4-1-2022

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HHS Public Access

Author manuscript

JAMA Health Forum. Author manuscript; available in PMC 2022 June 23.

Published in final edited form as:

JAMA Health Forum. 2022 April ; 3(4): . doi:10.1001/jamahealthforum.2022.0603.

A Framework for Promoting Diversity, Equity, and Inclusion in Genetics and Genomics Research

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Author Contributions: All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Drs Rebbeck, Mishra, Willman, and Sussman all contributed equally to the work.
Concept and design: Rebbeck, Bridges, Mack, Gray, George, Crossnohere, Paskett, Painter, Wagle, Kano, Henderson, Mishra, Willman, Sussman.
Acquisition, analysis, or interpretation of data: Trent, Nez Henderson, Willman.
Drafting of the manuscript: Rebbeck, Bridges, Trent, Paskett, Painter, Nez Henderson, Mishra, Willman, Sussman.
Critical revision of the manuscript for important intellectual content: Rebbeck, Mack, Gray, George, Crossnohere, Paskett, Painter, Wagle, Kano, Nez Henderson, Henderson, Mishra, Willman.
Obtained funding: Rebbeck, Bridges, Paskett, Wagle, Willman.
Administrative, technical, or material support: Rebbeck, Bridges, Paskett, Kano, Henderson, Mishra, Willman.
Supervision: Rebbeck, Paskett, Willman, Sussman.

Publisher's Disclaimer: Disclaimer: This article represents the opinions of the authors and not that of the NCI or the Participant Engagement and Cancer Genome Sequencing (PE-CGS) Network as a whole.

Additional Information: This article represents a collaboration of the initial awardees of the PE-CGS Network, an NCI project funded as part of the Cancer Moonshot Initiative. More information about the activities and all awardees of the PE-CGS Network can be found at pecgs.org.

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Abstract

IMPORTANCE—Research into the genetic and genomic ("genomics") foundations of disease is central to our understanding of disease prevention, early detection, diagnostic accuracy, and therapeutic intervention. Inequitable participation in genomics research by historically excluded populations limits the ability to translate genomic knowledge to achieve health equity and ensure that findings are generalizable to diverse populations.

OBSERVATIONS—We propose a novel framework for promoting diversity, equity, and inclusion in genomics research. Building on principles of community-based participatory research and collective impact frameworks, the framework can guide our understanding of the social, cultural, health system, policy, community, and individual contexts in which engagement and genomics research are being done. Our framework highlights the involvement of a multistakeholder team, including the participants and communities to be engaged, to ensure robust methods for recruitment, retention, return of genomic results, quality of engagement, follow-up, and monitoring of participants.

CONCLUSIONS AND RELEVANCE—The proposed engagement framework will guide investigators in optimizing equitable representation in research and enhancing the rigor of genomics investigation.

Motivation

Germline (inherited) and somatic (eg, tumor) genetic and genomic ("genomic") technologies hold great potential to improve health, yet not all individuals and populations benefit equally from these advances.[1] Racially and ethnically minoritized groups participate in research at much lower rates than majority populations.[2] Similarly, minoritized groups make up a small fraction of cases in genomic databases. Participation in randomized clinical trials does not reflect population demographics.[3, 4]

Intentional or unintentional exclusion of some populations leads to biased inferences, genetic misdiagnoses,[5, 6] and to clinical practices and care delivery that is insensitive to or fails to meet the needs of diverse populations. Genomic variation varies by self-identified race and ethnicity.[7] Current reference genomes, a critical component of precision medicine pipelines, oversample European ancestry. In 1 panassembly of genomes,[8] 10% of African DNA sequences were missing from currently used reference genomes. Limited reference genomes from minoritized populations can lead to elevated rates of variants of uncertain significance (VUS) that may lead to the misapplication of precision therapies as well as practices that fail to meet the needs of diverse populations and create or exacerbate health disparities in historically underserved populations.[9, 10]

To address the genomic gap in discovery, care, and guidance to institutions and policy makers, there is a need for theoretically driven approaches for engagement of diverse

participants and the communities to which they belong in genomics research. Engagement in genomics research involves many of the same principles as research in general, but the addition of genetic and genomic information necessitates addressing information complexity, culture, preferences, family relationships, individual- and community-level implications, education regarding the human genome, the role of genomic variations in disease causation, biospecimen use, data privacy and protections, appropriate data sharing, and the development of interpretative data narratives that are not unconsciously biased.

We propose a framework for participant engagement in genomics research that will facilitate a mutual partnership between communities and researchers, ensuring that participation in genomics research will accrue meaningful benefits (and limit harm) to the individual and community, and promote the development of genomics health policy that is equitable and inclusive. We have developed this framework to be applied in genomics research. However, many of the principles and actions presented here have been derived from and can be applied in biomedical research more generally.

Multistakeholder Structure

Stakeholders include all individuals who should have a voice in the preparation, planning, and execution of a research project. These groups include content area experts in study design, laboratory measurement, analysis, and other technical aspects needed to generate rigorous research results. Community stakeholder participation is required when the community has an interest in the way research is used, framed, or disseminated. Stakeholders may also include those who may influence the use of the research results, including health care professionals at community health centers as well as larger health systems, departments of health, health systems, policy makers, and payers.

The stakeholder team should be identified early in defining research goals and plans. Guidance in the formulation of multistakeholder research is found in Table 1. Researchers should ask why participants should be drawn from underserved, marginalized, or other populations; which participants should be considered; how to engage with these participants; what data and biosamples are needed and how they will be stored; how research results will be stored, accessed, disseminated, and interpreted to create a data narrative; and how success will be measured both for researchers and for the community.

Multistakeholder working groups may provide guidance and recommendations regarding research priorities and strategies and iteratively reflect on research progress and propose improvements or address issues that arise during research. Levels of stakeholder engagement should be defined, including those having roles central to the research vs those serving in an advisory role. Traditionally, definition of study aims and processes comes from research and clinical communities. To achieve optimal participation of participants, study aims and processes should be vetted by the entire stakeholder team. Because genomics research involves rapidly evolving technical advances and complex ethical, legal, social, and medical consequences, an effective means of communication across all stakeholders is critical. This may involve the development of communication tools, presentations, and other discussion forums so that all stakeholders have a working knowledge and understanding

relevant to the research. Funding support for all stakeholders should be considered early on so that appropriate resources are available, and that grant budgets appropriately recognize the contributions each makes in the research process.

Stakeholders should be made aware of the importance of their input throughout the research process and be made clearly aware of how this input may shape the development of future policies by ethics committees, clinical and public health organizations, and payers. Researchers should provide regular feedback about the positive substantive effect of stakeholder input.

Framework Values

We propose 4 values for engagement efforts to guide success metrics (Table 2):

1. Inclusivity: efforts should be inclusive of a broad population. This involves convening multistakeholder partners engaged in priority-setting and determining research conditions consistent with community values and cultural needs. This value should be maintained across the research continuum from planning through execution, and in postresearch monitoring and implementation.
2. Equity: research processes should include diverse perspectives in the development and implementation of research to achieve optimal diversity in research participation and translation of research results to clinical and public health applications. Researchers should limit roadblocks to participation that might prevent participation by historically underrepresented groups.
3. Usability: study materials should support a range of health literacy/numeracy levels, stages in development, and desires for depth of information with language or cultural linguistic adaptation.
4. Bidirectionality: study protocols should allow researchers to learn from participants, and participants to be engaged, empowered, and respected throughout the process. These values are highly interrelated, and promotion of each contributes to the fulfillment of the others.

Framework Elements

We focus on groups currently underrepresented in genomics research including minoritized racial/ethnic groups; those living in settings where access to genomic technologies is limited; and those who are diverse across age groups, sexual identities and gender orientations, disability, health literacy and numeracy, and those who have intersectional identities across these groups. The Figure presents a framework around which the inclusion of diverse participants in research is fundamentally influenced by current and historic patterns of systemic/structural racism, privilege, and power, as well as political, social, legal, and other factors that cause specific groups to be disadvantaged. These influences affect the individual and the communities and institutions with which they interact, and determine an individual’s interest, willingness, and ability to participate in genomics research or genomic

clinical diagnostics and genomic-directed therapeutic interventions and clinical trials. The key elements of our framework are as follows.

Conceptual Foundations

Numerous conceptual models have been proposed to optimize participant engagement.[11–16] The collective impact framework (CIF)[17, 18] provides conditions and metrics to assess success of participant engagement in research. Community-based participatory research (CBPR) facilitates collaboration among multisector groups who have common interests around health and disease.[19, 20] We adapt CBPR to genomics research to recognize the community from which an individual participant is derived as a unit of shared identity; facilitate bidirectional partnerships in all phases of research; foster colearning and capacity building among all partners; and achieve a balance between knowledge generation and health benefit of partner communities. These principles should focus on locally relevant health problems; appropriately engage participants in review of data and results and development of the data narrative; commit to sustainability; address issues of race, ethnicity, racism, and social class; embody cultural humility; and ensure research rigor and validity.

Context

Multilevel contextual factors that affect participant engagement in genomics research include individual, social, and health system influences on human health and disease. We draw from the theory of reasoned action[18] to consider:

- Cognitive issues: information processing, health literacy, ability to comprehend complex research/clinical proposals, knowledge of genetics/genomics and its use or value in their life or health care choices and decision-making.
- Attitudes and beliefs: preferences, fear, or patient experiences that contribute to willingness for research participation; trauma or stigma; individual genetic privacy and confidentiality; religious or cultural concerns regarding collection of biospecimens and their future use; and privacy and use of genomic results.
- Social and structural: social and community context, particularly in cultures for which community support or approval of decision-making influences individual decision-making, such as in American Indian communities. Socioeconomic position affects access to genomics research or services owing to cost or insurance barriers.
- Subjective norms and motivation to comply: physical access may be limited by individual needs including childcare, eldercare, time off from work, transportation. Cultural perspectives and beliefs of family or friends and other support networks including culturally based concerns such as ethnic or tribal identity or individual genetic privacy.
- Health system: health system context involves institutions with which research participants interact. Institutions may prioritize profit over service to diverse populations intentionally, unintentionally, or because of limited resources or infrastructure. They may provide limited accommodation in services or staff training to meet the needs of diverse participants and communities

they serve, or for their staff to be appropriately acculturated and trained in unconscious bias to accommodate language, culture, or preferences for informed consent, questionnaires, unnecessary exclusions or eligibility and participation requirements that disproportionately affect certain groups. Researchers may not take steps to present the study and garner buy-in from community leaders or other family or social, cultural, or religious networks that reach beyond the individual's consent to participate in research. Limiting which insurance plans are accepted by the institution may bar some groups from accessing genomics research and services.

Participant-Centeredness

Participant-centeredness is key to ensure optimal effect of research findings.[21] Research consent should explicitly explain that anonymized, deidentified data will be deposited into public databases. Participant-centered questions should be anticipated and included in study materials. For example:

- What are my options for receiving genetic information if I participate in research?
- What should I expect with regard to my health?
- What will happen to the biosample I provide for testing and analysis?
- How can my genomic data help others?
- Who will have access to my genomic data and how will they be used?
- How are my identity and privacy protected?

Recruitment

Population-based recruitment strategies can exclude subgroups that are difficult to reach or participate at lower rates. Newer approaches to cohort-based research such as All of Us,[22] Count Me In,[23] and MindCrowd[24] use internet-based platforms to engage participants who can enroll and participate in genomics-focused research remotely. Concerns about these approaches have been raised by some communities.[25] Virtual approaches are dependent on participants and communities having adequate internet access, which is challenging for many rural, underserved, and indigenous communities.

Retention

Realistic assessment of the feasibility and acceptability of research requirements is critical to avoid participation attrition. Literacy, numeracy, and multiple (in-person) visits represent retention barriers. Supports and structures that participants require to remain engaged could include use of telehealth and remote communication and consenting options, minimization of the need and time and cost of travel to a study center or support for travel and engagement costs, or community-based discussions responsive to community preferences. An understanding of attrition for genomic protocols in specific populations will lend itself to a stepwise, targeted approach to improve retention and maximize opportunities for participation in genomics research.

Quality of Engagement

Engagement quality depends on the development and maintenance of appropriate and tailored strategies that lead to the "meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process and beyond."[11] Engagement requires relationships and trust between the researchers and participants from concept, development, execution, monitoring, dissemination, and implementation. Development of a nonbiased data narrative, translation of the research both to the individual participant and their community, and assessment of its individual, community, and societal effect are required.

Return of Genomic Results (ROGR)

Knowledge that facilitates ROGR is increasingly available,[26–30] although standard processes for ROGR in diverse groups are challenged by rapid changes in technology and knowledge. The observation that Black, Asian, and Hispanic women are more likely to undergo genetic testing for therapeutic purposes (ie, after a diagnosis) than for risk assessment and management has informed participant and clinician issues in ROGR.[31] Uncertainty about clinical actionability[32–35] exists regarding somatic (tumor) ROGR, whether it be to the research participant or their clinician.[36] This is particularly true in understudied populations where reference genomes have not been developed and VUS may be common. Efforts to aid participants to understand genomic results can involve genetic counselors and other trained personnel,[36, 37] who are limited in supply and may not have training to manage the needs of minoritized groups. Even less is known about how best to present results to populations with lower levels of health literacy, the culturally diverse, non–English speaking, or adolescent participants.[38] Educational materials adapted to specific populations require tailoring around culture, beliefs, language, educational level, and other factors. Educational materials should also consider each community's individual or collective cultural context and explain how participation in genomics research will contribute to personal health and improve care for other members of the participant's community.

Monitoring

Participants who receive genomic results may require recontact if new clinically relevant and actionable findings are discovered that may affect clinical management or care. This is particularly likely where genomic sequencing is more likely to reveal VUS at the time of testing. It is critical that relationships with the participant be maintained throughout their study participation to ensure recontact is welcomed by and beneficial to the participant.

Implementation

Although the concepts presented in the framework will in theory improve diversity in genomics research participation, there are substantial barriers to their implementation. Historically, it has been difficult to obtain the funding required to undertake the labor- and time-intensive processes required to achieve this goal. Often, funders do not pay for the development of these processes, particularly because these activities may require long-term commitments and engagement with the community that involve ongoing costs (well beyond the usual NIH 5-year grant cycle). The lag between building community

engagement in research and downstream availability of diverse biosamples and data are a further barrier. This is exacerbated by the fundamental disconnect between the rapid pace of genomics research, which often involves quick discovery and turnaround of reporting, and the slow and continuous processes needed to establish community linkages. Currently, there are limited academic incentives for many in the genomics community to engage with communities. A partnership model between genomicists and community-engaged researchers and institutional community liaisons may be considered to achieve diversity goals. Given recent attention to the importance of diversity in addressing major health problems suggests opportunities for funding and other resources to address these issues may be forthcoming.

Phased Process

Our framework (Table 3) involves phases defined by the CBPR and CIF models[12, 13, 16, 19, 20] that include generation of ideas and dialogue, initiating action, organizing for effect, and sustaining actions and effect for each activity.

Phase 1: Define Context

Prior to research initiation, the knowledge landscape that guides research questions and actions should be explored and understood. The team should understand the historical, social, cultural, community, and economic factors that influence engagement (or lack thereof) in genomics research. The contextual background may be specific to each research question as well as the populations in which the data may be translated. Preresearch considerations include asset identification, local values, data gathering approaches, the policy-making process, visual and social media, and scale of future policy and implementation.[20]

The state of knowledge about genomic variation, population and evolutionary genetics, and biomarker distributions should be understood for the population under study. Practice gaps including access to sophisticated genomic technologies that may be unavailable to some relevant groups in future clinical practice should be understood. Continuous monitoring and updates of these settings should be undertaken in response to new data, knowledge, or conditions.[39]

Phase 2: Establish Partnership Processes and Governance

The research team should engage with cross-sector stakeholders, community advisory boards, laboratories, advocates, researchers, policy makers, ethicists, health care professionals, and others. Focus groups representative of future research participants and other stakeholders should be undertaken to understand the state of knowledge and community needs and preferences. Diverse cross-sector teams should identify stakeholder resources, social capital, shared values, and time commitments. Researchers should identify opportunities to execute and implement the research by understanding the cultural and linguistic setting. This process should result in a common agenda, goals, and strategy for the research. It should build stakeholder trust, plan for conflict management, and identify leadership in specific research domains.

Phase 3: Prepare for Research

By now, research goals, needs, gaps, and processes should have been discussed among all stakeholders. Stakeholder input should identify participant issues and future community implementation related to generation of genomic data; genomic data privacy and confidentiality; ethical, legal, social, and family issues; cost and insurance; data interpretation and use; data sharing; biosample storage, future use, and return; implications on current and future health and health care; and implications for treatment and monitoring for those who may currently be participants or who are at risk of developing a condition related to the genomic data.

Research protocols should consider stakeholder needs to motivate culturally appropriate shared surveys, metrics, indicators, and measurements. Biosample collection or laboratory assays can be adapted to the population under study at this time, and perhaps earlier if pilot testing of biosampling methods, collection, processing, or storage are required. Development and implementation of protocols for genomic data curation, communication, and storage must be consistent with the legal requirements, needs, goals, and preferences of the communities under study. Considerations for future data sharing, access, and risks of reidentification must be delineated. Because the knowledge and translation of genomic data changes rapidly, consideration for potential use of the data for purposes other than originally intended, including unpredictable future clinical actionability, must be stated.

In engaging stakeholders who are directly affected by disease, realistic and feasible responsibilities of research participants should also be defined. The psychosocial, economic, and personal burdens of disease to the participant and their caregivers are not trivial, and may impose burdens that are not clear to the researcher who does not have a good understanding of the participant-centered setting.

Culturally appropriate shared metrics, indicators, and measurements should be developed and applied by study staff that understand the context and community conditions where the study is being done. Unnecessary exclusion criteria that limit the participation of some groups can be understood and eliminated such as requirements to speak English or have no comorbidities. These exclusions not only excessively disadvantage some populations from participating in research, but also restrict the generalizability of future applications of the intervention. Expert guidance from knowledgeable oversight bodies (eg, clinical trials offices, IRBs) that minimize undue barriers from research participation should be sought.

Protocols should be developed to ensure optimal ROGR, particularly if these results have health or social implications to the participant and their relatives. The ROGR should assume participants may fall across a range of health literacy levels, ages, beliefs, and stages in development. Achieving this goal requires early consultation with stakeholders who can confirm that if ROGR is planned, communication is beneficent, causes no harm, can be acted on, and downstream health issues are clear to the participant, and possibly to their community. Potential for recontact should be developed in light of new clinically relevant or actionable information becoming available.

Phase 4: Conduct Research

Much of the activity required to undertake genomics research in diverse populations occurs well before the first participant is recruited. Continued dialogue with all stakeholders including formal (eg, advisory board meetings) and informal communication should occur regularly so that adaptations can be made to the protocols based on knowledge gained as the research is being undertaken. As in a clinical trial, a stakeholder advisory board can monitor adverse events (eg, miscommunications, improper information flow, unfavorable participant or community reactions to the research) and suggest remedies. A system for ongoing monitoring and reporting of research progress should be in place so that a rapid response can be mounted when new situations or adverse events arise.

Phase 5: Implement Findings and Inform Health Policy

Ongoing monitoring and evaluation of the research process, including diversity of enrolled population and participant attrition, will allow remediation of research in process and provide context around which research results can be interpreted and implemented. Ongoing assessment of clinical and policy effects, partnership viability, and shared goals is also required. An understanding of unintended events, barriers to participation, accrual, and retention will inform the potential effect of the research for translation to the stakeholder groups (eg, health care settings, communities) in which the results may be applied.

As research results become available and focused development of implementation or dissemination of research data are possible, stakeholders should assess readiness for change of the clinical, patient, population or others who may use the intervention.[39] An understanding of reasons for low participation, high attrition, or inadequate communication of results identified during the research process may inform future implementation. This information will also inform resource needs that can be applied or extended to disseminate research data to communities and identify change mediators and behaviors that will ensure genomic information can be broadly disseminated to diverse populations. Use of well-established implementation metrics, such as the Reach-Efficacy-Adoption-Implementation-Maintenance (RE-AIM) framework,[40] will maximize future implementation of evidence-based approaches into standard practices and processes. These practices and processes can inform the establishment of health policy for genomics research that are both scientifically robust and responsive to the unique experiences of diverse participants.

Limitations

The practices and processes described herein will require further theoretical and empirical research to refine and optimize effects.

Conclusions

The participation of historically marginalized, underserved, and understudied groups in genomics research has limited progress in understanding human disease genomics, and has been a barrier to addressing health disparities. The framework is developed without respect to a specific disease or clinical application, but we acknowledge that adaptations may be required to apply these concepts for specific diseases to accommodate biological, clinical, or treatment issues. For example, somatic genomics will be highly relevant to cancer, but

much less relevant to cardiovascular disease where germline genomics may predominate. The framework proposed here can guide research teams to improve their ability to engage traditionally understudied populations by guiding the planning and execution of genomics research to have maximal clinical, public health, and policy effects.

Conflict of Interest Disclosures:

Dr Rebbeck's spouse is a consultant to AstraZeneca. He holds grants from the National Cancer Institute. Dr Bridges reported grants from the National Institutes of Health (NCI) during the conduct of the study. Dr Mack reported grants from National Cancer Institute during the conduct of the study. Dr Gray reported other from TripTych Health Partners Consultant for a lung cancer seminar outside the submitted work. Dr Gray's spouse has equity in Magenta Therapeutics. Dr George reported institutional funding (clinical trials agreement) from Blueprint Medicines, Deciphera Pharmaceuticals, Daiichi Sankyo, Tracon, Merck, Theseus, Eisai, Springworks, personal consulting fees from Deciphera, personal fees from WCG (compensated DSMB member), personal fees from CStone (compensated educational talk), personal fees from Kayothera (compensated scientific advisory board member), equity from Abbott Laboratories, and royalties for UpToDate from Wolter Kluwers contribution outside the submitted work; and Vice-Chair, Alliance for Clinical Trials in Oncology Vice-President, Alliance Foundation. Dr Paskett reported grants from National Institutes of Health, National Cancer Institute during the conduct of the study; grants from Merck Foundation and grants from Pfizer outside the submitted work. Dr Painter reported grants from Broad Institute during the conduct of the study; personal fees from Nuscan and personal fees from One Health outside the submitted work. Dr Wagle reported grants from Broad Institute during the conduct of the study; personal fees from Eli Lilly and Company, personal fees from Relay Therapeutics, personal fees from Flare Therapeutics, grants from AstraZeneca, and grants from Puma Biotechnology outside the submitted work. Dr Mishra reported grants from National Institutes of Health/National Cancer Institute during the conduct of the study. No other disclosures were reported.

Funding/Support:

This work was supported by grants from the National Cancer Institute of the NCI (U2CCA252973, U2CCA252974, and U24CA252977.)

Role of the Funder/Sponsor:

The NCI had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

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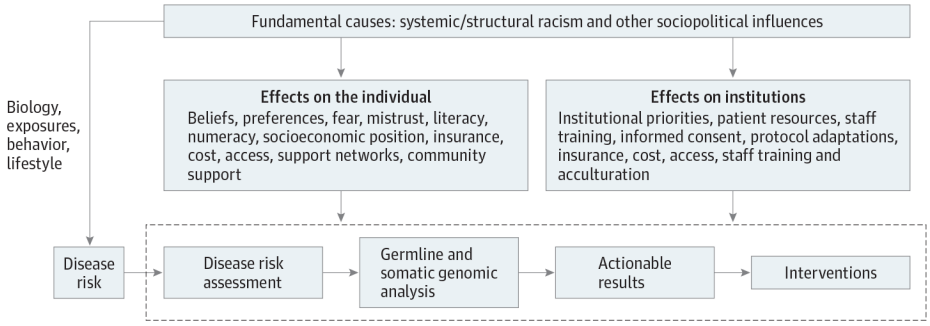

Figure.
Multilevel Influences on Genomics Research Participation

Table 1.

Considerations During Preparation for Genomics Studies Involving Participants Typically Underrepresented in Research

Domain	Questions to be considered
Sample design	• Are diverse populations needed to achieve the research objectives? If so, why? • What diverse groups should be included to address the scientific question of interest? • What sample size and statistical power are required to answer research questions and maximize the potential for generalizability in population subgroups (eg, analyses by race or ethnicity)?
Communication	• How should bidirectional relationships with participant, community, advocacy, and other partners be developed and managed to ensure appropriate community input for research design, execution, use and reporting of data, communication back to the community?
Process	• How will participant accrual, retention, and ongoing follow-up be collected, tracked, reported, and evaluated? • How will the biospecimens be collected, used (current and future), stored, returned, disposed? How can biospecimens be withdrawn? Need for active consent for secondary use or future use of biospecimens? How can tribal, traditional, and religious or spiritual leaders participate in defining processes for biospecimen handling? • What are measures of optimal engagement (ie, empowerment, trust, respect, such as respect for sovereignty of tribal and other nations)? • What informed consent, confidentiality, and other elements of human participants research need to be considered and how? Should these be culturally, linguistically, literacy, or otherwise tailored to the populations being studied? How can participants opt out now or in the future? • What authorities or institutional and/or community review boards, beyond that of the traditional health system institutional review board (IRB), such as tribal IRBs and community IRBs be engaged in protocol and consent review? • What data use and data sharing agreements need to be considered? How can sovereign Tribal Nations and other communities participate in developing these shared agreements? • What baseline data and biosamples are required? How will these be stored and accessed? How will future use and participant recontact be defined? • What common data collection instruments, interviews, and surveys should be available? Can these be standardized for common collection across studies and centers that may increase future data sharing? • Can data or samples be deidentified, or is participant recontact required, and if so, how will this be accomplished? • Are shared decision-making or other models appropriate for community engagement throughout the research process? • What success measures and metrics are required to maximize participant experiences, empowerment, and self-advocacy?
Outputs	• How will return of genetic or genomics results be managed? • What means of communicating ongoing participation, results reporting, and translation of findings back to the community should be undertaken? • What genomic findings will be reported back to the participants, and how? • What unintended consequences of research participation or receiving information might arise in genomics studies?

Table 2.

Framework Values and Success Metrics

Value	Processes and feedback	Potential success metrics
Inclusivity	• Participant reports of acceptability of recruitment materials and interfaces.	• Representativeness of enrollment and retention for full sample and subpopulations relative to population of inference.
Equity	• Participant identification of roadblocks in recruitment and retention process.	• Enrollment and retention rates (overall and at each step from consent through recontact, as appropriate) reflect the diversity of the full sample and subpopulations of interest. • Ability to generalize and translate research results to diverse populations.
Usability	• Participant and study staff feedback on materials and reports, including format, content, and how information is shared.	• Rates of return of genomic results. • Time to return of genomic results. • Uptake rates of genetic counseling. • Participant understanding of findings. • Participant understanding of clinical implications of results.
Bidirectionality	• Participation in feedback surveys and interviews. • Participation in initiatives focused on underserved populations. • Engagement of partners. • Efficiency of uptake of findings to standard processes (time from conclusion of pilot to incorporation).	• Effect on participants (participant empowerment, feeling respected and valued, willingness to continue engagement). • Time from conclusion of pilot work to incorporation into standard processes.

Table 3.

A Framework for Engagement of Diverse Participants in Genetics and Genomics Research

Community-based participatory research dimension	Collective impact dimension			
	Ideas and dialogue	**Initiate action**	**Organize for impact**	**Sustain action and impact**
Phase 1: define context	Map the current landscape: social, structural, policy, health care, capacity, readiness, and other factors relevant to the stakeholders' participation in genomics research.	Monitor and refine context in response to new data, knowledge, or conditions.	Monitor and refine context to response to new data, knowledge, or conditions.	Monitor and refine context to response to new data, knowledge, or conditions.
	Common agenda	Continuous communication	Continuous communication	Continuous communication
Phase 2: establish partnership processes and governance	Identify and hold dialogue with cross-sector stakeholders and champions, including laboratories, clinical service professionals, community members, researchers, policy makers, ethicists, and others.	Form diverse cross-sector teams. Assess need for agreements, resources, social capital, shared values, and time commitments. Ensure research teams include staff who can implement proposed research using culturally and linguistically tailored methods.	Create a common agenda, goals, and strategy. Facilitate stakeholder outreach, build stakeholder trust, conflict management, leadership, decision-making.	Monitor and refine context to response to new data, knowledge, or conditions.
	Mutually reinforcing activities	Backbone support	Backbone support	Continuous communication
Phase 3: prepare for research	Convene stakeholder dialogue to identify issues: genomic data, privacy, trust, data use, ethical, legal, family issues, insurance, current and future health and health care, implications for treatment and monitoring, and others. Determine stakeholder needs and requirements for moving forward with research. Possibly conduct a community health needs assessment.	Summarize baseline data to motivate planned research and identify key gaps and issues likely to arise. Involve stakeholders to develop culturally appropriate shared metrics, indicators, measurements, approaches. Create molecular panels or methods that adequately capture diverse genomic variation by (eg) race and ethnicity. Develop and implement protocols for genomic data curation, communication, and return of results. Create culturally tailored educational tools for research participants.	Create partnership infrastructure that incorporates stakeholder knowledge, empowering processes. Create stakeholdercentered interventions, research tools, and study designs.	Monitor and refine context to response to new data, knowledge, or conditions.
	Mutually reinforcing activities	Shared measurement	Mutually reinforcing activities	Continuous communication
Phase 4: conduct research	Record and re-evaluate dialogue on an ongoing basis as research proceeds.	Utilize culturally appropriate shared metrics, indicators, measurements, approaches. Streamline clinical trials processes, limit unnecessarily restrictive study exclusion criteria.	Regular bidirectional interactions across stakeholders to monitor research progress, arising issues, and impact	Collect, track, and report on research progress, including unintended events.
	Continuous communication	Shared measurement	Continuous communication	Continuous communication
Phase 5: implement findings and inform health policy	Record and re-evaluate dialogue on an ongoing basis as research proceeds.	Record and re-evaluate dialogue on an ongoing basis as research proceeds.	Establish predefined metrics of success. Identify, communicate, and remediate issues arising during research.	Assess clinical and policy impact, partnership viability, shared goals, cultural reinforcement. Research productivity and impact on focus

Community-based participatory research dimension	Collective impact dimension			
	Ideas and dialogue	Initiate action	Organize for impact	Sustain action and impact
				stakeholder groups. Reassess process in light of unintended events or new knowledge gained.
	Continuous communication	Continuous communication	Shared measurement	Shared measurement