



Building a community of practice through the PHA4GE Ethics and Data Sharing Online Platform

Nicki Tiffin

on behalf of the PHA4GE Ethics and Data
Sharing Working Group





The Ethics and Data Sharing Working Group

Aim:

To establish, facilitate and support an **inclusive, diverse, equitable** and **collaborative** ethics community

- **Promote ethics research**
- **Develop ethics training**
- **Increase capacity for informed, practical, agile solutions**





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The Ethics and Data Sharing Working Group

Most of us are:

- Applied ethicists
- Data-driven researchers
- Trying to promote or undertake research whilst upholding ethical principles

We need **practical, applied solutions** that can be relied on to keep us ethically compliant.





The Ethics and Data Sharing Working Group

Guidelines and recommendations:

- Lots already available.
- How to prioritise?

Build a community of practice for bottom-up problem solving:

- Organically identify current issues
- Organically develop solutions
- Tap into the wider network of skills and knowledge





The PHA4GE Ethics and Data Sharing Platform

<https://ethics-datasharing.pha4ge.org/>

- Online discussion platform
- Open to everyone with identified accounts
- Discussion and problem-solving of current ethics and data sharing challenges
- Share opportunities, collaborate, break down silo's



<https://ethics-datasharing.pha4ge.org/>



Ethics and Data Sharing Working Group

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+ New Topic

Category	Topics
Open Discussion General discussions, and those that don't fit neatly into the other topics and categories	3
Ethics and Data Sharing Welcome to this section where you can join existing conversations about Ethics and Data-Sharing; and you can start new ones. We hope you will use this section to have new conversations, join ongoing projects, and start new collaborations and projects based on your own ideas. Ethics and Data Sharing Advice Ethics and Data Sharing Experiences	8
Journals Please do let us all know about publications and articles that you have found interesting, enlightening, useful or controversial, so we can all benefit from them and have a wider discussion about ongoing work in the field. Please start a new discussion for new topics, or else get involved in the d... Published papers Find co-authors Suggest a paper PHA4GE papers	1
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Training and courses Welcome to the training and courses section of the platform. Please use this space to inform the community of available and upcoming ethics and data sharing training and courses. You can also use this space to find collaborators for ethics and data sharing training programs or	0



Public Health Alliance for Genomic Epidemiology



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Ethics and Data Sharing

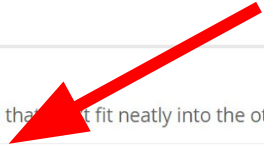
- Discussions
- Research collaborations
- Advice from the community





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Categories Most Liked

Ethics and Data Sharing

Can we establish a global principle to harmonize the disparities in data sharing guidance?

Ethics and Data Sharing Advice

B

0

4

13d

Successful Genomic Data Sharing Experiences: What lessons can we learn to take things forward?

Ethics and Data Sharing

B

Participate in an existing thread

Invitation to Collaborate: Building a practical ethics and governance framework for translation and commercialisation of human genomic data

Ethics and Data Sharing

N

Discussion: What ethical issues should be considered when sharing pathogen sequence data?

Ethics and Data Sharing

N

0

3

17d

Join me in writing a systematic review: Who takes the risks, and who gets the benefits of African health genomics studies

Ethics and Data Sharing

N

0

3

18d

Invitation to Collaborate: Building a practical framework to systematically identify risks to research participants, their communities and populations

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N

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Invitation to Collaborate: Building a practical framework to facilitate benefit sharing in research

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N

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18d

There are no more Ethics and Data Sharing topics. Ready to [start a new conversation?](#)





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Ethics and Data Sharing

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Sucessful Genomic Data Sharing Experiences: What lessons can we learn to take things forward? Ethics and Data Sharing	B	0	3	13d
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Start something new!

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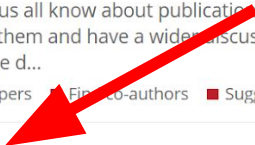
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Funding

- Funding opportunities

PHA4GE small grants





To make launching your new site easier, you are in bootstrap mode. All new users will be granted trust level 1 and have daily email summary emails enabled. This will be automatically turned off when 50 users have joined.

Small Grants: Funding Opportunity from PHA4GE for Ethics and Data Sharing Projects

Funding



Nicki_Tiffin

1 27m

Hi All, the PHA4GE Ethics and Data Sharing Working Group is able to offer some small grants towards short ethics and data-sharing projects that support the aims of PHA4GE and the Working Group.

This funding is available through a competitive process for small grants to complete projects initiated and conducted on this PHA4GE Ethics and Data Sharing Platform (<https://ethics-datasharing.pha4ge.org/>). All proposed projects must respect current COVID-19 safety protocols.

The total amount available for this programme is USD 50 000. The maximum amount that may be requested for a project is USD 5000, and this must include an open access publication fee. The PHA4GE and the Ethics and Data Sharing WG reserve the right to not disburse the full amount, and close the call once funding has been disbursed for successful applications.

The projects MUST be initiated on the PHA4GE Ethics and Data Sharing Platform.

Examples of successful types of projects might include, but are not limited to:

- Writing systematic reviews or scoping papers
- Building frameworks or guidelines for ethical and data sharing challenges
- Running an online workshop which develops guidelines, publications, tools
- Running a survey and analysing the results
- Building tools that support ethics and data sharing



29 Mar

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29 Mar

27m ago





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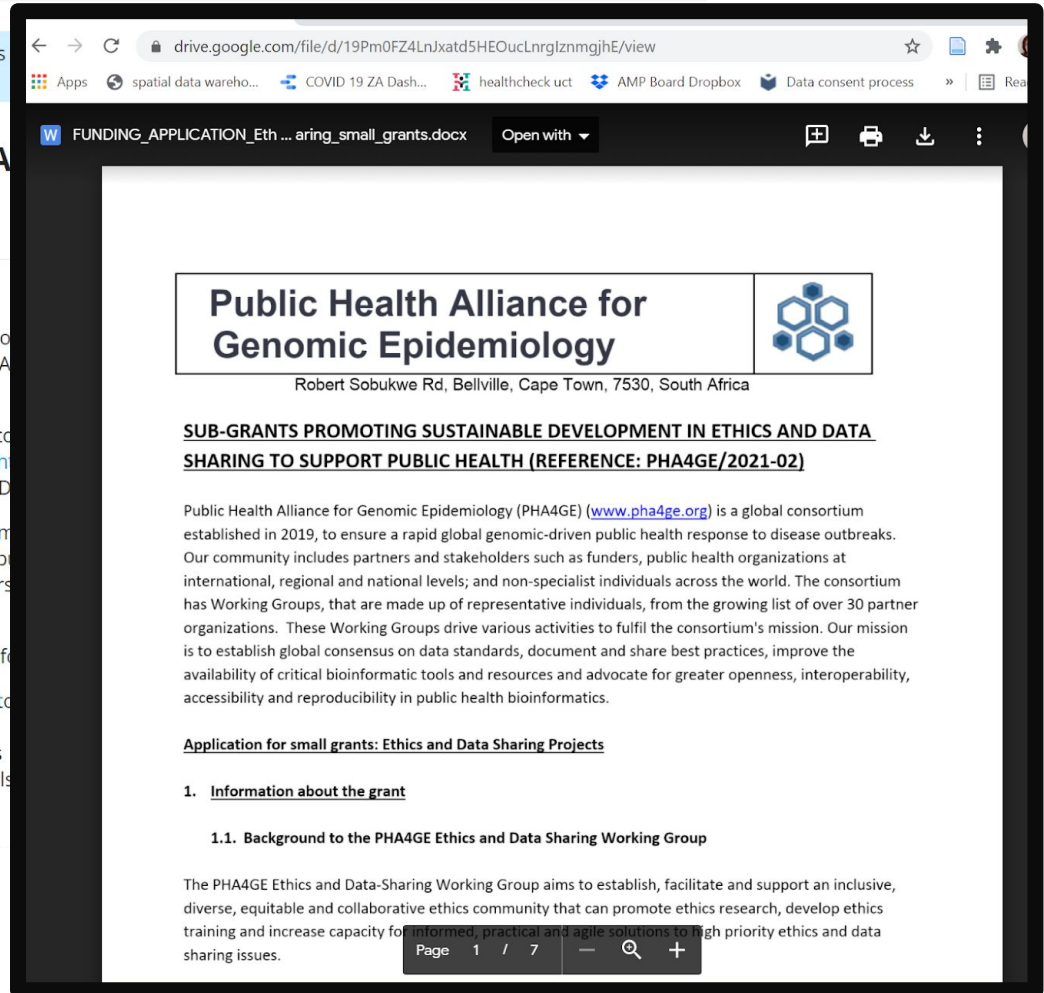
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Ethics & Data Sharing Community

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- Available training and courses
- Create a course collaborati...

Ethics and Data Sharing applications

It can be confusing making applications for Ethics Review... submitting requests to share data or samples.

- Ethics and Data Sharing application Advice
- Helpful Hints

PHA4GE

Announcements and projects from PHA4GE

- Projects

Journals

- Share interesting papers
- New publications

Training courses

- Training offered
- Collaborate to build training
- Identify required training

Ethics and data sharing applications

- Ask for help from the community





The Ethics and Data Sharing Working Group

The Team

Chair: Nicki Tiffin

Co-Chair: Anja Bedeker

Current Active Members:

Alice Matimba

Alwyn Mwinga

Brianna Lindsay

Oladapo Olagbegi

Taryn Allie

Victoria Nembaware

PHA4GE Secretariat

Alecia Naidu

Jamie Southgate

The PHA4GE Ethics and Data Sharing Online Platform was created using funds from the Public Health Alliance for Genomic Epidemiology funded by **the Bill & Melinda Gates Foundation**





Panel Discussion

1. Introductions
2. Sneak peak at some of posts already on the platform
3. Open the floor for questions, comments, feedback



Alice Matimba



Anja Bedeker



Brianna Lindsay



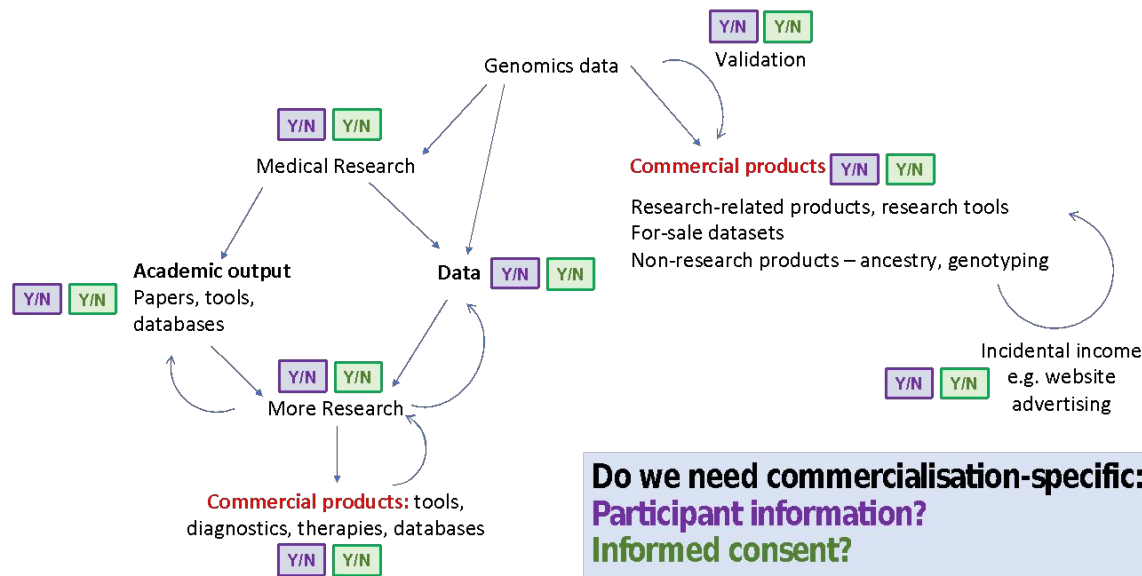
Invitation to Collaborate: Defining a meta-data standard for ethics research data

■ Ethics and Data Sharing

curate, archive, interrogate across various research projects datasets and identify what studies have been done, tools applied, what questions or issues have been explored and in which regions or populations.

Invitation to Collaborate: Building a practical ethics and governance framework for translation and commercialisation of human genomic data

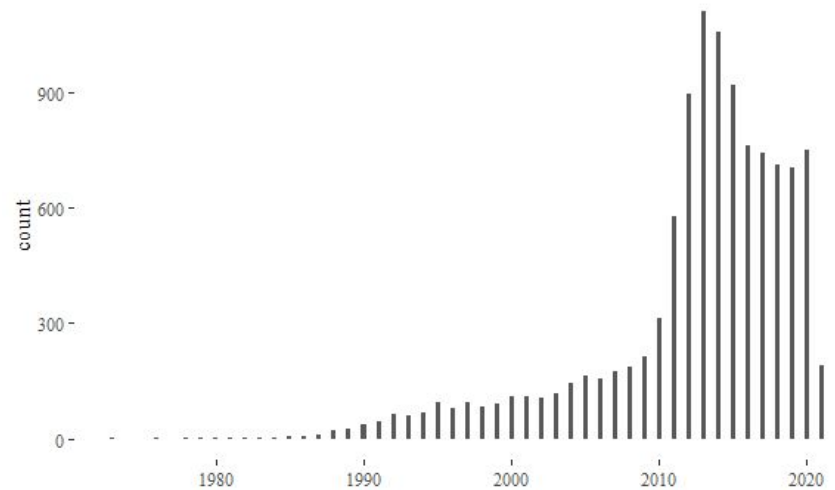
Using the framework



Do we need commercialisation-specific:
Participant information?
Informed consent?



Brianna Lindsay



Successful Genomic Data Sharing Experiences: What lessons can we learn to take things forward?

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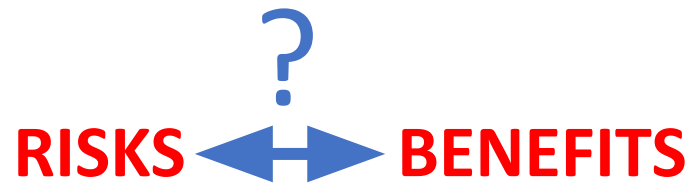
Can genomic data really be anonymized?

■ Open Discussion

Genomic data and anonymization

- EU's General Data Protection Regulation and SA's Protection of Personal Information Act protect people by placing restrictions on the use of their personal information
- These restrictions do not apply to anonymized data
- Anonymized data: irreversible de-identification of data
- However, can genomic data really be anonymized?





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