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GRNDaD: big data and sickle cell disease

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Big data are used in the pursuit of precision medicine in the general population. Applying these tools to patients with sickle cell disease (SCD) is essential for ensuring that they receive the most appropriate customized therapy for their disease. For these tools to be applied, there must be a large number of willing, fully phenotyped participants in collaborative registries. Working collaboratively to respond to unmet clinical needs and the lack of a large multisite registry, SCD providers at multiple sites developed The Globin Regional Data and Discovery (GRNDaD) registry. The specific goals of GRNDaD are to (1) prospectively obtain high-quality curated data on the evolving population affected by SCD; (2) improve adherence to guideline-based care; (3) provide a platform for ongoing quality improvement across sites; (4) allow for real-time investigation of therapies, and collaborate broadly to address research questions using GRNDaD as a shared platform. GRNDaD's current strength lies in the generous participation of people living with SCD, collaborative investigators, and the opportunity to conduct quality improvement activities across a large number of sites. GRNDaD will serve as the data collection tool for the Health Resources and Services Administration Sickle Cell Treatment Demonstration Program and for the newly established National Alliance for Sickle Cell Centers (https://www.sicklecellcenters.org/). GRNDaD is a robust collaborative registry that providers and researchers will use to identify genetic markers that will help predict outcomes and lead to a better understanding of the natural history of SCD in the modern era of novel therapies.