

A Comprehensive Stakeholder Engagement Plan for the Patient Centered Outcomes Research Network (PCORnet) Bariatric Study

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Background

The Patient Centered Outcomes Research Network (PCORnet) Bariatric Study is a nationwide collaborative of over 50 clinical systems and academic medical centers. At PCORnet sites, over 40,000 patients (more than 900 of whom are adolescents) have undergone bariatric surgery between 2004 and 2014. The PCORnet Bariatric Study will examine the weight, diabetes, and adverse event outcomes in these patients. An integral part of this study is an extensive stakeholder engagement plan that was developed to include the voices of a number of representative groups who have direct interests in bariatric surgery outcomes research.

Goals for the PCORnet Bariatric Study Engagement Plan

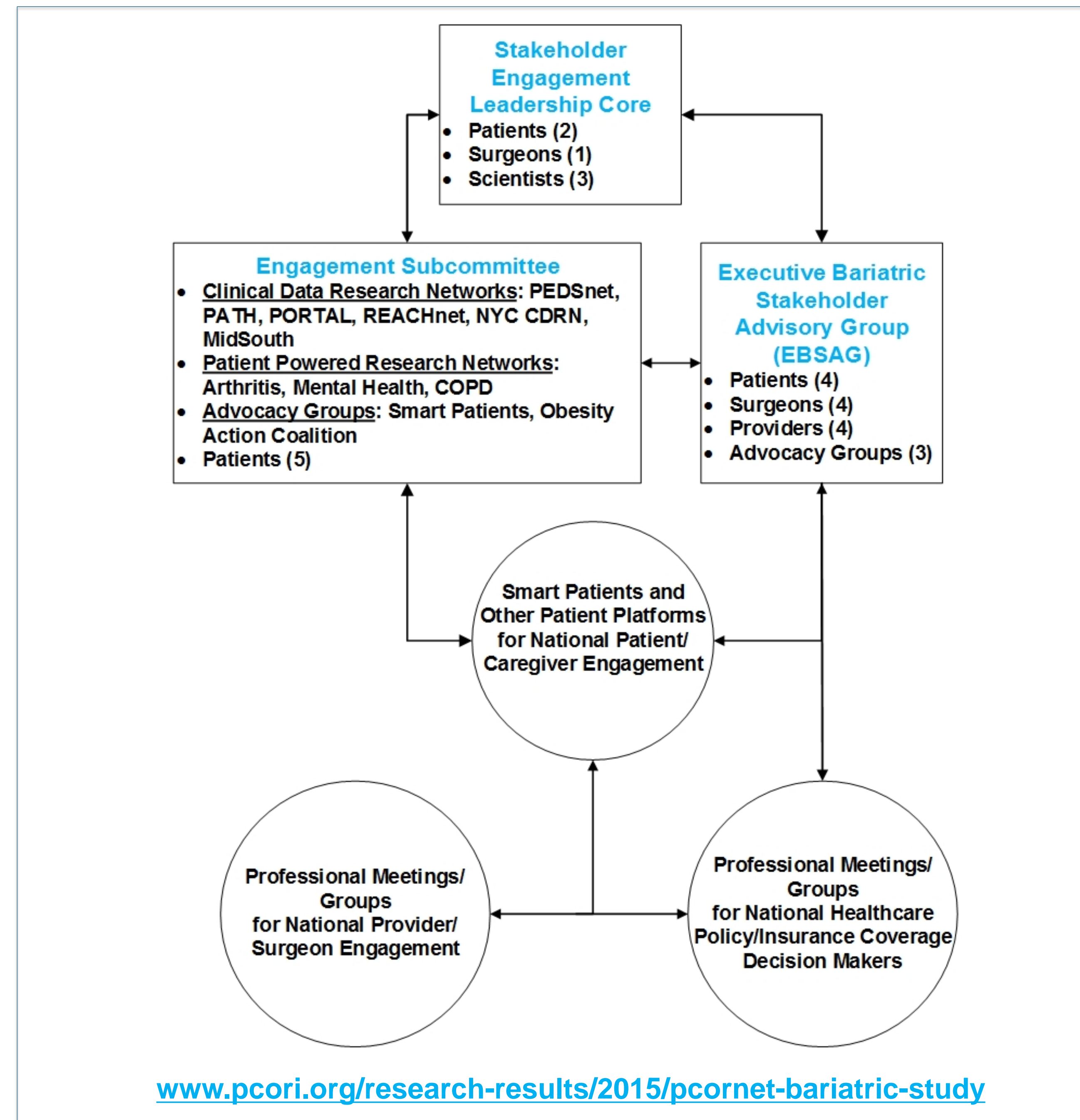
- ❖ Provide an equal voice for all stakeholder groups in the PBS study design, implementation, and dissemination.
- ❖ Create, test, and promote access to a national network of bariatric patient and family engagement platforms where patients and their families are free to exchange information and share experiences with other stakeholders in a neutral commercial-free environment (www.smartpatients.com).



- ❖ Understand how payer and insurance groups make decisions about coverage for bariatric surgery and design and implement the study such that it provides the evidence necessary for them to make informed coverage decisions.

Central to the achievement of these goals is the Executive Bariatric Stakeholder Advisory Group which is made up of patients who have had bariatric surgery, bariatric surgeons, obesity medicine specialists, community advocates, and research scientists.

Engagement Strategy Overview



This work was funded through the Patient-Centered Outcomes Research Institute (PCORI) Award OBS-1505-30683 for development of the National Patient-Centered Clinical Research Network, known as PCORnet.

Proposed Outcomes

Toolkits customized for the engagement of multiple bariatric surgery stakeholder groups:

- ❖ Methods for initially identifying and onboarding each stakeholder.
- ❖ Communication tools for the preparation of complex study methods and analytic strategies for lay audiences.
- ❖ Focus group and structured interview scripts specific to patients eligible for surgery as well as those who have had surgery.
- ❖ Strategies for gathering information from bariatric stakeholders.
- ❖ Tips for how to build this information into the interpretation of study findings.
- ❖ A dissemination guide that will assist researchers in preparing materials for a variety of audiences interested in bariatric surgery including community, advocacy, and healthcare policy and insurance coverage decision makers.

Conclusions

With this comprehensive stakeholder engagement strategy we hope to provide a rapid translation of the relevant findings from the PCORnet Bariatric Study into real-world clinical practice. Our engagement strategy will provide the methods and tools to do this so that a variety of stakeholder groups can understand and use our findings in their day-to-day lives and professional work.