Mountain States Regional Genetics Network State Team Case Study Final Report

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Executive Summary

The Mountain States Regional Genetics Network (MSRGN) is a regional network which includes eight states: Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming. The 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, consumer advocates, and public health stakeholders. In 2017, MSRGN created a system in which states establish and operate teams clinicians, public health professionals, and individuals and family members. The state teams focus on the needs of identified populations (e.g. rural, Hispanic, American Indian) living in areas where genetic services are scarce or access is otherwise limited. The goal of this study is to understand how the state teams are being implemented across all eight states in the mountain states region.

The study was designed as a prospective multiple case study examining implementation of eight states teams in the MSRGN. A total of three or four individuals from each state team were recruited for the study, with an intentional goal of interviewing one person from each key stakeholder group represented in the state teams (clinical provider, public health, individual/family member). The Consolidated Framework for Implementation Research was used to guide semi-structured interviews with study participants. The overall response rate for the study was 89%, with a range of 66% to 100% across states.

A total of nine themes emerged from the interviews including access barriers in state, state team benefits, state team challenges, state team culture, state team processes, suggestions and recommendations, cross state team collaboration, MSRGN support, and sustainability. High level findings include:

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

These finding illustrate both the benefits and challenges of the MSRGN state team model, and can be used to continue support of and improve functionality of the MSRGN state teams.

Introduction

The Mountain States Regional Genetics Network (MSRGN) is a regional network which includes eight states: Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming. The 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, consumer advocates, and public health stakeholders. MSRGN also supports telegenetics implementation and quality improvement activities to expand access to genetic services for populations living in medically underserved areas (MUAs). Part of this work includes developing and offering educational resources to various stakeholders including clinical teams (genetics and primary care physicians, nurses, nurse practitioners and other clinicians), public health experts, and consumers (persons with genetic conditions and their families).

In 2017, MSRGN created a system in which states operate in teams and where members focus on the needs of identified populations (e.g. rural, Hispanic, American Indian) living in areas where genetic services are scarce or access is otherwise limited. Each state-based team includes individuals representing public health, healthcare providers/systems, and individuals and family members affected by genetic conditions. All members are volunteers. The state teams are organized by MSRGN staff and have co-leads who facilitate ongoing state team activities. The state teams meet routinely, some monthly, and focus their efforts on identifying areas of need and formulating strategies to address ongoing access-related needs. In addition, state teams interact with each other to learn from their experiences and share best practices within the mountain states region.

Though established at the state-level, the MSRGN state teams are designed to function in much the same way as community coalitions. Given the vast differences in state geographies, populations, and infrastructure, the MSRGN state teams organize specifically to prioritize state needs related to genetic services and to identify opportunities to improve access to care given known barriers in the state. As a relatively new model for accommodating local priorities and needs in the MSRGN, the goal of this study is to understand how the state teams are being implemented across all eight states in the mountain states region.

Prior Research and Research Gaps

Interdisciplinary partnerships and community coalitions can serve an important role in identifying local needs and implementing interventions that accommodate specific local context. A 2015 meta analysis of coalition-led community interventions found that these coalitions can also find success in addressing disparities, specifically racial and ethnic disparities (Anderson, Adeney, Shinn, et.al., 2015). Further research demonstrates that characteristics of the coalitions, and those who are members, may influence their functionality and the outcomes they seek to change (Brown, Wells, Jones, & Chilenski, 2017; Nagorcka-Smith, Bolton, , Dam, et.al., 2022).

Implementation science is an approach to understanding how certain internal and external factors affect implementation of interventions and policies. In their Consolidated Framework

for Implementation Research (CFIR), Damschroder et al. (2009) categorize these dimensions as innovation characteristics, the outer and inner settings, implementation climate, individuals involved, and implementation process.

Research Questions

This study seeks to address two primary research questions.

1. What is the organizational and operational structure of each of the eight state teams operating within MSRGN?
2. What factors explain variations in state team implementation?

Study Design

Study Sample and Recruitment

This study is a prospective, multiple case study following design considerations established by Yin (2009). Although the primary unit of analysis is the state team (n=8), the investigation also explored how organizational, local service, and geopolitical contexts affect, or could affect, implementation and outcomes.

A total of three or four individuals from each state team were recruited for the study, with an intentional goal of interviewing one person from each key stakeholder group represented in the state teams (clinical provider, public health, individual/family member). State team rosters maintained and provided by MSRGN staff were used to identify individuals to invite to participate in an interview. The roster included information on state team member type (provider, public health, family member) and whether an individual served as a state team co-lead. At the time of the study, a total of 90 individuals were official members of state teams. To the extent possible we spoke to state team co-leads and up to two other members. Recruitment occurred via email invitation. All participants were offered a $50 gift card for their participation in an interview.

Data Collection

We conducted semi-structured interviews with questions focused on the participants' relevant skills and their perceptions of their state team specific to each of the constructs as described in the CFIR (intervention characteristics, outer setting, inner setting, characteristics of individuals and process). All interviews were recorded and transcribed electronically. Table 1 summarizes measures used. Appendix A includes the interview instrument used.

Table 1. Measures

Construct	Measures
'Outer Setting' – i.e., the local (state) context for each state team	Availability of genetic services (# of geneticists); other health and human service availability; fit between state

Construct	Measures
	team processes and individual employer values, routines, and rewards; population characteristics
'Intervention characteristics' – i.e., the nature of the intervention	Description of the intervention from State Team members; strength and weaknesses of the intervention;
'Inner Setting' – i.e., the structure of the state team	Team structure (e.g., size, diversity; resources; time and space for meeting); access to resources; scope of team projects; linkage of team project to other activities in individual's organization or other activities in the state
Individuals Involved	Skills and experience (education); knowledge and beliefs about underserved populations, strategies for improving access to care
Implementation Process	Feedback to state teams on strategy and project; frequency and functionality of MSRGN staff-led calls/webinars; "value" of financial resources provided to team; having the "right people at the table"; overall engagement of members

Analyses

All transcripts were initially coded manually by grouping comments by interview question and sections. Additional thematic analysis focused on establishing initial codes and grouping those codes into themes. To confirm manual codes, additional analyses were completed using NVivo, a qualitative software program (QSR International Pty Ltd., 2020). All identified codes and themes were discussed by the two coders until consensus was reached.

Results

The overall response rate for the study was 89%, with a range of 66% to 100% across states. A total of 25 participants were interviewed including ten individuals/family members, seven providers, and eight public health professionals. Participants had an average of 17 years in their field or expertise and five years as state team members.

After analyzing the data, a total of nine themes emerged from the interviews including access barriers in state, cross state team collaboration, MSRGN support, state team benefits, state team challenges, state team culture, state team processes, suggestions and recommendations, and sustainability. Each theme had at least two sub-themes. These themes are summarized below, starting with a description of the types of access barriers reported in each state.

Access Barriers

Many respondents reported access barriers in their state including the limited availability of genetic services, the lack of knowledge about genetic services among the provider and patient/family communities, the lack of funding, and other challenges experienced by families in accessing healthcare services not specific to genetic services (e.g. transportation).

Affordability and Coverage

Various state team members mentioned the issue of insurance coverage when it comes to genetic testing while others stated that families cannot afford genetic services, even if they have health insurance. For example, one state team member reported:

> *"Oh, genetic testing is not offered. But if it's offered, it's too expensive. And I feel like that has to be something to be discussed because that's one of the biggest barriers is insurance doesn't cover testing."*

The lack of access to genetic providers is another issue that was reported since these families cannot afford or are not covered by their insurance for certain services. At least one participant linked this challenge directly to state team decision-making:

> *"If we purchase a piece of equipment for our state's genetics team, then the only children that benefit from that are the ones that are serviced by those providers, and there's a lot of people in our state who don't have access to those providers."*

There is also some variation in coverage barriers across states, given different insurance markets and Medicaid eligibility. One participant noted the impact of Medicaid eligibility on getting their child needed care:

> *"I don't qualify for Medicaid, my child is special healthcare need[s], and I can't pay for what their needs are."*

Cultural Barriers

Several cultural barriers emerged from the data, including language barriers. In addition, several state team members mentioned challenges experienced by the American Indian population in their state. Participants mentioned cultural sensitivity and a culture of privacy as substantial barriers that may impact use of genetic services among the American Indian population. Other cultural barriers included different cultural perspectives, time sensitivity, and trust issues. One state team member mentioned the need to be sensitive when it comes to using certain terms among the American Indian population:

> *"I'll give you a quick example for many of the Native American communities. The term genetic disorder is not well-received. So, when we talk about how we provide services and support, we talk to them about their patients and families that are living with the health problem that may have an underlying genetic component."*

Other members discussed the importance of including the voice of the American Indian community on their team to learn more about the challenges that they experience.

> *"We're like, how can we get more Native Americans to the table? What are we missing? Are we not welcoming and not welcomed? Are we the wrong language? Is there some way we're talking about what we're doing that's off putting? So, we're trying to figure that out. So, I think that's something that's made it hard in [STATE TEAM]."*

According to one participant, the perspective from the underserved communities was lacking, but the respondent had not voiced that issue in their state team meetings. In a follow-up question related to building more diversity in the state teams to ensure the team addresses issues faced by underserved communities, one participant said:

> *"Oh, yeah. Just to give us a perspective because we can't keep learning by talking among ourselves. We need that perspective. We need information from where they're coming from…So, if they directly tell us that, 'Hey, this is what we're facing, can you make this happen?' It's a more direct goal for us to meet."*

Funding Priorities
The lack of funding, limited non-financial resources, and the lack of investments in treatments to treat genetic conditions are some of the sub-themes that emerged from the data. Respondents noted that sometimes this is related to competing priorities, for example, other service lines within a delivery system or organizational responses to the COVID-19 pandemic that took resources away from genetics.

Geographic Barriers
Some respondents discussed that geographical factors were challenges for accessing genetic services. The size and rurality of the state were mentioned several times during the interviews.

Limited Awareness or Knowledge about Services Available
State team members discussed the lack of knowledge or awareness about genetic services not only among consumers but also among providers. Additionally, some respondents reported the lack of resources and education about genetic conditions in their states.

Limited Services, Medical and Support
When it comes to services, both medical and support, some respondents acknowledged the lack of access to genetic services, but also transportation and translation resources. In addition, one state team member pointed out that there is one genetics center at the state level, which also serves a larger region and may not be aware of local resources for families. One respondent stated:

> *"But even when you are referred to a geneticist, often they do not know about the services that are offered to people. Speaking to a geneticist, does not mean that you*

will talk to a genetic counselor who knows your particular condition if it's a rare disease."

Limited Technology for Telehealth

Some state team members mentioned the lack of access to computers and smartphones for telemedicine purposes, limiting access to care, even through mechanisms designed to facilitate care from a distance.

Long Wait Times

Long wait times was a recurring sub-theme reported by state team members. Waiting times, which can be greater than six months, were noted as especially challenging for diagnostic testing or referral to genetic services. Some respondents suggested that families would be better served, especially when they were still waiting on a diagnosis, with a one month versus six month waiting period. As justification, one respondent acknowledged a "gray zone" period where families are unsure of what to do while they wait for their child's appointment. One state team member stated:

> *"And I know they know that because I've been stating this over as I am with you about, I'd like to see us share resources across the region for direct patient care so that patients can get more timely evaluation and management and that they don't have to wait an amount of time to get input from a today professional regarding their condition."*

Provider Shortages

Similarly, respondents mentioned that there is a lack of genetics providers, noting some states with no or only one geneticist for the entire state.

State Team Benefits

The following section summarize themes around the benefits of the MSRGN-facilitated state teams.

State Team Members Collaboration

One of the benefits mentioned by state team members was the collaboration aspect of their work. As mentioned by two participants:

> *"Great opportunity to meet other people around the state and get a feeling of what the medical and genetic needs are around the state."*

> *"There's no hierarchy. Everybody is an equal. Everybody's perspective matters, and I think that's one of the things that has been phenomenally unique about the genetics team, and I think it's an incredible strength and contributes a lot to its effectiveness, because people aren't afraid to speak up and say things because they know that their voice matters and it's heard. I don't know if there's a way to put that in there, but for*

> *me that is just a critical component of this team, and it's one thing that sets it apart from every other group I work on, and that's why I'm still here."*

Diversity and Representation

Others discussed the diversity and representation of the state team in terms of culture, experiences or professional backgrounds, and geographical locations. Moreover, state team members appreciate the diversity of their teams with genetic professionals (geneticists, genetic counselors), other healthcare providers, educators, insurers, government representatives, advocacy groups, and families being involved. They appreciate the various perspectives that each group provides to the state team. One state team member stated:

> *"I think, I understand things somewhat from a public health point of view and definitely from a family point of view, because I have experience navigating genetics, but I absolutely have zero perspective as a provider or clinician and rely on those members to bring that lens and to bring that perspective to us."*

Information Sharing and Dissemination

Some state team members mentioned the value of having a state team for sharing information and the dissemination of resources. Being on the state team, they appreciate the platform that they have where they can share the information and experience with other state teams. State team members also shared that they appreciate the state team since they can share ideas, resources, experiences, perspectives, challenges, good feedback, and discussions around resources or activities that individuals are not aware of. One respondent mentioned:

> *"Before the state team, the resources were isolated but with the state team, there is no isolation."*

Operational Benefits

State team members voiced how the collaboration between members is beneficial for them, especially when it comes to the leadership design of the state team. In other words, when one member is not available, they can be covered by the other co-lead. Various tasks with shared decision making were described by the respondents including the development of projects, the decision on how money is supposed to be used, the work becomes more productive, and the shared information, encouragement, and organizational support.

Responsive to State Needs and Environment

Some participants recognized the advantage of the state teams in being responsive to the environment of their own state with its strengths, challenges, resources, services, and the community. These unique attributes help answer the needs of the population affected by genetic conditions.

Shared Purpose

From the data, a persistent theme was a sense of working together and sharing the same objective. Also that the state teams house a sense of volunteerism and openness, working

toward the same goal/objective and together, and identifying challenges and providing solutions. Figure 1 below summarizes the common findings around shared purpose in a word cloud.

Figure 1: State Team Benefits, Shared Purpose, Word Cloud

State Team Challenges

Respondents also discussed relevant challenges that they experience within their state teams. Financial challenges, inconsistent participation, limited time for innovation, recruitment and turnover, scheduling issues, technology and physical barriers, and time to lead and participate are some of the main patterns that emerged. Some participants mentioned that the financial support that they received was not enough for their state team but others have struggled to spend what they are allocated.

Some state team members acknowledged the lack of participation from some members on their team, especially among clinicians who may never attend a state team meeting. Relatedly, recruitment and turnover was reported as a challenge, specifically recruitment during the COVID-19 pandemic, the challenge of consistent co-leads, and limited racial and cultural diversity in new state team members (see prior quote related to recruiting American Indian members to state teams).

Limited time for state team meetings, and limited time availability among members, is another challenge that limits even completing the agenda for any one state team meeting. Additionally,

state team members mentioned that there is a need for innovation in addressing the complex issues faced in their state, but that there is a lack of time to innovate as a state team given only monthly, one-hour calls.

Finally, some participants mentioned the challenges they encounter with technology especially with the internet. Meeting in person was also discussed as a barrier especially because of the COVID-19 pandemic and geographical factors.

State Team Culture

State team culture was described as good, respectful, collaborative, positive, openness, supportive, and professional. Additionally, respondents mentioned that state team members are engaging, confident, and have a sense that they are being heard. One participant stated:

> *"Well, [Interviewee name], you're a parent, so you tell us what you think." I was like, oh my God. And then I gave my opinion and realized that everybody was very open to different opinions. I wasn't nervous or afraid that people would think I wasn't worthy to be part of that team."*

One participant stated the importance of changing the co-leads so that each state team member can learn more about the work completed by the co-leads.

State Team Activities

Participants were asked questions related to current activities of their state teams and activities that are not the focus of the state team but should be. These were not limited to external activities but could also include activities related to internal operations, growth, and sustainability. Activities reported ranged from recruiting new members, creating and disseminating resources, providing educational sessions, holding events, reaching out to families and providers, expanding genetic services, and partnering with universities and various stakeholders.

Respondents reported some important activities that should be the focus of their state teams including:

(1) Building new partnerships with children's hospitals, communities, families, underserved populations, and the state departments of health;
(2) Identifying resources, both financial and non-financial;
(3) Building connections between state teams, and with/across MSRGN;
(4) Expand recruitment, especially at the leadership level; and
(5) Prioritizing work on insurance for genetic testing.

State Team Processes

Case study participants were also asked about the processes used to complete the work of the state teams.

Co-Lead Roles

Most co-leads mentioned that they have a facilitative role within their state teams while others also stated that they take on administrative roles, such as taking notes and drafting meeting minutes.

Communication

Participants described that member communication occurs primarily during monthly meetings and that members are mostly confident and comfortable to voice their opinions. Participants also expressed that they had somewhat routine communication with other organizations in their state to establish collaborations.

Decision-Making

Respondents reported that the atmosphere of the state team is democratic. For voting purposes, most of the participants acknowledged that the process is informal. In addition, the voting seems to be consensus-based. Respondents stated that decisions are mostly made during meetings or monthly calls. State team members mentioned that they will brainstorm ideas, discuss topics and issues, and sometimes officially vote on those ideas or topics, though it seems not all decisions are made by a vote. Most state team members acknowledged that if no decision has been made or if members were absent, then, they will follow-up with emails to reach consensus and agreement. In some cases, decisions are made intentionally via emails, especially when it comes to more salient topics so that state teams will get input from every state team member, even if they are unable to attending meetings.

One respondent reported that discussions are centered around immediate needs versus long-term needs. Lastly, state team members stated that the decisions are made by both the state team leadership (co-leads) and the team. Figure 2 below summarizes key findings around atate team decision-making.

Figure 2: State Team Processes, Decision-Making, Word Cloud
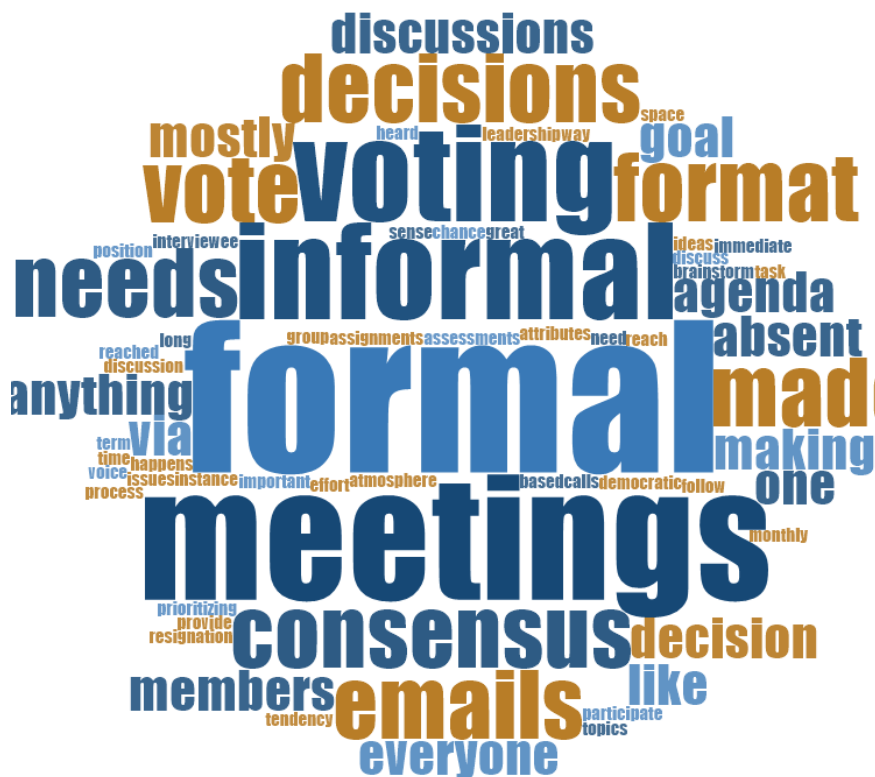
Member Understanding of Purpose

Some participants reported that state team members do not always understand the purpose of the state team. Others stated that there is a time adjustment period for learning experiences from each other. For example, it might take some time for providers to understand the family perspective, and vice-versa. That said, state team members appear to value the diverse perspectives and experiences of the team members and acknowledge that even when it takes time to come to common understandings, their shared goal of improving access to genetic services persists.

Recruitment

Before joining the team, participants acknowledged that they learned about the team from various sources including a state team member, a MSRGN staff member, during a conference, through work, and through other interactions with MSRGN. Some were officially recruited through their work (former coworker), another state team member, and from a representative from their state newborn screening program.

Onboarding New Members

To describe the process of onboarding new members, some respondents provided their own experience. A new member is introduced to the state team during one of their regular meetings and added to the email list. Some described this as an informal process that takes time. When asked how long it takes for new members to be formally integrated into the team, some reported one to two months, and others indicated it took several meetings/months to acclimate., indicating that there is a balance between offering times and space to integrate into

the state team and "jumping into" the work. Several respondents noted that a more formal orientation/onboarding process could be helpful.

Work Process

Most respondents reported that they work in small teams and value teamwork. Others mentioned that they divide their tasks during the meetings, with state team members generally choosing how they will contribute to projects.

MSRGN Support

Various state team members acknowledged the support they received from the MSRGN team. Financial support, information about other MSRGN programs and activities, administrative support, and staff support were the sub-themes that emerged from the data. Several respondents reported the financial support that MSRGN provides to their team. Others discussed how MSRGN team members acted as facilitators especially when it comes to annual genetics meetings, collaboration and connections with other state teams, and the development of resources like videos and the Time for Genetics program. One respondent stated:

> "**They'll come, and they'll say, 'Another state is doing this. That might be something for you guys to think about and consider.'**"

While some state team members mentioned the support from MSRGN, others proposed some ways in which the MSRGN can help even more, including creating a space where state teams will learn about the activities from other state teams, providing guidance for collaboration with other state teams and using the funds, and providing more financial support (though there is some noted disagreement about how much money would be helpful for state teams). When it comes to the staff support, many participants noted, with positive sentiment, on the work that MSRGN staff has done for the state teams. One participant mentioned:

> "*I think that there's been some good support from them in helping us and making sure that we're doing what we need to do within the scope of the grant.*"

Cross State Team Collaboration

State team members reported that there are not a lot of collaborations between state teams within MSRGN, outside of briefer interactions during MSRGN meetings and conferences. Several participants mentioned that they would like to learn more about other state team activities, strengths, and challenges as a way to problem solve together and to learn about successes.

State team members did mention that they have collaborated with other state teams on different activities during quarterly co-lead meetings, yearly genetic ambassador meetings, and state team meetings. However, some respondents recognized that there is still room for improvement when it comes to state team collaborations. They also proposed support from MSRGN in connecting the state teams.

State team members recommended various solutions to problems around the lack of time, collaboration with other state teams, membership, work process, and improving participation. Facing time constraints in state team meetings, participants suggest more streamlined prioritization of discussion and activities.

Respondents agreed that more collaboration with other state teams is also needed to gain exposure to other state team work and to identify opportunities to apply lessons from other states to their own work. For example, one participant stated:

> ***"And New Mexico and Arizona, how did they get the Navajo Nation involved?"***

Some respondents proposed that state teams and MSRGN undertake some strategies to get members to get members to participate more often and consistently, though no specific strategies were suggested. Respondents did recommend that potential members mith more availability to work on the various tasks should be identified to improve participation. Others mentioned that they would like to see more goal driven decision-making present, as well as focused recruitment of key stakeholders not currently at the table. Some respondents thought more time together (in person or virtual) could help state teams.

Finally, participants proposed working closer with the MSRGN leadership to identify ways to recruit and disseminate information and resources. One participant mentioned:

> ***"What I'd love to see in the future from MSRGN is some type of testimonial page. Parents coming back and saying, "I took the red flag for genetics to my doctor, and they finally listened to me, and I was able to get genetic testing done for my child.""***

State Team Sustainability

Members provided various responses when it comes to the sustainability of the state team as a model. Some participants mentioned that it might be challenging to sustain the state team model without any external funding. Others stated that time and lack of consistency are barriers to development. The presence of accountability has been provided as a solution to sustainability while the lack of administrative support was cited as a challenge to sustainability. Importantly, participants noted that sustainability is only achievable if the state teams are productive and show an impact.

Summary of Findings

This case study intended to understand implementation of the MSRGN State Team model, focusing on perspectives of members from each of the eight MSRGN-supported state teams. Our analyses of data collected from interviews with state team members representative of different perspectives reveals eight key findings that can be used to reinforce and improve state team processes, supports, and, ultimately, outcomes of the projects implemented by each of the state teams.

Access barriers in the mountain states are persistent and include cultural, geographic, workforce, and technology barriers for providers and families

State team members view their work as beneficial and responsive to state needs

Though state teams prioritize diverse representation, they have been challenged by recruiting members of underserved communities to serve on the state team

Member participation can be inconsistent with some limited participation

No strong consensus on exactly how much time or resources are needed to do the work of the state teams

Cross-state interactions are highly valued as opportunities to share work and problem solve together

Streamlining of state team processes may offer efficiency in operations, e.g. minutes by MSRGN staff versus co-lead, new member onboarding processes

State team members feel the teams could be sustainable in the long-term with consistent resourcing and an emphasis on showing impact.

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MSRGN State Team Case Study – Semi-Structured Interview Guide

Remind participant that you are recording and ask for permission. ("I am planning to record the rest of our conversation so I don't miss anything you share with me, is that ok with you?")

Participant first name:

Participant last initial:

Co-lead (y/n):

State:

Demographic Characteristics

Tell me about your professional role? Do you work in public health, are you a clinical provider, are you a family member or individual with a genetic condition or advocate?

How many years have you been working in the field?

How long have you been a state team member?

- Less than a year
- 1-2years
- > 2 years

General Questions about State Team

How did you hear about the state team?

Can you tell me how you were recruited to your state team?

What do you like about the state team model?

What are some of the benefits of being on your state's team?

What are some of the challenges that you have experienced in participating in your state team?

How did you overcome those challenges?

If you haven't overcome them, what would help you to do so?

Intervention Characteristics

What activities are the focus for your state team?

What activities/areas are not the focus of your state team but you think should be included?

Would you please describe the process of decision-making within your state team?

In your state team, do you have space and time to innovate or implement new ideas?

- How has that experience been for you?

IF RESPONDENT IS CO-LEAD: As a state team co-lead, what makes it easier when it comes to sharing new ideas or implementing new activities?

IF RESPONDENT IS CO-LEAD: As a state team co-lead, what has been difficult when it came to sharing new ideas or implementing new activities?

Can you tell me about the barriers that you encounter? Were there any financial or physical barriers?

- If yes, can you provide some example of physical barriers that you experience?
- What other barriers have been present?
- What have been the ways that were successful in overcoming those barriers?

Outer Settings

Are there barriers and/or facilitators when it comes to meeting patient needs and/or getting families resources related to genetic conditions?

- What are those barriers and facilitators? [PROBES: financing systems in your state, provider systems in your state or local communities, etc]

Are there resources outside of the state team that support the needs of your state, specific to serving individuals with genetic conditions especially those who are underserved?

- Which resources are those?
- Outside of MSRGN, who provides support that your state team needs?

Does your state team work with other organizations in your state? Which ones? How do you work with them?

Do you work with other state teams? How?

Please describe the support that you received from the MSRGN to meet your needs. [PROBE FOR FINANCIAL AND NON-FINANCIAL SUPPORT]

Are there things you need from MSRGN that you don't currently get, but that you think would make the state team more successful? Can you tell me about that?

Inner Settings

How do you organize yourselves? How does the work get done?

- Prompts: Small teams, project specific committees or work group, individual volunteers, etc

What is the culture of the state team? [PROBE-what are the attitudes and behaviors shared by the team] If there is not one, how do you envision the culture should be?

IF RESPONDENT IS CO-LEAD: As a state team co-lead, would you say the goal/mission of the state team is fitting with culture or work-ethic of the state team? How? If not, what would you do differently to achieve that alignment?

Do you perceive that individuals in your state team understand the goal/mission of the state team in the same way? [PROBE FOR DETAILS]

Tell me about the process of welcoming new members to the state team.

In general, how long does it take for a new member to learn the role and about the activities of the team?

Would you say that there is a good fit between the available resources (i.e. money, training, education, physical space, and time) and the state team mission and activities?

- If not, what is needed to improve?

Characteristics of the Individuals Involved

How well do other members know the goal/mission of your state team?

How are the state team members' attitudes toward the mission/goal of the state team?

Do they engage with the team if something is bothering them?

Do they participate in the activities? If not, in what ways would you want less active members to start participating?

How confident do you think your team members are when it comes to their participation in state team activities, their ability to providing input in state team planning and project implementation, or fulfilling the mission/goal of the state team?

As time has gone on, do you perceive that team members are more enthusiastic about their roles in the state team?

- If not, what are the ways you would involve them in the different activities?

The Process of Implementation

Would you describe the planning process within your state team as a formal or informal process?

IF RESPONDENT IS CO-LEAD:

- How would you define/describe your leadership role in your state team?
- What are some of the barriers that impact your successes in achieving your state team goals?
- What would you do differently to achieve those goals?
- How do you assess your state team's success or progress?

Sustainability

Do you envision the state team model to be sustainable? If yes, how? If no, why not?

Do you want the state teams to continue? Why or why not?

Do you hope to continue to participate in the state team?

Is there something we did not cover that you would like to share with us?

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