

Genetic Discrimination Observatory

Date: October 13, 2021

Time: 13:00 - 14:00 UTC

Meeting Chairs: Yann Joly

Objective:

- Discussing the progress to date on genetic discrimination efforts, and preparing for next steps

| | Agenda Item | Speaker | Time |
|-----|---|-----------|------------|
| 1.0 | Report back on GD information document <ul style="list-style-type: none"> - Public Comment Responses - Latest Draft | Yann Joly | 10 minutes |
| 2.0 | Update on consent forms | Yann Joly | 5 minutes |
| 3.0 | Update on Delphi study | Yann Joly | 15 minutes |
| 4.0 | Open discussion (next steps) | All | 30 minutes |

Minutes:

First item: information paper (Genetic Discrimination (GD) implications for data sharing)

Last opportunity to comment on GDO Informational document before REWS vote for approval for vote at steering committee

- Intended for a non-expert audience made up of research scientists involved in large scale data research projects.
- Bear in mind GD will depend on each country, or situational context
- First section informational to introduce GD
- Second part presents the evidence we have on GD until now
- Third focused on the various protections that have been put in place to protect people in different countries against genetic discrimination
- Fourth paragraph about the risk of genetic discrimination occurring in large scale genetic projects
- Followed by discussion about what information on GD should be given to participants
- The document finally also calls for consent clauses on genetic discrimination

YJ: Are there any suggestions/comments on the document? Uncertain about the inclusion of the final paragraph and whether or not it is needed.

SC: In the process of sharing consent clauses already so maybe the document is the wrong place to call or clauses. This could be better placed in the Delphi study.

YJ: One option is to keep the section calling for consent clauses but to change where it is placed in the document, or to change the formatting of it so it is not part of the main text

AH: Another option could say that we are asking for feedback and information on how people are addressing genetic discrimination in their own work, including consent clauses.

YJ: So perhaps we keep the section, but broaden it as a transition to next steps.

AH: Yes, so we keep the section but broaden it as a call for action for all relevant tools, in addition to consent clauses.

SC: I agree, broaden out the section to include next steps, call for clauses and a broad statement to welcome feedback and information which would help GA4GH/GDO

JR: Love the idea of a broader call for collecting resources on how genetic discrimination has been used. Will these be made available anywhere so people can access, use and learn from these documents?

YJ: Intention is to be transparent and to share documents that are collated with the community once it has been confirmed the resources are of good quality

Agreement to change the document to reflect this. As a result the document will not be approved at the REWS General Connect meeting - and will be deferred to a later date once it has been amended.

ACTION: Will broaden the call for any interesting initiative/tool to address genetic discrimination that we should be aware of, in addition to consent clauses relating to GD.

YJ: One other point for discussion is how we protect genetic information. Goes beyond genetic discrimination, and into data protection.

Should we take a genetic exceptionalism approach, or should we treat genetic data as we do any other type of health data?

People have not been comfortable taking a stance and unlikely a consensus will be met. Was not included in the informational document as a result. Was this the right decision?

No Comment

ACTION: something to think about.

Second Item: The Delphi Study

The Delphi Study is going well so far.

The study is required because there is a need to identify elements that could make effective anti-GD legislation

The goal is to create a knowledge base of clauses that can be added to legislation and other policy outputs to meet the needs of vulnerable individuals and groups at risk of genetic discrimination.

Can also be used to help in the field of genetic testing, research and consumer tests.

Methodology used has been 'Delphi' - which is a group of surveys (3 rounds in this case) applied to a group of expert participants. Mixed methodology as quantitative and qualitative. Asynchronous methodology, so people can answer in their own time, suiting experts from around the world.

The study permits structured communication among experts with different perspectives
Policy delphi - best placed to consider and explore alternative ideas. In this case it is based towards identifying consensus on the challenges of accessing genetic information highlighted by the experts

Survey timeline

We asked members to participate in the survey and to identify expert participants in their own network.

Aim was to recruit between 60-100 participants with different expertise from around the world
Wanted to recruit researchers in genetics, and researchers in legal and ethical implications of genetic discrimination, human rights researchers, those interested in bioethics and advocacy leaders of populations vulnerable to discrimination etc.

Study began in June 2021, Participants founded in September and then the survey was closed in October 2021. Now we will begin the analysis of these results.

We will create a summary, and then round 2 of the study will begin in November 2021. Experts are allowed to change their responses from the first round if they have learnt more from the results of Round 1.

Round 3 will happen around March 2021 and this will be closed in May 2022 for analysis.

We may see a change in consensus happening throughout the completion of the survey

Participant Demographics

62 people participated

Most participants have elected to be co-authors of a paper produced as a result of the survey and thus not remain anonymous.

Biggest group were scholars/professionals working on ELSI on scientific topics. But a range of groups of participants

Diverse population in terms of sex, areas of expertise and geographical area

Action: Analysing the responses of the Round 1 Delphi survey responses

Discussion:

PM: Do we have any practicing lawyers participating?

GD: Don't know. Asked experts to self identify their field of expertise and we don't yet know if some identified as practicing lawyers. Some were invited.

YJ: Should work on cleaning up and separating categories appropriately

PM: Will we allow participants to assign themselves into a category? Or are we assigning them?

GD: Assign themselves. There was a question on your domain of activity which was specific to categories. But could then also answer in an open ended way.

SC: Did we reach out to panelists from low and middle income countries or did we just get no responses or refusals? We are heavily skewed towards the west.

YJ: For recruitment we were dependent on advisors from REWS and from the external GDO. We went ahead with who was recommended to us. We did say we wanted inclusion, and did have a few, but we are in favour of further promoting inclusion. However, we need to consider that in developing countries the risk of genetic discrimination may be less due to the scientific level they are at, or there may be more urgent points of action these countries are addressing. We tried to recruit those from developing countries, and it didn't work that well, but there might be contributing factors that explain this.

SC: We should remain aware of our limitations, and we should be open about these. There might be reasons, however, we should be careful when going ahead to publish results that we are transparent about participation and also limitations.

YJ: it is on the radar. We should be as exclusive as possible.

Information we have gathered from the first round of the survey will be shared after we have analysed it so that we do not present inaccurate data. As we close the Delphi, we will have some sort of consensus on what elements may compose anti-discrimination law, including where there are controversies for example. Will be useful for policy makers thinking about adopting anti-discrimination law, or reviewing and updating their existing anti-discrimination laws.

YJ: Are there suggestions of how we can use this data and research? Open to suggestions about how we can get this information across, and how it can be used. Want to reach out to policy makers etc in the field.

No comment

ACTION: something to think about.

Third Item: Informed Consent Clauses

YJ: 5-10 genetic discrimination consent clauses have been collated, so not a significant number to be shared at this moment. Call for clauses to other tools/documentation in this area welcome.

Fourth Item: Next steps:

YJ: What are low hanging fruits for GA4GH in this area? What do we do next, if anything?

(Additional to the Delphi completion and subsequent publication)

SC: There is a fear of genetic information, including genetic exceptionalism and determinism. Alongside this comes a fear of participation in genetic research based on this discrimination. This is stronger with certain communities. Maybe we should think about what approaches to community engagement could be successful in alleviating these fears, and ensuring these individuals are better placed to participate in genetic/genomic research.

YJ: Excellent suggestion, makes sense to think about this. Instances of GD and concerns over being discriminated against are distinct numbers and concerns are often higher than actual evidence of GD. Definitions of genetic discrimination differ between individuals and groups, such as policy-makers - defining this could be useful.

JK: What framework is there to tackle this?

HS: Is there cryptic genetic discrimination that never arises to the awareness of the target? Are business models of identifying people where data is sold to ... Is hard to measure genetic discrimination as it is often an illegal action, so data on this will be difficult to surface.

YJ: Interested in gathering data on this topic, as it is a topic that is particularly difficult to measure.

SC: Appreciate looking at new types of discrimination. Challenge is that data will always be difficult. However, fears of discrimination will increase. While it is worthwhile to see what measures we can use to capture examples of cryptic or hidden discrimination. Is worth our time to talk to all stakeholders in this area and build trust around these fears.

YJ: let's think about how we can gather information and we can discuss this at our next meeting. Opening this as a potential new topic we can address.