

Board of Governors Meeting via Teleconference/Webinar

March 24, 2015

12:00-1:30 p.m. ET



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome and Introductions

Grayson Norquist, MD, MSPH

Chair, Board of Governors

Joe Selby, MD, MPH

Executive Director



Agenda

Time	Agenda Item
12:00-12:05 p.m.	Call to Order, Roll Call, and Welcome Consider for Approval Minutes of Feb 24, 2015 Board Meeting
12:05-12:20 p.m.	Consider for Approval: Revised and Draft Policies - Revised Pre-Award Policy - Revised Post-Award Policy - Financial Audit Policy - Budget Development and Approval Policy
12:20-12:35 p.m.	Consider for Approval: PCORnet Health Systems Demonstration Project PFA Development
12:35-12:45 p.m.	Update on GAO Review
12:45-1:25 p.m.	Review Q1 Dashboard
1:25 p.m.	Wrap up and Adjournment



Board Vote: Approval of February 24, 2015 Board Meeting Minutes

Call for a Motion to:

- **Approve** the February 24, 2015 Board Meeting Minutes

Call for the Motion
to Be Seconded:

- **Second** the Motion
 - If further discussion, may propose an **Amendment** to the Motion or an **Alternative Motion**

Voice Vote:

- Vote to **Approve** the **Final** Motion
 - Ask for votes in favor, opposed, and abstentions



Institute Policies

Larry Becker

Chair, Finance and Administration Committee

Regina Yan, MA

Chief Operating Officer



Annual Budget Development and Approval Policy

- The purpose of this policy is to solidify PCORI's commitment to creating an annual budget which will be brought to the PCORI Board of Governors for consideration, prior to the beginning of each fiscal year.



Annual Financial Audit Policy

- The purpose of this policy is to solidify PCORI's commitment to have an annual financial audit to ensure proper controls are in place to fulfill our fiduciary obligations.



Revised Pre-Award Policy

- The revisions of this policy capture PCORI's current practice which has evolved since this policy's initial approval in May 2013. The key changes include:
 - Additional guidance on limited PFAs;
 - Letter of Intent clarifications in deadline extension and late application process; and
 - Alignment with Merit Review processes.



Revised Post-Award Policy

- The revisions of this policy capture PCORI's current practice which has evolved since this policy's initial approval in May 2013. The key changes include:
 - Updated language that aligns with our contract language;
 - Greater specification around modification to contracts; and
 - Enhanced specification of the award close out.



Board Vote

Call for a Motion to:

- **Approve** the Annual Budget Development and Approval Policy, Annual Financial Audit Policy, Revised Pre-Award Policy, Revised Post-Award Policy.

Call for the Motion to Be Seconded:

- **Second** the Motion
 - If further discussion, may propose an **Amendment** to the Motion or an **Alternative Motion**.

Voice Vote:

- Vote to **Approve** the **final motion**. Ask for votes in favor, opposed, and abstentions.



PCORnet Health Systems Demonstration Project PCORI Funding Announcement (PFA) Development

Joe Selby, MD, MPH

Executive Director

Rachael Fleurence, PhD

Methods and Infrastructure Program Director

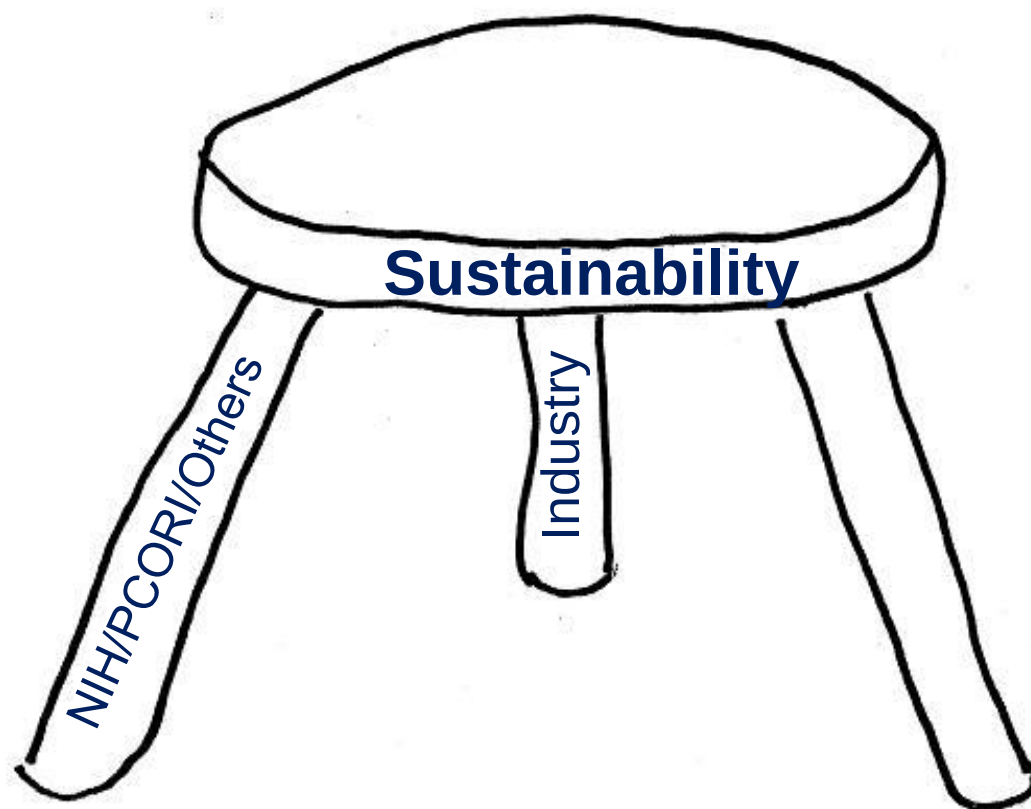


Background

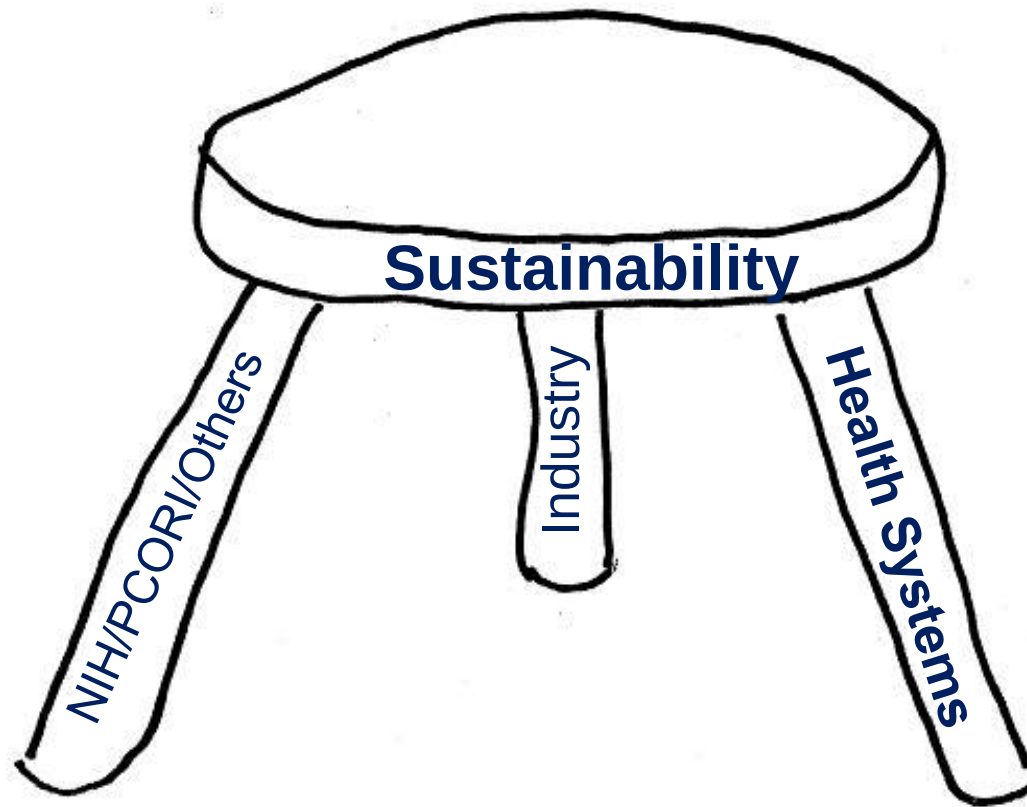
- From PCORI's National Workshop to Advance the Use of Electronic Data in Patient-Centered Outcomes Research
 - “For a data infrastructure to be sustainable, there must be a business case for everyone who needs to participate: for patients, clinicians, and health systems leaders as well as for researchers and research funders.” –*Basit Chaudry, IBM Research, July 2nd 2012*



PCORnet Sustainability Plan – 3 Primary Sources of Support



PCORnet Sustainability Plan – 3 Primary Sources of Support



Demonstration Projects

- Intended to “test and demonstrate” key aspects of PCORnet function
- **Aspirin Trial** – tests ability to ascertain patients aided by EHRs; work with IRBs and electronic informed consent; patient recruitment; ability to follow enrollees with periodic interviews (PFA approved)
- **Obesity Observational Studies** – tests ability to follow patients over time in electronic data; standardized capture of a wide range of claims and EHR data; demonstration of “complete data” for follow-up (PFA approved)
- **Health Systems Interaction Studies** – tests ability to engage systems leaders and clinicians across CDRNs; to do focused and agile research that leverages the Common Data Model and new health system data; and to do analyses rapidly and iteratively with systems leaders to facilitate their development of Learning Health Care Systems



“Health System Leaders Working Towards High Value Care Through Integration of Research and Practice”

- PCORI – IOM meeting held on June 20, 2014
- 29 health systems leaders (majority from PCORnet health systems – Vanderbilt, UIC, UPMC, NYU, Kaiser Permanente)
- Health systems leaders not especially interested in either embedded clinical trials or large observational studies
- But very excited by prospect of closer ties with PCORnet researchers and data; a focus on research on system performance and on opportunities for iterative data analyses and rapid-cycle turnaround of data



Proposal for Demonstration Project

- **Step One:** PCORI will provide support to PCORnet sites to engage health systems leaders to work jointly to identify and prioritize a set of data-driven research activities of high interest to systems and/or clinicians within the systems. This will be supported by the Coordinating Center's Health Systems Interaction and Sustainability Task Force, which has created an ad hoc workgroup.
 - **Total costs not to exceed \$1 million over 1 year.**
- **Step Two:** PCORI will encourage submission of proposals of high priority to health systems for up to five one-year studies. These studies will be awarded through a limited PFA.
 - **Total costs not to exceed \$4 million.**



Guiding Principles for Identifying Health System Research Demonstration Projects

- Project will be of interest and add value for **multiple** (≥ 2) PCORnet health systems
- Project will leverage data resources (PCORnet Common Data Model) with or without additional health system data
- Topics will be rated as priority by the CEOs/system leaders, and their input will be included in the PFA responses
- Topics will involve iterative review and discussion between researchers and health systems leaders
- Initial projects may be descriptive projects or they may evaluate utility of data sources for addressing specific questions of health systems leaders.



Next Steps and Timeline

- February: Received endorsement from the Research Transformation Committee on February 5th
- March:
 - Received endorsement from the Science Oversight Committee on March 17th
 - Seek approval from Board on March 24th to proceed with convening and PFA development
- May: Limited competition PFA released
- June: Applications Due
- August: Merit Review
- September: Seek Board approval of the award(s)
- October: Contract(s) executed



Board Vote

Call for a Motion to:

- **Approve** the development of a PFA to fund the Health Systems Demonstration Project for a total amount of up to \$5 million.

Call for the Motion to Be Seconded:

- **Second** the Motion
 - If further discussion, may propose an **Amendment** to the Motion or an **Alternative Motion**

Roll Call Vote:

- Vote to **Approve** the **Final** Motion
- Ask for votes in favor, opposed, and abstentions



Update on GAO Review

Joe Selby, MD, MPH

Executive Director



The first GAO 5-year review of PCORI

- We received our notification letter from GAO in March. It identified two primary objectives for the review, to determine:
 - To what extent has PCORI established research priorities and funded research in accordance with its legislative requirements?
 - To what extent has PCORI established plans and undertaken efforts to evaluate the effectiveness of its work?
- We had our Entrance Conference with the GAO Team in April
- We had a series of meetings with the GAO team in May, June, July, and September to discuss Advisory Panels, Dissemination, Evaluation, Merit Review, PCORnet, and Research Funding
- We had our Exit Conference with the GAO team in mid-December and received the draft report for review and comment in mid-January
- Our comments were due and submitted in early February
- ***The GAO released our report on March 9th***



The GAO's Main Findings Are:

- “PCORI has established priorities and processes for funding comparative clinical effectiveness research and is developing dissemination plans, consistent with its legislative requirements
 - PCORI has established research priorities and a research agenda
 - PCORI has established processes for funding research and monitoring contractors
 - PCORI is developing dissemination plans and coordinating dissemination activities with AHRQ
- PCORI has started awarding contracts for research, and plans to award additional contracts through 2019
- PCORI has established an evaluation plan and anticipates developing efforts to measure outcomes”



Dashboard Review

First Quarter of FY 2015

Joe Selby, MD, MPH

Executive Director

Michele Orza, ScD

Senior Advisor to the Executive Director



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Presentation Overview

- Evolution of our Board of Governors' Dashboard from 2013
- Latest revisions
- Overall organization and types of graphics
- Noteworthy and Yellow-flagged items
- Examples of background slides
- Examples of metrics proposed for Committee dashboards

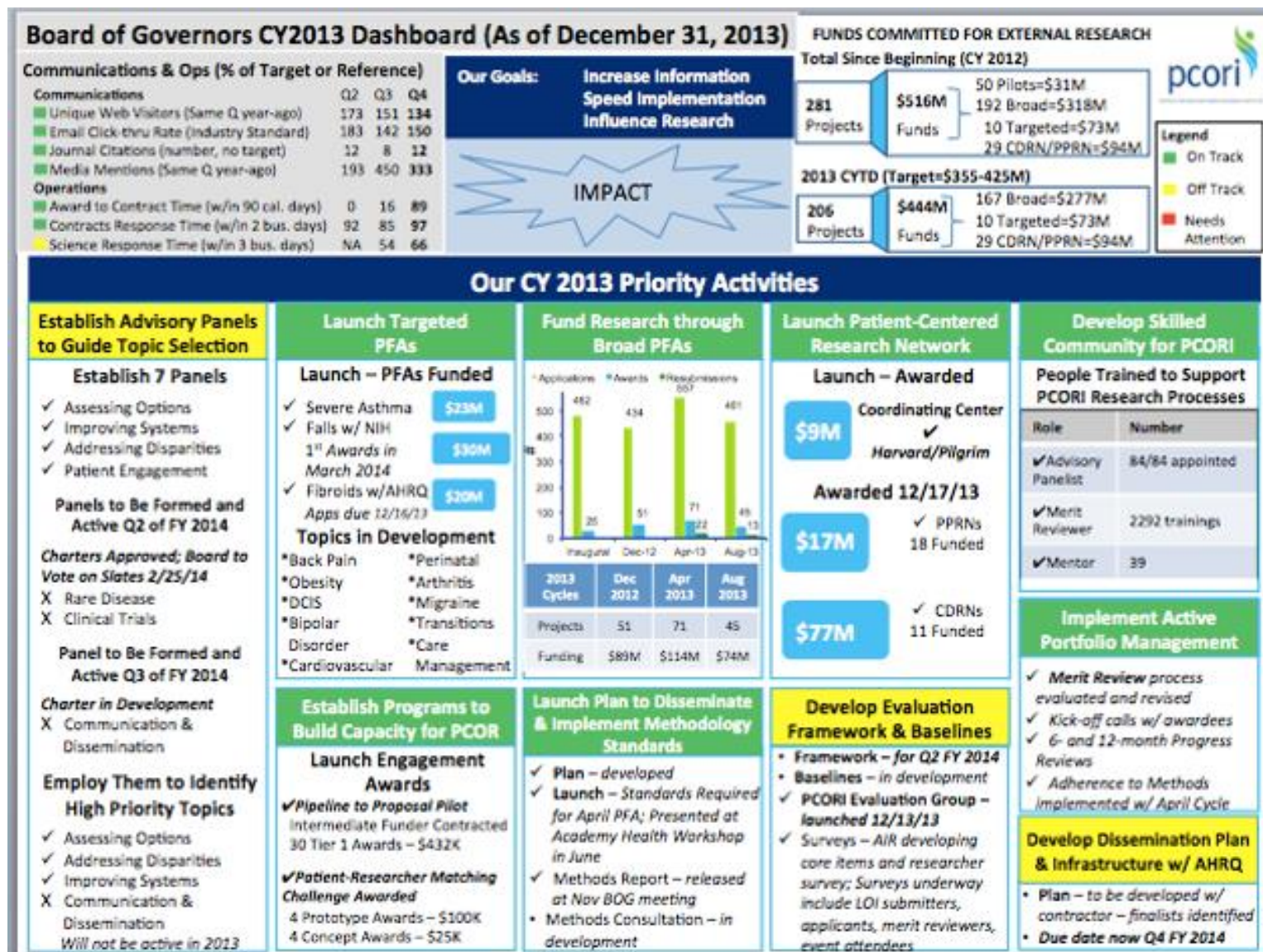


Discussion Questions

- Are there metrics that should be ***revised or retired or moved*** to the Committee Dashboards?
- Are there ***new or different metrics*** suggested by today's presentation and discussion? If so, are they appropriate for the ***Board or one of the Committees***?
- What ***further improvements*** should we consider so that our Dashboard and accompanying materials ***effectively convey the status of our work and progress toward our goals***?



Our End-of-CY 2013 Dashboard



Our End-of-FY 2014 Dashboard

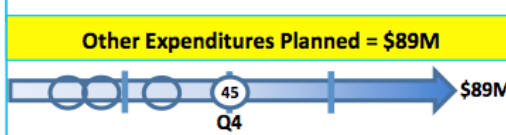
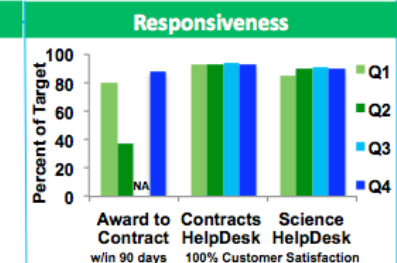
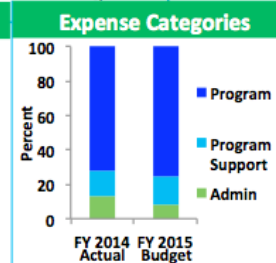
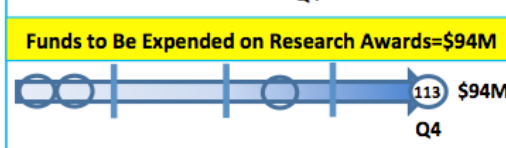
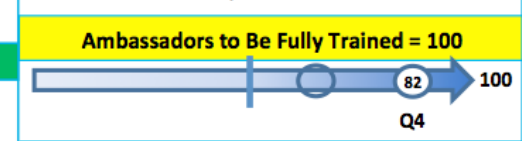
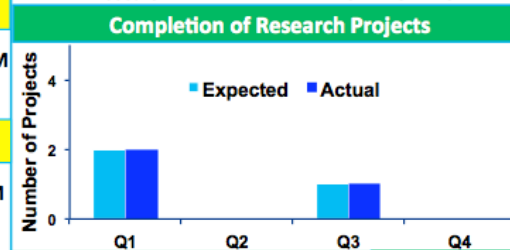
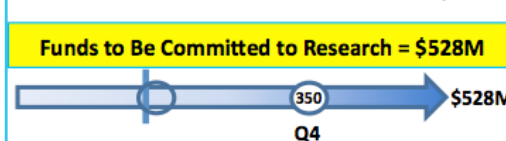
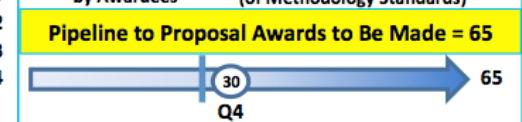
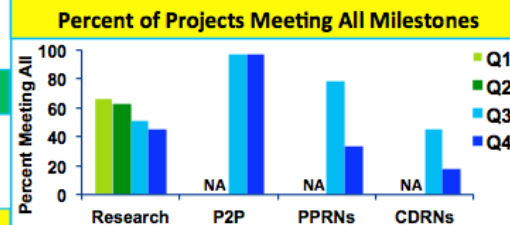
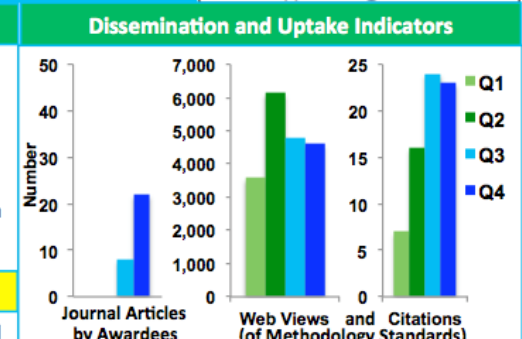
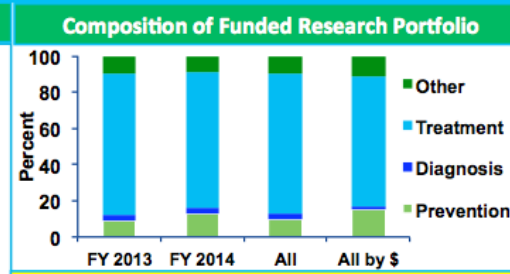
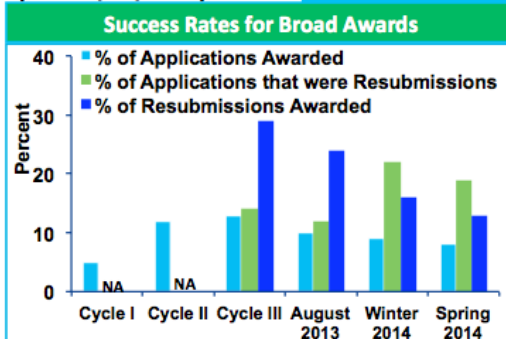
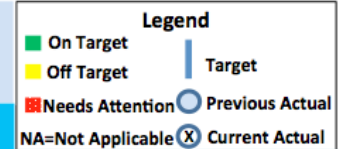


Board of Governors
FY2014 Dashboard – Q4
(As of 9/30/2014)

Influencing Research

Working with PCORI influenced Geisinger Health System to incorporate patient engagement into its strategic plan for research and require it for all projects

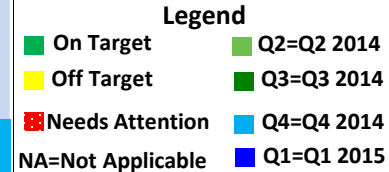
Our Goals: Increase Information, Speed Implementation, and Influence Research



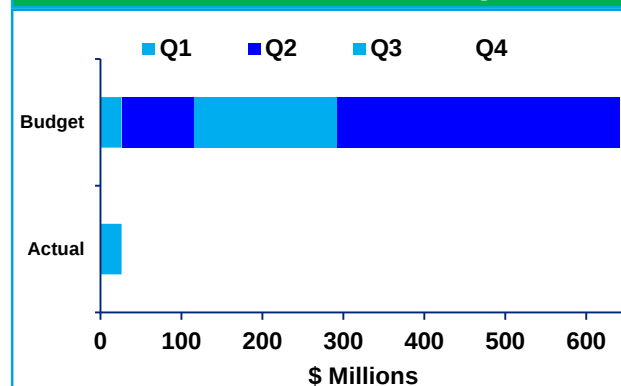
Influencing Research

PCORI inspired the American Heart Association to pilot the Citizen Scientist Think Tank, intended to foster patient engagement in the design of heart disease and stroke research

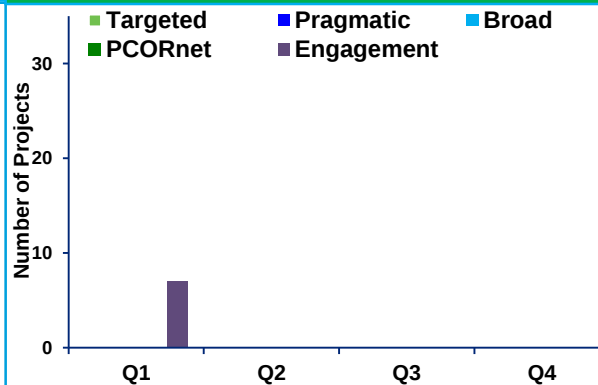
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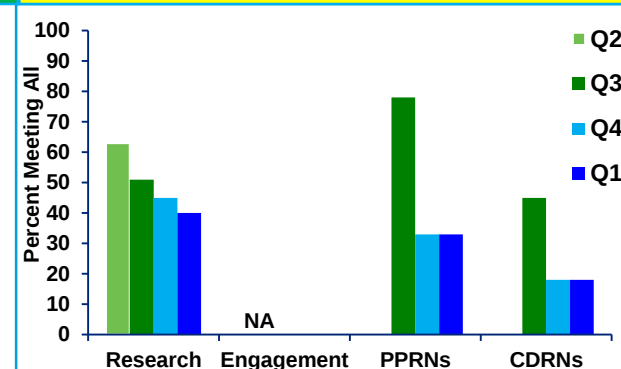
Funds Committed to Research – Budget=\$640M



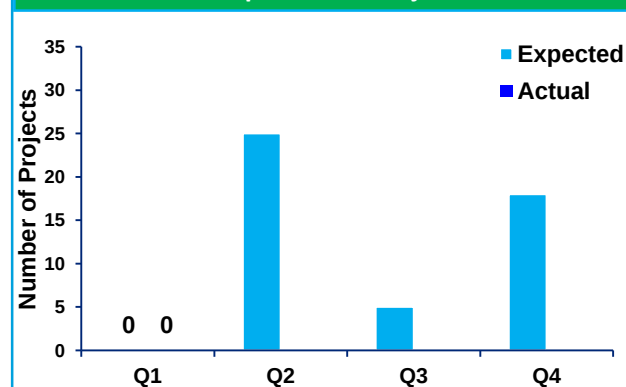
Projects Awarded



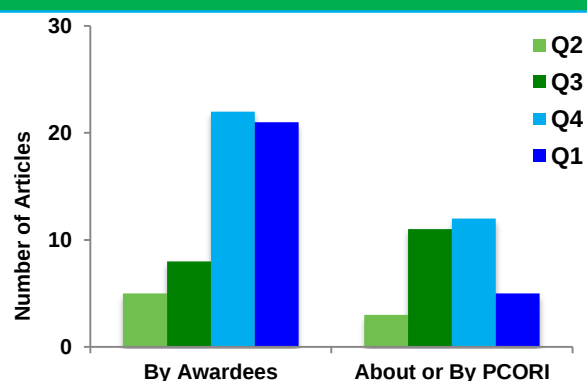
Percent of Projects Meeting All Milestones



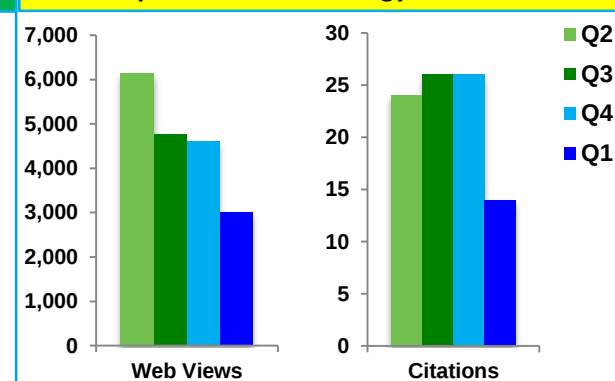
Completion of Projects



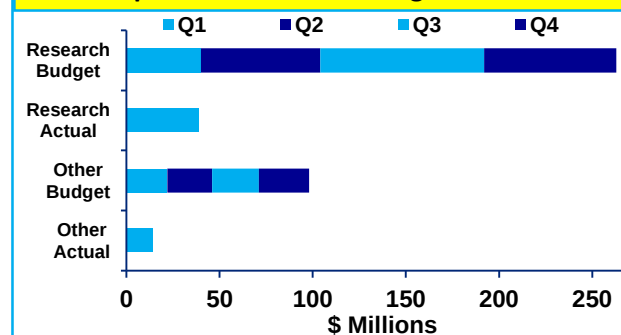
Journal Articles Published



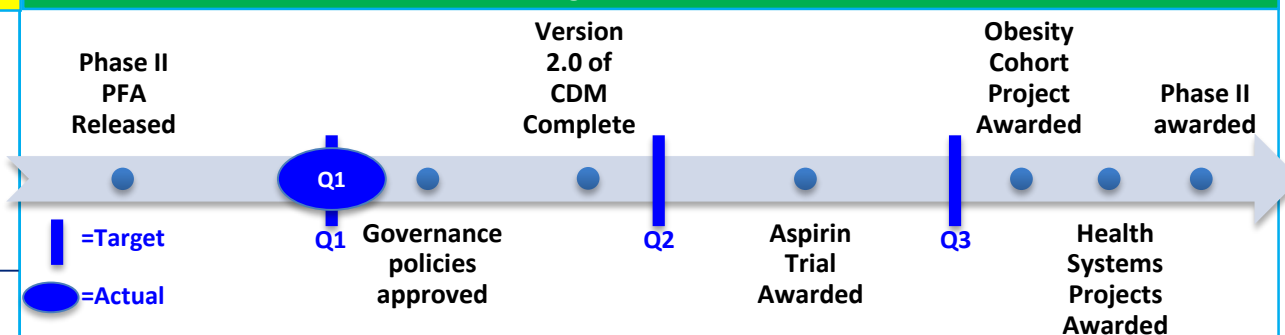
Uptake of Methodology Standards



Expenditures – Total Budget=\$362M



Progress of PCORnet



Concerns with FY 2014 Dashboard and Revisions in FY 2015 Dashboard

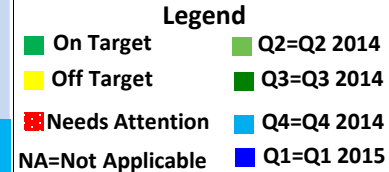
Concern with FY 2014 Dashboard	Revision in FY 2015 Dashboard
Cluttered – too many items	Cut from 17 boxes to 9
Hard to read	Remaining items enlarged
Arrow graphics difficult to interpret	Replaced with horizontal bar charts
PCORnet arrow provided no information	PCORnet timeline with key milestones
Many metrics not right level for Board	• Focused more on key Outputs and Goals • Others moved to Committee Dashboards



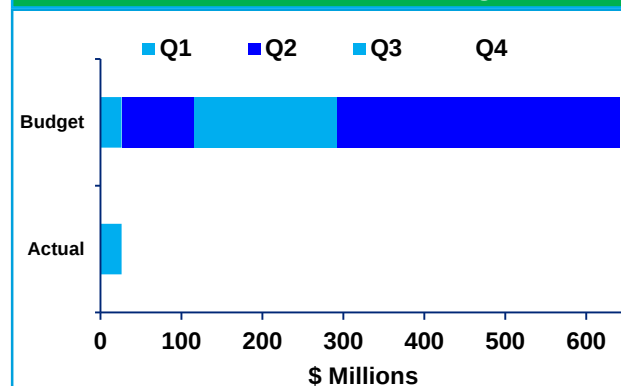
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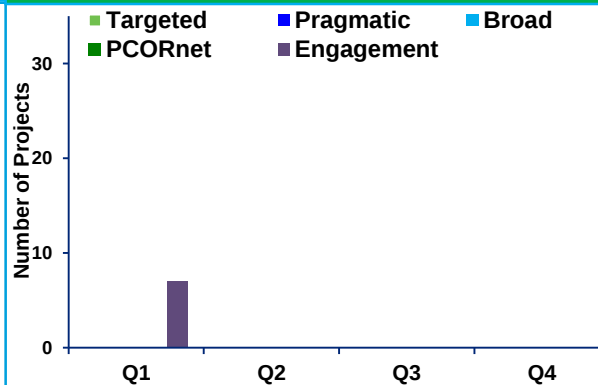
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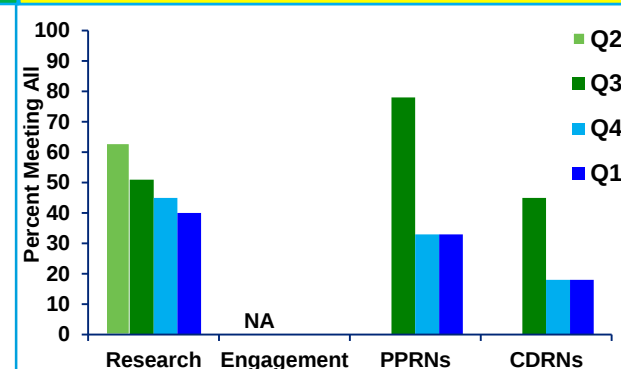
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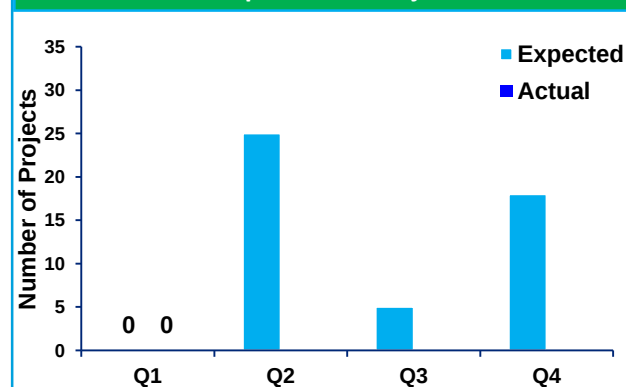
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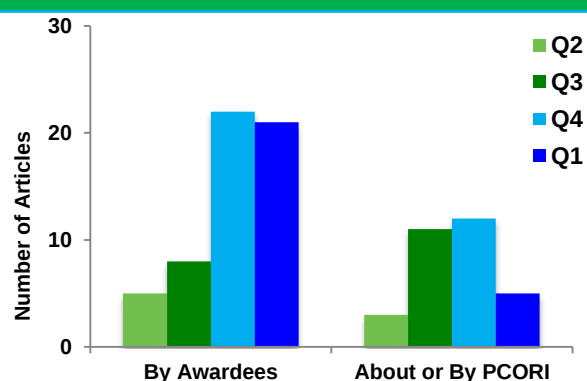
Percent of Projects Meeting All Milestones



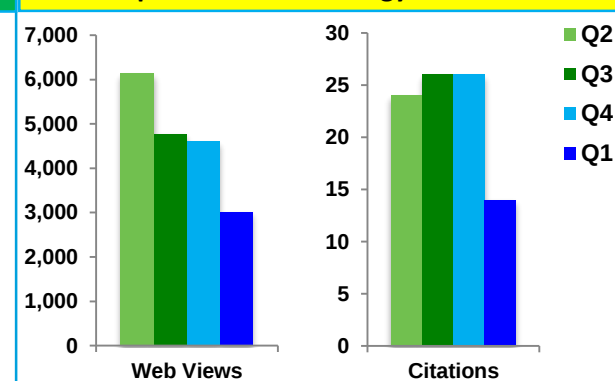
Completion of Projects



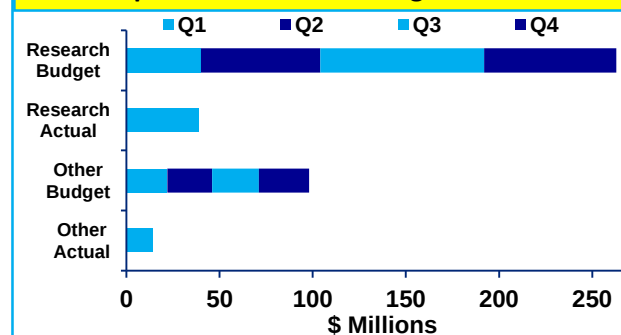
Journal Articles Published



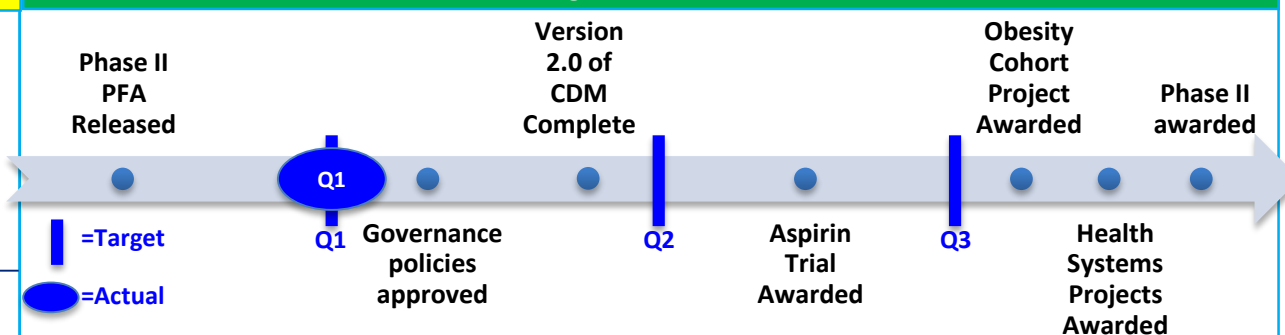
Uptake of Methodology Standards



Expenditures – Total Budget=\$362M



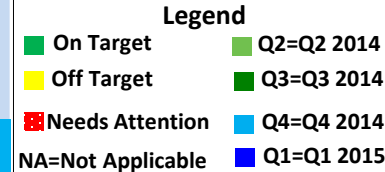
Progress of PCORnet



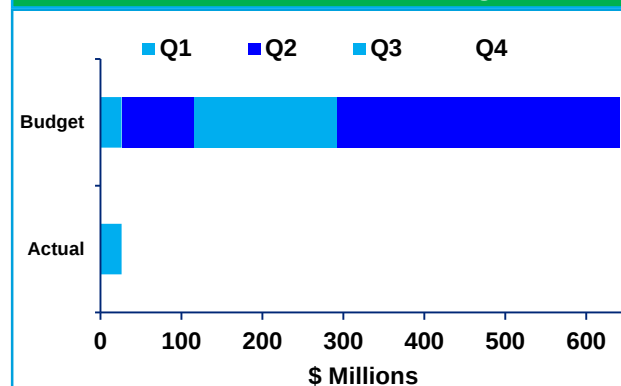
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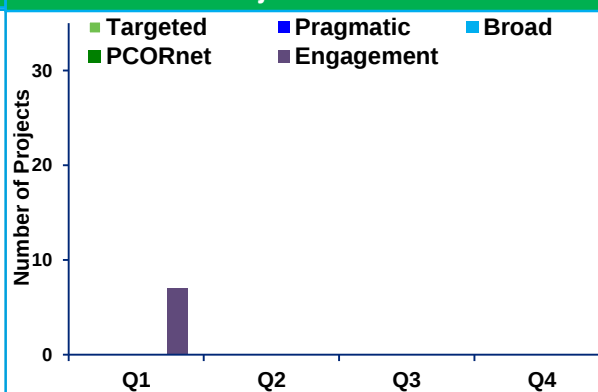
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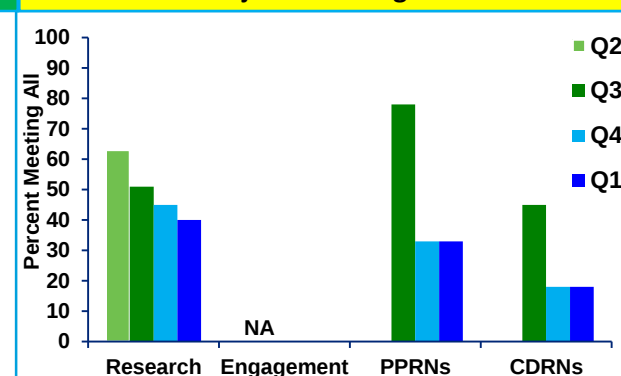
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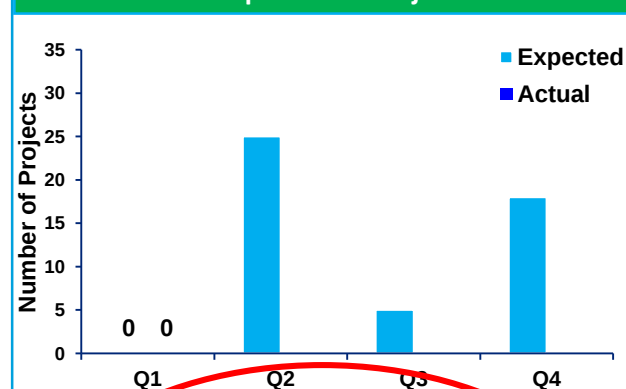
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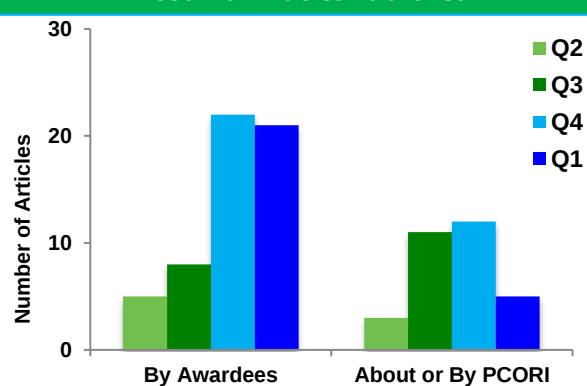
Percent of Projects Meeting All Milestones



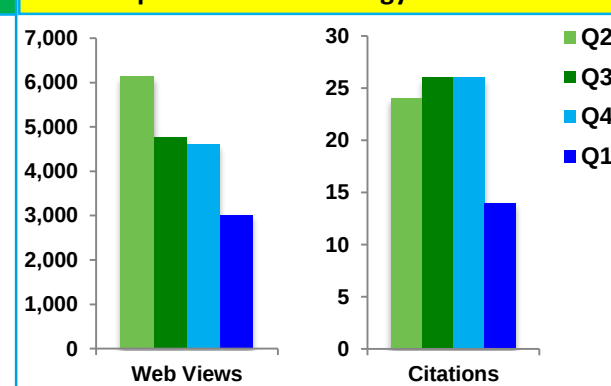
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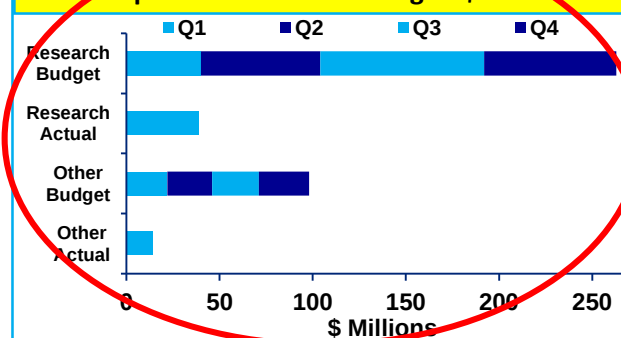
Journal Articles Published



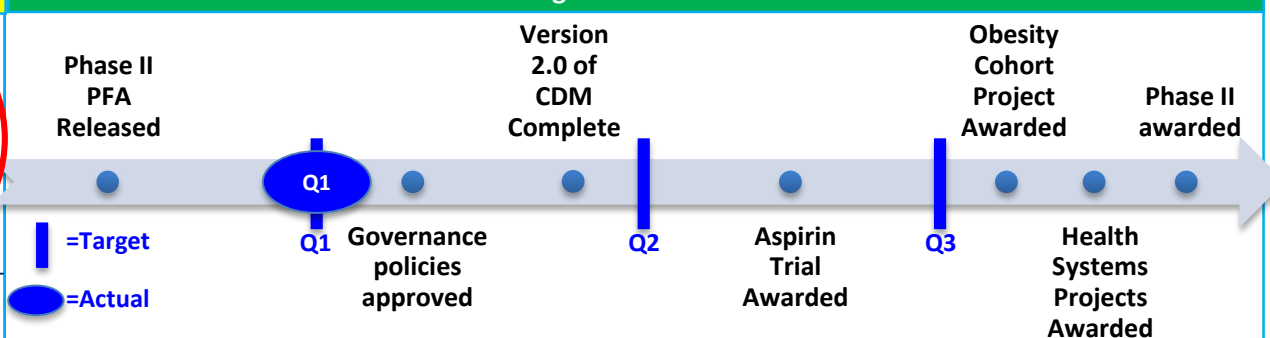
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Expenditures – Total Budget=\$362M



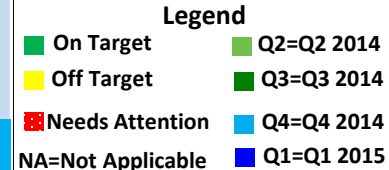
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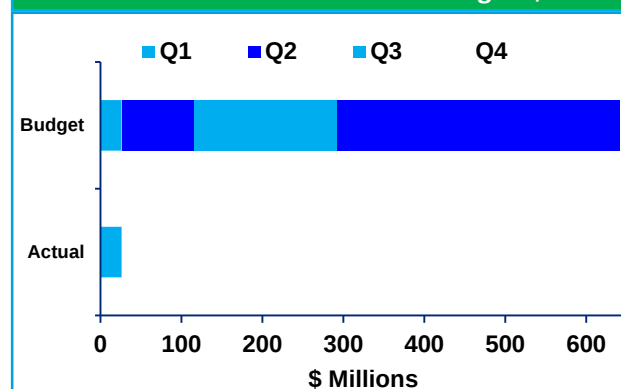
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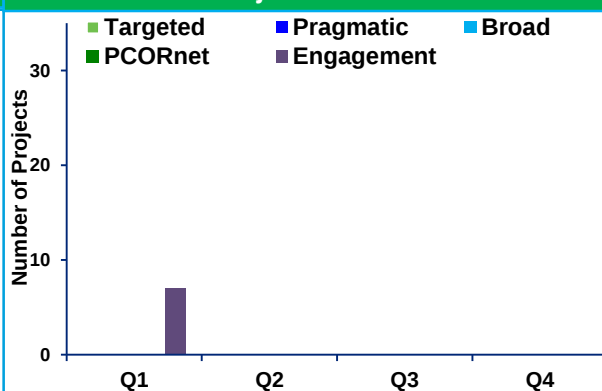
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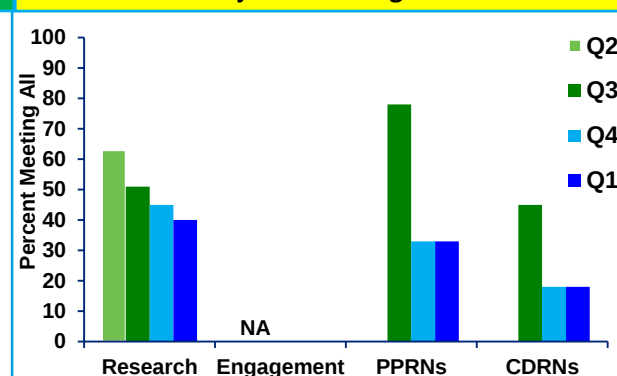
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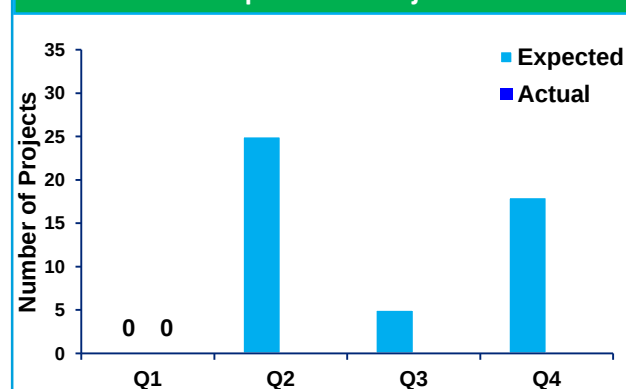
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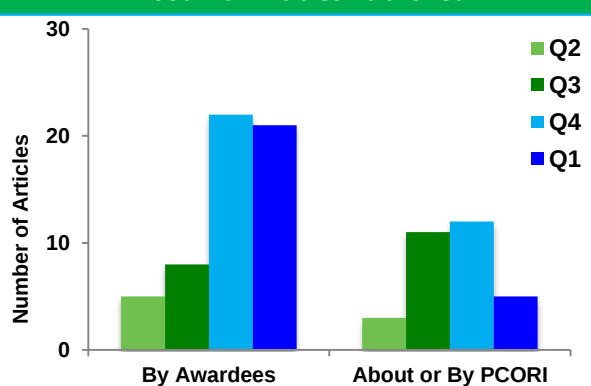
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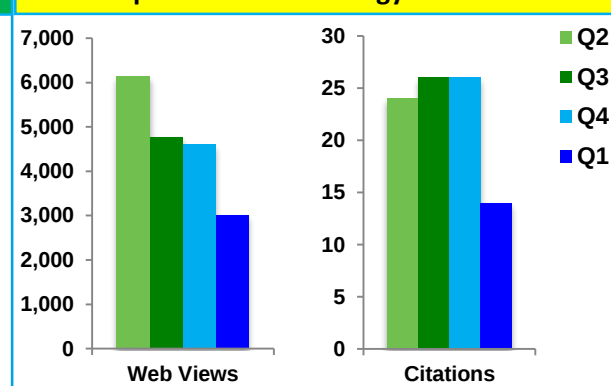
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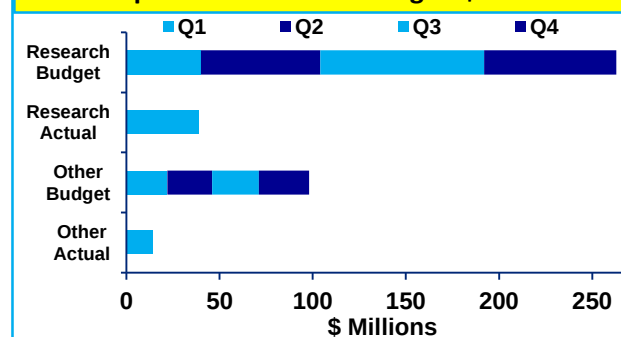
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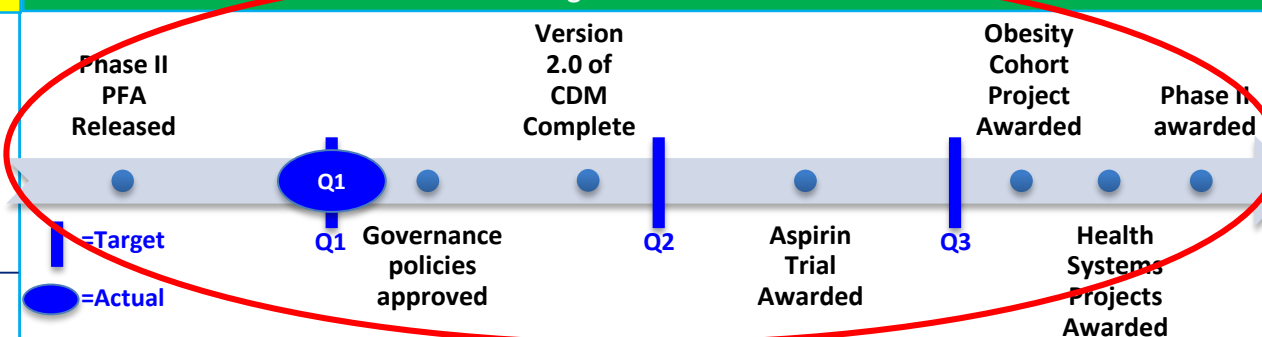
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Progress of PCORnet



Early Signs of Influence on Research

Influencing Research

PCORI inspired the American Heart Association to pilot the Citizen Scientist Think Tank, intended to foster patient engagement in the design of heart disease and stroke research

*“As PCORI has evolved, the notion of patient engagement has changed dramatically, and the **American Heart Association (AHA)** has sought more ways we can make the patient the focal point.”**

The AHA was an early adopter of PCORI's efforts to get people and organizations to focus on patient-centeredness. For example, they developed the

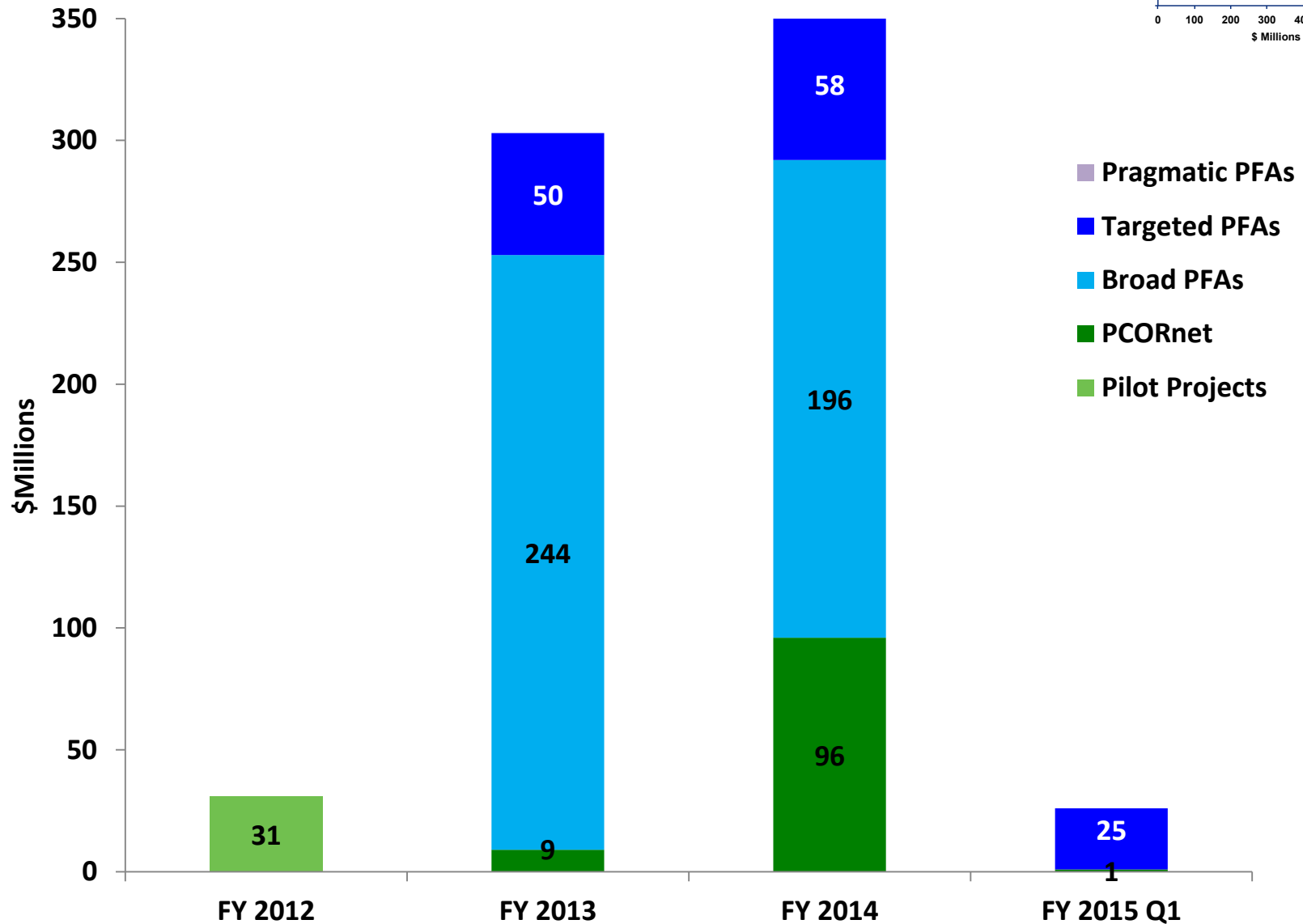
Citizen Scientist Think Tank (CSTT) Pilot

- A Community of patient and caregiver volunteers from AHA with availability and training to help design research studies for heart disease and stroke
- The pilot involved 30 volunteers, was successful, and AHA's goal now is to obtain funding and scale up to 300+
- The AHA explained that, although they are a patient advocacy organization, most of the research they fund is designed by clinicians and researchers, and the CSTT is intended to ensure that patients have a voice and the appropriate resources to engage in the research process

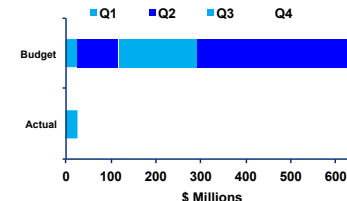
*Marko Mijic, Government Relations Manager, American Heart Association



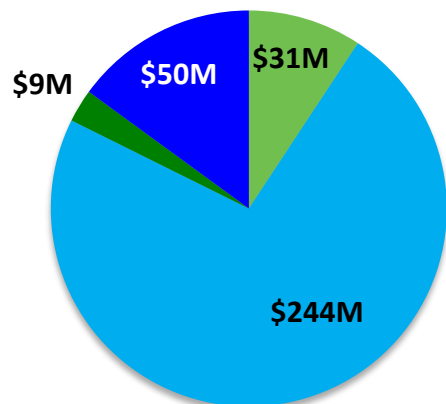
Funds Committed by Type of Project and Fiscal Year



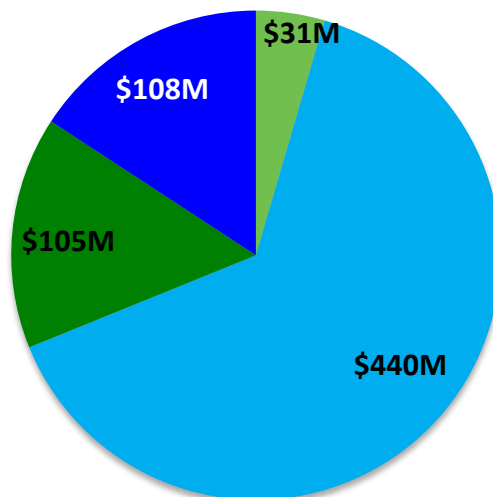
Funds Committed by Type of Project: Cumulative by Fiscal Year



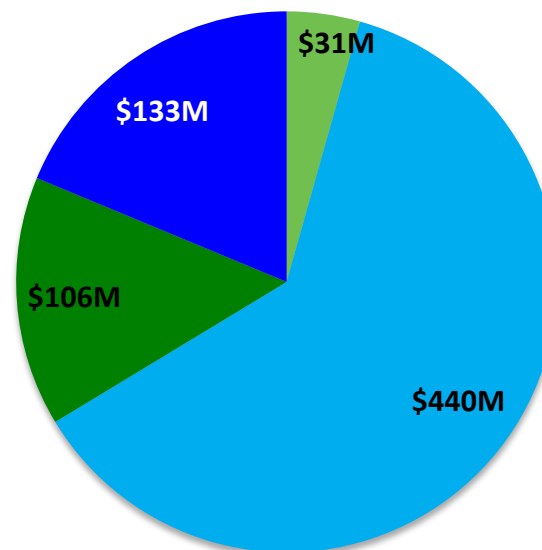
End of FY 2013
Total=\$334M



End of FY 2014
Total=\$684



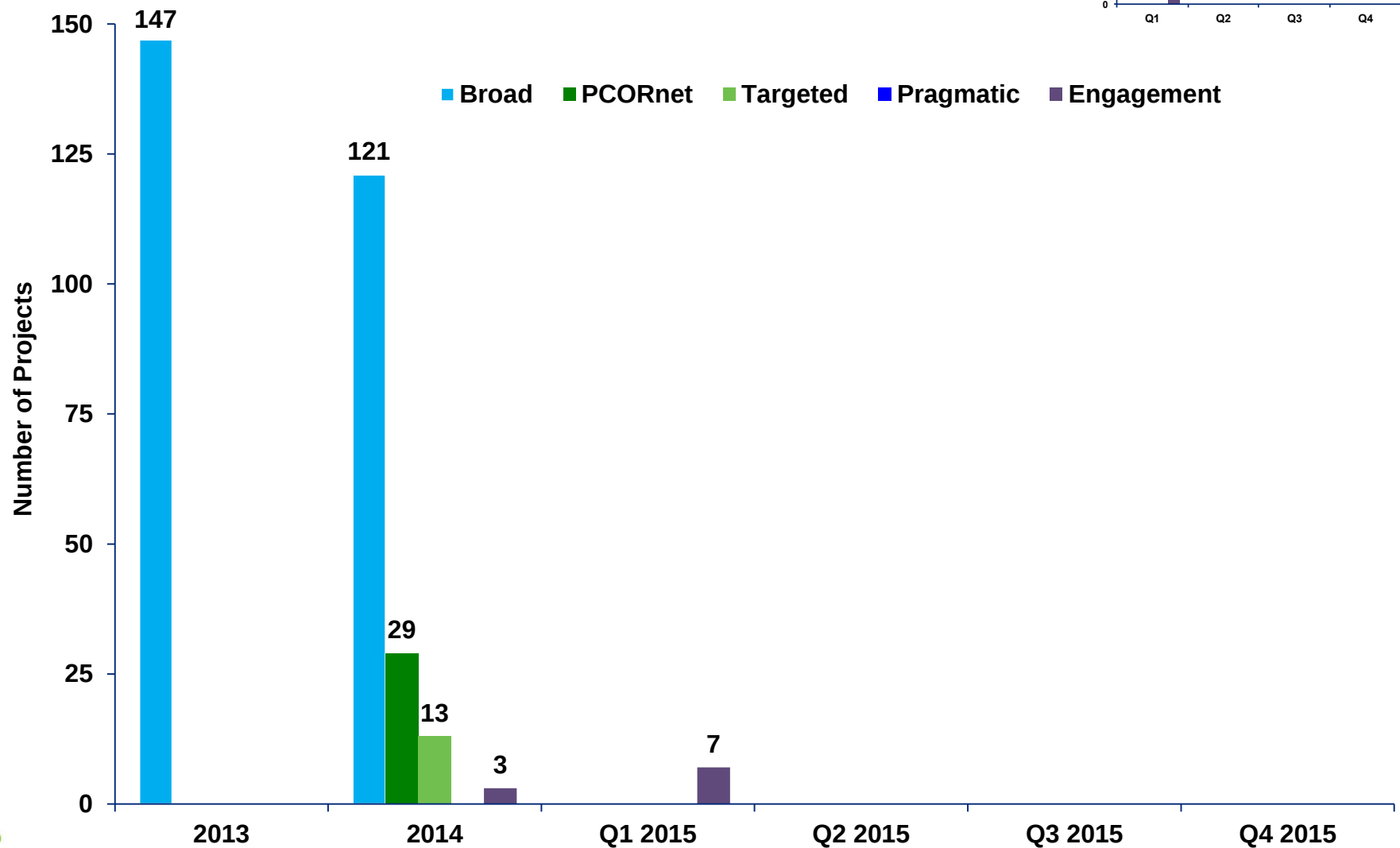
As of Q1 FY 2015
Total=\$710M



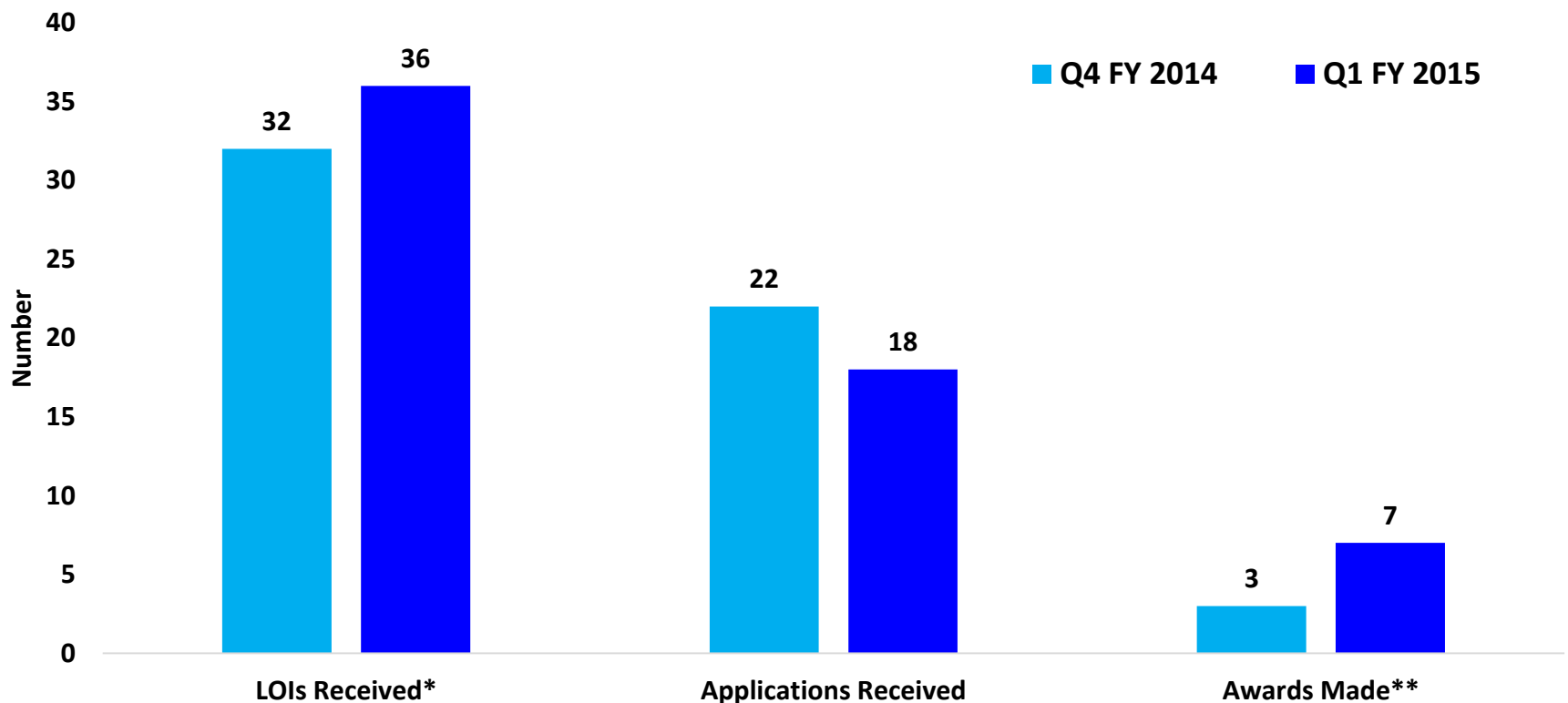
- Pilots
- Broad
- PCORnet
- Targeted
- Pragmatic



Number and Types of Projects Awarded



Engagement Awards

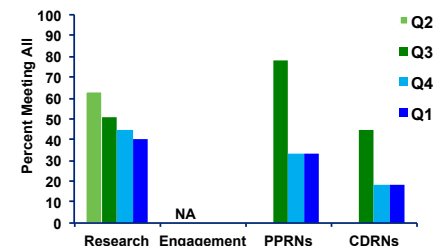


*The January 2015 submission cycle closed on 1/2/15. For this cycle, we received 36 LOIs by the close of Q1 FY 2015 (12/31/14), and an additional 28 LOIs by the close of the cycle (1/2/15).

**Awards include only contracts that were fully executed during the quarter



Progress of Research Projects: Milestones

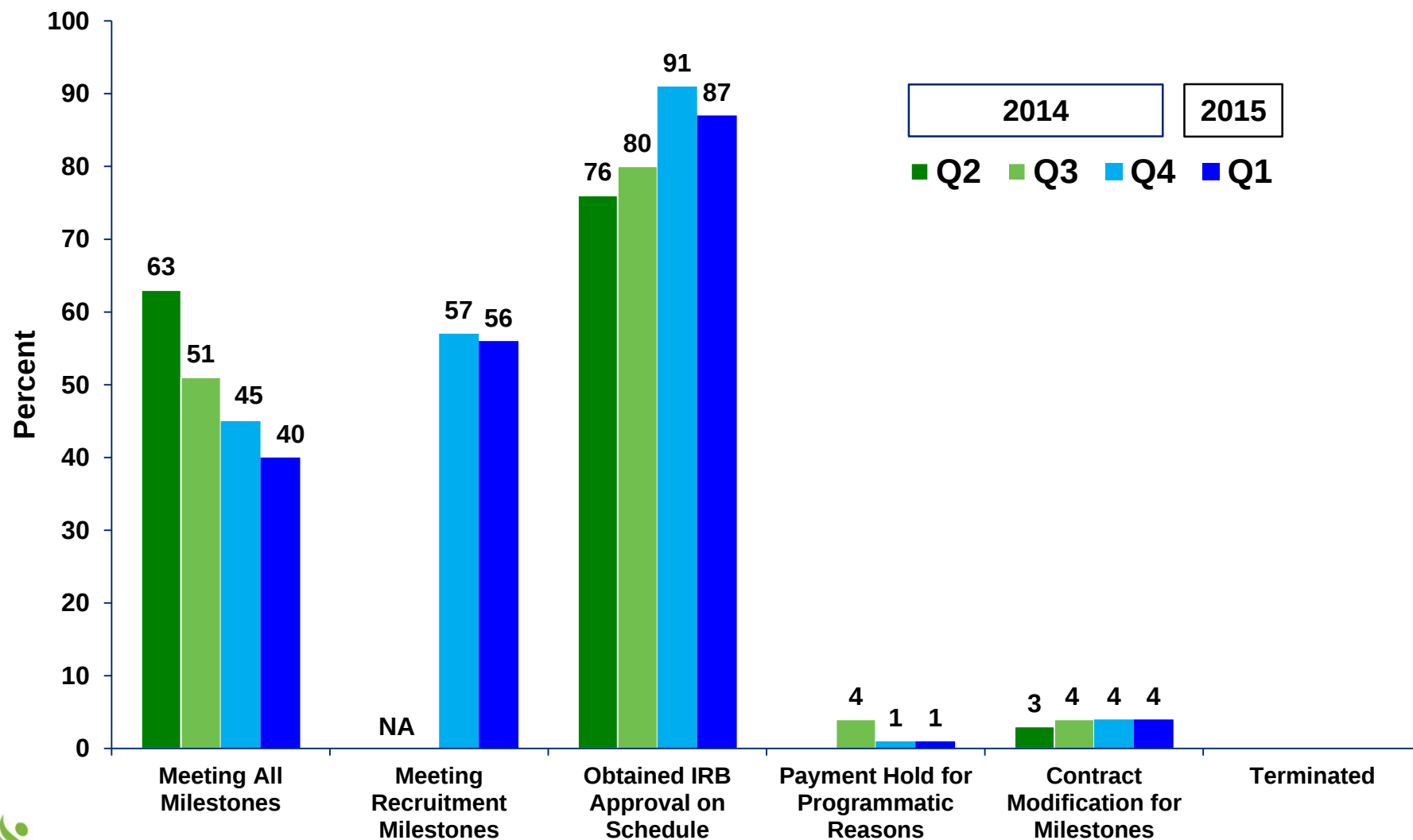
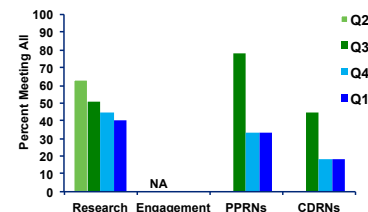


	2014			2015
	Q2	Q3	Q4	Q1
Number of Projects with a Progress Report Due • 62 with 6-month reports • 87 with 12-month report • 46 with 18-month reports	57	140	186	195
Percent of Projects Meeting All Milestones Due	63%	51%	45%	40%
Average Percent of Milestones Due that Were Met	87%	85%	84%	83%

We continue to refine our approach to measuring and reporting on the progress of projects and will present additional analyses as we have sufficient data for them.

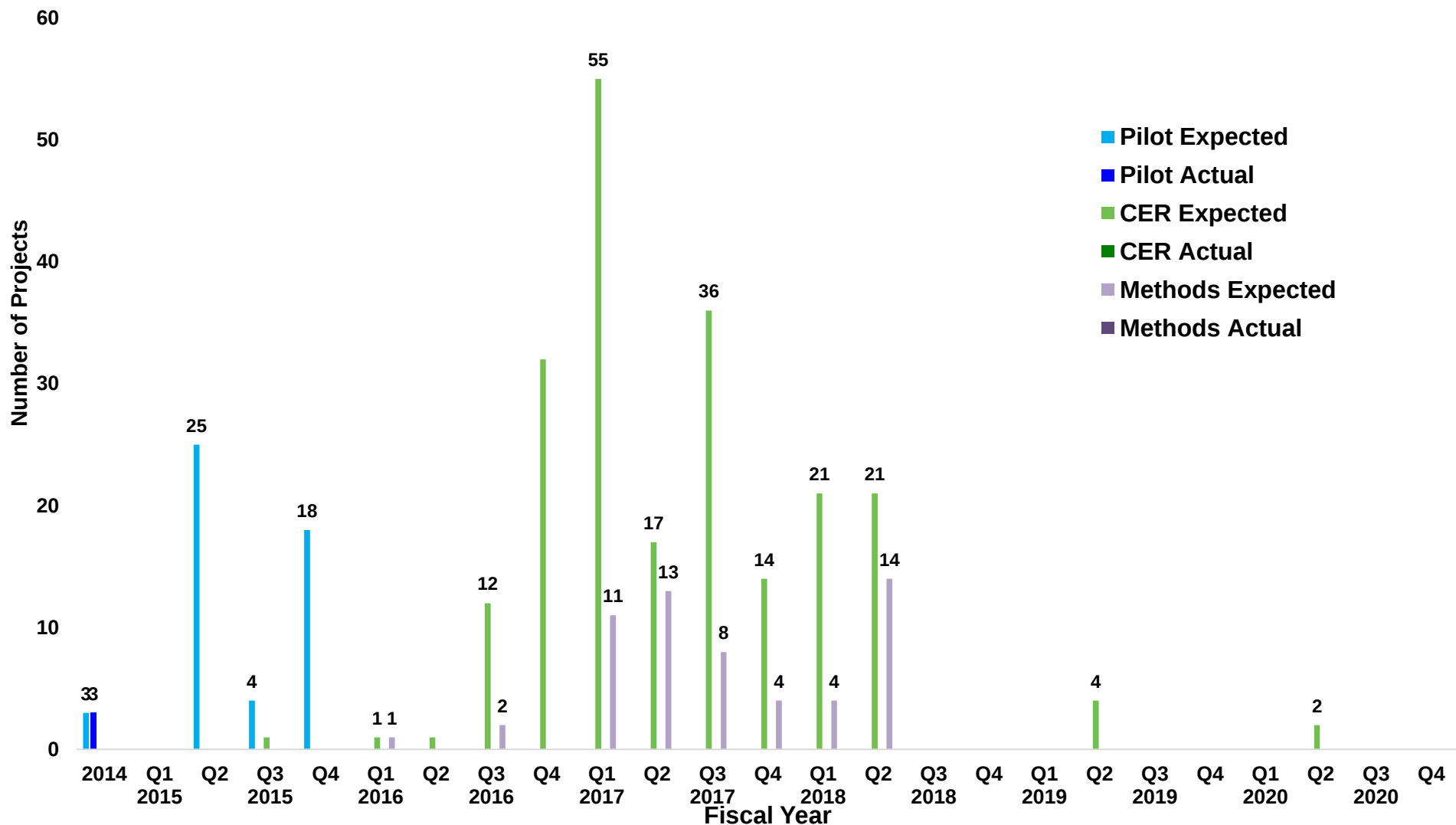
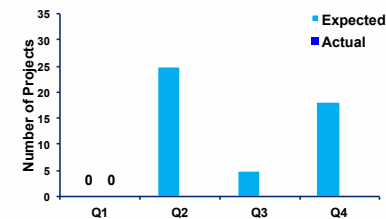


Progress of Research Projects: Additional Measures

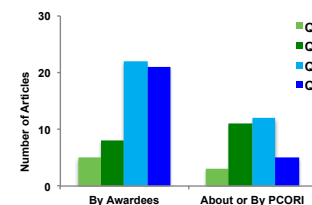
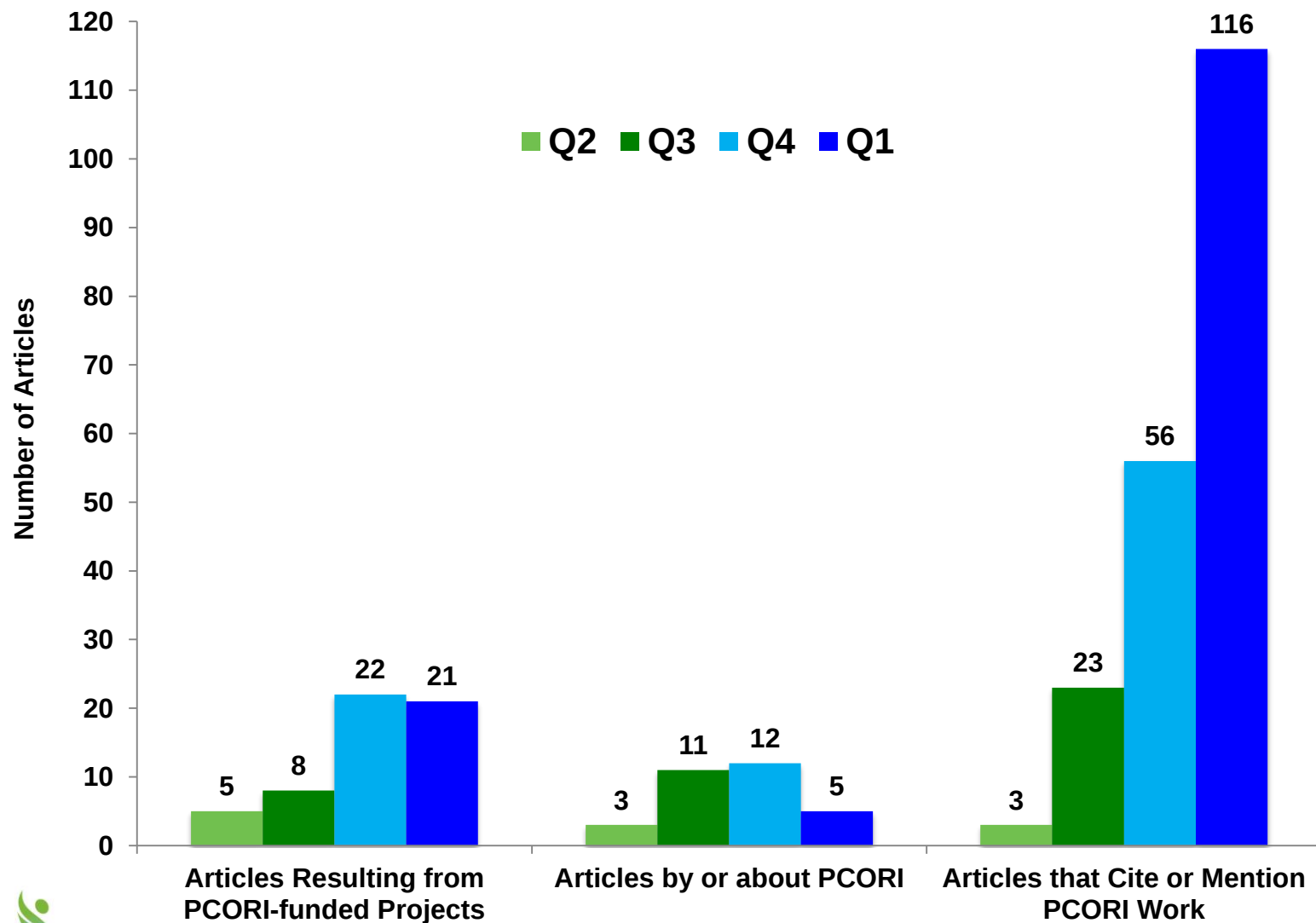


Actual (2014) and Expected (2015 >>) Number of Contracts Ending per Quarter

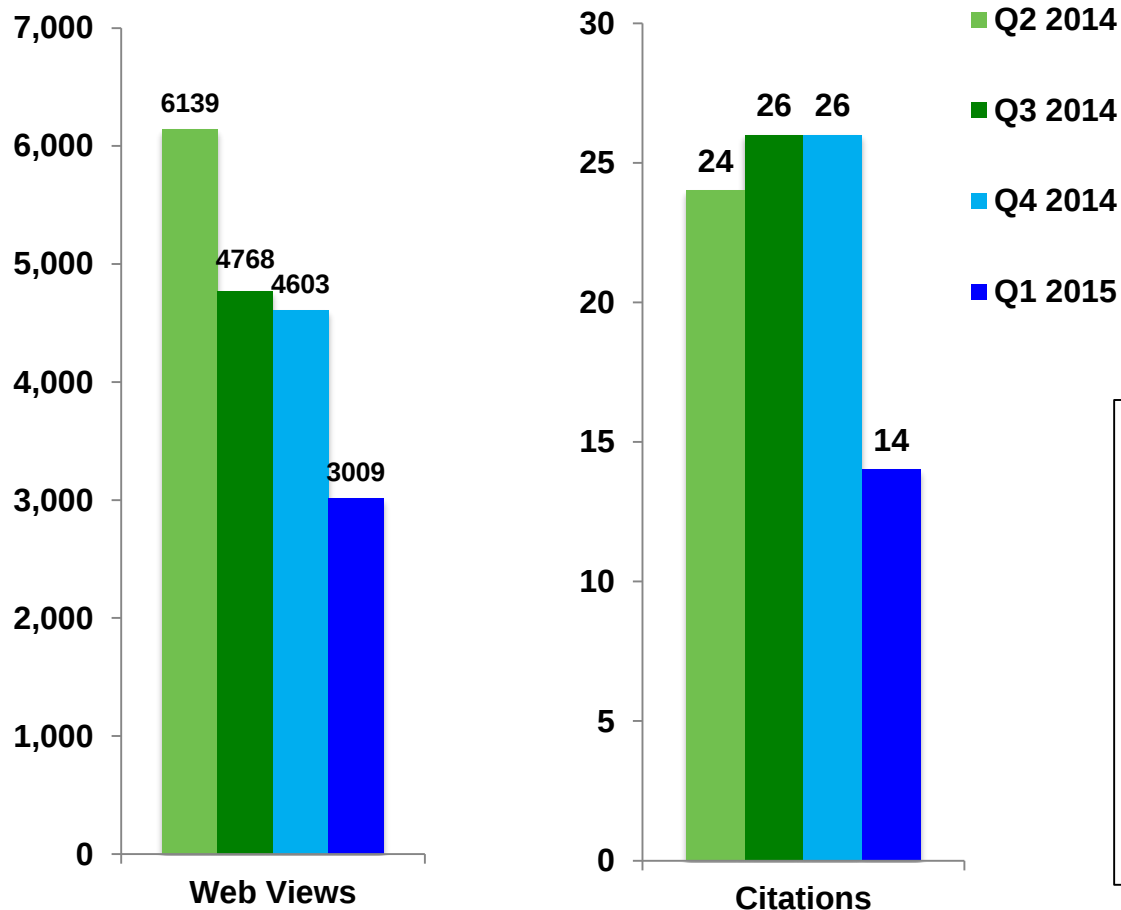
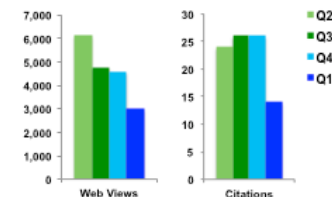
(Includes estimates for some contract modifications in process)



Number of Journal Articles Concerning PCORI



Uptake of Methodology Standards



We are also tracking:

- Adoption
- Endorsements
- CE/CME (Q3)
- Uptake into Curriculum
- Use of PCORI-developed Curriculum (2016)



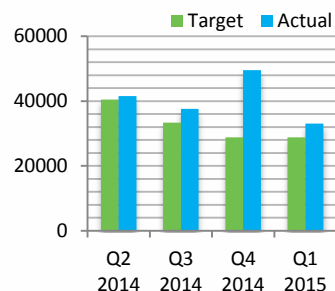
Communications: Website, E-mail, Social Media, and Media Coverage Metrics

Communications

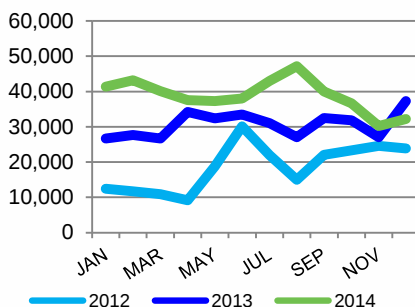
Website

Our Q4 unique website visitors numbers continue to beat our target.

Website Unique Traffic



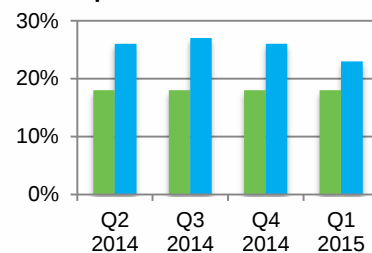
Monthly Unique Traffic



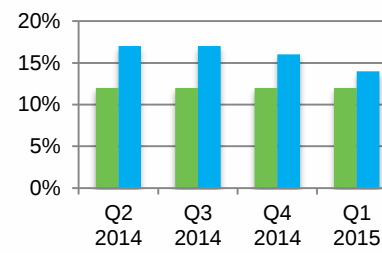
E-mail

We continue to exceed industry standards for open and click-through rates by a wide margin.

Email Open Rate



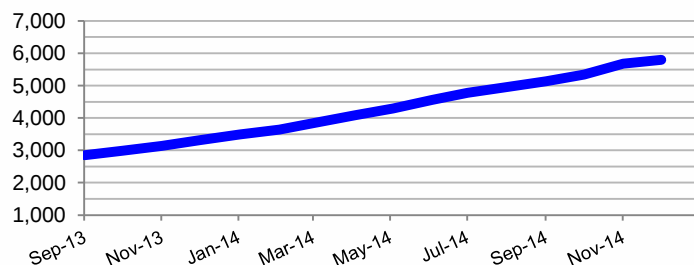
Email Click-Thru Rate



Social Media

Because our early Twitter stats were low, year-to-year comparisons against targets aren't useful. We're tracking follower growth and impressions and working on a more sophisticated reach analysis.

Monthly Twitter Follower Growth



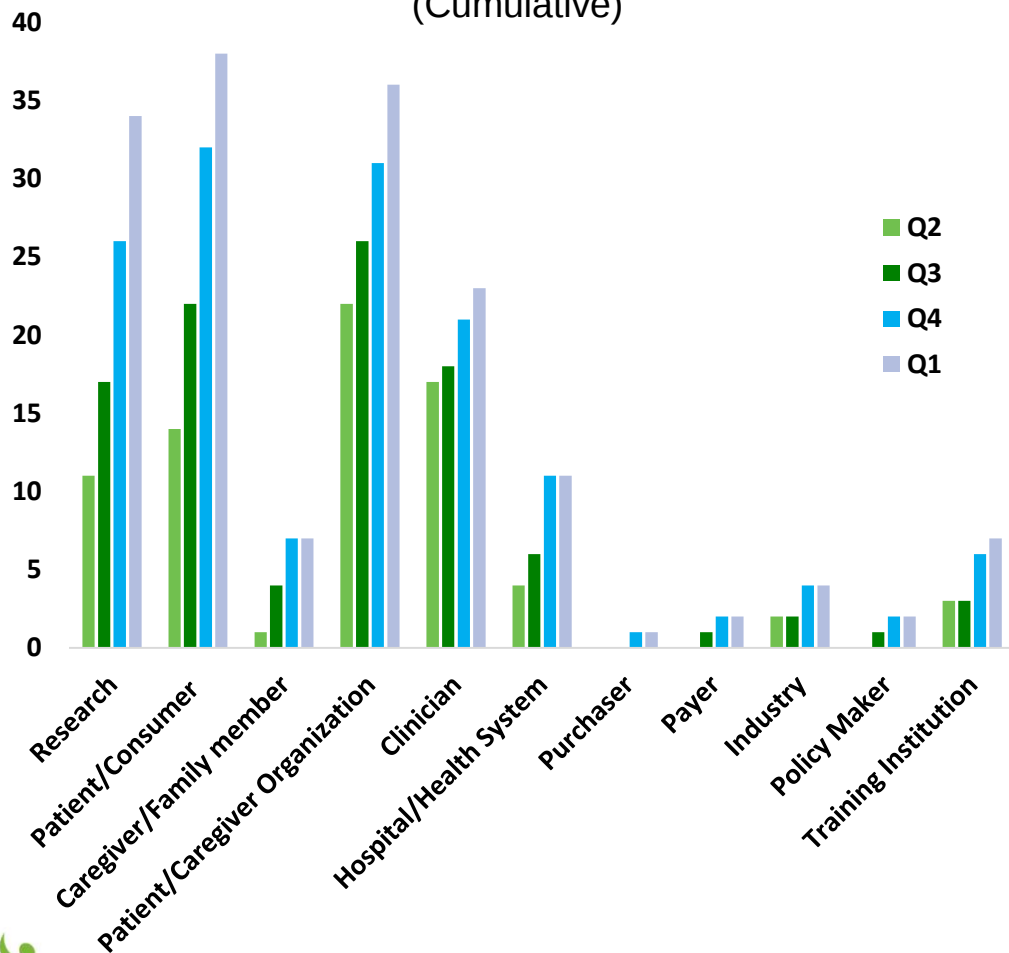
Media Coverage

We continue to grow the number of mentions of our work in general/trade media.

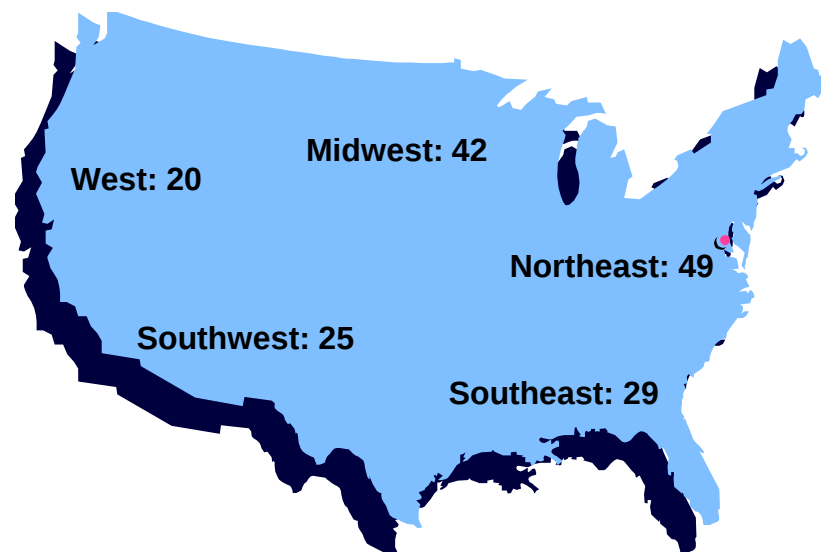
	2013	2014	2015
Q1	45	150	157
Q2	48	212	
Q3	89	149	
Q4	117	166	

PCORI Ambassadors Program

Ambassadors Enrolled by Stakeholder Group
(Cumulative)



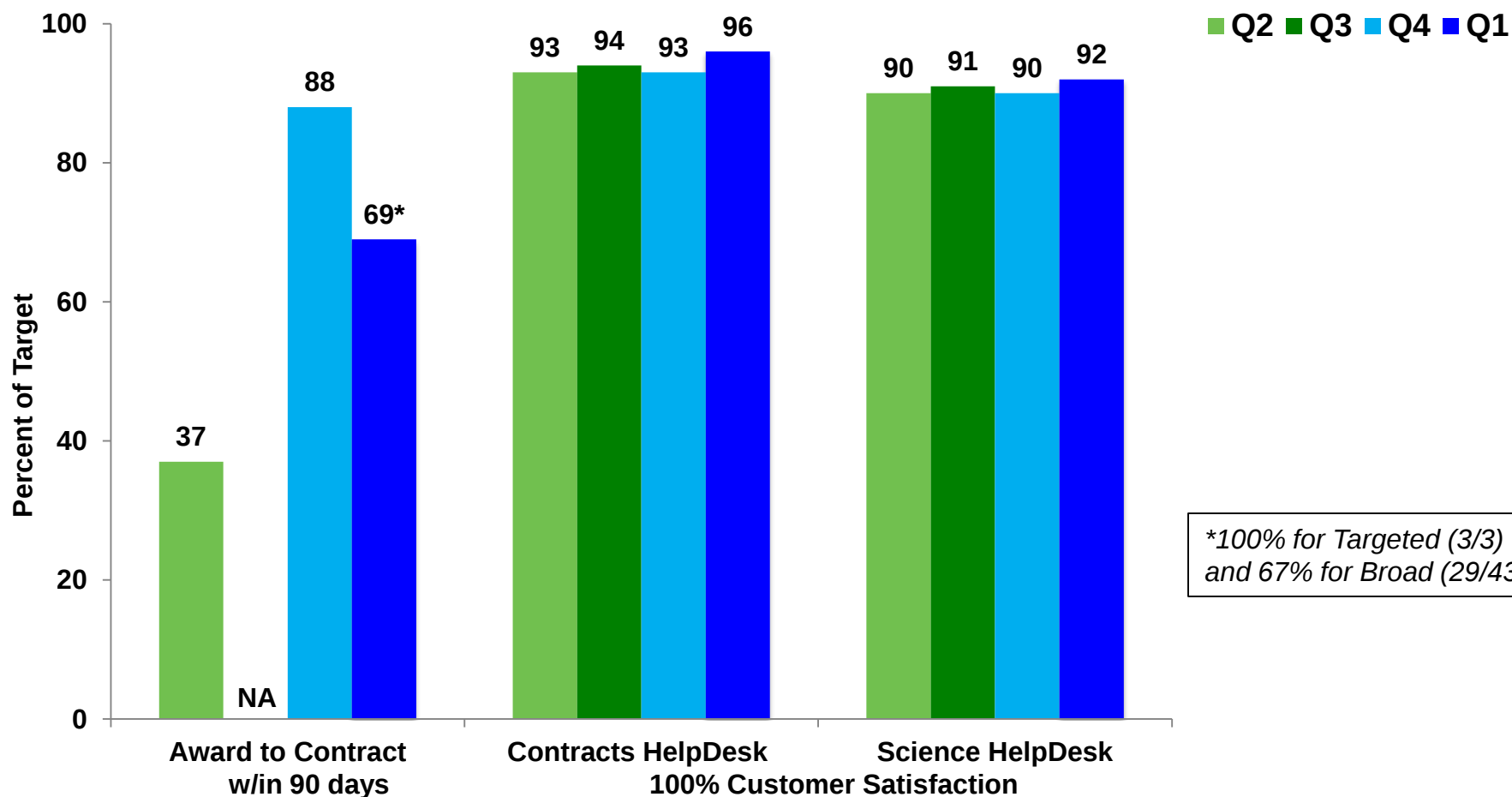
Ambassadors Enrolled by
Geographic Region
(Cumulative)



***Cumulative Total
as of Q1 2015 = 165***



Operational Excellence



Discussion Questions

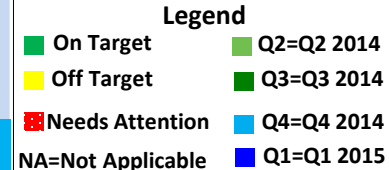
- Are there metrics that should be ***revised or retired or moved*** to the Committee Dashboards?
- Are there ***new or different metrics*** suggested by today's presentation and discussion? If so, are they appropriate for the ***Board or one of the Committees***?
- What ***further improvements*** should we consider so that our Dashboard and accompanying materials ***effectively convey the status of our work and progress toward our goals***?



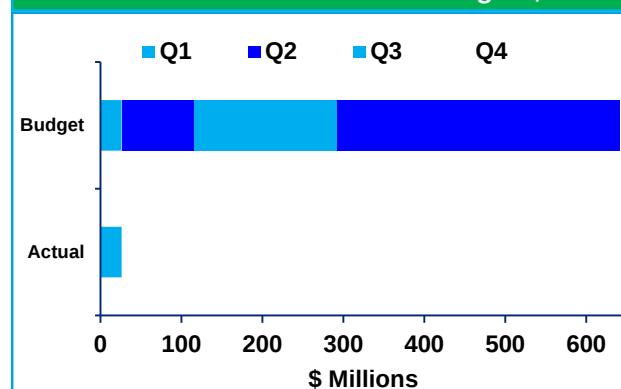
Influencing Research

PCORI inspired the American Heart Association to pilot the Citizen Scientist Think Tank, intended to foster patient engagement in the design of heart disease and stroke research

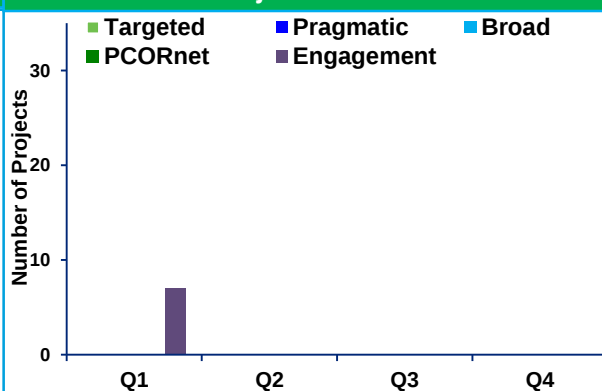
Our Goals: Increase Information, Speed Implementation, and Influence Research



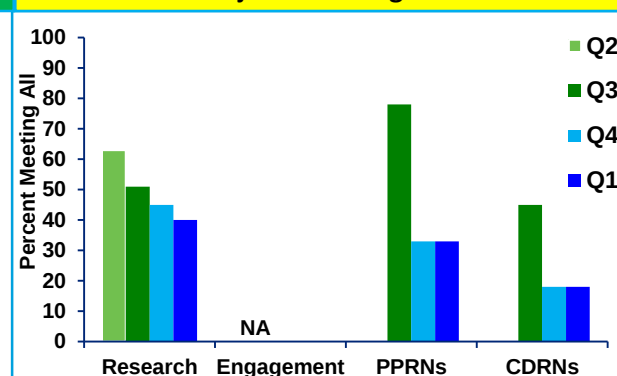
Funds Committed to Research – Budget=\$640M



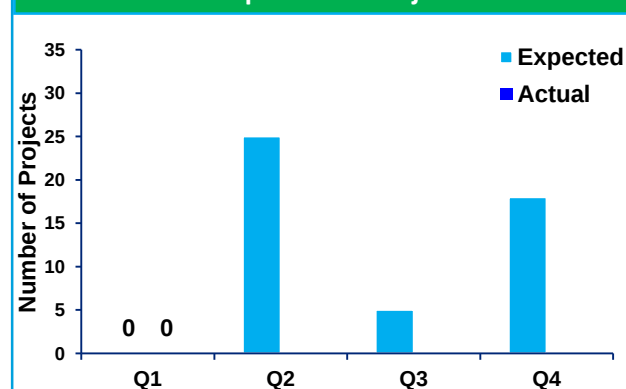
Projects Awarded



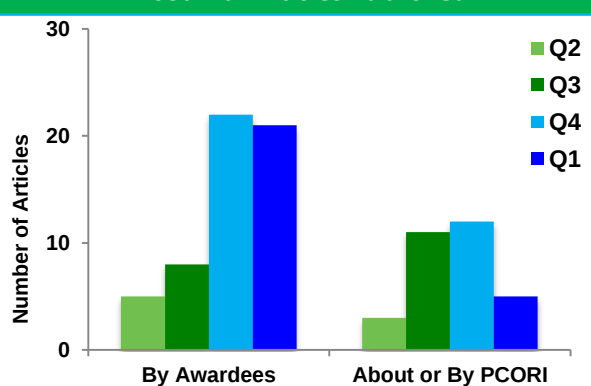
Percent of Projects Meeting All Milestones



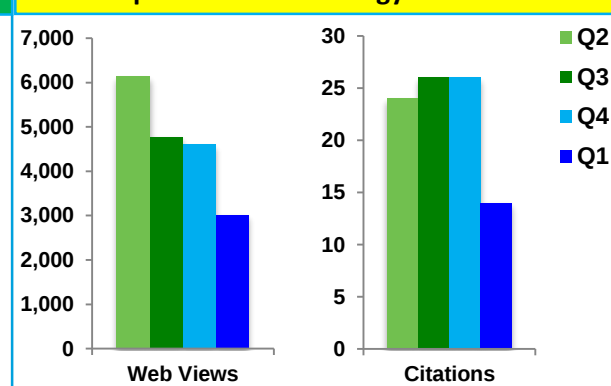
Completion of Projects



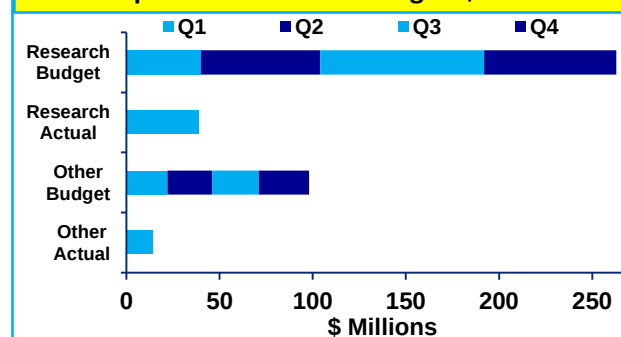
Journal Articles Published



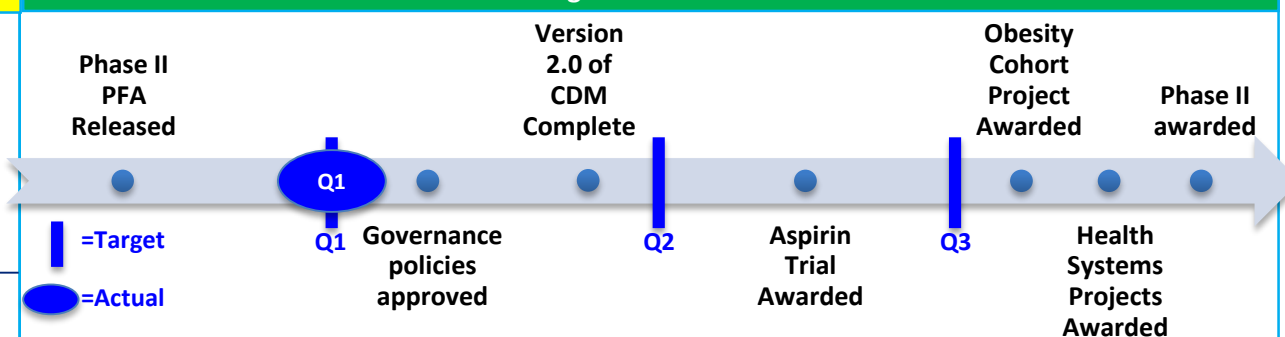
Uptake of Methodology Standards



Expenditures – Total Budget=\$362M



Progress of PCORnet



Wrap Up and Adjournment

Grayson Norquist, MD, MSPH

Chair, Board of Governors



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE