

Quick recap - May 21, 2026 R69 Initiative Meeting

The meeting focused on establishing the R69 Initiative's constitution and governance structure. Helen led the session with approximately 18 participants from around the world, including rare disease advocates, researchers, and healthcare professionals. The group decided to prioritize developing a constitution with amendment capabilities and creating a mission statement, with Tony tasked to draft the mission statement initially. The five decision-makers agreed to review the existing four-point constitution template and provide feedback within two weeks through a shared Google Doc, with plans to present the finalized documents at the June meeting. The group also discussed the need to incorporate equity considerations into the constitution and ensure global applicability while maintaining simplicity.

Next steps

Helen

- Create a Google Doc of the Constitution and mission statement, share with all 245 invited participants for review and comment
- Send out a consent survey to all participants who shaped the Constitution and mission statement to gather final approval
- Present the first round of the Constitution at the June meeting if consensus is reached
- Include translation capabilities for the final Constitution document into different languages

Tony

- Draft an initial mission statement for the R69 Initiative and share with the group

Collaboration

- All attendees of the May 21st meeting: Review the initial 4-point Constitution document and provide comments/edits within 2 weeks
- All participants: Review the mission statement draft from Tony and provide feedback
- All participants: Consider and provide input on how to incorporate equity considerations into the Constitution's language

Summary

Initiative Meeting Introduction Discussion

Helen welcomed attendees to the meeting and noted they were expecting about 18 people. She offered to help anyone with questions about the initiative and mentioned she had prepared a condensed recording of her introduction. Trudy mentioned an article about R69 being used in Zimbabwe, which she agreed to look up and share. Helen discussed her previous conference presentations, including one at the Society to Improve Diagnosis in Medicine in 2022 and a recent presentation in Seattle.

R69 Initiative Decision-Making Meeting

Helen led a meeting for the R69 Initiative, explaining the consent-based decision-making approach and outlining the agenda, which included polls to understand participant roles and

locations. The group discussed the composition of attendees, noting representation from various countries and roles such as patient advocates, researchers, and physicians. Next steps included selecting decision makers for specific topics and gathering feedback on the meeting process, with an emphasis on improving attendance and representation in future sessions.

R69 Diagnostic Code Implementation Challenges

Helen discussed the challenges of implementing the R69 diagnostic code, noting that previous proposals to make it mandatory in the US through the CDC have been rejected twice. Dionne expressed concerns about the financial incentives for using the code while highlighting the importance of patient outcomes and the impact of undiagnosed conditions. The group agreed to discuss increasing positive incentives, protecting against negative incentives, and finalizing topics for June's meeting, with plans to break into smaller groups to further address these issues.

Decision Maker Role Assignment Meeting

The meeting focused on identifying decision makers from various breakout rooms to deliberate on specific topics. Helen facilitated the process, confirming participants in each room and assigning decision maker roles. The group discussed beginning with the R69 Initiative Constitution as a topic for discussion, with Steve suggesting they first establish parameters or a template if none existed.

Constitution Finalization Process

The group agreed to focus on finalizing the constitution as the foundation for their initiative, with all five decision-makers present consenting to this approach. They decided to review the existing four-point constitution document over the next two weeks, with Tony tasked to draft an initial mission statement. The team will collect feedback from all 245 people who received the invitation, with plans to present the revised constitution at the June meeting for final approval.