

Mountain States Genetics Regional Collaborative Evaluation

Project Summary & Goals

The purpose of this study is to evaluate the Mountain States Genetics Regional Collaborative (MSGRC). The study used primary and secondary data to examine implementation and outcomes of the MSGRC across a five-year period. The MSGRC was one of seven HRSA-funded Genetics Networks, and covered an eight state region that includes Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah and Wyoming. The MSGRC is now known as the Mountain States Regional Genetics Network, of which researchers from the University of Louisville School of Public Health and Information Sciences (SPHIS) and the Commonwealth Institute are evaluators.

Project Dates

2016-2017

Principal Investigators

Liza Creel, PhD, MPH

Communities and Partners Involved

The Commonwealth Institute team engaged state and community organizations involved in delivery of genetic services or providing family support services in 8 states in the Mountain West.

Funders

This research was funded by the Health Resources and Services Administration and Texas Health Institute.

Key Findings

Across five years, the MSGRC supported:

- **Five Workgroups (Consumer Advocacy, Emergency Preparedness, Newborn Screening, Telegenetics, and Medical Home)**
- **Three Special Interest Groups (Metabolic Consortium, Hemoglobinopathies, and Health Information Technology)**
- **Fourteen Mini-Projects**
 - **Colorado Tele-Genetic Counseling for Newborn Hearing Loss and Metabolic Disorders** – this project sought to expand access to genetic services for families with children who are deaf and hard of hearing or have been identified as having a metabolic disorder by using existing telemedicine infrastructure to connect families and providers.
 - **Improving Access to Services for Children with Special Health Care Needs in American Indian Communities of Northern Arizona Project** – Also known as the Tuba City CHC mHealth project, this project had as its goal the provision of mobile health technologies to clinics in northern Arizona that provide services to American Indian individuals with special healthcare needs and their families.
 - **Cook Children’s Telemedicine Project** – This project supported the purchasing of new telemedicine equipment to expand the capacity of the existing telemedicine program at Cook Children’s Hospital in Ft. Worth, TX.
 - **Montana Telegenetics Project** – This project supported expansion of the existing telemedicine program at Billings Clinic to include tele-genetic counseling for oncology and prenatal patients. The project also supported educational outreach to providers and the public about the availability of these services.
 - **Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics** – The goal of this project was to improve transition services for patients with inborn errors of metabolism (IMD) by examining the transitioning needs of patients served in the IMD clinic, and the needs of their providers in both pediatric and adult care settings.
 - **Mountain States Medical Home and Family Partnership Project** – The Mountain States Medical Home and Family Partnership Project sought to create formal family partnerships within the pediatric primary care practice to strengthen the medical home in a cost-effective manner that promotes health. This

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project trained four to six parent partners, each of whom was a parent to a child with special health care needs, to work in pediatric primary care offices in Montana and Wyoming.

- **Metabolic Newborn Screening Long Term Follow Up Study** – The primary objective of the MSGRC Metabolic Newborn Screening Long Term Follow Up Study was to develop a long term follow up program over a sufficiently large population in a suitably homogenous manner that allowed the systematic analysis of factors that affect long-term outcome of all patients with inborn errors of metabolism identified by newborn screening.
- **Family History Project** – The goals of this project included developing a strategic plan for regional implementation of electronic family history tools; developing a request for proposals to facilitate introduction of these tools within practices; and supporting practices (funding permitting) to pilot the use of family history tools in clinical practices in the mountain states.
- **Hemoglobinopathies Long-Term Follow-up Project** – The goal of this project was to expand long-term follow-up and improve the medical home for individuals with hemoglobinopathies.
- **Mapping Project** – Through the MSGRC mapping project, genetics clinics were surveyed to understand their capacity to deliver within clinic, outreach, and telemedicine services, as well as document the number of providers available to see patients. The first phase mapped genetics providers in relation to county-level birth defects estimates. The second phase mapped genetics providers in relation to the zip code of residence for patients seen by any mechanism in their clinic.
- **Cook Children’s Telegenetics Case Study** – MSGRC conducted a case study with Cook Children’s Medical Center in Ft. Worth, Texas to describe a successful telegenetics program with the objective of promoting uptake of telegenetics by other regional genetics clinics.
- **ACA Project on Cost Template Development for PKU and Sickle Cell Model Conditions** – The NCC received supplemental funding from HRSA to support implementation of the Affordable Care Act (ACA) for individuals with genetic disorders and their families. MSGRC was awarded supplemental funding for Project #1. This project updated care plans for PKU and Sickle Cell Disease across the lifespan and developed cost/billing templates for elements of these care plans.
- **ACA Policy Brief** – Based on original work from the NEGC, the MSGRC developed a policy brief to inform policymakers and administrators in the Mountain States Region about the impact of ACA in relation to children with genetic disorders.
- **Emergency Preparedness (EP) Surveys** – Led by the MSGRC Emergency Preparedness Workgroup, two EP surveys were developed and disseminated regionally. The first survey targeted providers and sought to understand provider perceptions regarding the impact of emergencies and disasters on their patients, and to identify specific guidelines and practices currently used to help families prepare for emergencies. The second survey targeted consumers and had an objective of understanding the risk perceptions of families, how families actively planned for emergencies, and availability of resources about emergency planning.