

Project Title: The Mountain States Genetics Regional Collaborative (MSGRC)

Applicant Organization Name: Texas Health Institute

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Project Abstract

Problem: The mountain states region (Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming) is challenged to deliver genetic services over large distances and to unique populations of Americans, many of whom are culturally and linguistically distinct from the majority population.

Priorities and Goals: The overall program goal of the Mountain States Genetics Regional Collaborative (MSGRC) is to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home. The MSGRC has identified eight program priorities through which this goal can be accomplished over the next five years:

- 1) enhance collaboration within MSGRC, with National Partners, and with other Regional Collaboratives;
- 2) treat genetic disorders (and risk factors) in the context of a medical home;
- 3) contextually use the role of cultural competence and diversity to adopt innovative outreach projects;
- 4) build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services;
- 5) strengthen public-private partnerships, communication, and collaboration;
- 6) collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices;
- 7) expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment; and
- 8) continue to address Emergency Preparedness with state laboratories, clinical genetic centers, and families.

Methodology: MSGRC fulfills these program priorities through staffing the activities of six workgroups and funding regional mini-projects to address identified access barriers that limit available genetic and medical home services. Each MSGRC program priority has defined goals and strategies that will be implemented over five years.

Coordination: MSGRC will coordinate six regional workgroups comprised of diverse stakeholders representing multiple disciplines, including public health, genetics subspecialties, primary care, consumer advocates, local and state government, community-based organizations, and regional and national partners that share similar goals. MSGRC staff and partners will also continue serving on external projects and workgroups of national significance.

Evaluation: MSGRC uses an external evaluator to conduct a formative, outcome-based program evaluation to inform ongoing program improvement and to demonstrate regional success. MSGRC also participates in national evaluation activities led by the National Coordinating Center.

Annotation: The MSGRC ensures that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home by facilitating regional collaboration, encouraging involvement of diverse populations, and supporting innovative mini-projects that inform quality improvement and systems change in the newborn screening and clinical genetics health care delivery systems.