

10/21/21 Patient Engagement 10:00-10:50am

Lead Facilitators: Alecia Malin Fair, DrPH and Jabari Ishimura, B.S. (Vanderbilt University Medical Center)

Alecia Fair & Jabari Ichimura

STAR CRN Stakeholder Engagement Team

SLIDE SHOW IS AVAILABLE TO ATTACH

- SET Stakeholder Engagement Team is chosen by the PI at the site.
- They work individually with patient stakeholders at the sites.
- SAC Stakeholder Advisory Council is chosen by PI and SET – each site chooses their own
- Stakeholders are patients, caregivers, consumers, community organizations, Healthcare organizations, clinicians, providers, and
- SAC Review Process
 - STAR Navigator connects SET with investigator and study team
 - Set Identifies SAC reviewers and requests review within 2 weeks
 - SAC completes review and either approves or requests follow up
 - SET forwards reviews to study PI for STAR leadership approval

Star Engagement

Measurable Engagement Practices

Multi-Level Engagement

Shirley Bloodworth-As a person who has recently signed up for a proposal. She feels that informed consent should be made into a legal format. She believes the informed consent form is so long that it becomes confusing for the person to sign into a study.

Gillian Bartlett-Informed Consent systematically excludes people. Is it possible to get a copy of the article explaining the scale. Some of the information is not worded in a way that the patient can get a better understanding of what the study entails.

Jeff Ordway- Was there a variance between patient responses academic vs non academic?

Yes