



Liberty and protection, fear and security: Ethics and the uncertain threat of infectious diseases.

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Ethics and the impossibility of imagination

- ☞ Most models of reasoning, care and health resource allocation cope better with clinical dyad, individuals and micro-allocation.
- ☞ Most data is poor or based on computer modelling and/or speculation
- ☞ Infectious diseases are incomprehensible:
 - Black Death killed one third of the European population in C14th (9 – 11 million people)
 - 1918 flu killed 20 – 100 million people
 - Small pox killed 300 – 540 million people in C20th (more than all wars and all other epidemics)
 - ID cause 13 million deaths per year
 - HIV killed 23 million people in 26 years

Ethics and the invisibility of infectious diseases

Until recently, infectious diseases (and public health) have been largely ignored by (bio) ethicists:

- interest has been in biotechnology
- Persuaded by rhetoric of 60's that infectious diseases would be conquered by medicine
- Infections are the problems of others
- No data
- Not philosophically interesting (yeek!)
- Hijacked by the church (responding to the illiberal policy agenda of the church)

Ethics and pandemic preparedness

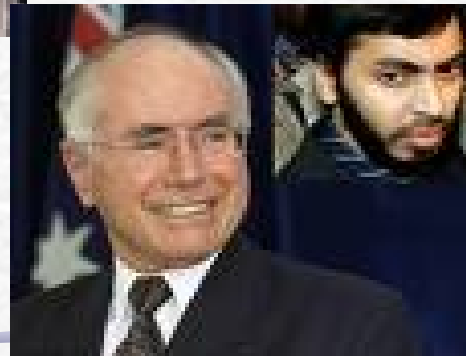
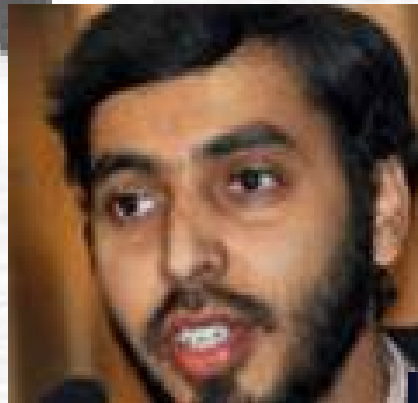
- Impressive
- Stakeholder involvement
- All levels of government
- 'Whole of government' approach: care of sick, containing disease, preservation of civil society etc
- Comprehensive
- Proactive
- Evaluated (Exercise Cumpston)
- Widely acknowledged

Values relevant to SARS (Pandemic planning)

Singer et al BMJ.2003;327:1342-4.

1. Individual liberty
2. Protection of the public from harm
3. Proportionality
4. Reciprocity
5. Transparency
6. Privacy
7. Protection of communities from stigmatisation
8. Duty to provide care
9. Equity
10. Solidarity

Liberty and trust in times of insecurity



Proportionality (justifiable restriction of liberty)?



Public health, security and liberty: I

- Public health has moral force: security and flourishing.
- BUT this moral force is often assumed.
- This becomes a problem in situations that require restriction of values/liberties that are generally protected eg right to work, move, socialise etc.
- Pandemics and threats of (bio)terrorism provide a basis for social isolation, home quarantine, restriction of mass gatherings, restrictions of intimate contact (stay 1m away from everyone – no kissing etc), travel restrictions, closure of childcare and educational institutions, mandated activities eg vaccination.

Public health, security and liberty: II

BUT

- ☞ Public health threats do not provide **unlimited power** (kill HCPs who refuse to be vaccinated?)
- ☞ A **range of moral arguments** may come into play: utilitarianism, rights, virtues, principle-based reasoning etc.
- ☞ Restriction of the liberty of individuals and communities may occur without **sufficient justification**. (Long sad history in public health.)
- ☞ Where **trust** is claimed/required, then the system had best work and be seen to be fair and comprehensible! (Haneef)
- ☞ Fear, 'otherness' and threats to security may provide an environment in which liberty and cultural security is threatened.
- ☞ Difference and **disadvantage** (power) may be highlighted in such situations.

Duty to treat/care and right to refuse: I

- Individual liberty and rights concerns have had particular traction in relation to health professionals.
- Duty to treat/care based in social contract, virtue ethics and professional codes (Hammurabi, Hippocratic, AMA).
- Long history: Plague, leprosy, TB, HIV
- Recent pandemics eg SARS challenge these duties: disproportionate risk (30% of reported cases were among HCPs).

Duty to treat/care and right to refuse: II

- Anecdotal data suggests that issues relating to the duty to treat have not been a major issue:
- Black Death: *..and I, to avoid infamy dared not absent myself but with continual fear preserved myself as best I could Guy de Chauliac 1348*
- 1918: Many doctors stayed and died. Desertion and refusal was the exception rather than the rule.
- SARS: HCPs generally felt compelled to provide treatment despite feeling guilt at risking their own families and others.
- Recent surveys: majority would choose to treat although most reject this being mandated.

Duty to treat/care and right to refuse: III

- ☛ Moral duties appear to have real force BUT:
 - Vague or coercive
 - ARE limited (don't require suicide or extreme heroism)
 - One of many duties (self, family etc)
 - Require maintenance of social contract
 - Contextual (protection, transparency etc)
 - Reciprocity important but unclear (free health insurance, compensation, funeral expenses etc)
 - **Mandated or left to personal moral reflection (limited voluntariness about degree of acceptable risk)???**
(The usual in Australia).

Collateral damage

- ☛ SARS caused massive disruption to 'normal' services (and expectations).
- ☛ In Toronto thousands were denied medical care, incl for cancer and heart disease. Reports of deaths due to treatment delays. Those admitted were also isolated from visitors/social contact (SARS or no SARS). Similar reports from HK, Taiwan and China.
- ☛ Unavoidable necessity to consider opportunity costs and make hard choices. Unavoidable harms.
- ☛ Some *services* and some *communities* WILL be excluded.
- ☛ **THUS, pandemics are not really about ID but about what we want from our health service (and what we can expect from it in times of crisis).**

Pandemics: Costs and controls

- Social isolation, adequate housing, quarantine, vaccination, personal protective equipment, cough etiquette, disinfection, patient care at home, avoidance of public transport etc are part of the pandemic plan.
- These all require education, co-operation, trust and access (availability).
- **BUT none of these requirements are equal.** Poor are less receptive of public health messages, are less often the (real) target, are less able to make choices in health and social life and have less access to a range of health and social resources.

Pandemics: Public participation and risk education

- Public Health often assumes a Deficit Model (deficit of knowledge or trust).
- BUT: this assumes that education will improve this deficit and that ignorance is the only reason the public does not trust
- Haneef case (and other scandals) suggests that there are other reasons the public does not trust. Eg horror!
- If reject Deficit Model in favour of democratisation then we may seek to engage public and strengthen both risk communication and community

Risk communication????

1. All we have to do is get the number right.
2. All we have to do is give this number to the public.
3. All we have to do is explain to people what we mean by the numbers.
4. All we have to do is explain to the public that they have accepted similar risks in the past.
5. All we have to do is show the public that it's a good deal for them.
6. All we have to do is treat them nicely.
7. All we have to do is make the public partners.



Fischhoff B Risk analysis. 1995;15.

Globalisation and the 'sharing' of infectious diseases



Infection in a globalised world

- ☛ World has changed since 1918: smaller, faster, more interdependent, more accessible.
- ☛ Populations move, interests vary and borders leak.
- ☛ The diseases of the poor, the violence and unrest of the 'other' are now our concerns.
- ☛ (The perception of) isolation collapsed with the Twin Towers
- ☛ SARS leapt the Pacific to Toronto on a plane.
- ☛ H5N1 'moved' from Asia to Europe.

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- Pandemics require serious moral attention to globalisation as basis for honesty (China – SARS) and solidarity, rather than simply a framing of the world as both a market for the West and a source of cheap labour and resources.
 - Pandemics also raise possibility that contribution to global community, including aid, market fairness and political stability may be self-interested, rather than altruistic.
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Extending the impact of pandemics: economies

- Global interdependence increases the instability resulting from pandemics.
- (US Market: RAMS, interest rates and Maq Bank)
- 2003: HK, Singapore and Taiwan lost US\$80bn and 0.5% of GDP from SARS (800 deaths)
- 1918: Flu 20-100 million deaths ?impact
- Influenza pandemic in Australia (estimated AUS\$50 billion)
- ?Impact of collapse of markets (internal and global)
- Aust Govt Plans: expansionary fiscal policies etc. Speculative and unclear place for compensation for business.
- Developing World: Massive social and economic impact of control methods (poultry culling)
- Social and economic costs unclear. Compensation valuable??

Biotechnology, research and the 'dual use' dilemma

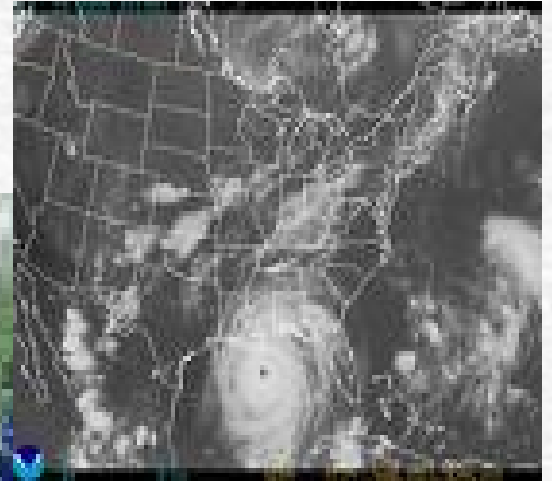
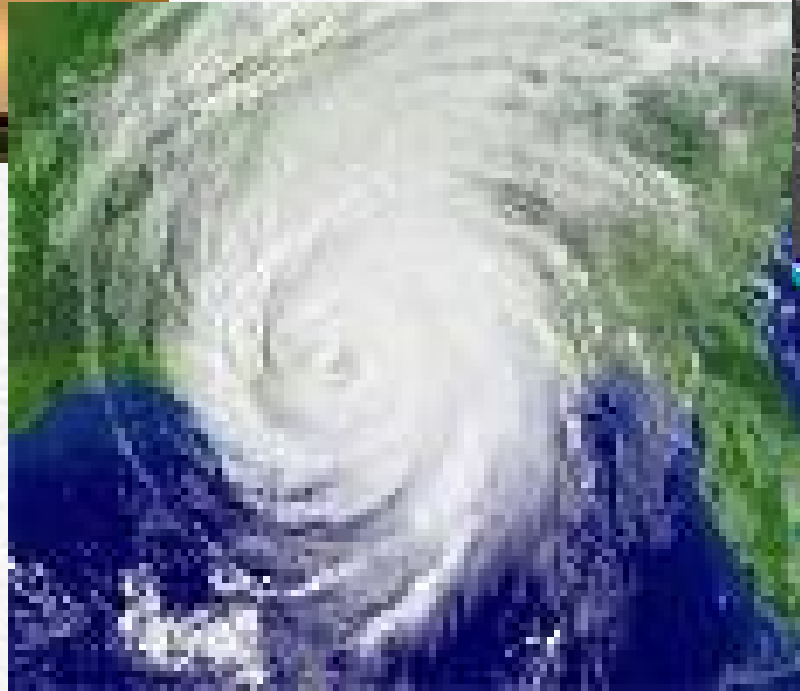
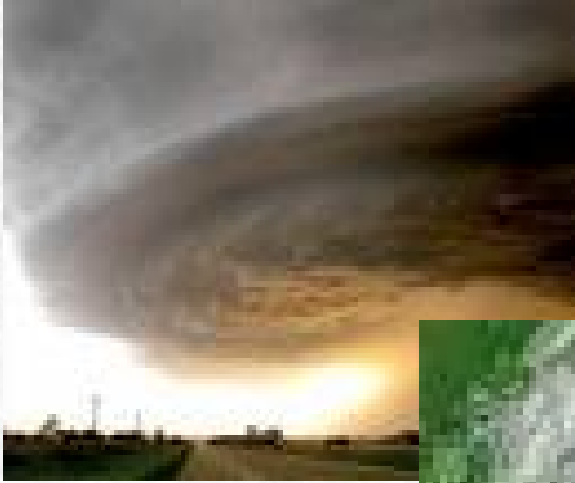
- ☞ Medical research is a massive (uncontrolled) enterprise: 10,000 journals and 500,000 papers per year (Medline)
- ☞ Biomedical research is increasingly private.
- ☞ Biomedical research is increasingly global
- ☞ Mousepox virus: increased virulence and capacity to evade vaccination via introduction of IL-4 gene (*Jackson et al; J Virol, 2001:75:1205-1210.*)
- ☞ Biotechnological and ID research have the potential for harm via;
 - Agents being stolen or diverted for malevolent purposes
 - Research results, knowledge or techniques being used to create novel pathogens

National Academies of Science

Report: *Biotechnology Research in an Age of Terrorism. 2004*

7 Recommendations:

1. Educate the scientific community
2. Review research proposals (specific)
3. Review (relevant) research pre-publication (censorship on grounds of national security risk)
4. Creation of a Scientific Advisory Board for Biodefense
5. Review relevant legislation
6. Establish permanent lines of communication with life sciences
7. International harmonisation (consistent with US)



'Natural' threats and moral exposure



Disasters and ontological threats

- ☛ Catastrophes require prevention, acute and long term responses.
- ☛ Catastrophes are also borne unequally.
- ☛ Katrina shocked because it was a reminder of vulnerability and inequity and because it exposed existent failures in the health and social infrastructure. The impact of Katrina and the response to it was shaped by its social history.
- ☛ Seems likely that pandemics may expose current failings and inequities in Australia.
- ☛ Necessity/opportunity to address health system.

Concluding remarks

- ✔ Pandemic planning has been done well.
- ✔ Degree to which planning is impossible.
- ✔ Core values that create and sustain (S, HF, E) society are likely to determine success of pandemic plan.
- ✔ Emphasis should not be on making the public trust but on making the response/plan more trustworthy.
- ✔ Major ethical issues are likely to be those relating to global communities, the market and the existing inequities and social failings.