

Ethical frameworks should be applied to computational models of infectious disease interventions

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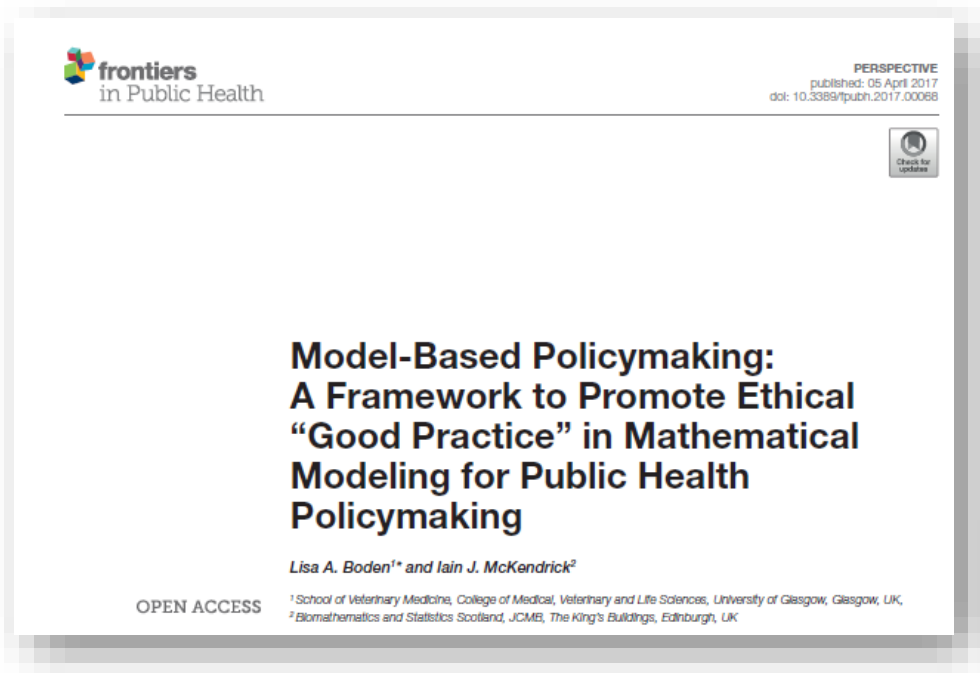
Introduction

- A little about me
 - Agent based modelling
 - Complex systems
 - Infectious disease modelling
 - Modelling to inform COVID response in Australia
- Why am I talking about ethics?
 - ABMs of detailed intervention scenarios
 - Quarantine
 - Case isolation
 - “Narrative” debugging technique told troubling stories...
 - Realistic models of people’s actions and situations clarify ethical implications

When should we consider ethics in IDD models?

- IDD models can be ethically neutral
 - i.e., studying and understanding disease transmission from a theoretical perspective
- IDD models that inform interventions are usually not ethically neutral
 - Models include assumptions, e.g. -
 - Human behaviour
 - Access to personal data
 - Capacity to comply
 - Risk of disease
 - We model trade-offs that usually prioritise reducing clinical burden from one specific contagion.

Prior work (selected)





Model-Based Policymaking: A Framework to Promote Ethical “Good Practice” in Mathematical Modeling for Public Health Policymaking

Lisa A. Boden^{1*} and Iain J. McKendrick²

OPEN ACCESS

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² Biomathematics and Statistics Scotland, JCMB, The King's Buildings, Edinburgh, UK

Models are useful “thought experiments.” However, if model evidence is intended to inform policy in the real world, modelers have a duty of care to consider and communicate ethical issues. Ethical risks are influenced by model variability and uncertainty that have important impacts on the distribution of beneficial or harmful consequences.



Systems thinking and ethics in public health: a necessary and mutually beneficial partnership

Diego S. Silva¹ · Maxwell J. Smith^{2,3} · Cameron D. Norman^{3,4}

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“Despite the sporadic use of terms like ‘complexity’ and ‘systems’ in public health ethics, to date there are few explicit attempts to evaluate how systems theories can help people reason through ethical challenges in public health.”

COMMENTARY

Open Access

Should infectious disease modelling research be subject to ethics review?



Ben Green^{1*} 

“Imperial College conducted research leading to the website publication of a paper, Report 9, on non-pharmaceutical interventions (NPIs) and COVID-19 mortality demand dated 16th March 2020, arguing for a Government policy of non-pharmaceutical interventions (e.g. lockdowns, social distancing, mask wearing, working from home, furlough, school closures, reduced family interaction etc.) to counter COVID 19. Enquiries and Freedom of Information requests to the institution indicate that there was no formal ethical committee review of this specific research, nor was there any peer review prior to their online publication of Report 9.”

What should modellers be able to do?

- Modellers should not be the ones defining ethical frameworks
- But – we should be able to confidently design models that:
 - Are coherent with the framework specified by stakeholders
 - Do not embed *implicit* assumptions about human behaviour (these should be explicit)
 - Can be adapted to account explicitly for value trade-offs
- And – we should be able to engage with ethics concepts from the design stage
 - Not limited to post-hoc evaluation of the ethical implications of our models

What will this achieve?

- If modellers can use ethical frameworks as design principles, we can:
 - Quantitatively evaluate prospective ethical trade-offs
 - Be confident that our models are compatible with stakeholder values
 - Help evaluate and compare alternative ethical frameworks to inform policy
 - Help avoid unintended consequences

Examples

- Untargeted interventions
- Targeted interventions
- Context-specific interventions
- Surveillance

Untargeted interventions

- Untargeted interventions produce equity concerns:
 - Capacity to comply
 - Relative burden of compliance
 - Outcome efficacy
- Example: lockdown
 - Compare Melbourne with Santiago

Targeted interventions

- Interventions can be more efficient if they are targeted
- This produces ethical trade-offs:
 - Beneficence vs. privacy
 - Equity of outcomes vs. equity of treatment
- It's a slippery slope!
 - i.e., behavioural profiles for selective restrictions

Context-specific interventions

- What is appropriate depends on context, e.g.,
- Vaccine mandates:
 - Are normal for healthcare workers
 - Are not normal for abattoir workers
- Video surveillance:
 - Is normal for military personnel
 - Is not normal for civilians in household quarantine

Some general categories:

- Beneficence
 - Averting harm (i.e., clinical disease)
 - Non-maleficence
- Justice
 - Representation
 - Equity
- Autonomy
 - Privacy
 - Physical Liberty
 - Informed consent

What is an ethical framework?

- A system for prioritizing values during a decision process, to achieve the intended moral outcome.
 - A set of values, organized according to priority
 - Often, ethical frameworks are presented as an unranked set of values or principles.
 - I find this unsatisfying, and difficult to put into action.
- Example:
 - <https://www.santepubliqueottawa.ca/fr/professionals-and-partners/resources/Documents/Ethical-Framework-for-Pandemic-Response-April-24-2020-.pdf>

Public health ethics

- PHE evolved out of clinical and medical research ethics
 - PHE moves some of the emphasis from autonomy, prioritising duty of care
 - “relational autonomy” – the actions of one affect the lives of many
- PHE frameworks are conceptually useful but have been criticized as unactionable:

**Why ethical frameworks fail to deliver in a pandemic:
Are proposed alternatives an improvement?**

Chris Degeling✉, Jane Williams, Gwendolyn L. Gilbert, Jane Johnson

First published: 13 July 2023 | <https://doi.org/10.1111/bioe.13202>

- Modelling can help define useful and actionable PHE frameworks.
- Simultaneously, PHE frameworks can help us develop better models.
 - i.e., emphasizing the current focus on endogenous behaviour and equity in next-generation models.

More practice: Autonomy

						examples				
		values and principles	practical concepts	ethical questions	model features	model design questions				
Autonomy	privacy (confidentiality)	relational structure	How do an individual's actions affect others?	contact networks, mixing matrices	Are transmission networks clustered by clinical/exposure risk?					
	physical freedom personal liberty	coercive norms	How much autonomy would someone normally have in this environment?	context-specific interventions that limit autonomy	What limits NPI compliance in different workplaces?					
	informed consent non-interference	endogenous behaviour change	Is behavioural intervention necessary?	feedback between disease dynamics and protective behaviours	Do contact rates depend on prevalence?					

More practice: Justice

examples					
	values and principles	practical concepts	ethical questions	model features	model design questions
Justice	equity fairness positive rights (i.e., the obligation to improve existing conditions)	risk equity	Are some people at higher risk than others? Does everyone have the same capacity to avoid risk?	heterogeneous distributions of clinical risk factors, or capacity to avoid risk	What limits people's capacity to avoid exposure? Are these factors correlated with clinical risk?
	representation	historical bias in data	Is the data informing the model biased due to underlying inequity?	local incidence counts, healthcare seeking behaviour, health service density	Does the probability of detecting an infection vary by region?

More practice: Beneficence

examples					
	values and principles	practical concepts	ethical questions	model features	model design questions
Beneficence	non-maleficence proportionality	unintended health effects	Will this intervention affect access to basic resources such as food? Will this intervention produce psychological distress?	effects of interventions or disease on psychological distress or access to essential resources	Should we assume homogeneous impact when simulating large-scale NPIs?
	duty of care	contextual rules (deontological constraints)	Is the model simulating interventions that violate assumed social rules?	interventions that separate families, or require unacceptable types of surveillance	How much information should we assume is available for contact tracing?

Further reading:

Ethical frameworks should be applied to computational modelling of infectious disease interventions

Cameron Zachreson,¹ Julian Savulescu,^{2,3,4} Freya M. Shearer,⁵ Michael J. Plank,⁶ Simon Coghlan,^{1,7} Joel C. Miller,⁸ Kylie E.C. Ainslie,^{9,10} and Nicholas Geard¹

Available at SSRN: <https://ssrn.com/abstract=4719620>

Summary

- Computational modelling of infectious disease interventions can have a reciprocal relationship with ethical framework development
- This will allow
 - Better models (accounting explicitly for ethical trade-offs)
 - Better frameworks (that are actionable, specific, and quantitative)
 - Ultimately, better interventions that are balanced and effective
- Doing this will be a challenge – we need:
 - Better submodels of human behaviour
 - Better incorporation of underlying risk factors and historical inequity
 - Better understanding of mental and physical health impacts of interventions (especially NPIs).

Ongoing work

Interface Focus special issue:

Mathematical Modeling for the Design of
Ethical Infectious Disease Interventions

Please contact me!

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