



*DATA HARMONIZATION FOR NATIONAL
PATIENT-CENTERED CLINICAL
RESEARCH NETWORK (NCRN)*

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Patient-Centered Outcomes Research Institute

Responses to Group 2's Questions

- How do we define success? When are we 'done'?
We're never done.

Success is increasing capacity to do efficient multi-site CER, both observational and experimental; progress will vary across sites, depending on starting point

Growth over time in scope of captured, standardized, validated data

Ability to attract funding from other sources; sustainability

Addition/partnering with other external networks

Increasing engagement of patients, clinicians and systems in using the data resource

Responses to Group 2's Questions

- Who is the customer? Who defines 'good enough'?
 - Host systems, patients, clinicians
 - Other patients, clinicians, their organizations
 - The research community
 - Other funders.
- What are we harmonizing? Patient-level data? Analysis? Data exchange?
 - Foundation is patient-level data; possibly additional data from higher levels – delivery sites, healthcare systems, geographic data
 - EHR data, administrative data, claims data, patient reported data

Responses to Group 2's Questions

- Will funding influence success?
 - PCORI funding will increase chances of overall success
 - Funding from other sources is a sign of success.
- Will different partners have different capabilities?
 - Different partners will bring different expertise, different achievements
 - Expectations will certainly depend on where a site begins.

Responses to Group 2's Questions

- Iterations are key but over what period? What can we expect to iterate on in 6 months?
- Are we trying to establish a physical model that can be physically instantiated and executed, or we are trying to provide conceptual guidance about standards and best practices and leaving the implementation details to each of the users?