

Sustaining Community Engagement in Genomics Research: A Workshop

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Post-Workshop
Survey



Session I Keynote Highlights: Joon-Ho Yu

- Culture of medicine is invisible
- Strengthening (sustaining) engagement
- Product, **people**, process
 - relationships are at stake
 - spectrum of engagement: community-based, community-led, community engaged
 - CHIRON as an example
 - data reuse is good
 - research is better when communities are involved
- Korean Community Service Center: example of moving from consulting to shared leadership
 - learning community-based organization
 - how community engagement can lead to collect impact
 - opportunities for researchers to get involved with communities

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Session I Panel Highlights: What is Important to Know about Community Engagement

- Disability community has a history of trauma which is rooted in eugenics (Schelhaas)
- Understanding definitions and how communities use terms is important (e.g. discrepancy between ADA and disability) (Schelhaas)
- Understanding needs of the community from the community is key (Schelhaas, Roth)
- Include patients and families at every step of the way (Schelhaas, Trimnell)
- Communities are often dealing with multiple health priorities (e.g. access in general, chronic conditions, dental care) (Beans)
- Sharing failures and being transparent helps build trust within communities (Trimnell, Roth)
- Navigating gender meaning in the context of cancer care relies upon trust-building and allyship with individuals, advocacy groups, and clinicians (Roth)

Session II Highlights: Challenges and Opportunities for Sustaining Partnerships

- “Not about us without us” (Hiratsuka, Tsosie, Scott)
- Avoid “engagement washing” and only engaging at minimum required levels (Tsosie)
- Tribally-managed biorepositories could improve trust and transparency dynamic; consider dynamic consent models (Tsosie)
- Research and recruitment teams should be representative of those they are trying to recruit (Scott, Mittendorf)
- Engagement should happen throughout the study process (all)
- Community can be scientists too (Mittendorf)
- Be present, transparent, respectful of time, follow through, listen (Scott)
- Hire experts from the community as consultants (Mittendorf)

Session III Highlights: Methodologies for Sustaining Engagement

- Democratic deliberation can be used to educate, engage, and elicit views about the research (Gornick)
- Move from transactional to partnership (Lunn)
- Sustained community engagement may entail a combination of (Lunn)
 - university-based seed grants for start up
 - CE-specific funding
 - traditional funding (e.g. NIH grants)
- Meet participants where they are (Lunn)
 - consider remote access
 - in person listening sessions
- Close the loop by sharing results with participants (Lunn, Tindana) with a public dissemination plan (Lunn)
- Type of study defines what communities to engage with (Tindana)
- CE is both an art and a science where context matters (Tindana)

Session IV Highlights: Measuring and Assessing

- Community engagement is meaningful only if people in the community deem it meaningful (Anise)
- All community engagement models are flawed but some are useful (Anise)
- Metrics that matter should be disease agnostic (Henry Akintobi)
- Models should include what equitable power looks like (Henry Akintobi)
- Community engagement cannot be measured by recruitment (Watson)
- Publications will not reach the communities, it will be through other methods of knowledge mobilization (Watson)
- Effective engagement is demonstrated by doing something different and creating measurable changes (Watson)
- Transparency is the foundation of trust (Henry Akintobi)

Thank you and Next steps

- Please complete our post-workshop survey
- Slides and videos will be posted to the workshop webpage within a couple of weeks
- A proceedings-in-brief will be published later this year to capture the discussions here today
- Thank you for participating with the Roundtable on Genomics and Precision Health!

