

How Can Ethics Help APPRISE?

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How can ethics help?

- Understanding ethical concepts and arguments
- Understanding social complexity
- Understanding legal, political difficulties
- Constructing frameworks, guidelines and processes

Structure

1. Zika
2. WHO Public Health Surveillance Guidelines
3. Priorities for the coming year
4. Next Steps

1. Zika: Literature Review of Ethics & Policy Documents

- Little, if any, until declared a 'PH Emergency of International Concern'
- PAHO & Nuffield Council of Bioethics
- Shadow of Ebola
- Predictable application
- Limited focus – what is missing?

Themes in Literature (I)

- Maximise autonomy/freedom of individuals
 - Provide information
 - Informed consent
 - Privacy
 - Intervention ladder
- Reproductive choices (particularly PAHO)
- Public engagement
 - understand views
 - participatory
 - procedural fairness

Themes in the Literature (II)

- Role of the state
 - Infectious disease
 - Surveillance
- Individualism
- (Responsibility) e.g. care of children with microcephaly
- How to conduct research
 - GM Mosquitoes
 - Vaccines & treatments
 - Trials

What's missing?

- Public Health Ethics, One Health, Environmental Justice
 - Solidarity, common good, justice etc
- Prevention and protection (Importation, Outbreak)
- Collective response
- Social, political and environmental context (jurisdictional, responsibility)
- Disadvantage
- Human-mosquito interactions - development

2. WHO Guidelines on PH Surveillance

Guideline 1. Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems. Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.

Guideline 2. Countries have an obligation to develop appropriate, effective mechanisms to ensure ethical surveillance.

Guideline 3. Surveillance data should be collected only for a legitimate public health purpose.

Guideline 4. Countries have an obligation to ensure that the data collected are of sufficient quality, including being timely, reliable and valid, to achieve public health goals.

WHO Guidelines on PH Surveillance

Guideline 5. Planning for public health surveillance should be guided by transparent governmental priority-setting.

Guideline 6. The global community has an obligation to support countries that lack adequate resources to undertake surveillance.

Guideline 7. The values and concerns of communities should be taken into account in planning, implementing and using data from surveillance.

Guideline 8. Those responsible for surveillance should identify, evaluate, minimize and disclose risks for harm before surveillance is conducted. Monitoring for harm should be continuous, and, when any is identified, appropriate action should be taken to mitigate it.

WHO Guidelines on PH Surveillance

Guideline 9. Surveillance of individuals or groups who are particularly susceptible to disease, harm or injustice is critical and demands careful scrutiny to avoid the imposition of unnecessary additional burdens.

Guideline 10. Governments and others who hold surveillance data must ensure that identifiable data are appropriately secured.

Guideline 11. Under certain circumstances, the collection of names or identifiable data is justified.

Guideline 12. Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. Under these circumstances, informed consent is not ethically required.

WHO Guidelines on PH Surveillance

Guideline 13. Results of surveillance must be effectively communicated to relevant target audiences.

Guideline 14. With appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.

Guideline 15. During a public health emergency, it is imperative that all parties involved in surveillance share data in a timely fashion.

Guideline 16. With appropriate justification and safeguards, public health agencies may use or share surveillance data for research purposes.

Guideline 17. Personally identifiable surveillance data should not be shared with agencies that are likely to use them to take action against individuals or for uses unrelated to public health.

3. Priorities for the next year

Priority	Description	Deliverables
1	Map current research ethics structures & consider feasibility & barriers to any 'rapid' research ethics review and alternatives (e.g. pre-approved protocols etc.) – including vulnerable populations	Literature review
		Develop plan for future research & consultation in this area
2	Explore and promote the contribution that one health/ecohealth/planetary health can make to APPRISE agenda	Vector-borne disease workshop
		Mapping paper of potential emergencies involving non-human animals in Australia (in the next year)

4. Next Steps

- Linked up with EU project: Platform for European Preparedness Against (Re-) emerging Epidemics (PREPARE) – Nina Gobat
- Barriers/Solutions doing research
- Good for comparison and contrast
- No real expertise in normative work and framework development etc.
- Antimicrobial resistance work