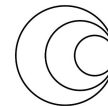


Day 4: Session 2

Ethics of Specimen and Data Sharing

Dr Leigh Jackson, Dr Kareemah Suleiman

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Course roadmap

Sun 7 May
Introduction Day



Mon 8 May
**Day 1
Capacity Building**



Tue 9 May
Day 2
**Specimen and
Sequencing**



Wed 10 May
Day 3
**Data Tools and
Pipelines**



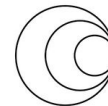
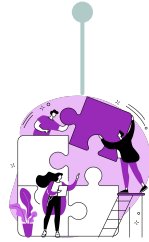
Thu 11 May
Day 4
**Frameworks,
Guidelines, and
Decision-making**



Fri 12 May
Day 5
**Projects Review and
Action Planning**



**Next steps and
Beyond**



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**Frameworks, Guidelines,
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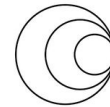
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Next steps and Beyond



Ethics and datasharing
Sustainability
Communication



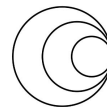
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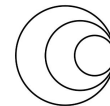
Session objectives

- Setting up ethical processes in advance of outbreaks
- Reciprocity in MTAs, research collaborations and public health partnerships
- Ethical issues and pitfalls



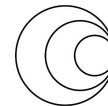
Session outcomes

- Develop an outline of the steps required to obtain ethical approval for taking and processing samples
- Evaluate the key points around how to make collaborations fair and equitable
- Discuss some of the ethical issues arising from the current pandemic



Ethical approval for outbreaks (WHO)

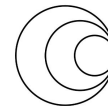
- What is the appropriate role of research during an infectious disease outbreak?
- How might the circumstances surrounding infectious disease outbreaks affect the ethical review of research proposals?
- How might the circumstances surrounding infectious disease outbreaks affect the process of informed consent to research?
- What methodological designs are appropriate for research conducted during infectious disease outbreaks?
- How should research be integrated into broader outbreak response efforts?



Group activity 1

Discuss in small groups

- Requirements for ethical approval of research in your institute, country or subject area
- How requirements for ethical approval might change during an epidemic emergency
- Is there a way to have pre-approved protocols to reduce the time required for ethical approval?
- How could you design such a protocol to be flexible to different pathogens?

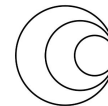


Collaboration agreements

Material transfer agreement (MTA's) is the legal contract between a provider and a recipient that sets out the terms and conditions under which genetic resources are transferred.

Key items for collaboration agreements

- Description of material and associated data
- Terms and conditions
- Signature and duration
- Definitions
- Annexes



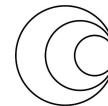
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Basic principles for community involvement (AU)

- Predictability and transparency
- Clarity and legal certainty
- Prior informed consent
- Equitable benefit sharing
- Dialogue and Negotiation

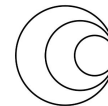


Group activity

Discuss in groups

- What are the markers of equity and fairness in collaborations?
- To what extent are these markers fixed or flexible during outbreaks?
- How might a public health collaboration agreement look both within a country and internationally?

After discussing these issues, draft an agreement containing the key issues important to your group.



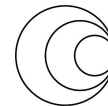
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Key ethical issues concerning pathogen genomics

- Sample and data sharing in a fair, equitable and properly acknowledged manner
- Cost/benefit of pathogen genomic surveillance
- Research versus public health considerations
- Scientific independence from politics
- Informed consent
- Individual vs population considerations
- National, regional and global communication and collaboration

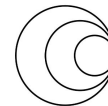


Group activity

Discuss in groups

- Identify important ethical issues which you have encountered within your area of work, which are shared amongst your group and are any unique?
- Are there any additional issues that arise during outbreaks?
- How might you overcome or mitigate some of these issues?

Generate a check-list of things to consider to minimise ethical problems during the next outbreak or large-scale use of genomics in your field of interest



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