MOUNTAIN STATES REGIONAL GENETICS NETWORK
STATE TEAM CASE STUDY

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MSRGN STATE TEAMS

- State Team Model introduced in 2017

- Includes members from public health, healthcare providers/systems, and individuals and family members affected by genetic conditions

- Volunteer-based participation

- Modeled after community coalitions, organizing specifically around:

  - Prioritization of state needs related to genetic services

  - Identifying opportunities to improve access to care given known barriers in the state

Our goal: To understand how the state teams are being implemented and assess stakeholder perspectives on the model

CFIR

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 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

DESCRIPTIVE STATISTICS

- Response Rate = 89% (n=25)
  - Range across states: 66%-100%
- 10 individuals/family members
- 7 providers
- 8 public health professionals
- Participants had an average of 17 years in their field or expertise
  - Five years as state team members (so we tended to talk to longer-term members)

KEY THEMES

Access barriers in state

State team benefits

State team challenges

State team culture

State team processes

Cross state team collaboration

MSRGN support

Suggestions and recommendations

Sustainability

ACCESS BARRIERS

Affordability and Coverage

Cultural Barriers

Funding Priorities

Geographic Barriers

Limited Awareness or Knowledge about Services Available

Limited Services, Medical and Support

Limited Technology for Telehealth

Long Wait Times

Provider Shortages

"…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."

STATE TEAM BENEFITS

Collaboration

Diversity & Representation

Information Sharing & Dissemination

Operational Benefits

Responsive to State Needs & Environment

Shared Purpose

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

SHARED PURPOSE

STATE TEAM CHALLENGES

- Financial
- Inconsistent Participation
- Limited Time for Innovation
- Recruitment & Turnover
- Scheduling
- Technology & Physical Barriers
- Time to Lead and Participate

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…."

STATE TEAM DECISION MAKING
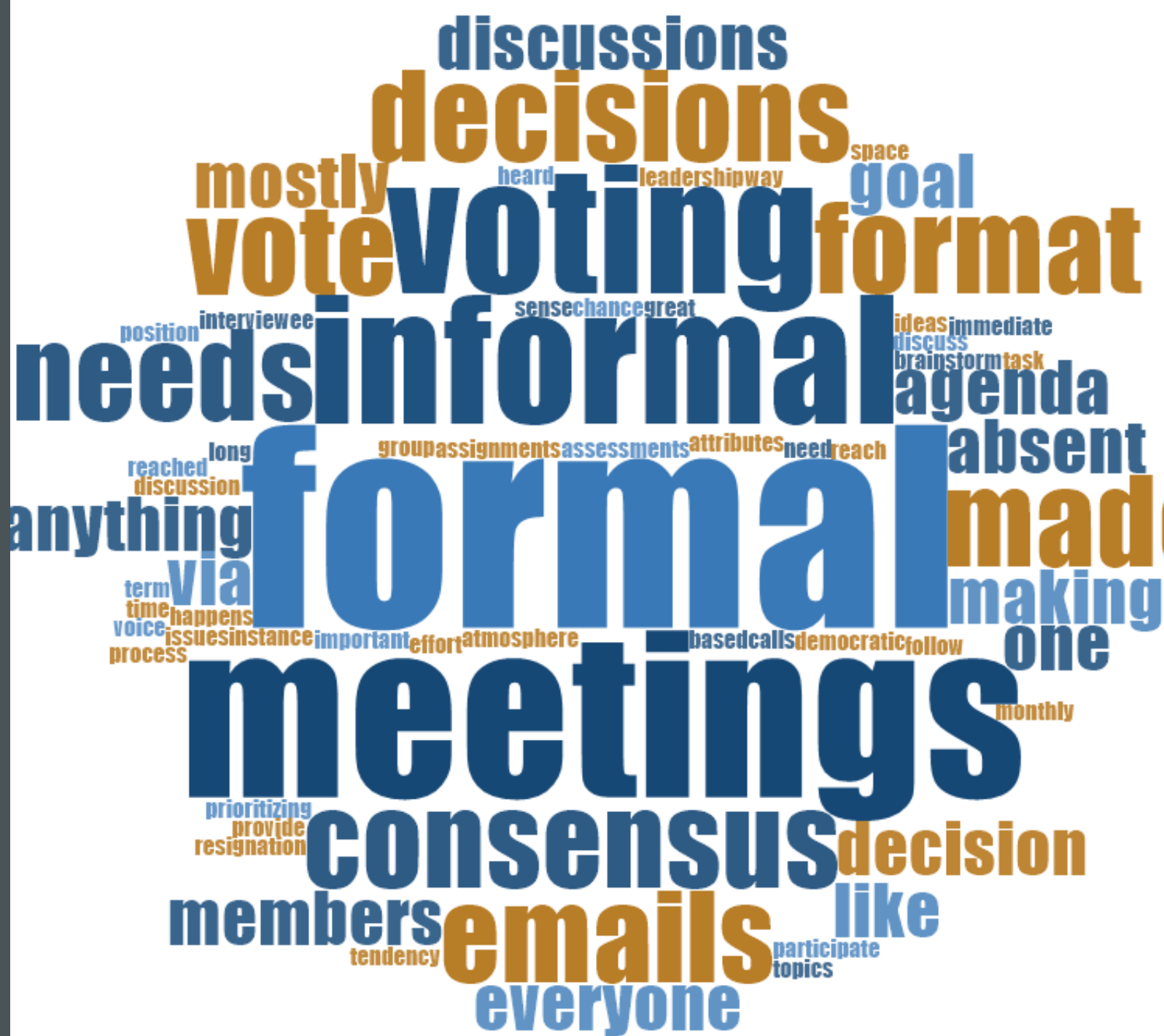
SUGGESTIONS

Co-Lead Engagement and Time Commitment

Cross-State Interactions

Membership

Operations

Improving Participation

HIGHLIGHTED FINDINGS

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.

FINAL THOUGHTS...

"Well because it gives an opportunity to, you know, get people together from various sectors or components or aspects of the genetic services in the state. It's an idea... It's a place to share ideas. And it offers opportunities, whether they're taken advantage of or not, to develop new programs, new approaches, new connections."

"It's not like, "Oh so, and so's speaking again." It's like, "Oh, well, that's great. Thank you for that resource. Or this is a good idea. And let's see if we can pursue that.""

THANK YOU!