent/Young Adult
- Autism
- Orthopedic
- Prisma Employees with Diabetes
- PAD



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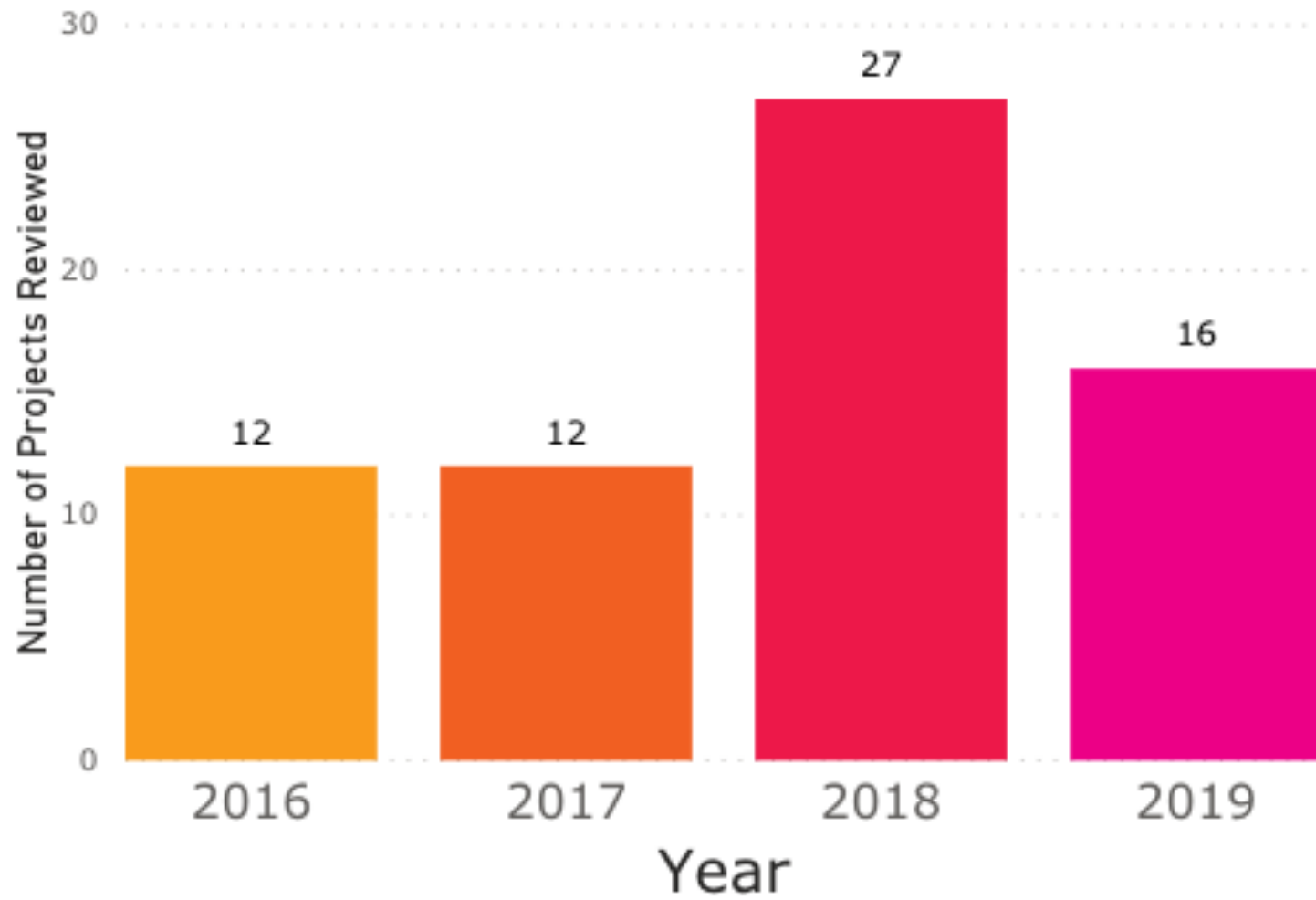
Total Number of  
Projects Reviewed by  
PES

67

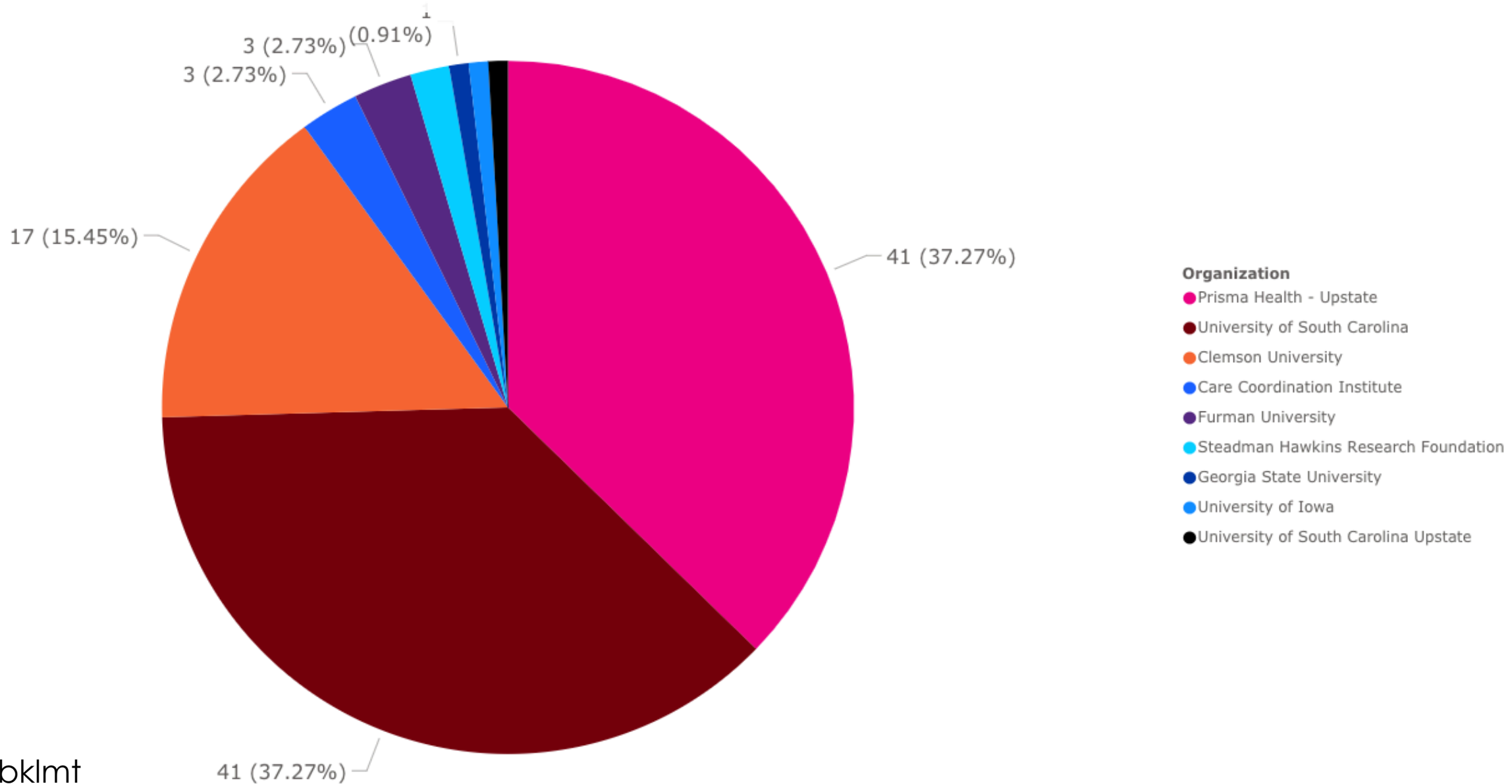
Total number of researchers  
who are listed on projects  
presented to the PES

168

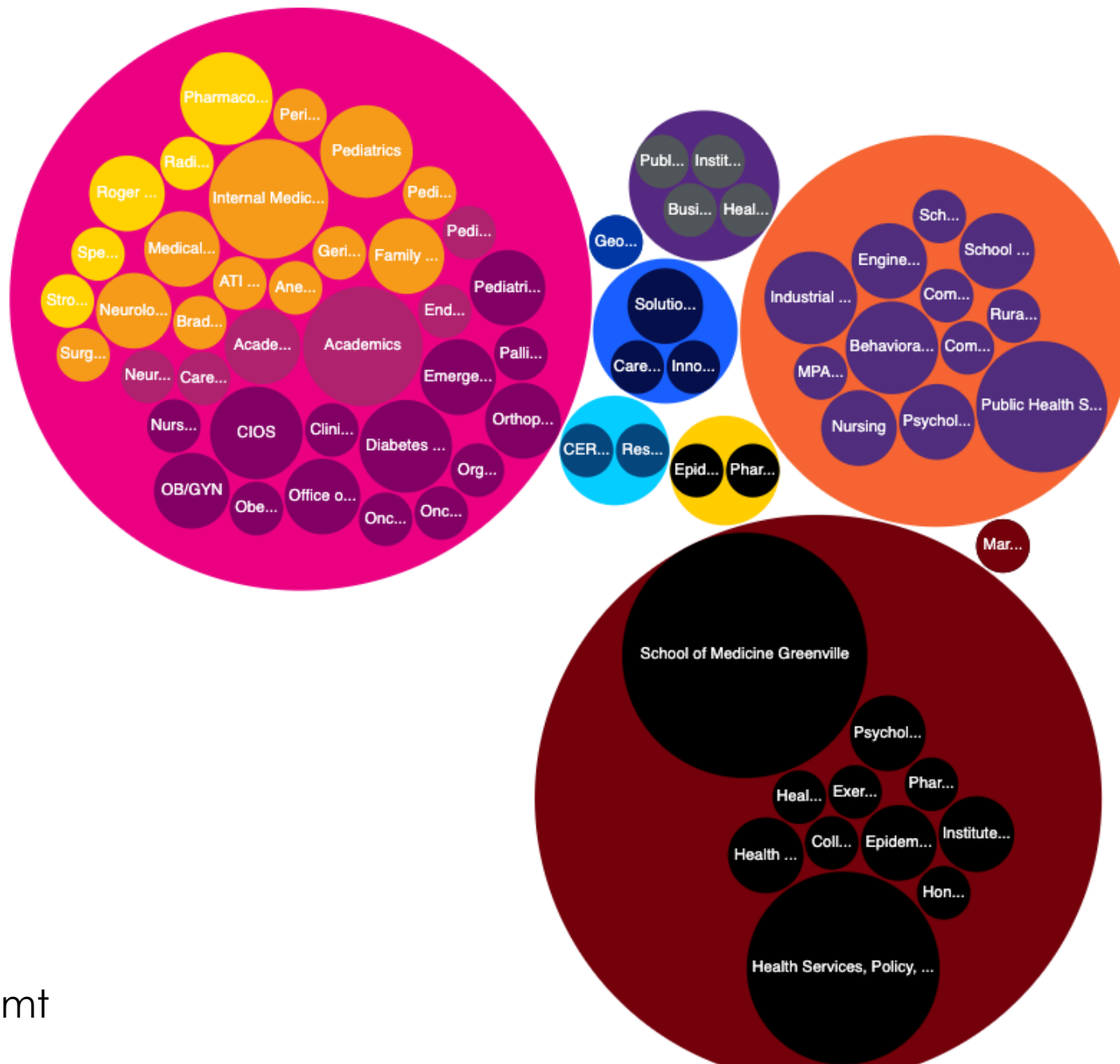
## Number of Projects Reviewed by Year



# Number of Projects by Organization



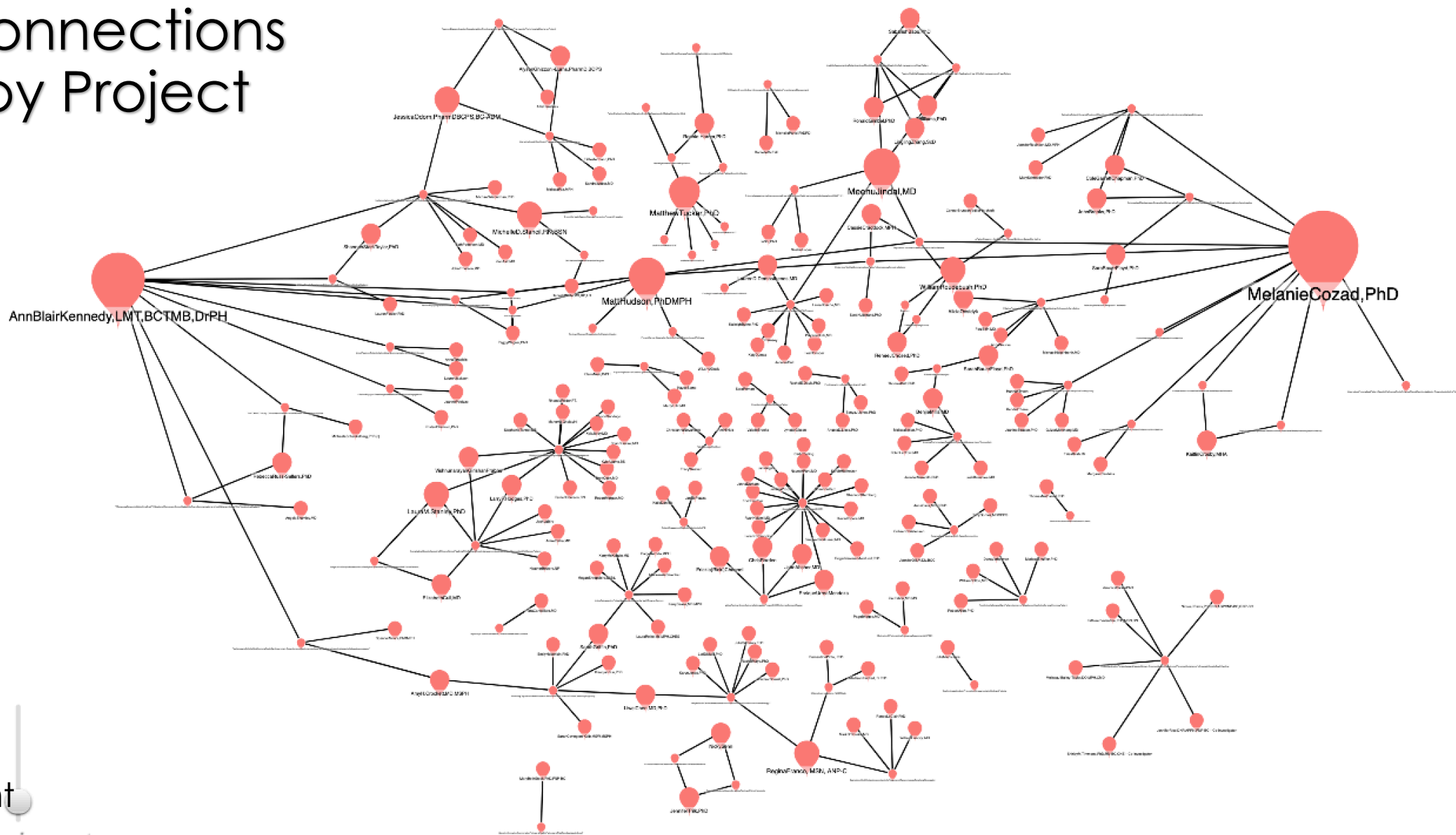
NUMBER OF PROJECTS BY DEPARTMENT WITHIN THE ORGANIZATIONS



- Organization
- Care Coordination Institute
  - Clemson University
  - Furman University
  - Georgia State University
  - Prisma Health - Upstate
  - Steadman Hawkins Research Foundation
  - University of Iowa
  - University of South Carolina
  - University of South Carolina Upstate



# Researcher Connections by Project





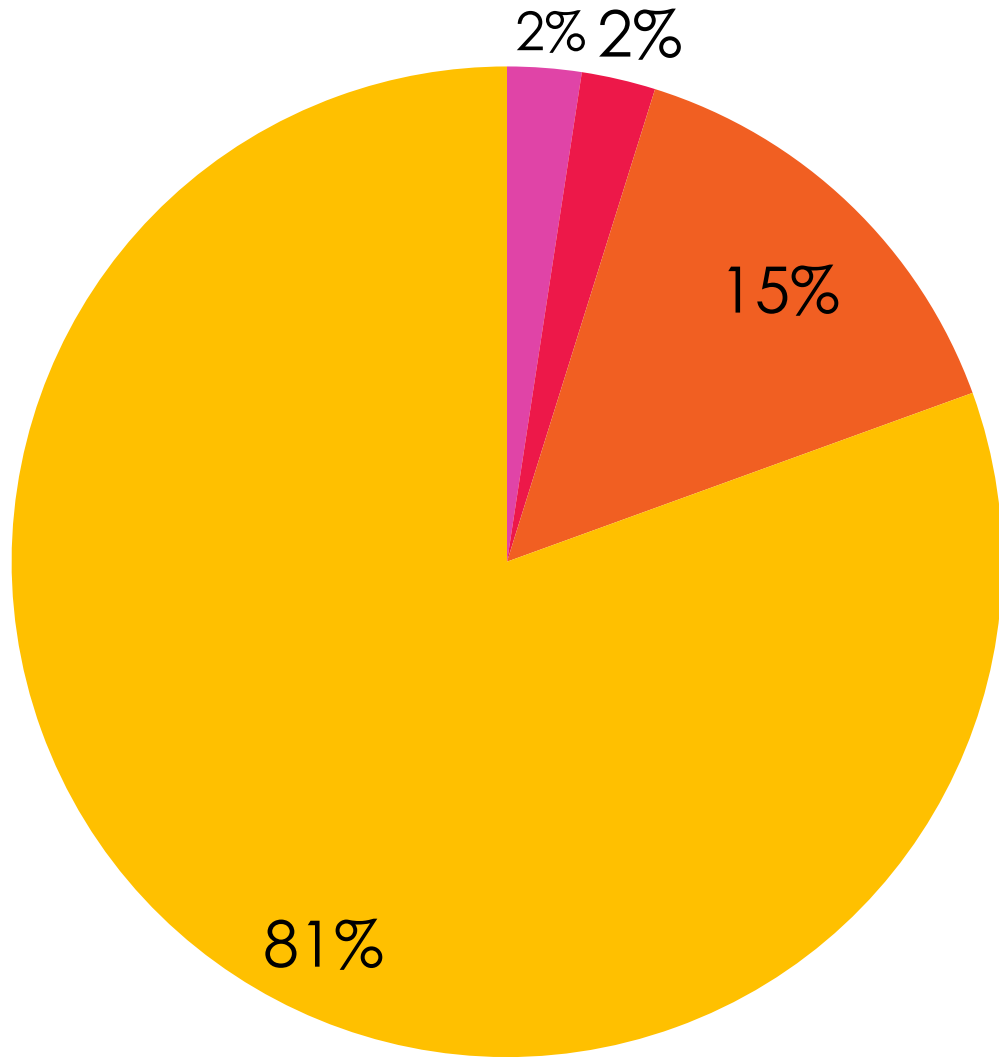
- Interviewed 54 interviews from 46 different projects interviewed by medical and undergraduate students over the summer

Reaching Out to  
Researchers



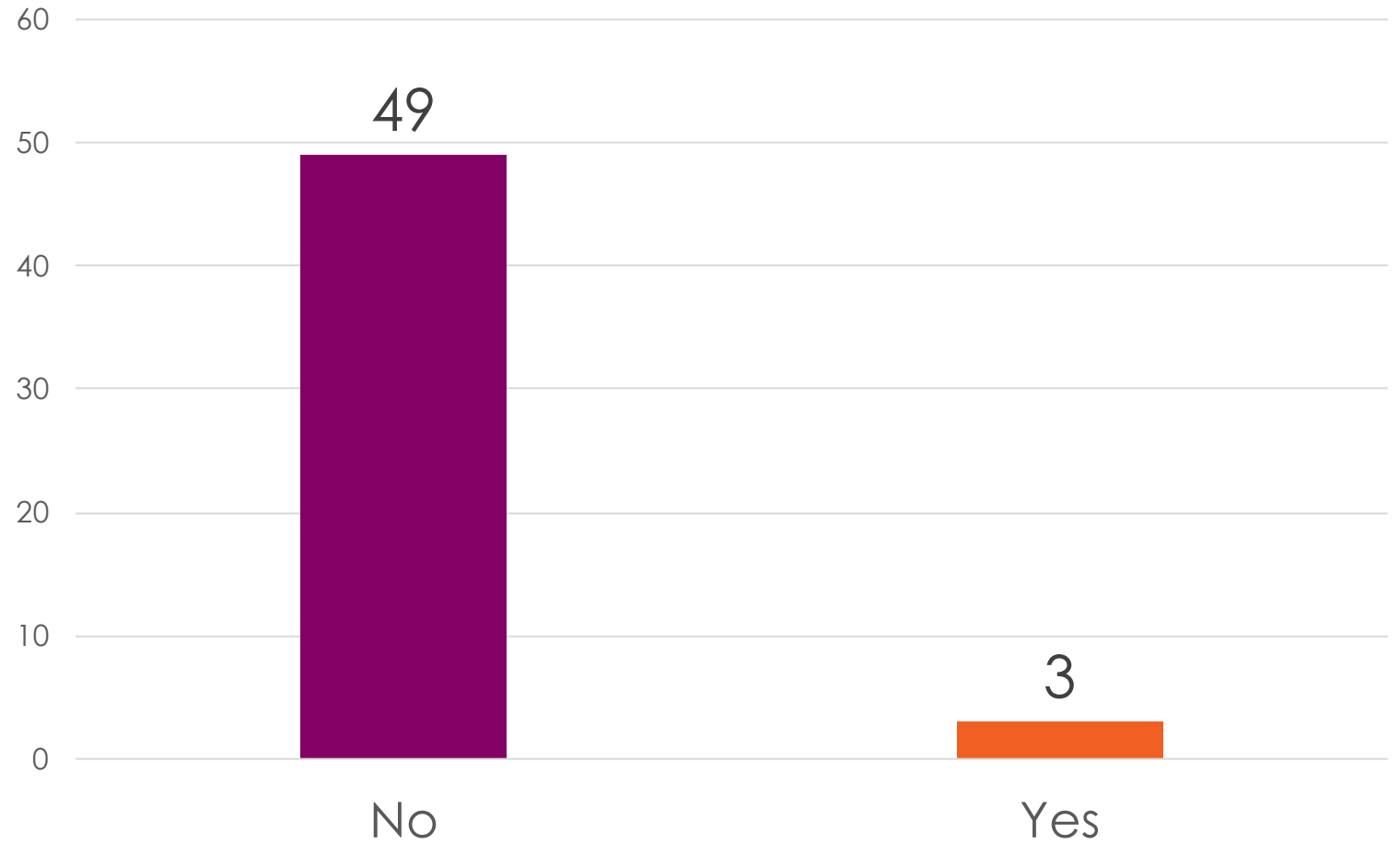
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# Stage of Project

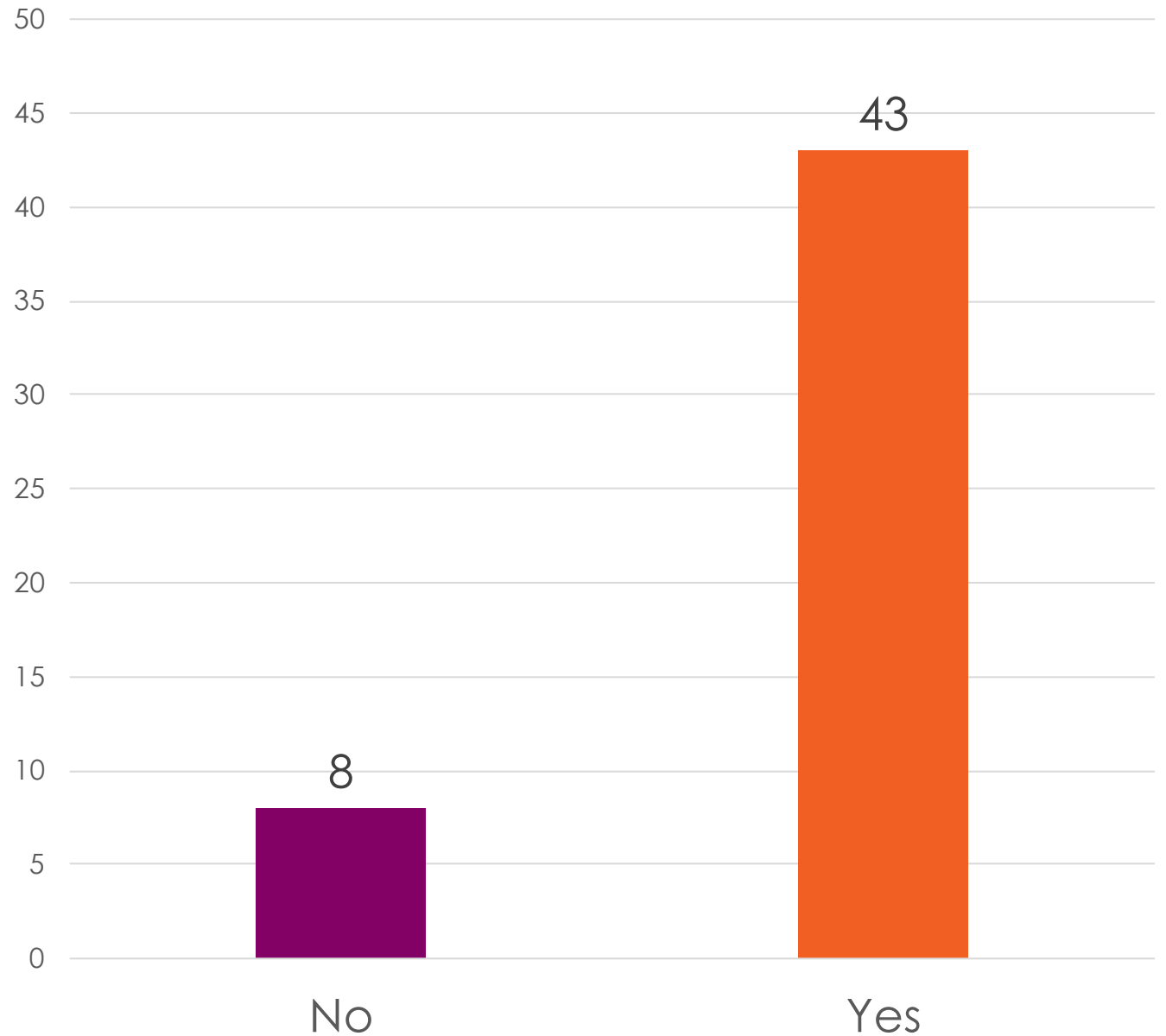


- Collection/Analysis
- Conducting the study
- Formative planning the study
- Study design

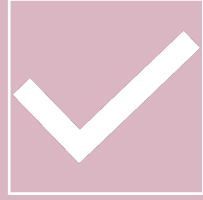
Did you return to the PES with the same project?



“Did you make changes suggested by the Patient Engagement Studio?”



## Main Themes of Recommendations



Clarifying patient priorities



Minimizing disruptions or reducing barriers for study participation



Improving communication and information delivery to patients

# Main reasons for not making changes



Timing



Finances

# Researchers Impressions of Presenting to the PES







# Loyalty Score

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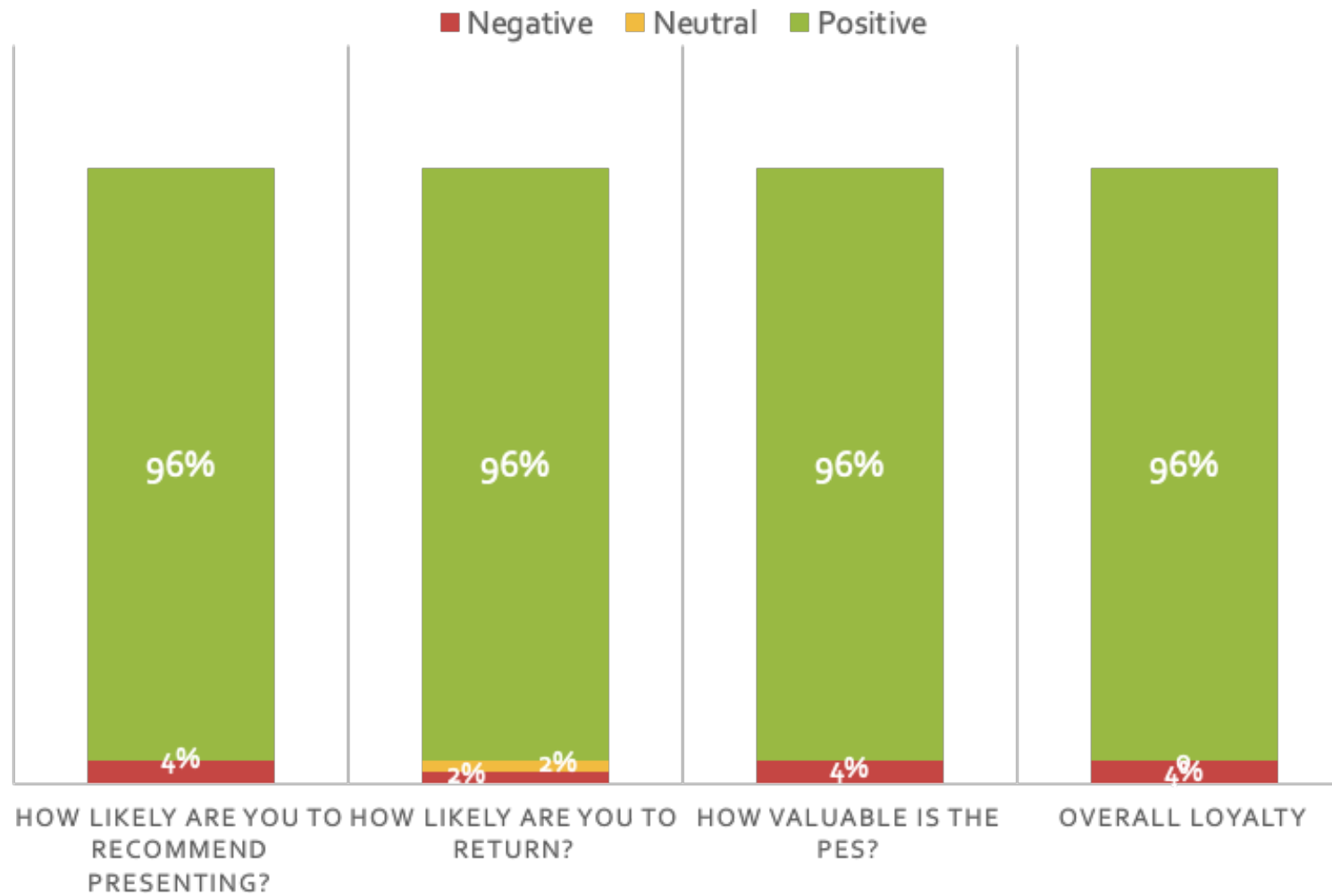
# How is loyalty determined?

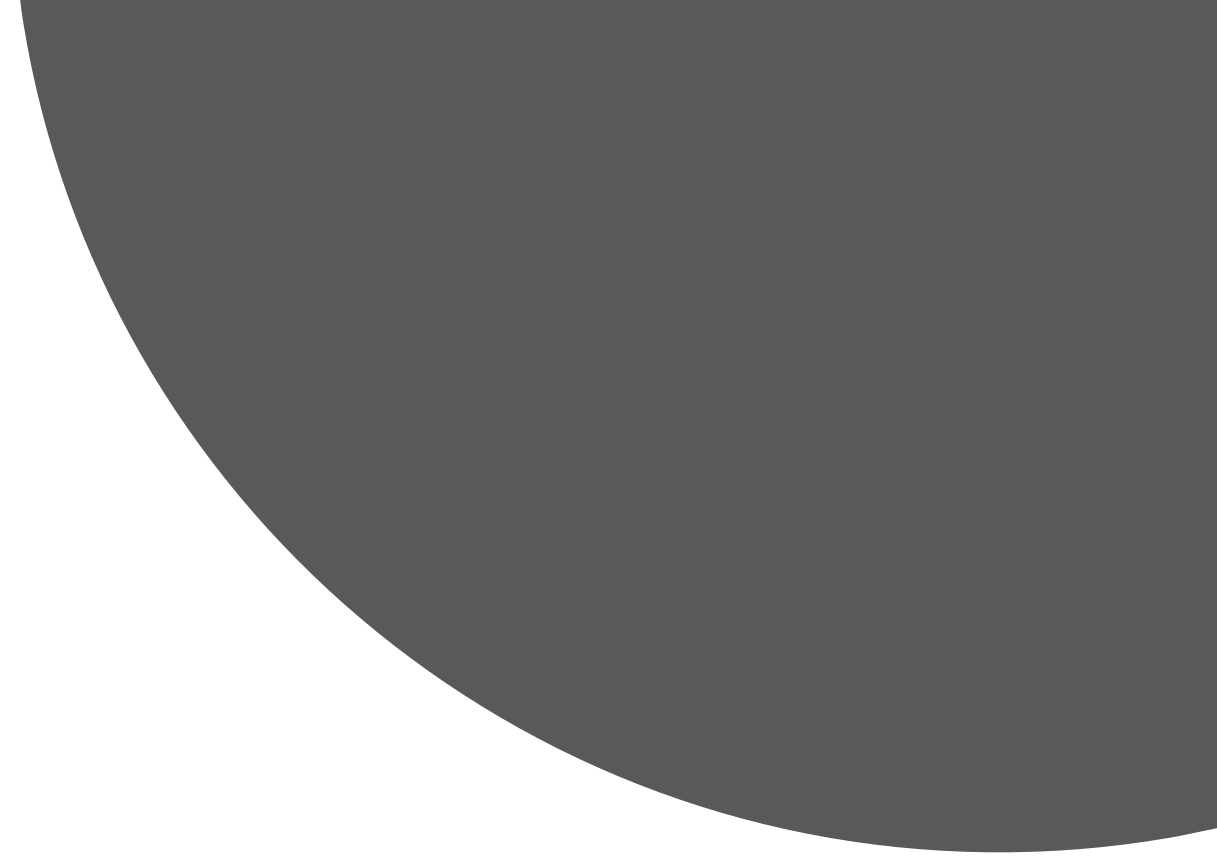
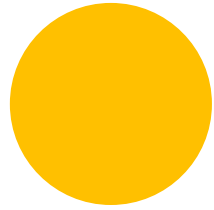
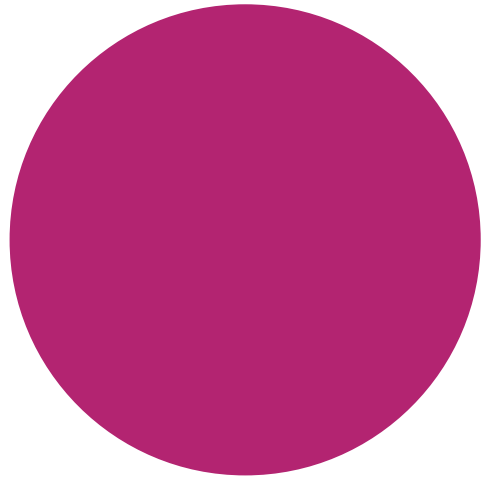
How likely are you to recommend presenting to the Patient Engagement Studio to others?

How likely are you to return to the PES?

How valuable do you find the PES?

# Loyalty Results





# Main Studio Self Evaluation



100% of  
Respondents  
Agree or  
Strongly Agree

- They are able to express their views freely
- They feel their views are heard and respected
- A wide range of views are shared
- A broad range of perspectives are represented
- Are confident researchers consider their input
- Their work with the Studio makes a difference
- Feel working with the Studio is a good use of their time

# PES Perspectives of Strengths and Rewards for Participation in the Studio



Questions?

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# Contact info



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