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Appendix of All Recommendations from the Convenings

These are all of the recommendations through the convenings. They are a collection of recommendations noted from discussions following panels, gathered from interactive activities, and submitted online. They have been lightly edited for readability, but are otherwise unchanged. Here they are, organized into the "buckets" and "tags" you see below.

Buckets	Tags
ACTION	ADVOCACY
	COMMUNICATIONS
	FUNDING
	INTERNAL
	NEXTGEN
GENERAL	CAUTION
	PEOPLE
	PRINCIPLE
	WHO, academia
	WHO, advocacy
	WHO, community
	WHO, govt
	WHO, health
	WHO, philanthropy
POLICY	POLICY
RESEARCH	DATA, access
	DATA, analysis
	DATA, collection
	DATA, security
	DATA, utility
	DATA, variable I
	DATA, variable II
	RESEARCH, analysis
	RESEARCH, design
	RESEARCH, process
	RESEARCH, question

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ACTION	ADVOCACY
	COMMUNICATIONS
	FUNDING
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Advocacy

- Build relationships between researchers and advocates to align their intentions with achieving the health equity of racial and ethnic subgroups.
- Integrate the consultation and feedback of community representatives on research design and question wording. For instance, the Census and American Community Survey questions on racial and ethnic subgroups.
- Assess public perception of data disaggregation of racial and ethnic subgroups.
- Build and spread awareness around data disaggregation issues. For example, internal vs. external identification, misclassification, fluidity of identity, and ethno-racial sampling frames.
- Generate buy-in and consensus with communities of the most potential benefit from data disaggregation. For example, Indian country and small populations.
- Communicate the salience and potential solutions of data disaggregation to the federal administration.
- *Specifically for the AI/AN community*, support and execute all relevant research with the Common Rule (Subpart A of 45 Code of Federal Regulations Part 46) and the National Institutes of Health Single Institutional Review Board (sIRB) Policy, which respect tribal sovereignty within the research process over activities on tribal lands and with tribal citizens.
- *Specifically for the Black community*, support the cultural movement of "Black is Beautiful" to counter the negative association of characteristically Black phenotypic traits (e.g. skin tone, facial features, hair) with ugliness and to counter internalized racism.

Communications

- Promote the message of community-based participatory research, targeted universalism, cultural humility, and data sovereignty across all communities of practice.
- Build and spread awareness about existing research and empirical evidence with data disaggregation and health equity. For example, genomics, migration, vitamin D, health status, and health care utilization.
- Use data disaggregation as a through line in the analysis and reporting of health care access and utilization of racial and ethnic subgroup communities.
- Generate official definitions for the immigrant and migrant population groups in the health field, with explicit underlying concepts.
- Encourage further research on skin tone and health, which has "near zero missing report data" when contextualized with other objective biomarkers.
- Build and articulate a strong economic argument for the data disaggregation of racial and ethnic subgroups, and the cost of not disaggregating data at the state and local levels. For example, effectively targeting resources to needs, voting rights, having experiences of subgroups visible and heard, knowing the composition of society, better data-driven policies.

- Create community buy-in for data disaggregation with the appropriate media streams for racial and ethnic subgroups (e.g. social media, in-language media).
- Leverage social media to address misinformation about data disaggregation.
- *Specifically for the multiracial community*, craft and amplify messaging that counters a "zero sum" framework of disaggregating the multiracial community with other racial and ethnic identification data in order to develop interpretations of multiracial health.

Funding

- Identify and advocate for increased sources of funding from survey funders, philanthropies, and government agencies.
- Align funding and investments for data disaggregation with social justice.
- Target funding to encourage greater comparative research between racial and ethnic subgroups.
- Target funding to utilize currently existing data.
- Target funding to address survey burden among survey respondents.
- Target funding to address the associations between skin tone and health.
- Target funding beyond implementation efforts to evaluation efforts.
- Target funding to health care providers and social service agencies, so that they can update electronic health systems and paper forms to align with the data disaggregation of racial and ethnic subgroups.
- *Specifically for the AI/AN community*, fund and invest in AI/AN tribes, researchers, and activists to realize indigenous data sovereignty, tribal data capacity, and indigenous statistics.

Next Generation

- Support researchers to adapt and respond to the influx of "new" populations with evolving data practices. For example, "only Hispanic" and "Hispanic multiracial."
- Support initiatives to train frontline staff in the health care services industry when asking about the race and ethnicity of a patient at the point of intake.
- Support initiatives to recruit and train the next generation of researchers with a safe space for them to lead.
- *Specifically for the AI/AN community*, support initiatives to recruit and train young folks and build curricula and resources for universities, in order to bolster indigenous data sovereignty.

POLICY	POLICY

Policy

- Develop protocols to motivate the collection of granular data, to assist the appropriate utilization of available data, to guide the analysis of disaggregated data. For example, disaggregated data about migrants, immigrants, and ethnic minority groups.
- Build shared understanding of how specific multiracial combination data are used to inform policy (e.g. White/Black, White/Asian, Black/AI/AN).
- Develop policies that are flexible to the fluidity of identity while considering the legal interpretation of race and ethnicity.
- Develop policies that build funding for data collection and research on migrant and immigrant groups.

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- Develop policies that are aimed to protect the identity of immigrant groups.
- Revise the Patient Bill of Rights to include misclassification issues (e.g. multiple definitions of race, multiracial communities, internal vs. external identification).
- Advance and defend Section 4302 of the Patient Protection and Affordable Care Act.
- Develop policies that bolster agreement, standardization, and enforcement of data collection to Office of Management and Budget standards across federal, state, and local agencies.
- Seize opportunities with the Office of Management and Budget and Congress to advocate upon legislative policies. For example, OMB policies to improve classification of racial and ethnic subgroups and integration of tribal interests to AI/AN identification.
- *Specifically for the AI/AN community,* develop policies with the Office of Management and Budget and the U.S. Census Bureau that are supportive of indigenous data sovereignty, tribal trust responsibility, tribal consultations, and government-to-government relationships.

RESEARCH	DATA, access
	DATA, analysis
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	DATA, security
	DATA, utility
	DATA, variable I
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Data, access
- Increase access to data by addressing challenges of the Census Research Data Centers.
- *Specifically for the AI/AN community,* improve data sharing among tribes and research entities.

Data, analysis
- Analyze data with consideration of social justice and human rights.
- *Specifically for the multiracial community*, analyze data with consideration to the size and heterogeneity of the community. For example, the AI/AN and Latino/a/x communities are both small and interdependent subgroups.

Data, collection
- Collecting data using standardized methods and vetted questions (e.g. country of origin, ancestry, generational status, nativity status, language proficiency).
- Collect data with tools that are in-language and accultured to capture linguistically-isolated and/or low-education individuals.
- Develop questions to ask for racial identification in consideration of internal vs. external identification issues (e.g. how do you self identify? how do people see you?).
- *Specifically for the AI/AN community*, support indigenous data sovereignty for tribes to collect, own, and apply tribal data for their rights and interests.

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- *Specifically for the AI/AN community*, follow the principles and recommendations of the Native Nations Institute's Indigenous Data Sovereignty Group in data collection.
- *Specifically for the AI/AN community*, collect data acknowledging the sensitivity of data collection among this community.
- *Specifically for the multiracial community*, collect data using free text responses, as well as multiple responses, to capture greater granularity and increasing the population's response rate.

Data, security
- Build and defend data security to ensure the privacy of survey respondents. For example, undocumented immigrants.
- Build and defend the few data sets on small populations that can be comparative across data sets. For example, data on the LGBTQ community.

Data, utility
- Harness the potential of administrative data. For example, training administrators to allow researchers to interact with the healthcare data system.
- Develop measurement tools for predictors of health among migrant and immigrant groups that are consistent.
- Defend sets of questions in government surveys to allow for continuity.
- Support the ability of U.S. Citizenship and Immigration Services to cross tabulate their data by state on immigration visa type.
- Determine the relative costs of sample size expansion vs. adding and modifying existing survey questions.
- *Specifically for the multiracial community,* create data linkage strategies to build data sets.

Data, variable I (specific variables identified, in alphabetical order)
- Collect these variables:
    o Address (geocoded)
    o Age
    o Age of Immigration
    o Birth Place
    o Citizenship (naturalized, birth)
    o Ethnicity
    o Generational Status
    o Grandparent Country of Birth or Birth Place (maternal, paternal)
    o Immigration Status
    o Languages Spoken (monolingual, multilingual)
    o Languages Spoken at Home
    o Languages Spoken at Work
    o Legal Permanent Residency
    o Moves within Home Country (geocoded)
    o Moves to US (geocoded)
    o Moves within US (geocoded)
    o Parent Country of Birth or Birth Place (maternal, paternal)
    o Reason for Immigration
    o Remittances

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- o Sex
  - o Skin Tone
  - o Visa Status
  - o Year of Entry
  - o Year Naturalized
- Collect these longitudinal variables:
  - o Ethnic Identity
  - o Immigration Status
  - o National Identity
  - o Parental Birth Place
  - o Racial Identity
- Collect these proxy variables:
  - o Immigration Status - # of years in the US, nativity
  - o Undocumented Status
- Collect data regarding:
  - o Acculturation (reflected)
  - o Cultural markers
  - o Demographic trends concerning multiple racial identities
  - o Differential health outcomes by nativity status
  - o Discrimination (beyond everyday, continuum, perceived, related to immigrant status, within-group)
  - o Gender Identity (continuum)
  - o Internal migration among non-immigrant groups
  - o Nuclear family members still in country of origin
  - o Reason(s) for staying in US
  - o Reflected race
  - o Skin Tone (continuum)
  - o Socio-economic status in country of origin prior to migrating to the US
- Collect metadata on who is "assigning" the race/ethnicity of patients in observed classification systems (e.g. self, intaker, nurse)

Data, variable II (develop research and questions about these variables)
- Collect data regarding:
  - o Acculturation (in federal surveys)
  - o Community make up
  - o Home and host countries context and effect on health profiles of immigrants
  - o Migration and internal migration
  - o Immigrant barriers to accessing government aid (e.g. five-year bar, lack of documentation)
  - o Skin tone (objective measures beyond self-identification)
- Collect data at the state and local level regarding:
  - o Anonymized ethnicity
  - o Anonymized race
  - o Immigrant health
  - o Immigration status
- Collect denominator data for all immigrant groups by visa or nonimmigrant status.
- *Specifically for the AI/AN community*, collect data on tribal and urban areas.

- *Specifically for the NHPI community*, collect data about immigration status to capture the implications for eligibility and access to government safety net programs (e.g. US citizens, US nationals, Compact of Free Association immigrants, foreign nationals).
- *Specifically for the multiracial community,* collect data in geographic areas that have substantive amounts of the multiracial population. For example, California, Hawaii, and urban centers.

Research, analysis
- Analyze migration data with consideration of gentrification.
- Analyze skin tone data with consideration of the geographic context (e.g. US, Brazil).
- Analyze data from free text responses with a flexible hierarchical categorization to enable a very high degree of disaggregation. For example, a categorization that can be expanded or collapsed.
- Analyze research with consideration of differences across subgroups attributable to age, cohort, or period effects.
- Analyze the eligibility of respondents to certain government programs within government surveys about health outcomes.
- *Specifically for the AI/AN community*, analyze data using indigenous statistics to counter the 'deficient indigene' approach (e.g. simple comparisons without context).
- *Specifically for the AI/AN community*, analyze data with consideration of internal migration.

Research, design
- Design research that is culturally sensitive.
- Design a nationally representative, longitudinal panel study on the role of race and culture on health.
- Design research using "Delphi group" to ascertain the primary uses and thrusts for ethnic data (e.g. immigration status, health disparities by race and ethnicity).
- Design research based on the assets, strengths, resilience, and positive outcomes of racial and ethnic subgroups.
- Design research that leverages Big Data, electronic health records, and existing data.
- Design research with methods to address small populations and small sample sizes. For example, Bayesian methods, pooled statistics, small-scale surveys, and field research, in homogeneous and heterogeneous neighborhoods.
- Design research about immigrants in standalone studies (e.g. Native Hawaiian and Pacific Islander National Health Interview Study).
- Design research with methods to address the differences between and among immigrant groups.
- Design research about immigrant participation in surveys at the small scale.
- Design research that enhances strong suggestive evidence of the clear health differentials by legal status.
- Design research that enhances the clear health differentials by immigrant generation and length of stay in the US, above and beyond race and ethnicity.
- Design research that enhances the strong theoretical basis and emerging empirical evidence of the contributions of country of origin and context of reception to health status.
- Design research on skin tone that is comparative, contextual, and restorative.
- Design research to examine different aspects of discrimination in lieu of different measures of skin tone, using the National Health Interview Survey, the National Health and Nutrition Examination Survey, and Adverse Childhood Experiences Survey.

- Design research to capture different racialized experiences depending on the target health outcomes.
- Design research about acculturation measures to learn from the perspective of the international community.
- *Specifically for the AI/AN community*, design research with tribal organizations, indigenous populations, and elders in the discussions regarding interventions, methods, data collection, etc.
- *Specific to the AI/AN community*, design research to learn best practices for collecting and reporting data from the Maori in New Zealand.
- *Specifically for the multiracial community*, design research that standardizes the data management of race and ethnicity.

Research, process
- Develop research methods for examining the intersection of identities.
- Overhaul sampling bias by encouraging research with better units and system changes.
- Generate recommendations for researchers and reports about up-coding.
- Encouragement engagement of immigrants in the research design and process for research about immigrant health.
- Support commanding research on the issue of internal vs. external identification by folks who are experiencing racial misclassification.
- Anticipate mental health outcomes in research on the issue of internal vs. external identification.
- Research skin tone directly in the context of health.
- Encourage research with the ability to "pull out" the multiracial population as needed.

Research, question
- Research how disaggregated data reflects communities.
- Research the cost-benefit analysis of disaggregated data and ethno-racial sampling frames with community consultation.
- Research the use of estimation techniques in lieu of survey data.
- Research misclassification issues and outcomes on the health of racial and ethnic subgroups.
- Research the issue of "accuracy" in mixed ancestry identity (e.g. if racial groups do not exist, how can multiracial groups exist?).
- Research how multiple-race selection intersects with health surveillance. Research general opinion of talking about skin tone via social media.
- Research social media as a forum to remain contact with participants over the course of a health intervention.
- Research diaspora measures on health.
- Research borders and migration. For example, fluid borders in international contexts and internal migration of AI/AN populations.
- Research whether domestic migrants and international immigrants have similar health profiles.
- Research acculturation. For example, its effects on self-identities over time and stress among urban AI/AN populations.
- Research current challenges for collecting immigration status on surveys, the barriers that specific immigrant communities face in accessing health care services, and how data collection may help those barriers.

- Research the fluidity and factors affecting racial and ethnic self-identity over the lifecourse. For example, immigrants' experience in their home countries, country of origins' views of different immigrants, and acculturation over time.
- Research the correlation of offspring of immigrants and higher generations of immigrants driving diversity within the US, assimilating to the median, and experiencing fewer health disparities (e.g. socioeconomic status, health status).
- Research lingering and unaddressed issues. For example, child migration, hyperpoliticization of contemporary immigration, and faith as a proxy for race and ethnicity.

GENERAL	CAUTION
	PEOPLE
	PRINCIPLE
	WHO, academia
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Caution
- Avoid operating on the assumption of altruism (e.g. collect pilot data, partner with larger data sets).
- Be cautious about ethnic identity not being fully captured by country of birth and parental country of birth (e.g. 5th generation Chinese-American).
- Anticipate the costs, time, and buy-in required at the local and state level for oversampling to address representation of small populations.
- Advance and defend sets of questions in the American Community Survey and other surveys for major race and ethnic groups for continuity, the protection of civil rights, and the access to benefits and services.
- Anticipate push-back about researching skin tone and health (e.g. political sensitivity, within-group discomfort, differences among subgroups, White supremacy).
- When discussing skin tone and health, anticipate built-in incentives for certain White audiences to move away from race (e.g. it is not about Whites, but about light-skinned Blacks vs. dark-skinned Blacks).
- Anticipate challenges among non-White communities of "discrimination Olympics," "oppression Olympics," and model minorities that compromise health equity for all.
- Anticipate the challenges of asking about immigration status (e.g. highly politicized, danger for individuals responding to survey).
- Anticipate policies detrimental to immigrant communities that may undercut the effective outreach, response rate, and analysis of any immigration status measures, proxies, and variables.
- Address the fear and uncertainty of oversight, privacy, and security of too much disaggregation.
- Anticipate issues of frontline health care professionals fearful of their job security over misclassification issues during emergency room instances and patient intake.

- Anticipate the Federal Interagency Working Group for Research on Race and Ethnicity as not valuing data disaggregation if federal agencies are framing it as expensive and problematic.
- *Specific to the AI/AN community*, anticipate perceptions of indigenous data sovereignty being less rigorous.
- *Specific to the AI/AN community,* anticipate push-back from data keepers about increased accessibility of AI/AN data.
- *Specific to the multiracial community*, anticipate challenges due to single race reporting being most common in federal agencies and the push-back from organizations who receive money based on single race funding formulas.

People
- Build the base with:
    o Federal entities (fiscally conservative)
        ▪ Department of Health and Human Services
        ▪ National Health Interview Survey
        ▪ National Science Foundation
    o State entities (non-identification states)
        ▪ Association of State and Territorial Health Officials
    o Local entities
        ▪ National Association of County and City Health Officials
    o Tribal entities (tribal leaders, Indian Country
    o Philanthropy
    o Academics (researchers, survey managers)
        ▪ Critical Mixed Race Studies Association
        ▪ National Network of State and Local Health Surveys
        ▪ Collaborative Psychiatric Epidemiology Surveys
        ▪ National Survey of American Life
        ▪ National Latino and Asian American Study
        ▪ National Comorbidity Survey Replication
    o Communities (immigrant, community members, residents, large urban areas, youth, multiracial, organizers, Native Hawaiian, Pacific Islander)
        ▪ Black Immigrant Network
    o Key organizations (advocacy, service, nonprofit directors, program managers, civil rights organizations, youth advocates, research advocates, disability advocates, reproductive justice advocates)
        ▪ Arab Community Center for Economic & Social Services
        ▪ Black Lives Matter
    o Health industry (care providers, hospitals, pharmaceutical companies, administrators, doctors, nurses, associations)
        ▪ Anthem Multicultural Health Division
        ▪ Kaiser Permanente
        ▪ Ascension
    o Systems (criminal justice, software designers)
    o Data (Big Data, electronic data)
    o Policy makers

Principle
- Use a social justice lens.

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- Involve the community at all stages of the process when developing the classification of racial and ethnic subgroups for measuring and reporting.
- Strive for equitable universalism.

Who, academia

- Researchers
  - Enrico Marcelli
- Survey leaders
- Data administrators
- National Network of State and Local Health Surveys

Who, advocacy

- Advocacy groups
- Community organizations (AI/AN, individuals and organizations, tribal and urban)

Who, community

- Local communities most affected by the policies and practices
- Non-federal stakeholders
- Community partners
- Elders
- Tribal epidemiology centers

Who, govt

- Federal, state, and local government (policymakers, governors)
- Office of Management and Budget
- Department of Health and Human Services
- Centers for Medicare and Medicaid Services
- National Center for Health Statistics
- National Institutes of Health
- Department of Justice, civil protections
- Department of Homeland Security, deportation forces
- Data policy leaders at every "key agency" (e.g. Education, Health and Human Services, Housing and Urban Development, Transportation, Agriculture)
- Funding agencies

Who, health

- Administration staff

Who, philanthropy

- Foundations (private)