Attendees
NEGC: Greg Prazar
NYMAC: Dana Yarborough, Kunal Sanghavi, Bob Ostrander
SERC: Mary Salvatore
Region 4 Midwest: Kristen Hawkins
Heartland: Not present.
Mountain States: Chuck Norlin
Western States: Louisa Iwaishi
NCC: David Flannery, Alisha Keehn, Megan Lyon, Debbie Maiese
NGECN: Not present.
HRSA: Jill Shuger
AAP: Alex Kuznetsov

Welcome and Introductions
- Chuck Norlin welcomed the group and introductions were made.

Future Steps (Group Discussion)
- Chuck provided an overview of the last discussion in October. During the summer of 2016, the workgroup created a driver diagram to develop measures related to patient, family, and provider satisfaction with care coordination activities. Two different paths to work with the driver diagram were proposed (full proposal here):
  1. Use the driver diagram as a foundation for an article to submit to a journal, such as the Journal for Maternal and Child Health, to promote care coordination in pediatric care;
  2. Use the driver diagram as a basis for a grant application to test the usefulness of potential measures. Overarching questions the workgroup need to address are: What is the future direction of our workgroup? What could be accomplished over the next four months? Would creating a small group to complete tasks be an efficient model to complete the work?
    - Bob Ostrander asked if literature published in journals have an actual impact on practices? Additionally, how would the grant application be written?
      - Debbie Maiese stated that foundations, such as the Lucille Packard Foundation, accept grant proposals that are related to care coordination. If a grant application was submitted and accepted, it would be a multi-year project.
    - Louisa Iwaishi noted that money is tight for every system so it is important to understand what areas are of most importance such as workforce development and telegenetics outreach.
    - Alex Kuznetsov stated that the National Center for Care Coordination and Technical Assistance (NCCCTA) has been working on creating an automated process for care coordination and the development of measurement tools. Additionally, a report was published in Pediatrics that discusses parents’ perspectives of integrated care for children across
providers The report, Validation of a Parent-Reported Experience Measure of Integrated Care, can be found here.

- Jill Shuger suggested that Rich Antonelli should be invited to speak with either this workgroup or to the NCC/RC PD/PM monthly call.
  - Alisha Keehn noted that the workgroup would have to be mindful of what can be accomplished in the next five months. It is not known who will be funded in the next iteration of the NCC/RC system so all work will need to be completed by May 31st.
  - Jill suggested that the group could submit the proposal to HRSA. GSB always accepts proposals and reports that identify existing barriers within genetic services. If supplemental funding becomes available, GSB can use these submissions to draft new projects and initiatives.
    - Chuck thought that the group could pull together a draft proposal that demonstrates the need for repeatable care coordination measures and how the driver diagram could be used to develop these measures.
    - Since the proposal will need to be submitted by May, Jill thought a brief (one to two pages) submission about what barriers exist and how collecting data can help alleviate the barrier. She suggested that the proposal should be written only for HRSA and should not discuss future activities.

- Chuck suggested that the group could take the driver diagram and demonstrate the need for funding care coordination measures that address outcome and value for families and providers to patients with heritable conditions. This one/two page brief would then be submitted to HRSA.
  - The group agreed that this could be a feasible project over the next few months.
  - Chuck called for volunteers to help craft the brief concept paper.
    - Louisa stated that while she is unavailable to help write the paper, she would be willing to review anything written.

Regional Updates (Group Discussion)

**NEGC (Greg Prazar)**
- A webinar will be held on March 30th with Family Voices to share how families handle accessing care and insurance denial issues. The webinar registration link can be found here.
- The GEMSS website was developed to be used by school nurses and other school officials. NEGC would like to expand the resource to reach out to primary care providers.

**NYMAC (Kunal Sanghavi)**
- The Medical Home Webinar Series is available for on-demand viewing including for CME credits.
- The NYMAC 2016 Summit was recorded and the region is in the process of uploading the recordings and including CME with the webinar.
- On January 20th, a webinar will be held to discuss Patient-Centered Communications.
• The NYMAC Needs Assessment found that providers and consumers would like to know what resources are available and different models of care.
• Announcements for webinars are sent to partners, through NYMAC News and Facebook posts.

SERC
• No update provided.

Region 4 Midwest (Kristen Hawkins)
• Region 4 Midwest Family Forum developed a guideline for parent’s when they have a child with a genetic disorder. *Journey through Diagnosis Guide* includes families’ experiences and broad information that allow for dissemination outside of the region.

Heartland
• Not present.

MSGRC (Marilyn Brown)
• No update provided.

WSGSC
• Not present.

AAP (Stephanie Mucha)
• Stephanie Mucha has begun working for the Council of Children with Disabilities and can provide updates about the council to the group moving forward.
• A report, *Recognition and Management of Medical Complexity*, was published in *Pediatrics* that discusses cases of medical complexity. A webinar was held in December that shared the report.

Call ended: 1:41 PM ET