

Attachment 13:
Justification of Focus Group Allocation by Site

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- **CCHMC:** Patients served by the Comprehensive Sickle Cell Center in Cincinnati, Ohio come from an eight-county catchment area that includes southwest Ohio, northern Kentucky, and southeast Indiana. Five of these counties have been designated as rural locations based on the US Census. Of the **300 pediatric SCD patients at CCHMC**, 89% are African-American. Given the ethnic and geographic makeup of the CCHMC patient population, one focus group for each of the patient, parent/caregiver and provider stakeholder segments would capture key issues faced by minorities in rural and urban areas in the Midwest by researchers and clinicians who are experienced in conducting and analyzing focus groups and have worked extensively with the SCD population. In addition, practices in this geographic location may differ from those in the urban east coast health care practices and patterns allowing greater diversity of results. Due to CCHMC's experience conducting focus groups with children, they will lead the patient ages 9-13 focus group.
 - **CNMC:** CNMC has a distinct immigrant population with nearly 35% of its **1200 sickle cell patients** being either Caribbean or 1st generation African. This population has been found to draw from their experiences of care for SCD from their home country resulting in different expectations around care management compared to those who have only been in the US. Some of these differences likely impact health outcomes and experiences with transitions of care (from hospital to home and vice versa or from pediatric to adult care) that will be incorporated into the development of a technology-enabled tool to address SCD care transitions. As it has the largest number of sickle cell patients of the 3 clinical sites, CNMC will host four focus groups (2 patients, 1 parent/caregiver and 1 provider). CNMC's size also uniquely suits them to lead the last patient focus group that includes mixed ages and will be used to fill in gaps that remain after the earlier groups. In addition, CNMC already has a clinic focused on SCD care transitions from which participants for the focus groups will be drawn.
 - **Nemours:** Nemours Children's Clinic-Jacksonville (NCC-J) cares for approximately **375 children with sickling syndromes**. The NCC-J patient population includes 15% rural patients and 5% Hispanic-American, both of which are under-represented by the other focus group sites, but are important at-risk populations. This site also includes a very large suburban population that is not included in either of the two other sites. Further, NCC-J's southern geographic location is another important differentiator that no other site duplicates. Nemours will host two focus groups (one patient group and one parent/caregiver group).
 - **NICHQ/Lewin:** The team will conduct one IT Developers focus group to capture the insight of this stakeholder segment not captured through other means. NICHQ's Dr. Berry will play an important role in convening this focus group given his experience in application development for chronic conditions. This group will help the team to understand how to translate the needs of tool users (patients, caregivers, providers) into tool specifications and use cases such that the technical aspects of the actual tool are shaped effectively. In timing, this focus group will be conducted between other stakeholder groups to allow findings from previous stakeholder discussions to inform the IT Developer topics as well as help the project team to understand questions that need to be posed to the remaining focus group participants that are relevant for tool development from the developer's perspective.
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