

The PCORnet Bariatric Study - Engaging patients and other stakeholders across the US to improve bariatric care

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The PCORnet Bariatric Study will compare the effectiveness of the three most common US bariatric procedures, using real-world health data from over 60,000 patients (adult and adolescent). It aims to demonstrate the utility of PCORnet, the National Patient-Centered Clinical Research Network. A secondary aim will examine patient and provider perspectives on key decisions related to surgery. Multiple engagement strategies help ensure a patient-centered approach. Patients and surgeons were active participants of the team that shaped the initial study concept and aims. The study leadership includes a patient co-Principal Investigator and other patient study team members. During the proposal writing process, patient partners affiliated with each of 11 participating clinical data research networks expanded study engagement, as did a nation-wide advisory group including patient advocates, surgeons, and caregivers. Their input shaped the study's design and dissemination plans. The team has focused on minimizing jargon and inviting shared ownership and decision-making during study conference calls. When documents are circulated, key areas are highlighted to focus attention on topics in most need of patient input, and to minimize readers' burden. Spoken feedback is a welcomed alternative to written comments. Conference calls are scheduled with options to accommodate different schedules. An in-person meeting kicked off the research after funding; feedback from attendees suggests that it helped team members contribute and feel valued. Social media will further expand community engagement moving forward. This study aims to exemplify a model for engaging patients and community in the research process to maximize the benefits for all stakeholders.