



**AGENDA (2)**  
**Public Attitudes for Genomic Policy (REWS Your DNA Your Say)**  
Tuesday 5th July 2022 @ 11am UTC

[Zoom recording](#) [password: rHE6&8\*k]

|     |   |                                |        |
|-----|---|--------------------------------|--------|
| 1.0 | Welcome and member introductions<br>- <a href="#">Membership document</a>   | Everyone                       | 5 min  |
| 2.0 | Dual Trust/Trustworthiness <a href="#">Blog</a> and <a href="#">Infographic</a><br>- What we did<br>- Feedback on the content<br>- Key take-aways:<br>- Vulnerable people and vulnerabilities – is it better for find different words given the very specific meaning in bioethics<br>- Trust, mistrust and distrust – do we need to define and take care in how we use these terms?<br>- More nuance between respondents and countries<br>- Future uses – how much can be known? | Richard and Dianne<br>Everyone | 20 min |
| 3.0 | Next Steps for the Dual Trust/Trustworthiness Blog/Brief<br>- Next draft timeline and hopes   | Richard and Dianne             | 5 min  |
| 4.0 | Next Blog Topic Discussion<br>- Pick next topic<br>- Shall we follow the same approach?   | Richard and Dianne<br>Everyone | 10 min |
| 5.0 | A.O.B and Next Steps  |                                | 5 min  |

**Zoom Details:**

Join Zoom Meeting

<https://us02web.zoom.us/j/84974458102?pwd=c012MTlpVzRxRnMvcXhuVGpNVXNWQT09>

Meeting ID: 849 7445 8102

Passcode: 384740

**Attendees:**

1. Maili Raven-Adams
2. Dianne Nicol
3. Lindsay Smith
4. Bronwyn Terrill
5. Christine Patch
6. Bimal Chaushari

7. Beatrice Kaiser
8. Yvonne Bombard

9. Richard Milne
10. Missy Heidelberg

### **Minutes:**

DN: Looking at the themes in the feedback, came up with a few things: 1) vulnerabilities and how to deal with them, 2) trust/mistrust/distrust and 3) nuances between countries and 4) future uses, how much can be known?

RM: Finding the appropriate balance between stripping out details to keep it brief but keeping what we need.

DN: The cosmetic editing but there are themes to talk about as well. Can we talk around those issues?

RM: Explain the phrasing I put in there, why trust is needed in this situation. Open to alternative ways of phrasing, but trust is needed because there's an openness to harm. Using vulnerability to capture that potential of being harmed.

CP: It's a word issue, vulnerability has other sorts of things around it.

CN: Vulnerability has its own broad and technical sense in literature so it's a word that's better used elsewhere but not sure what the alternative is

RM: Rephrase to may be harmed. Is everyone happy with us using this definition of trust in this context?

[Yes]

BT: Many of my questions were around who the audience is and who will be understanding this.

MRA: The brief was to inform other policy makers, but open for discussion how broad we want to make it. Researcher and even the general public looks at our papers. Keeping it lay might be more helpful.

RM: The way we phrase researchers need access, slightly more extractive

MRA: Some of the papers Bronwyn linked in had defined things nicely. Some definitions or even linked to established definitions could be useful.

RM: Do we also want to define mistrust and distrust? Happy to use "lack of trust" or "absence of trust". People actively place their trust in somebody and sometimes they just go with the flow, others actively do not trust someone, and that is potentially an useful distinction, but maybe not in this context.

DN: Agree, can see how difficulties might arise

BC: Not opposed, but definitions can go a long way if you don't know where your readers are going to come from

RM: Your suggestions of having a wrap around set of links is something to come back to.

Going through the list, nuances between countries. That's a straightforward wording I think. It's about respondents.

RM: Bimal, comment opened up about if you can inform people about future uses. Or can you come back so you don't have to make decisions on their behalf. Situations where we're asking people to make data available for future uses we can't define

CP: Case of many sequencing initiatives that are happening right now. In GEL, there's a framework but even that includes uncertainty. Can't be specific about uses unless we are constraining in some way that the data becomes useless.

RM: Think I can find a wording and run it past Chris

YB: Don't know how much we want to blend the considerations of the other groups. From the work I engage with, when I think of trust and vulnerability I think about underrepresented groups. Flag some of the ways we can provide more context, to the extent I don't want to divert the focus of the work, but flag what I thought viewers might be missing as well. Added some commentary about several steps beyond the transactional idea that trust is just something you obtain rather than build and maintain.

DN: Keep these things brief, and trust/trustworthiness is only one of these things we might create. Could have another post that focuses on some of the things you have raised. Can we capture those in this document, or capture in a way that leads to another blog post that delves into them more fully.

RM: The preamble is to set out that trust is important because of the vulnerability that comes with sharing data, but even more so when that is layered onto other forms of vulnerability. We've piled trust/trustworthiness together. It glosses a huge amount of work. The work you've described is more tangible

MRA: Like the approach of expanding on it more somewhere else

RM: Keeping it brief and policy oriented but pulling the literature together

YB: I like the way you talked about layers of vulnerability. With the idea of keeping it focused, but recognized to the community that is not as familiar, spend one sentence explaining the vulnerabilities and highlight that in another document we'll go into more detail

RM: Had the blog brief done, but while working on the next one, if we come to the situation where there are spinoffs, do we wait until we have a package of them to release.

DN: Could raise the critiques that YB talks about if we release. Inclined to go in the direction of a package.

MRA: Agree, I think a package could be a nice thing to do. Close the loop before moving on to a next topic.

YB: I wonder for those very keen audience readership who are likely also directed to researchers looking to collect samples will then want you to square the circle that overlays trust in underserved communities.

RM: The more we go out from YDYS, the more work we will have to do.

DN: YB do you have the space to start the brief on trust in underserved communities?

YB: Yes, just received a grant to do that work. Pragmatic next question is timeline because this is just getting started.

YB: Should we be highlighting one form of evidence over another.

RM: Part of the thinking behind this group was that YDYS was meant to inform GA4GH, and one of the main outputs is the papers that don't necessarily have the ability to speak back into GA4GH. Main goal was to make the results more accessible, but to your point I don't want to say that YDYS is the evidence. Circled around this before, how much other literature to include in these documents. One of the advantages of YDYS is the comparative element, have a lot of literature that is only single country based.

MRA: Can consider opening up the brief to opening it up or keeping to YDYS.

DN: To do something bigger would be valuable but would be an enormous task.

YB: Recognizing this is a blog, blog often focus on one study. Maybe what we can do is add a line at the beginning saying something along the lines of “there has been a lot of literature on trust” and add some flagship papers and reference those at the top.

RM: I think that would work.

RM: Did anyone have any specific comments about the infographic?

BT: Added some comments about branding and shareability of the graphic

### **Next Steps**

RM: Got to the point where we’ve covered the main comments on the brief to date. We’ve opened up a can of worms to take us in lots of different directions. Have a group of briefs about trust, one will be about building trust in vulnerable communities that YB is going to work on down the line. Might be worth me incorporating the comments and recirculating a new draft. Wonder whether its worth moving on to the next topics - eg. familiarity. Stick with the call list of themes.

MRA: Have the first blogs focused on the topic drawn from YDYS, and from those, find those separate spin off ones.

DN: Important for people to understand its part of a bigger picture and understand the other aspects that are coming. If we can include that in the first framework, that would be good.

MRA: Other topics on willingness to donate, genetic exceptionalism, familiarity, return of results

RM: Happy to the same approach for the next brief unless anyone has a desire to take over. If YB and others have papers/reports that would be useful or that we could link out to, please add those in at the end.