

NeoQIC Family Engagement Collaborative: Overview of “Data Tracks”

Purpose: Data collection on key metrics is an integral part of any perinatal quality collaborative. We collect data so that we can assess if the changes we are making over time are leading to improvement at the local level and among all participating hospitals at the state level. Like other NeoQIC projects, we will try to make the data collection highly informative and minimize data burden as much as possible.

How does it work? We will ask participating teams to submit data that captures our key drivers of family engagement to a centralized REDCap database. Because NeoQIC is a virtual organization where projects are typically individually-funded, we will “house” the data at Boston Medical Center, the prime institution of our grant. Each participating hospital will have access to their hospital’s data at any time. Hospital may also choose to add customized data fields if they choose. Teams will receive bimonthly or quarterly reports that demonstrate their progress on key data metrics that compare their progress to the overall state. In this project, we propose two data tracks for teams to choose from.

Track 1: Chart Abstracted Measures

- **Overview:** This is the traditional approach of past NeoQIC projects and many perinatal QI collaboratives. Teams will submit data from a retrospective medical chart only.
- **Data type:** No identifying information, such as name or date of birth will be included. We will collect data on visitation, receipt of family meetings and social work contacts, breastfeeding, skin-to-skin, and discharge teaching.
- **Inclusion criteria:** We will collect data on infants that are admitted at least 14 days whose family members are not restricted from visiting their infant in the hospital.

Track 1 Data Regulation Needs:

IRB: We will use quality improvement methods and therefore we do not anticipate that an IRB review is needed. Like our past NeoQIC projects, we encourage individual hospitals to reach out to their IRBs to confirm if desired. We will provide details of the overview of the project which you may supply your IRB officials.

Data Use Agreement (DUA): Whenever data is shared from one institution to another a DUA is required. This involves a legal agreement between institutions and is a regular occurrence at most hospitals/medical institutions. The stipulations in the DUA will clarify the type of data being shared and purpose of sharing. In this case, each hospital will need to complete a DUA with Boston Medical Center. We plan to share data that is classified as “limited” because it will include month of birth and zip code. We will not share identifiers.

Track 2: Chart Abstracted and Family Reported Measures

- **Overview:** For this project focused on family engagement, we additionally want to obtain feedback from **actual family members** that assess our key measures. To do this we will administer short surveys delivered by email or text soon after discharge and about 4-8 weeks after discharge. These results will be tied to the chart abstracted measures.
- **Data type:** In this case we need to collect the family members’ phone numbers and email address for the purpose of administering the surveys. These are considered identifiers. **Each hospital will be responsible for approaching families prior to discharge and asking them if they would like to provide their contact information for this purpose. We will not send surveys to families without asking first (see family form).** The data collected from families will be de-identified and kept separate from the contact information. We will collect data on parent’s experience.
- **Inclusion criteria:** This is the same as the chart abstracted measures, but we will only administer family reported measures to English and Spanish-speaking families.

Track 2 Data Regulation Needs:

IRB: We will again use quality improvement methods, however, we will be asking parents for their phone number and email address to administer our surveys. We suggest that each hospital reach out to their IRBs to inquire whether any kind of review is needed. Our team will provide details of the overview of the project.

DUA: As stated in track 1, a DUA will be needed to share the data. A DUA that encompasses track 2 will need to additionally include use of email addresses and phone numbers that will be used for the central NeoQIC team to administer the surveys.

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