

Implementation of an Innovative, State-based Approach to Improving Access to Genetic Services

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Introduction

The Mountain States Regional Genetics Network (MSRGN) includes eight states: Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming.

MSRGN provides support to individuals with genetic disorders and their families by facilitating activities that promote access to genetic services and establishing connections with and between genetic clinicians, primary care providers, consumer advocates, and public health stakeholders. In 2017, MSRGN created a system in which states operate teams of volunteer clinicians, public health professionals, consumer advocates, and individuals and family members with or at risk of genetic diagnoses.

The state teams focus on the needs of identified populations living in areas where genetic services are scarce or access is otherwise limited. State teams identify barriers to genetic services and target interventions to address those challenges, focusing on improving awareness, education, and service delivery.

Access barriers persist across states



How state teams address barriers depends on **population needs** and available **mechanisms of change**

Results

- 1 Access barriers are persistent and include cultural, geographic, workforce, and technology barriers for providers and families.
- 2 State team members view their work as beneficial and responsive to state needs.
- 3 Though state teams prioritize diverse representation, they are challenged by recruiting members of underserved communities to serve on the state team.
- 4 Member participation can be inconsistent with some limited participation particularly by clinicians.
- 5 There is no strong consensus on exactly how much time or resources are needed to do the work of the state teams.
- 6 Cross-state interactions are highly valued as opportunities to share work and problem solve together.
- 7 Streamlining of state team processes may offer efficiency in operations.
- 8 State team members feel the teams could be sustainable in the long-term with consistent resourcing and an emphasis on showing impact.

Methods

- Prospective, multiple case study examining implementation of eight states teams.
- Recruited 3-4 individuals from each state team to include at least one person from each key stakeholder group (clinical provider, public health professional, individual/family member).
- Key informant interviews guided by the Consolidated Framework for Implementation Research.
- Response rate was 89% (range across states: 66%-100%).
- Data analyzed with thematic analysis using NVivo.

Conclusions

The state team model accommodates variations in needs and change capacity by resourcing and supporting states to address high priority needs in creative and innovative ways. These findings illustrate both the benefits and challenges of the MSRGN state team model and can be used to continue and improve the MSRGN state teams and replication of the model in other regions. MSRGN is using these findings to reassess and refine the state team model to aid in long-term functionality and sustainability in the region.



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