Genetic Discrimination Observatory

Regulatory and Ethics

Date: Thursday April 8
Time: 7am PT / 10am ET / 3pm BST / 12am (Fri) AEDT.
Meeting Chair(s): Yann Joly
Attendees [Name(Affiliation)]: Yann Joly (CGP/McGill), Angela Page (GA4GH), Lindsay Smith (GA4GH), Edward Dove (UofEdinburgh), David Lloyd (ELIXIR), Yvonne Bombard (St.Mikes/UofToronto), Soichi Ogishima (GEM-Japan), **Laetitia Sabatier** (Genome Quebec), Iddil Bekirov (NIMH), Pilar Nicolás, Palmira Granados Moreno, Esmeralda Casas (NCI), Shu (Sue) Hui Chen (NHLBI)

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	Agenda Item	**Speaker**	**Time**
1.0	Welcome - Please email rews-coordinator@ga4gh.org to be added to the GDO mailing list	Yann Joly	3 min
2.0	Reviewing the draft information document on genetic discrimination	Yann Joly, All	25 min
3.0	Discussing the proposed Delphi survey on genetic discrimination policies	Yann Joly, All	25 min
4.0	Next Steps	All	5 min
5.0	A.O.B. - ELIXIR GDO Webinar - Thu 29 April 2021, 16:00 BST	All	2 min

Minutes:

YJ: Follow up on the documents that were circulated to the group. Will go by item. The first was the information document, pinpoint general issue of genetic discrimination. Meant to be in fairly lay language. Will leave online until next Monday for any additional comments. Didn't see any comments that required a major revision of the document. Need fine-tuning but going in the right direction. Any major concerns? Will send to REWS group unless there are last major comments prior to Monday.
DL: Have you sought feedback from DUO or the consent team?

YJ: Could ask the question if there are any clauses relevant to genetic discrimination. Great idea. First will integrate comments, then circulate again to this group. Following that I will circulate to the large REWS groups for comments. Can present to Steering Committee when ready.
TD: Just looking at section 6. I see that there are three great suggestions of your own. Wasn't sure what value a discrimination clause would provide. Curious to know your thoughts on this. Might be scope for collaboration with driver projects.
YJ: Last part won't be included in the final document, more generating ideas. Idea of looking at consent clauses and seeking input from community on which clauses they are using. Could poll community members or DPs. Let's consider polling the group.

YJ: Suggest moving to the policy delphi. Clarify who we are going to poll in this delphi. Delphi is a type of survey where we get a consensus on specific questions. Used as a tool to see the trajectory things might take, only to be used with an expert public. Agree with the comment on patient advocates. Could also include experts in the core science discipline, experts in human rights and equity law, bioethics, lawyers that are familiar with court proceedings in these topics. This is a broad mention of the groups that could be included. Addtl Q on the types of expertise we would seek?
PM: Are we looking for people that specialize in genetic discrimination or an expert in discrimination in general
YJ: We want people that can contribute some expertise to this larger question.
PN: Would we need to have different profiles?
YJ: Ideally we want this to be well distributed so we don't have people only from a specific expertise. We are going to benefit from members of the GDO. What I'm hoping is that between this group and the GDO we can find a sufficient number of experts. Since Delphi studies do not have a quantitative approach, we don't need a big number, so if we can get something between 40-50 experts that would be willing to participate that would be good for this exercise. Yvonne, do you have any advice?
YB: Not at the outset but happy to help with the design.
TD: I think the idea of a policy delphi is sensible, and supports a broad definition of who constitutes an expert. I think one thing we might want to think about is that it might be a challenge to define what is a policy for this subject matter and what are the key elements. Scope, thinking about legislature vs any private entity.
YJ: The way I'm thinking about this is first let's agree we're talking about public policy. Not something a private company would adopt. An interesting part of this survey is to check whether a moratoria would be of interest, or a decree. As long as it meets what a public policy is, and we can propose a definition. Another issue to start thinking about is the regionality - maybe one type of law is better for a particular region. Should we be trying to get this international consensus or will it be flawed because of that. There are things we could have international consensus or others where we should note that there will be different perspectives.
SC: I think I put this into the draft document, things may be culturally or community based.

YJ: Give options for people to say that response depends on country. Then we know that for particular questions need to be addressed at the country/region level. A challenge that I see all over the place is that policies, whether law or moratorium, have often not been accompanied by an information campaign to make it known by the greater public. Solutions are sometimes ignored because the public is not aware. Here we might find broder consensus.

Propose to address the specific point of what kind of contribution from this group. One thing I want to establish is the type of questions - choice of answers, open questions. Once we've agreed on the types of questions, there are two contributions we could have from members. 1) Helping to identify experts. Would like people to nominate 3-5 people from their jurisdiction, could reach out to them and provide information. Should we also allow people to nominate themselves?
YB: If multiple people send information about the project during recruitment I'm worried about the logistics of this. But outreach from someone that you know will improve recruitment and response.
YJ: I think people could nominate themselves as experts. What I will do to help the logistics of this, what I would do is build a matrix where people could propose experts. I think it works, but will have to keep viewable only to my team for privacy reasons. I was also thinking of having people propose questions. However, there is the possibility that someone who proposes a question could be an expert that answers the question.
Nominate 3-5 experts, and possibly formulate a few questions.
DL: I agree that finding those people will be a challenge. Jumping ahead in the agenda, you'll see the Elixir webinar advertised and that YJ will possibly attend. Been focusing promotion among data stewards, but wonder if we will have some expertise in these groups. Might be timely if we can those people attending the webinar and getting those people involved.
YJ: I could discuss a little bit about the Delphi project at the webinar.
PM: For us to provide the 3-5 names, what is the deadline, and are we expected to talk to these people and get them onboard.
YJ: For recruitment we could give ourselves 2 or 3 months. At the same time, because we are working collaboratively we are working at a low cost. We're fairly flexible on timelines but would like to advance at a good pace. Ideally ready to go by then. YJ will take around a month to have all the necessary information and methodological guidelines to be delivered to the experts so they can proceed with ID'ing the 3-5 experts in their region.
SC: Are we specifically looking at researchers?
YJ: Just need expertise, not necessarily researchers. In case of doubt in qualifications please reach out to me. Advocacy groups yes, not sure about politicians. Open to it.
YB: Stems from the goal of the survey. If it's not to gain drivers or perspectives of all involved in the policy, then not necessary to include them.
YJ: Focus on what makes the policy effective, what are the hurdles of the policy itself, rather than its adoption.

DL: We found in the past that some European countries come to a halt in July and August. I wouldn't be surprised if peoples' minds are on other things during that time.
YJ: For recruitment purposes, can start informally reaching out to experts now. Could make the survey longer if need be.

Last question on the Delphi is the question of ethics approval. Will need to obtain approval and will do so in Montreal. Do we need to obtain approval in your own country to do this. In most, my understanding is that it won't be necessary. As a reminder, the information we received will be deidentified and coded.
YB: The personal information will all be housed at Mcgill?
YJ: Yes. If you think there is an issue in your jurisdiction, might just be we need approval, not insurmountable.

DL: Informal conversations about the GDO have raised quite a bit of interest in ELIXIR. If we get it wrong, then a lot of work being done to make data accessible will blow up in their faces. Would like to provide a bit of access and content on this.
YJ: Exactly the kind of opportunity I was hoping would come out of this.
We would like to poll members about some questions, like consent clauses. Informal, don't need ethics approval. Any other questions we could ask? We could gauge the interest of a survey. The idea of consent clauses is a good one, but do we then make a bank of consent clauses on genetic discrimination. I could talk to Kristina on this. Something to add or contribute to consent clauses.

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