

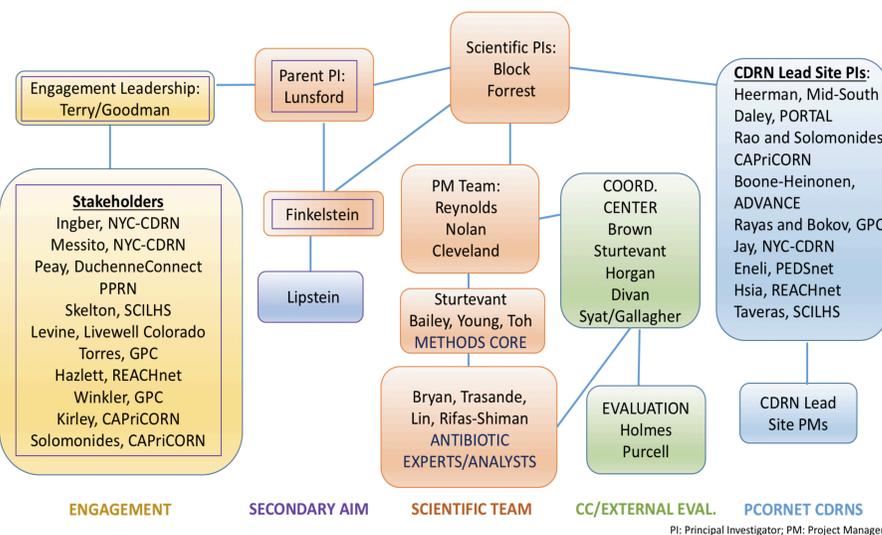
PCORnet Obesity Observational Study: Short- and Long-term Effects of Antibiotics on Childhood Growth

Gathering Stakeholder Feedback to Improve Engagement Process

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Background

Using an innovative, multi-site network called the National Patient-Centered Clinical Research Network (PCORnet), the PCORnet Antibiotics and Childhood Growth Study utilizes electronic health record data from 36 healthcare institutions across the nation to explore the effects of antibiotic use during the first two years of life on body weight at ages 5 and 10. As part of the governance for this study, an Executive Antibiotics Stakeholder Advisory Group (EASAG) works alongside the scientific team to carry out the study's objectives. Members of this group include parents, caregivers, pediatricians, pharmacists, investigators, and advocacy/health systems leaders.



Introduction

The EASAG has driven the creation of lay study materials, provided feedback on study protocols and documents, participated in dissemination planning, and shared ideas for improving engagement processes. The EASAG has regular calls as a group to discuss engagement with the study, and EASAG members regularly participate in scientific calls that are designed to review methodologies and results from the study analyses. Several members have been included as authors in manuscripts that are in development.

Methods

In early 2017, the EASAG and its facilitators decided collaboratively to disseminate a survey, for which they drafted questions and provided feedback as a group. Once final, the EASAG facilitators surveyed stakeholders to evaluate their involvement and engagement. Goals included:

- Determining stakeholder satisfaction
- Informing the study's engagement process
- Documenting lessons learned to benefit future studies

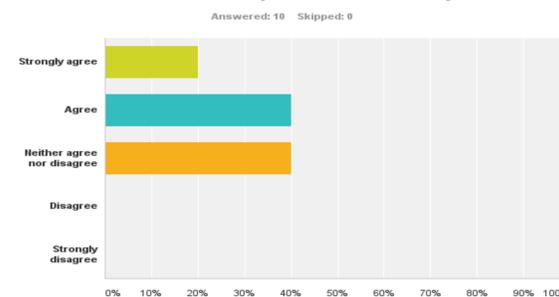
The survey included 19 questions and was sent to the 10 members of the EASAG. Responses were on a 5-point Likert scale, ranging from strongly agree to strongly disagree. Examples of questions included in the survey were:

- Individuals whose lives are most impacted by children's antibiotics use or pediatric obesity are well-represented
- ABX study stakeholders engage in open communication and demonstrate a willingness to listen to others
- Study information and materials are always shared, and presented in ways that I can understand

Results

The survey garnered a 100% participation rate. Responses indicate that overall stakeholders felt satisfied with their engagement; had a decision-making role in the study; and were able contribute meaningfully to study objectives.

Q5 I have decision-making authority and believe I contribute meaningfully to relevant outcomes and objectives for the study.

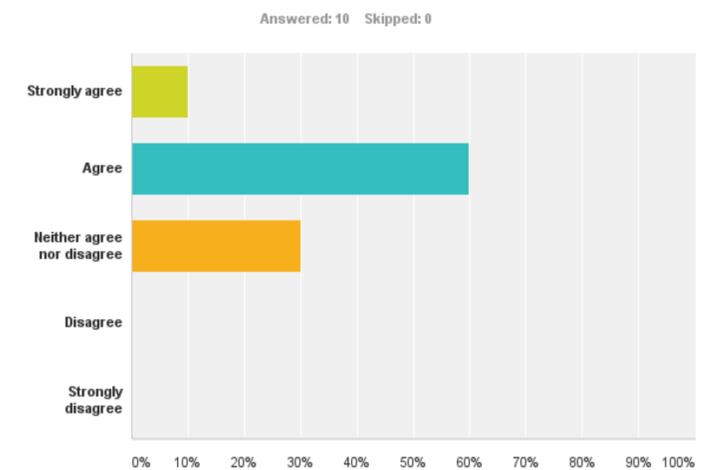


All respondents agreed that stakeholders engaged in open, respectful communication. Some stakeholders indicated their expertise could be better utilized, while some were unsure how to best contribute to the study. 80% of stakeholders agreed that individuals whose lives are most impacted by children's antibiotics use or pediatric obesity are well-represented in the study. Two stakeholders disagreed with the statement that they had been compensated appropriately, while three stakeholders said that compensation was not a motivating factor.

Discussion

Stakeholders in the PCORnet Antibiotics and Childhood Growth Study believed that engagement efforts were successful and provided opportunities for meaningful involvement in the study. While stakeholders generally felt as if they had opportunities to participate in the study, they didn't always know how best to contribute or where their skills were most needed. Stakeholders might contribute more, and feel more valued as contributors, if they had more opportunities to learn about the research process prior to starting their stakeholder role. Going forward, a "master class" on research and clear definitions of roles and opportunities could benefit the stakeholder experience.

Q6 I feel the study team has a clear understanding of stakeholders' expertise, strengths, and roles.



Conclusion

This survey was an opportunity to learn more about the stakeholder experience and engagement techniques utilized by the PCORnet Antibiotics and Childhood Growth Study. The findings of this study will be used to improve stakeholder involvement for the remainder of this study as well as shape the role of stakeholders in future studies. Findings will be shared broadly to inform stakeholder inclusion in scientific studies, sustain engagement, and enhance future PCORnet stakeholder engagement. Special consideration and effort will be devoted to providing more background education to stakeholders.

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