Genetic Discrimination Observatory

Regulatory and Ethics

Date: Monday March 1
Time: 21:00 - 22:00 UTC**Meeting Chair(s):** Yann Joly
Attendees:
Yann Joly, Lindsay Rutter, Alef Janguas, Stephanie Dyke, Meg Doerr, Palmira Granados, David Lloyd, Gratien Dalpe, Pilar Nicolas, Ted Dove, Peter Goodhand, Stephanie Li, Jessica Reusch, Ericka Thomas, Katherine Blizinsky, Shu (Sue) Hui Chen, Esmeralda Casas, Lindsay Smith, Ashley Hobb, Pooja Chitre, Yvonne Bombard, Ada Hamosh, Kristina Kekesi-Lafrance, Iddil Bekirov, Diana Iglesias, Alice Matimba

	Agenda Item	Speaker	Time
1.0	Welcome and roundtable introduction	Yann Joly	5 min
2.0	Presentation on the GDO	Gratien Dalpé	10 min
3.0	Addressing genetic discrimination @ GA4GH: open discussion	All	35 min
4.0	Action items for next meeting	Yann Joly	10 min

Minutes:
[Roundtable Introductions]

YJ: Find the best ways GDO can contribute to GA4GH. GDO is represented in more than 21 countries, be interesting to find the common points of interest.

Intro to GDO
GD: Worldwide network of researchers dedicated to preventing genetic discrimination. Includes professionals from law, health policy, geneticists, etc. GDO members are engaged through scientific meetings, scientific panels, online conferences, etc.
Goals: Document genetic discrimination in a scientific manner, asses what normative model works best (and create new ones), and engage the public, policymakers and stakeholders. The broad approach is based on human rights principles - right to science, right to know.

The online platform is for all to use, includes tools and policies. One example of tools is our real-time genetic discrimination maps. Interactive maps where you can hover over countries of interest and display incidences of discrimination in life insurance or implemented policies.
Developed a project called “share you experience” - allows individuals to report their experience, allowing better documentation of genetic discrimination. This project is not meant to provide legal guidance. Currently only available in US and Canada due to ethics approval, but hoping to expand.
People behind the GDO - Secretariat: Yann Joly, Gratien Dalpe, Hortense Gallois and Francois Brouillet.
The GDO is involved in two collaborative projects: 1) Creating a harmonized survey to be applied in each jurisdiction, and 2) assessing the performance of various normative instruments.

<u>Questions for the group</u>
How does genetic discrimination or patient concerns about genetic discrimination impact the activities of GA4GH members and the larger research community?
How can an international organization like the GDO best contribute to the mandate of the GA4GH, while fulfilling its anti-GD mandate?
Would a GDO/GA4GH resource on addressing GD be useful?
Linkages with GA4GH-EDI work?

MD: Alliance could serve as an ally, ensure people benefit from genetic discovery.
PN: Very important role is to disseminate policies against discrimination. My feeling is that people could be afraid of genetic discrimination or even scientist about what science will mean for the subject. Disseminate the idea and ensure people become aware of policies. Little knowledge of this area.
YJ: Something we can easily do. The GDO has the live maps where we have tracked the policies. Information is extremely important.
JR: We have limited protections in US. No national coverage. Studies looking at places that have more comprehensive protection leads to more willingness to participate in studies.
KB: Could even add to that and look at the changing landscape of state laws.
YJ: I like the idea of looking at policies, don’t know if we would go as granular as states given the global vision of the observatory. See how impactful these laws and policies have been. Could look at level of research or the anxiety/apprehension of genetic discrimination.
EC: Great point. There appears to be a strong concern, at least in the US about whether or not data contributed is going to be protected and if there will be any effects down the road. What you can or cannot expect would be helpful.
YJ: Two roles for observatory: one is more research-oriented and one as a resource to provide information on what the protections are and what the alternatives are in other countries. With regards to the EDI groups, there is an equity component in the GDO. Laws against discrimation are also seen as laws promoting equitable treatment. Another interest is on the point of

intersectionality - idea that people who are the victim of discrimination are people who are already more vulnerable.

YJ: Idea is to come up with the most useful resource project for the global alliance. We have a bit of funding but need practical projects that are also relevant given the experience we have and the interest of people on this call. See two suggestions emanating: 1) Importance of disseminating information to stakeholders, and 2) Need to better document our laws and how they impacted participation in research.
MD: Second idea of looking at laws from the perspective of policy, since GA4GH is a policy developing organization.

YJ: Email the rews-coordinator to get involved. See which countries we have representing, determine what metrics we are going to look at. How do you measure success of such a law. Our group could define what these markers are, agree on common elements for showing impact.
TD: To go beyond the mapping, look at intervention and implementation studies and see how those laws are enforced. Could have interviews, conduct surveys of relevant authorities. I think mapping studies are important and I don't think that step is yet complete, only a fraction of the globe is mapped. We should see that as but one step in the ladder leading to policy change.
YJ: The mapping is complete, the white parts are because there are no laws.
TD: If indeed only 20 countries have laws as we are defining it within the GDO, then that says quite a bit. Keep a watch on developments as they arise. Still ought to see mapping as one element.

PN: Go deeper in analysis of countries. Context of the laws in the country are important to interpreting the structure (ie. health system) and other laws of the country. We have the experts from each country now.
YJ: Context is very important. Speaks to a case study sort of approach. Easier to learn more about the context and assess laws using some of the more sophisticated quantitative and qualitative methodologies. Select some case studies/countries where we know we have some strong expertise.

YJ: Open to use many different social science methodologies. Please propose countries that could be good for case studies, metrics.
DL: At least two of us mentioned hearing about this recently. Our World in Data captures map of human rights. Is it possible for GDO data could be added to this map so it's measured alongside other maps of human rights interactions, raise the profile.
YJ: I'll have to have a look, very interesting.

SC: There are a lot of community engagements we can benefit from, like longitudinal cohort studies. Looking at those that have social determinant research in studies or protocols.