Proposed By: Nanibaa' A. Garrison

Proposed Moderator(s): Nanibaa' A. Garrison and Keolu Fox

Session Topic Area: 12. Genetic Counseling, ELSI, Education, and Health Services Research

Session Content: Social Issues

Session Title: Silent Genomes: Indigenous-led Initiatives on addressing equity in genomics health care and research

Session Description:
Indigenous populations worldwide face unique health challenges, inequities, and barriers to healthcare. As such, they typically have poorer health outcomes than do non-Indigenous groups. While genetics/genomics research has greatly advanced health outcomes in mainstream populations, there is danger of increasing health inequities including the 'genomic divide'. The 'genomic divide' is a much written-about, complicated reality that is based in unequal access to genomic technologies, social-economic determinants, and also considers the lack of relevant background genetic variation data, potentially preventing accurate diagnosis, and limiting effectiveness of genetic/genomic research. Indigenous people may be hesitant to participate in genetic/genomic research and clinical testing when it is available. Historical and current reasons that might prevent participation include unconsented secondary use of biological samples (including research that traces ancestry), funding agency requirements for data sharing, conflicting researcher/community priorities, and general concerns of exploitation of Indigenous communities for the benefit of mainstream science and economics. Throughout the United States, Canada, Australia and New Zealand, Indigenous Scholars are leading initiatives to improve access to genetic/genomic research and healthcare based in their unique cultural context and within governance models acceptable to their populations. We welcome an engaged audience, including through our Twitter hashtag #IndiGenomics. Our all-Indigenous international panel will be co-moderated by a bioethicist (@NanibaaGarrison) and genomic scientist (@KeoluFox) and will consist of a highly interdisciplinary group of experts, including a surgeon, internist, epidemiologist and translational researcher, who will present the initiatives they are involved in, within their respective regions, to narrow the genomic divide.

Session Rationale:
We aim to initiate a discussion to characterize the growing 'genomic divide' that separates Indigenous populations from genetics/genomics research. Though significant progress has been made in the recent decade to identify and reduce health disparities across populations, Indigenous populations are underrepresented in genomics research and as a result, cannot fully take advantage of precision medicine. Additionally, the non-inclusion of Indigenous people in genetic studies frustrates non-Indigenous researchers who wish to contribute to the knowledge base of population genetics and human diversity in a culturally-appropriate manner. This session will outline the historical issues that have contributed to the lack of participation in Indigenous communities and provide concrete examples of relationship-building in Indigenous underserved populations. The presenters will share strategies and

initiatives that they are leading to promote equity and address the lack of diversity in across several international contexts.

Proposed Structure for the 2-hour session:

Moderator 1: Nanibaa' Garrison PhD (bioethics) will start with a 10-minute introductory talk to set up the historical context to describe why Indigenous people have been reluctant to participate in biomedical research and will describe policy developments that tribes have used to exert greater control over how their biospecimens are used in research. She will briefly describe the panel format and introduce the panelists.

Panelists: Each panelist will give a 10-minute talk (40 minutes total) to describe their work and efforts to engage Indigenous people within their own communities in genetic research.

Moderator 2: Keolu Fox PhD (genome scientist) will give a 10-minute talk to briefly synthesize the international approaches and describe genomic tools that may benefit Indigenous people, strategies for the democratization of genome technologies, and envisioning an equitable and just future for Indigenous peoples. He will set the stage for the moderated discussion.

Audience Discussion: The Moderators will prepare questions in advance to engage the audience in a 60-minute discussion about Indigenous-led Initiatives for equity in genomics, health care, and research. Moderators and panelists are interested in hearing about any preconceived notions the audience may have of Indigenous-led research initiatives after panelists' discussions of their research and efforts to engage Indigenous people. As the panelists are currently developing new tools, guidelines, and policies for Indigenous people to participate in research, we will open the discussion to engage in direct feedback from audience members who may offer additional insights to strengthen different approaches or who may offer experience with approaches that are not as successful.

Learning Objectives
1. Identify and develop strategies to encourage successful partnerships and avoid future harms related to genetic research.
2. Describe the context and process for the establishment of indigenous biobanks.
3. Understand global Indigenous efforts to ensure genetic research is inclusive and beneficial to Indigenous Peoples.
4. Identify strategies to enhance Indigenous Peoples' control over the secondary use of genetic samples and data.

Attendee Benefits:
Attendees will hear from a highly interdisciplinary and international panel of experts who will describe challenges and strategies for improving equitable access for Indigenous people to participate in genetic research and benefit from genomic medicine. The attendees will have the opportunity to not only hear from the panel, but engage in a moderated discussion about concepts and initiatives described.

Target Audience:
The target audience will be clinical and research geneticists who work with cohorts of research participants, regardless if they are homogenous or are representing diverse communities. The goal of the presentations is to engage laboratory and clinical geneticists, community-engaged scholars, and ELSI scholars in a discussion to identify strategies to incorporate Indigenous worldviews in genomics to promote equitable participation in genomic research. The panel will present strategies for effectively engaging communities in research to increase diversity in genetic/genomic research.

The competencies and attributes the session will address:
Medical Knowledge

Speaker 1: Maile Taualii
Presentation Title: Misuse & Abuse: When Good Intentions Result in Harm
Presentation Content: Proposed as a tool to assist Indigenous People, genetic testing has been loosely thrown around as a solution to quandaries like blood quantum, membership and identity. Negating the rule setting by nation states and the United Nations Declaration on the Rights of Indigenous Peoples for membership to be set only by Indigenous Peoples themselves, genetic testing could be misused to limit or eliminate rights of Indigenous Peoples. Limited or misunderstanding of the potential harms, Indigenous Peoples and researchers need to collaborate to ensure the inherent rights of Indigenous People are upheld. Researchers, although well intended, may not understand the challenges faced by Indigenous Peoples. This talk will help to raise awareness of how efforts to "help" can unintentionally result in harms.

Speaker 2: Nadine Caron
Presentation Title: Addressing inequity in genomic diagnosis and research: Development of Governance and Culturally Relevant Policies
Presentation Content: The positive impact that genomic research is having within the Canadian health care spectrum, from prevention, screening, diagnosis and treatment, is not questioned – but the equitable distribution of these research benefits on health and health care is. An unfortunate example is the marginalization of Canada's Indigenous populations in the area of genomic and genetic research and the downstream impact on disparate access, utilization and impact on subsequent health care decisions that are driven by this research. Over the last two years in Canada, great effort has been mobilized to address this with two separate but overlapping projects that start upstream. These are not commencing at the typical level of a disease-based research question involving genetic testing or genomic sequencing but rather addressing the paucity of awareness and understanding of this type of research, the impacts it can have and what Indigenous communities may be missing. They are addressing the absence of culturally-based governance and policies in this field – from establishing a First Nations Biobank to creating guidelines on how research proposals being submitted to research funding agencies or Research Ethics Boards should be culturally safe and community-based. The phenomenon of "bench-to-bedside" research has great potential but Indigenous scholars, communities and their allies are now asking, "what bedsides are getting to the bench?" We are finding our answers on how Indigenous Canadians can be active participants in this field.

Speaker 3: Ngiare Brown
Presentation Title: Australian Aboriginal Culture, Genomics and Biobanking
Presentation Content: Within the context of increasing pressures from the research community to explore and share Indigenous genetic material, including from existing collections, Australian Aboriginal researchers have been pro-actively working in parallel to establish a comprehensive model of Aboriginal led and governed biobanking and genetic/genomic research practices. Australian Aboriginal research leadership, in partnership with Aboriginal communities, Elders, consumers, and cultural authorities, have established an Indigenous specific biorepository at the South Australian Health and Medical Research Institute (SAHMRI). Prof Brown will describe the years of engagement and preparatory work which has led to the SAHMRI benchmark processes and best practices standards for prospective genomic research with Aboriginal and Torres Strait Islander and Indigenous peoples, including engagement, consent, governance, access and utilisation of material, data sharing and repatriation. The SAHMRI team are trialing these systems with funding awarded through a competitive NHMRC grant, exploring Aboriginal genetic risk profiles and the development of chronic disease and complication.

Speaker 4: Maui Hudson
Presentation Title: Building an Indigenous genomics platform in Aotearoa New Zealand
Presentation Content: Genomics Aotearoa is a new collaborative platform established to create a step-change in behaviour in the New Zealand genomics and bioinformatics communities. Genomics Aotearoa aims build capability broadly across the life sciences by investing with and across the research themes of health, environment, and primary production. These themes intersect with the development of the enabling infrastructure and conceptual platforms of genomics, bioinformatics, and Te Ao Māori (Māori worldview). Led by Associate Professor Maui Hudson and Dr. Phil Wilcox, one of the key pathways to impact is the creation of an indigenous genomics platform. This will facilitate Māori management of indigenous genomic research and data, build Māori research capacity, as well as support the uptake of genomics information and tools to benefit their communities.