

Data sharing and governance for pathogen genomics

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Best practices for sharing pathogen data

Equity

- Benefit sharing
- Full participation by data generators, equitable sharing agreements

Ethics

- Protecting patients, communities and populations (often ID-related stigma)

Capacity

- Building capacity and skills for research locally

Sustainability

- Leveraging data for onward funding and support

Context

- Harnessing local clinical knowledge for appropriate interpretation of findings

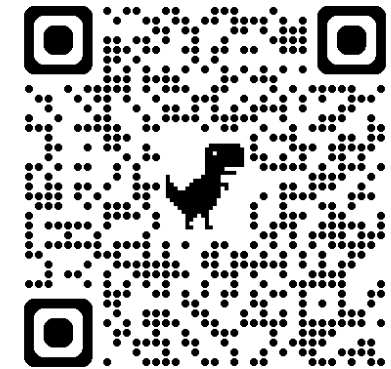
Legislation

What are the baseline rules for pathogen data sharing?

PHA4GE Accord: Establish a baseline, consensus set of rules

- Baseline “etiquette” for sharing microbial data
- Does not replace data-sharing legal agreements/MOUs
- Provides a generally accepted guidance on do’s and don’ts
- Does not replace Data Sharing Agreements/MOUs
- Provides a common, agreed starting base for sharing microbial data
- Opportunity to waive or modify any of the clauses

*e.g. “These data are shared according to the PHA4GE Microbial Data-Sharing Accord, with a waiver on **Clause 9: Invitation to Collaborate**, which is not required.”*



PHA4GE Microbial
Data-sharing Accord
Griffiths et al. 2023
BMJ Global Health



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PHA4GE Microbial Data Sharing Accord

1. Attribution

Acknowledging data generators

2. Overview of outputs prior to publication

Opportunity for data generators to review manuscripts for valid use of data

3. Onward sharing of data

Onward sharing only occurs with explicit agreement of data generator

4. Host and phenotype data anonymization

Protection of individuals from whom microbes/pathogens are sampled

5. Geospatial data

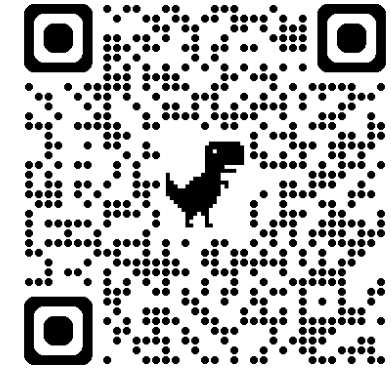
Protection of communities and individuals through responsible mapping

6. Intellectual property

Protected for data generators, transfer of IP only with specific agreement

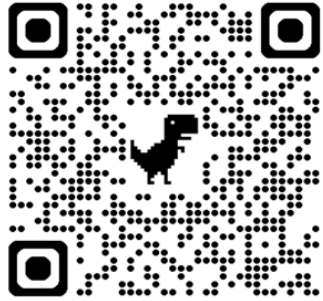
7. Opportunities for collaboration

Reasonable attempt to invite collaboration



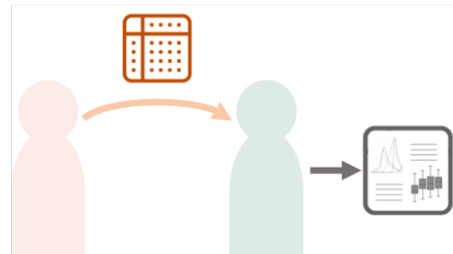
PHA4GE Microbial
Data-sharing Accord
Griffiths et al. 2023
BMJ Global Health

Thinking creatively about models of data sharing

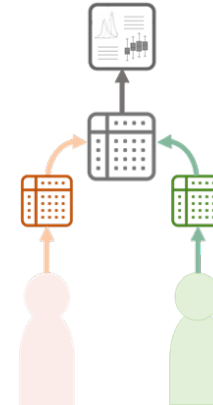


Modes of datasharing
 Tamuhla et al. 2023
 BMJ Global Health

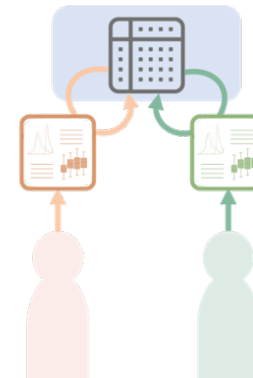
Direct sharing



Collaborative meta-analysis



Federated analysis



Trusted research environment

Fit-for-purpose data-sharing agreements

Increase confidence in equitable and ethical data sharing

ADBEx programme, input from PHA4GE:

- Online tool for building data-sharing agreements
(also called Memorandum of Understanding, MOU)
- Options for sharing agreements for data or biospecimens
- Options for types of sharing incl. direct, collaborative, federated, TRE and commercial
- ~35 prompts to capture information about the data-sharing plan.
- Modular, with skip logic – specific to biospecimens, data, different sharing models
- Produces Word Document Data-sharing agreement/MOU
- Word document that is generated can be used to draft legal agreements



MOU Builder

T. Tamuhla *et al* 2024,
Manuscript in prep



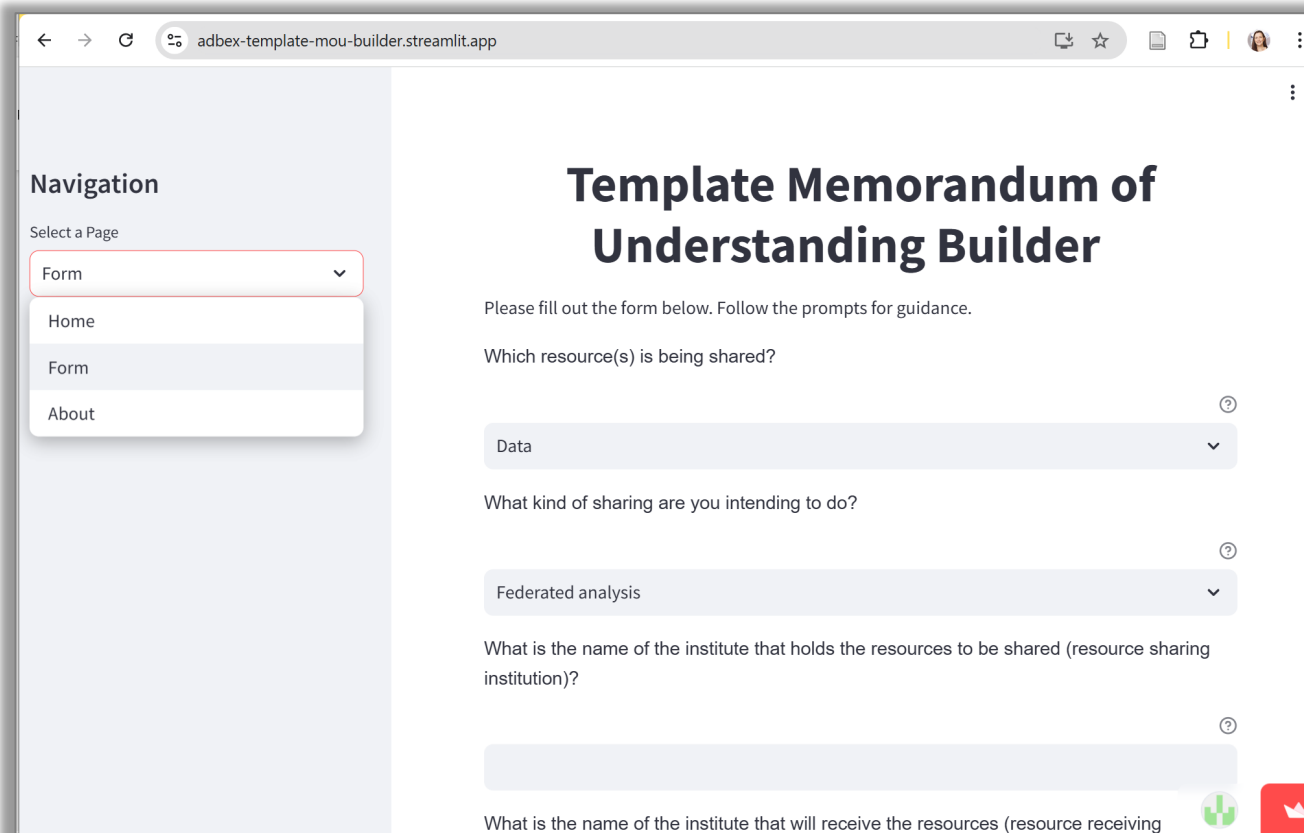
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MOU Builder App

<https://adbex-template-mou-builder.streamlit.app/>



The screenshot shows a web browser window with the URL `adbex-template-mou-builder.streamlit.app`. The app interface has a left sidebar with a "Navigation" section containing a "Select a Page" dropdown menu with options: "Form" (selected), "Home", "Form", and "About". The main content area is titled "Template Memorandum of Understanding Builder". Below the title, it says "Please fill out the form below. Follow the prompts for guidance." The first question is "Which resource(s) is being shared?" with a dropdown menu showing "Data". The second question is "What kind of sharing are you intending to do?" with a dropdown menu showing "Federated analysis". The third question is "What is the name of the institute that holds the resources to be shared (resource sharing institution)?" with an empty text input field. The fourth question is "What is the name of the institute that will receive the resources (resource receiving institution)?" with an empty text input field. At the bottom right, there are two buttons: a green one with a plus icon and a red one with a crown icon.



MOU Builder
T. Tamuhla *et al* 2024,
Manuscript in prep

Setting an intention for equitable and ethical benefit sharing

The PHA4GE Benefit-Sharing Framework

- Is the research contextually relevant?
- Ethics: Do participants in research see the benefits of the research?
- Equity: Do data generators benefit?
 - develop local capacity
 - recognition of contributions
 - sustainability



Bedeker *et al.* 2022.
BMJ Global Health



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Governance for Wastewater Surveillance

What's in the water?



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**Wastewater
sample**



**Molecular
species**



DNA, RNA



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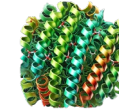


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**Wastewater
sample**



**Molecular
species**



Protein



DNA, RNA



Chemicals

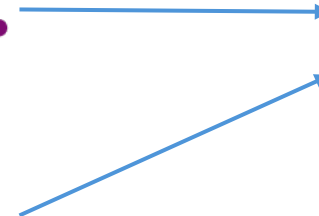
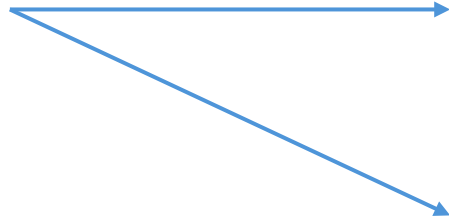


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Wastewater
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Molecular
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Protein



DNA, RNA



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Wastewater
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Molecular
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Protein



DNA, RNA



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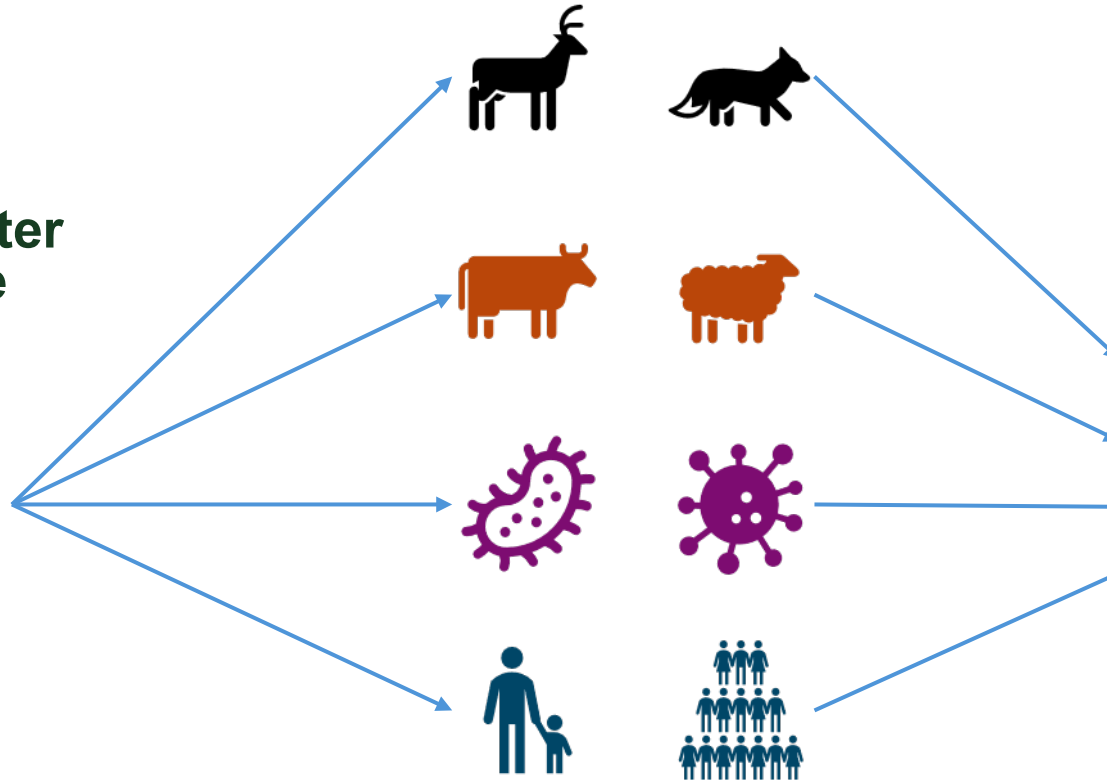


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Wastewater
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Molecular
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Protein



DNA, RNA



Chemicals

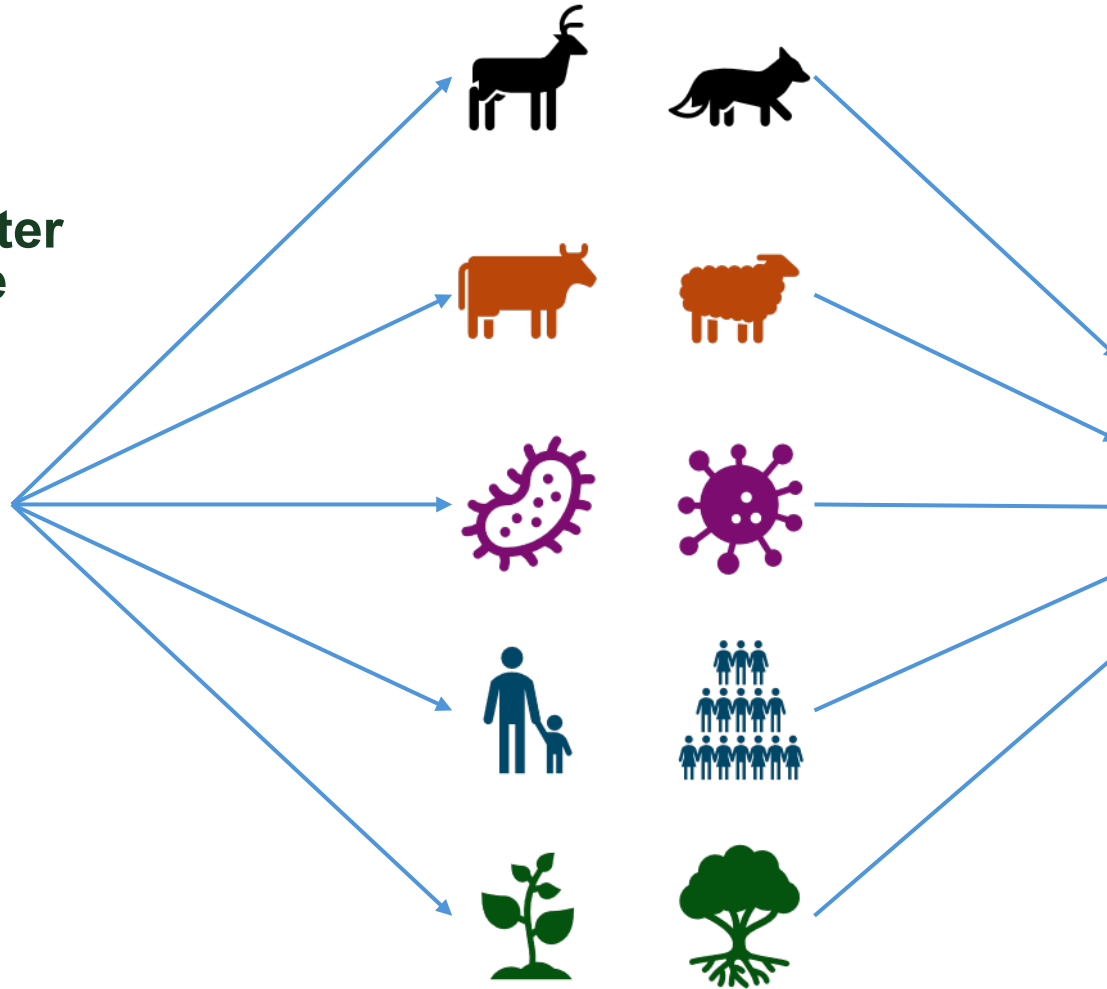


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Wastewater
sample



Molecular
species



Protein

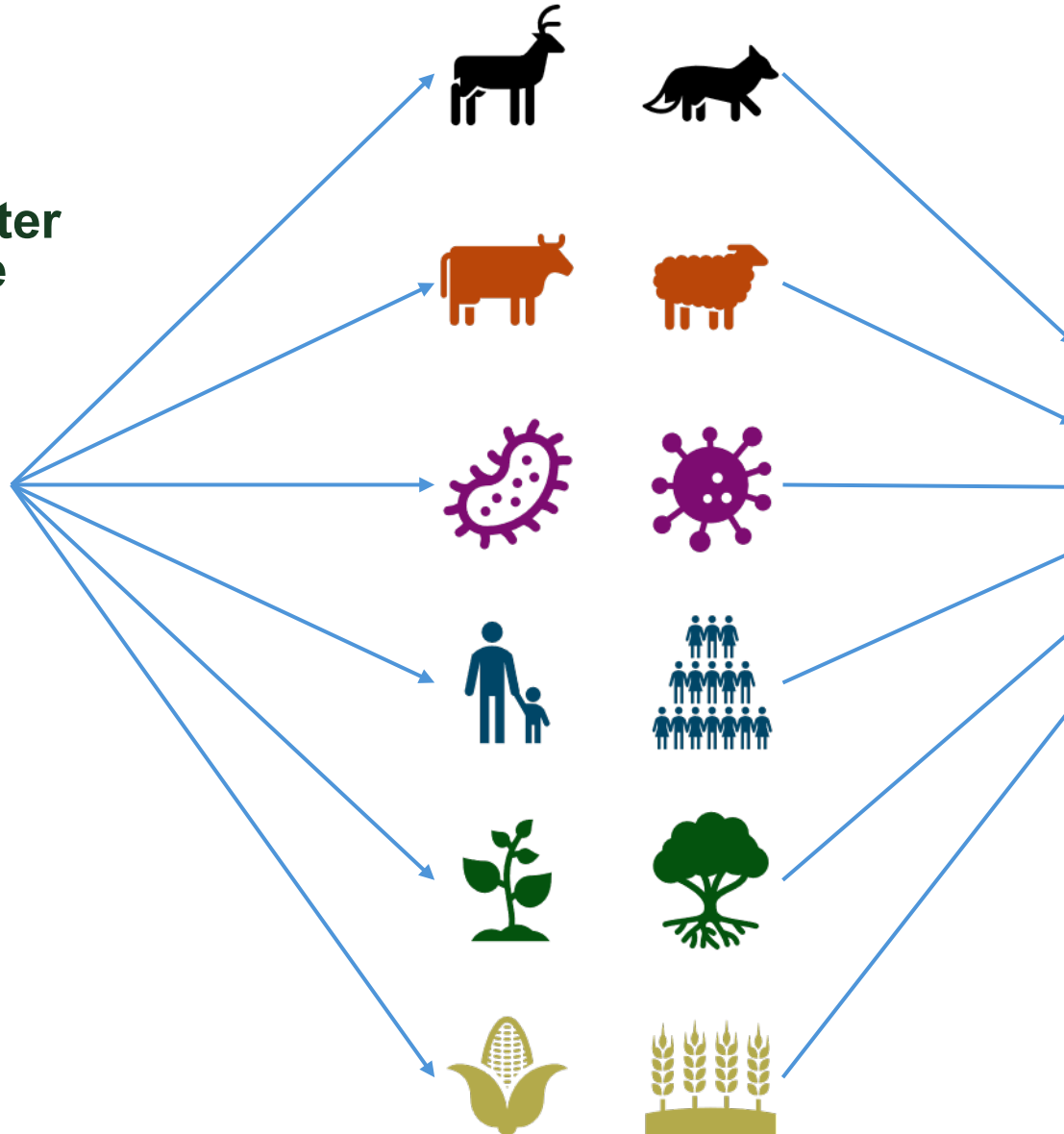


DNA, RNA



Chemicals

Wastewater
sample



Molecular
species



Protein



DNA, RNA



Chemicals



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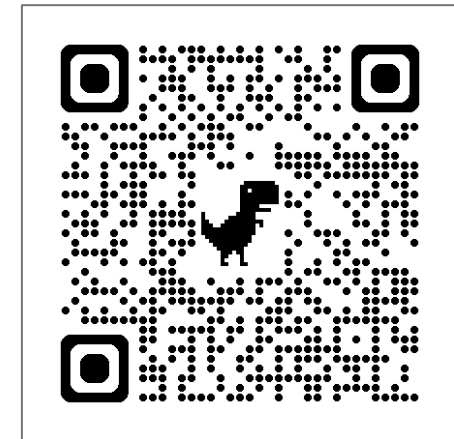
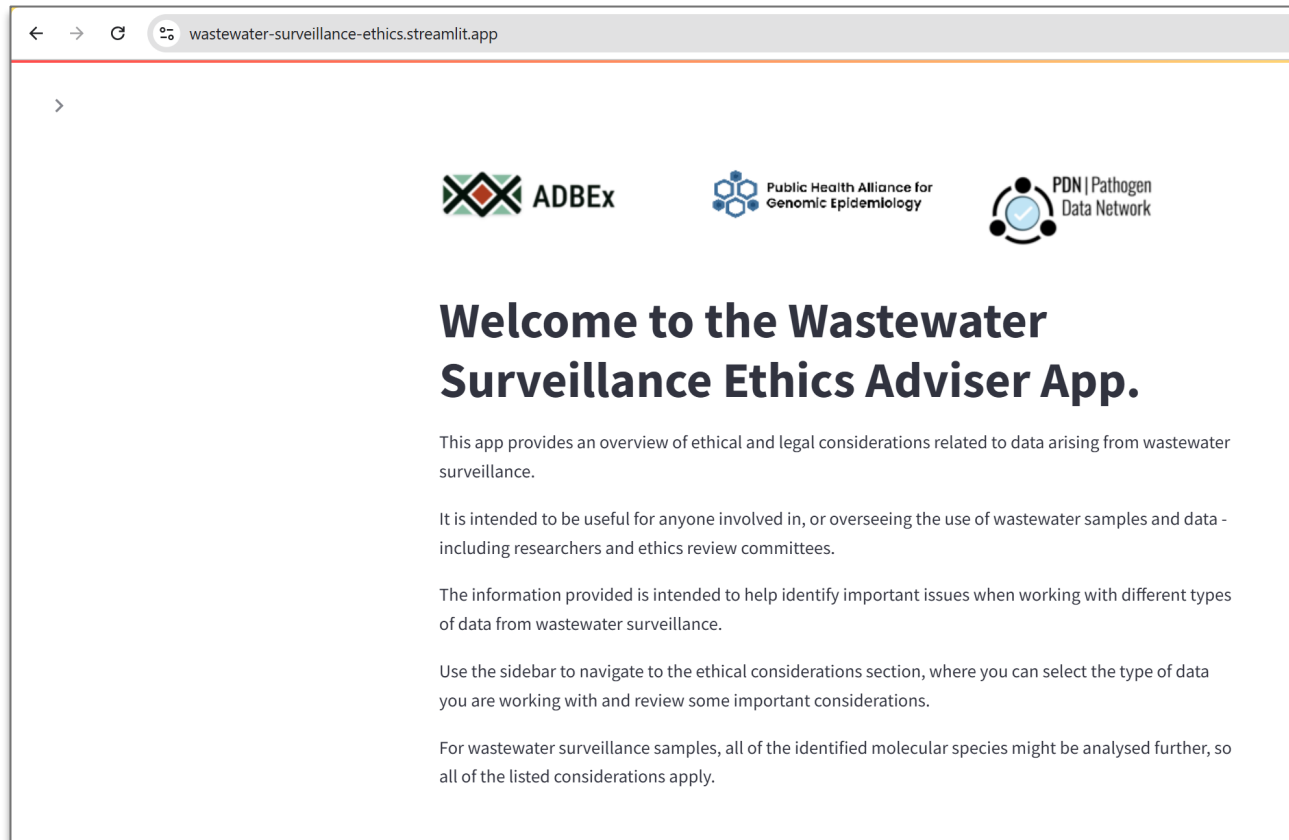
Ethical and legal considerations for ALL types of data

- **Wastewater samples contain all of these molecular species**
- **Each data type has specific considerations**

For each Species of Origin, molecule and data type:
Ethics: Potential benefits Potential harms Autonomy and Respect *CE and informed consent Justice *Those at risk get better benefits Equity
Benefit sharing
Governance: Responsible party Data protections Access model
Legislation and protocols: Privacy Acts Environmental, agriculture, conservation laws Health Acts (e.g. notifiable pathogens) Data sovereignty IP

Ethical and legal considerations for ALL types of data

<https://wastewater-surveillance-ethics.streamlit.app/>



WWS Ethics Adviser App

T. Tamuhla *et al* 2025,
Manuscript in prep



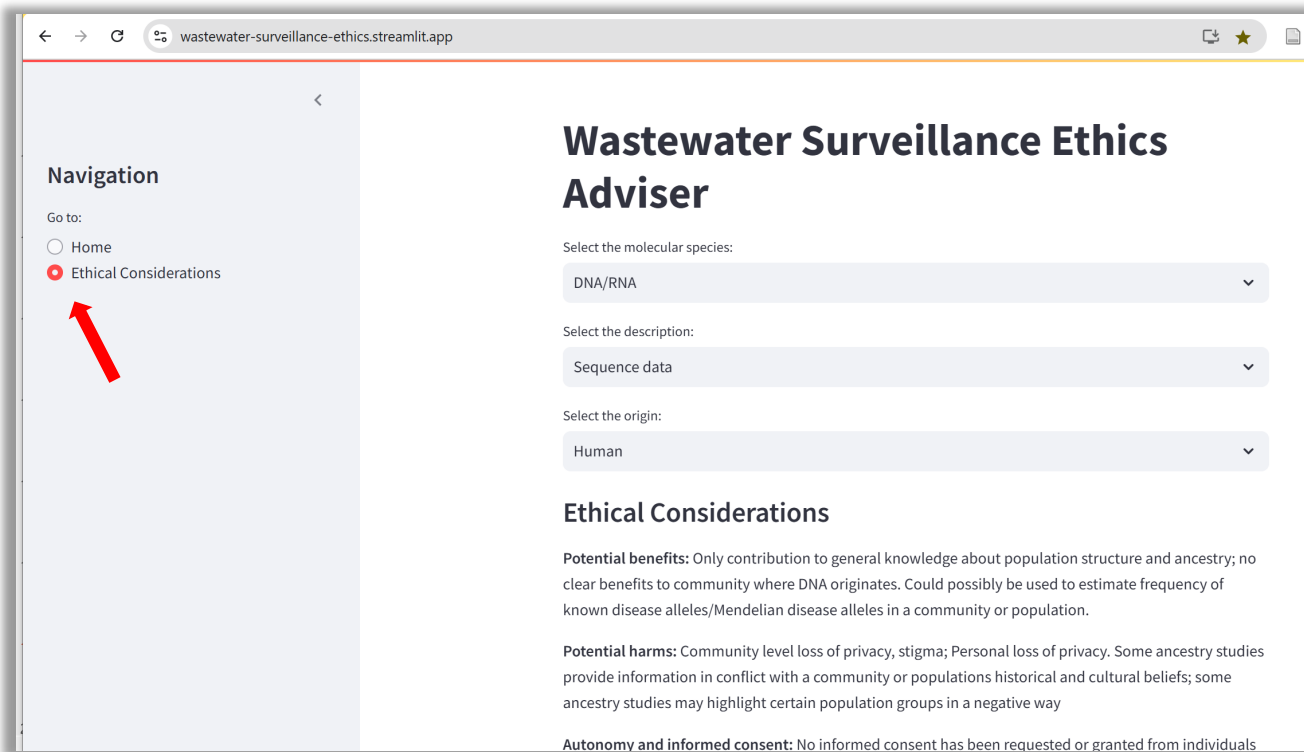
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Ethical and legal considerations for ALL types of data

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Wastewater Surveillance Ethics Adviser

Select the molecular species:
DNA/RNA

Select the description:
Sequence data

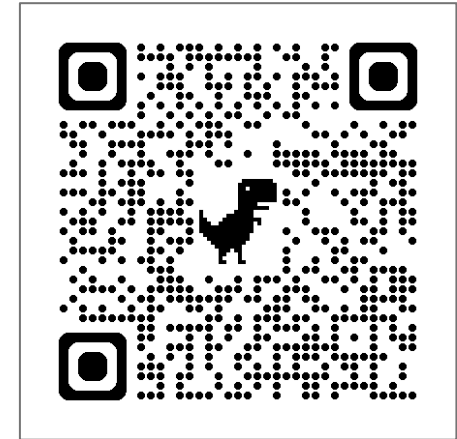
Select the origin:
Human

Ethical Considerations

Potential benefits: Only contribution to general knowledge about population structure and ancestry; no clear benefits to community where DNA originates. Could possibly be used to estimate frequency of known disease alleles/Mendelian disease alleles in a community or population.

Potential harms: Community level loss of privacy, stigma; Personal loss of privacy. Some ancestry studies provide information in conflict with a community or populations historical and cultural beliefs; some ancestry studies may highlight certain population groups in a negative way

Autonomy and informed consent: No informed consent has been requested or granted from individuals



WWS Ethics Adviser App

T. Tamuhla *et al* 2025,
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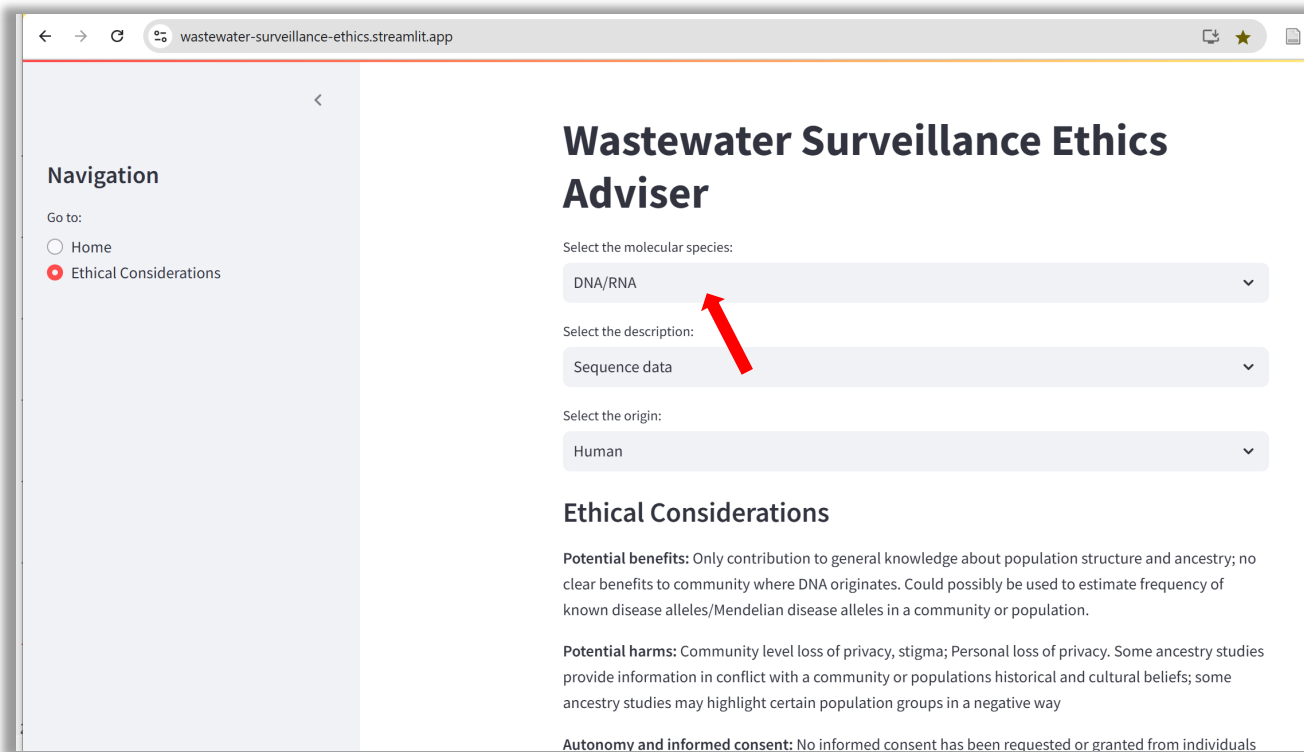
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Ethical and legal considerations for ALL types of data

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The screenshot shows a web browser window with the URL `wastewater-surveillance-ethics.streamlit.app`. The app interface has a sidebar on the left with a "Navigation" section containing two options: "Home" (unselected) and "Ethical Considerations" (selected with a red dot). The main content area is titled "Wastewater Surveillance Ethics Adviser". It features three dropdown menus: "Select the molecular species:" with "DNA/RNA" selected, "Select the description:" with "Sequence data" selected, and "Select the origin:" with "Human" selected. A red arrow points to the "Sequence data" dropdown. Below these menus is a section titled "Ethical Considerations" containing three paragraphs of text. The first paragraph discusses potential benefits, the second discusses potential harms, and the third discusses autonomy and informed consent.

Wastewater Surveillance Ethics Adviser

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DNA/RNA

Select the description:
Sequence data

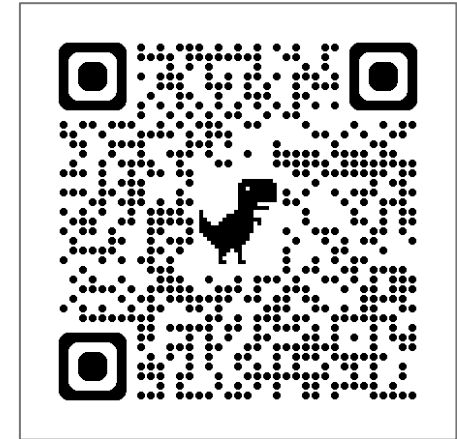
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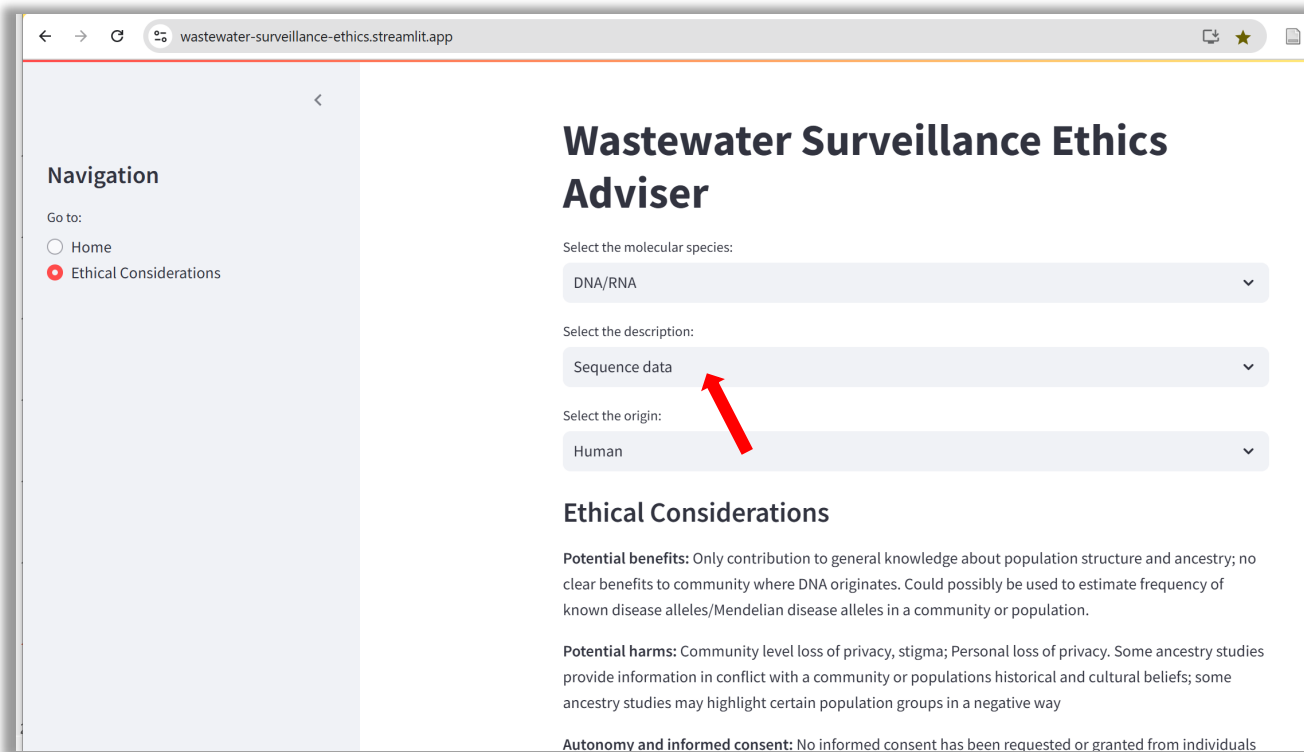
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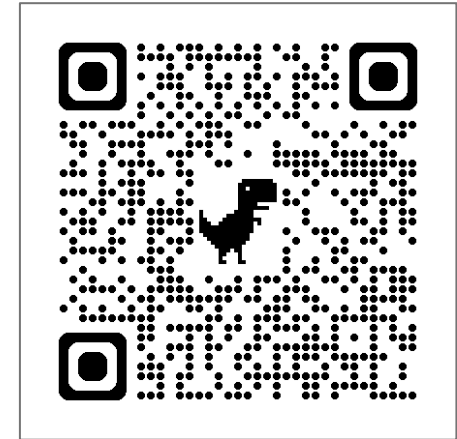
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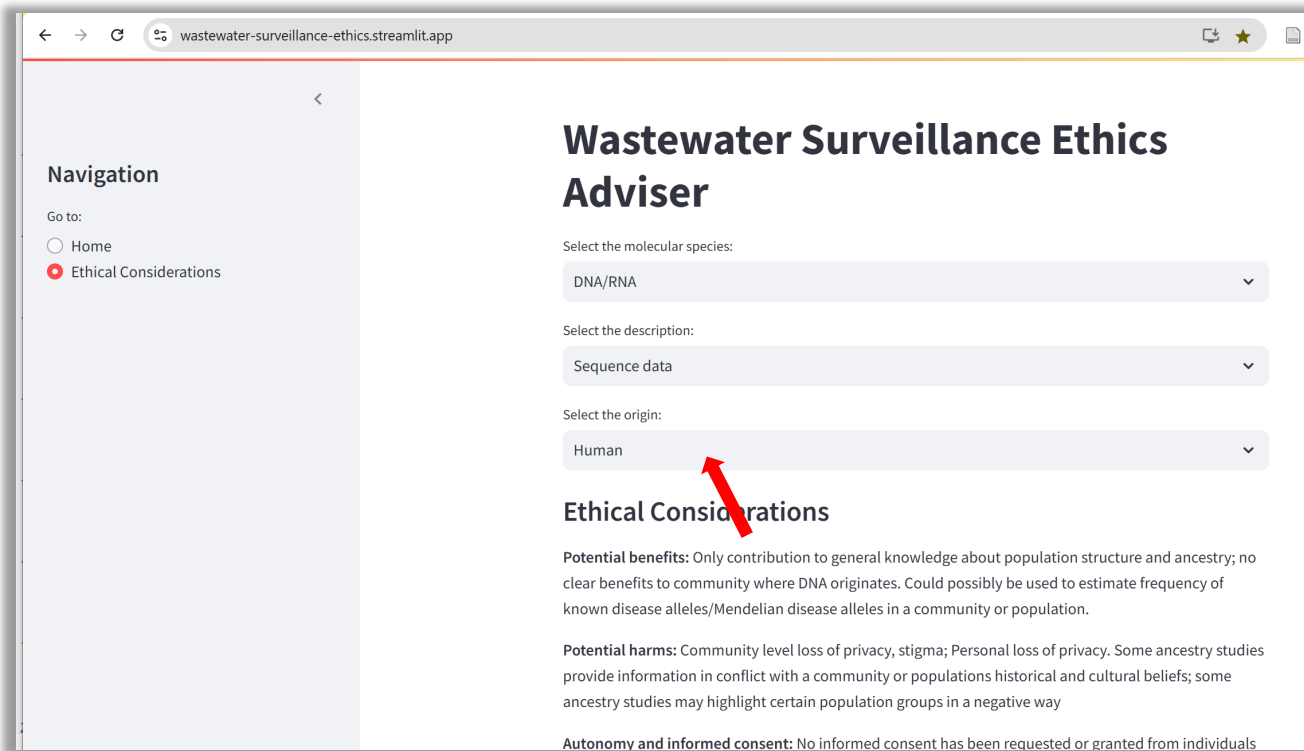
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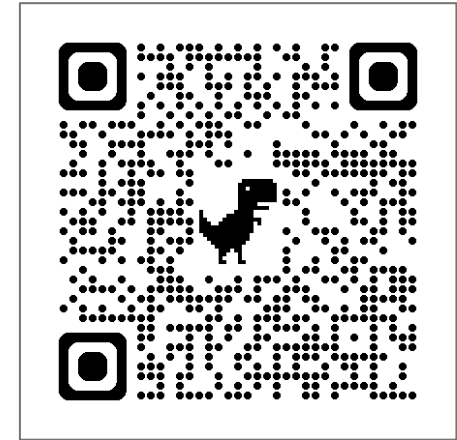
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WWS Ethics Adviser App

T. Tamuhla *et al* 2025,
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Thank you

Health data integration group

Team members – data sharing

Tsaone Tamuhla: streamlit apps

PHA4GE collaborators (PI Alan Christoffels)

PHA4GE Ethics and Datasharing WG

WWS Ethics and Datasharing Matrix contributors

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- PHA4GE funding

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