



AGENDA

Public Attitudes for Genomic Policy (REWS Your DNA Your Say)

28th/29th April 2022 (21:30-22:30 BST/06:30-07:30 AEST/16:30pm EDT)

[Zoom Recording](#) [password: fqc^8miJ]

1.0	Welcome and member introductions - Leads: Richard Milne and Dianne Nicol - Membership document	<i>Everyone</i>	<i>5 min</i>
2.0	Overview of Your DNA Your Say (YDYS) and key findings - Slides	<i>Richard Milne and Dianne Nicol</i>	<i>10 min</i>
3.0	Open discussion on how public attitudes research translates into policy relevance - Identify key priorities that have emerged from the YDYS research that we should target	<i>Everyone</i>	<i>20 min</i>
4.0	Suggestions for specific outputs (aims and outputs)	<i>Everyone</i>	<i>20 min</i>
5.0	Next steps - Agree on meeting schedules (alternating times?)	<i>Richard and Dianne</i>	<i>5 min</i>

Zoom Details:

Join Zoom Meeting

<https://us02web.zoom.us/j/82396275848?pwd=QlVIZENJc0ZlQW5pcUg0WXZ4ZXVWUT09>

Meeting ID: 823 9627 5848

Passcode: 473963

Attendees:

Richard Milne
Dianne Nicol
Chris Patch
Swayamsiddha Sahoo
Go Yoshizawa
Danya Vears
Ainsley Newson
Bronwyn Terrill
Lindsay Smith

Minutes:

Introductions:

RM: Based at Wellcome Connecting Science and University of Cam

DN: took part in the Australian component of Your DNA Your Say. Interested in Translating the findings of YDYS into policy development

CP: Work with Anna and Richards group at Connect. Previously worked for Genomics England. Background in Health Service - nurse and genetic counselor, and have been part of policy development.

AN: Professor of bioethics in Australia. Always been interested in ethics in genetics and genomics, with a little bit of legal and social research too. Interested in methodology and how normative/conceptual research interacts with other methods. Experience with public engagement methods. Interested in empirical evidence and policy and its relationship is of interest. How can we get data into policy in a legitimate way?

BT: Education project officer for Australian Genomics, but have been an educator and practitioner in genomics. Have been watching YDYS and looking forward to getting involved.

DV: Social scientists, working at biomedical research at Murdoch. Background in genomic counselor, but span social science, bioethics and genetic counselor. Been involved in GA4GH since 2015. Helped design YDYS survey originally. Focus groups have been done with public with data use and data storage recently undertaken.

GY: Based in Japan - part time researcher. Background in history of science and policy. Working in bioethics and policy (ELSI issues) and public engagement with science. Have been involved with YDYS and Japanese colleagues. Working on how the public can be more aware of emerging technologies. Biomedical technologies and synthetic biology papers have recently been developed on public engagement to explore how people show ambiguous attitudes, as well as for or against. Interested in how research outcomes can impact policy.

SS: Social science and public policy and governance background. Been working with YDYS and did the survey with the Indian public. Interviews etc have been done with the public to understand their attitudes to data and data sharing. Health and genomics interest with research.

RM: attitudes, policy and research relationships is what we want to get to the heart of.

What is the current state of play (slides):

RM: Will outline our aims and what we might produce. Aims - to distill and translate the findings of YDYS and wider research into public attitudes into an international policy relevant format. Also want to work out what priority areas are that we may want to take to policy. Also want to produce outputs that are more amenable to translation to those who are making standards or policies within GA4GH or more widely.

RM: interested to find the gaps within research and policy that we may want to build on further

RM: Many people have been involved in YDYS over the years. Want to acknowledge their contributions

What are the findings?

RM: This survey emerged from a participant values taskforce in GA4GH. It then kept growing, and is still growing outwith GA4GH. Core dataset of 37,000 responses, from 22 countries, 15 languages. Looking at representative publics.

RM: Series of papers have been published developing the meta analysis of the YDYS study. Has focused on willingness to donate, trust, genetic vs health data and return of results. Is a lot of data on re identification that still needs writing up as meta analysis. Also individual country

analysis papers are still in progress, or have already been published. Comparisons between countries have also been included. So there are things that have already been published in papers. We have things we can take off the shelf and think about how we can make best use of this.

For discussion:

RM: How might public attitudes in research best reach genomic policy? What are our priority areas? What outputs are best placed to achieve this?

RM: Possible outputs include: Briefing notes based on YDYS and other public attitudes data that translates clear findings (REWS GDPR group has briefing notes that has usefully and clearly laid out complex terms), Infographics and visual materials for reuse and interactive visualization platform.

Discussion:

DN: Things that stand out are conceptions around trust and trustworthiness. Lots of interesting data on these concepts, and what builds trust. Interested in what negatively impacts trust. This could be a good thing to explore. Is high level of trust in researchers and research organisations but it is a fragile thing. What are the risks when it comes to reducing trust issues? There is a lot to dig into here that has significant policy implications. However, there are lots of other aspects of the data that has already been analysed that are also interesting, such as return of results, as well as data that has not yet been analysed.

DN: So much analysis has already been done - what do we want to touch upon in policy.

AN: Return of results is important. And if we feel like we haven't fully explored that topic, this is something we should look at. Would be good to look at views of non-experts on genetic exceptionalism. This is a key undertone to many discussions and would be interesting to see how people outside our world think about this. What methods can we use to allow trade off between options to communicate complexities. Best scaling and discrete choice? What elements can we use to play off these complexities?

DV: Focus groups that have been done - discrete choice experiment has been looked at - interesting things that came up were accessibility of data, issues of not wanting everyone to have access to that. Access should only be bonafide researchers, and not commercials. More exploration here, on top of Australian work on this would be great

CP: On, Further analysis on data - it was a moment in time. That analysis happened pre covid. We are in a different world now. Need to be careful not to use the same data in a way that may go beyond what it may not mean anymore.

RM: Tried to close things off in a sense. Among an ELSI audience we can have interesting conversations, how can we turn that into policy. A briefing that strips away nuances and complexities useful in executive summary form.

DN: It's tricky isn't it. The pre-covid distinctions are going to be really important. From the context of this group, it's useful for us to be able to know what data is out there in the post-covid world. The focus of this group is on what we do next with the data to develop policy, rather than more analyses of the data.

RM: There's the immediate questions around what are the things that maybe haven't changed, or what we might want to focus on. Who is our audience for those, can it go outside of GA4GH as well.

DN: My vote is for things that are far reaching and go outside of GA4GH. Things we can do both locally and globally.

AN: As much as possible, make things accessible at a global and national level. All of us probably have things going on that can align with this. Some synergy mapping might be useful. We could pick 1 or 2 questions or use cases that we find particularly relevant and then broaden if feasible.

RM: In terms of picking the doable things, we have Dianne the two you mentioned around trust and building trust, and around return of results. Those are clear areas where we might start off. It also comes up repeatedly. As an output has an ability to have a hook.

DN: Question for the group: would you be happy if we chose those areas, or are there others that need to be explored as well?

DV: +1

CP: The notion of why we focus on something special and different, genetic exceptionalism.

AN: If there is a list we can take a look at to ensure there's nothing we're missing.

BT: I think where trust and genetic exceptionalism meets familiarity is that interface. Something broader reach that goes into policy, could look into interventions.

RM: The difficulty is to tease familiarity out of trust. There isn't so much a longlist, mostly the dataset as a whole with all of the variables. Willingness to donate and its relationship with familiarity and trust, and whether the genetic data is seen as different. Interesting that it evenly splits with half of countries saying yes, the other half saying no.

AN: May not be one answer, could depend on the dataset. It's also dynamic over time.

SS: Wanted to add - familiarity, how aware people are. Major factor in the Indian population.

Difficult keeping your biases aside. I would suggest that if we are giving any policy suggestions, it should cater to the most vulnerable who do not even know what DNA is.

RM: Put up some suggestions about what the outputs might look like, maybe a 1-2 page briefing with an infographic.

DN: Need to know what else exists beyond YDYS.

BT: Doing a scoping review in this area, particularly with COVID, eg. would language around variants have changed. Everyone probably has similar work.

RM: Would be great to see that review when it's out. Having some sort of shared resource, or place where we can drop things. What will the actual work process look like, how do we view the writing and reviewing.

RM: infographic is already being written around trust. If I start a draft around trust.

MRA and DN can help.

RM: Work that into a shape and model and bounce to the next.

CP: I would support that. RoR is really important, but we've done a lot of work on that in REWS.

BT: I wonder if what is covered in trust might help us shape the others.

AN: I can help with background literature and conceptualizing trust.

Next Steps:

Heading towards a list of 4 topics - possible outputs are a 1-2 page briefing with an infographic.

Action: RM to start a draft/Google Doc on trust, with support from MRA, DN and AN.

Create doc for adding resources. Include terms of engagement.

End of June seems feasible.

Meeting cadence: monthly/bi-monthly

Google Folder for the group:

https://drive.google.com/drive/folders/1853aBl0NcEliL2O4di6t4OXaty7vlg_x?usp=sharing