



CONSULTING > SOLUTIONS > OUTSOURCING

TRANSPARENCY

Data Sharing sans frontières

WENSURE REGULATORY

Putting Global Good before Personal Privacy?

Paul Cheshire

Global Forum, Paris November 2000

The Black Death 1347-1351 ... 1400

Death sans frontières



- 30% of Europe's population 25 million people died
 - Wars and trade ceased (only briefly)
- Wages increased (labour in short supply!)
- Erosion of hitherto rigid stratification of society
- The stimulus for future public health reform
 - » a system of sanitary control for contagious diseases
 - observation stations
 - isolation hospitals
 - disinfection procedures
 - » major efforts to improve sanitation
 - development of pure water supplies
 - garbage and sewage disposal
 - food inspection.



500 years later ...

Action sans frontières

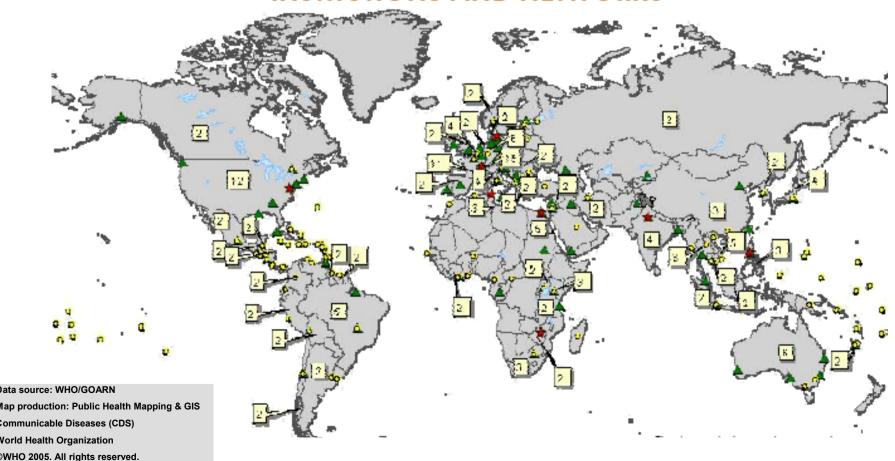


- Paris 1851: The first formal international health conference
- Prelude to similar conferences to draft international quarantine regulations.
- A permanent international health organization was established in Paris in 1907
 - » to receive notification of serious communicable diseases from participating nations
 - y to transmit this information to the member nations
 - » to study and develop sanitary conventions and quarantine regulations on shipping and train travel
- This organization absorbed into the World Health Organization (WHO) in 1948
- WHO is a clearinghouse for information about disease throughout the world
- The Global Outbreak Alert and Response Network (GOARN) provides field support

GOARN network



WORLDWIDE DISTRIBUTION OF GOARN PARTNER INSTITUTIONS AND NETWORKS



Can we do better?

mprovement sans frontières

- Faster detection of disease?
 - More certainty in detection and diagnosis?
 - » confirmed
 - » suspect
 - » clear
 - Pre-emptive and ex-post actions
 - » screening?
 - » quarantine?
 - Faster central reporting of cases
 - » from multiple sources
 - » on an individual basis
 - » level of detail?
 - Better processing of reports
 - » for outbreak management
 - » for individual follow-up?





Who might be involved?

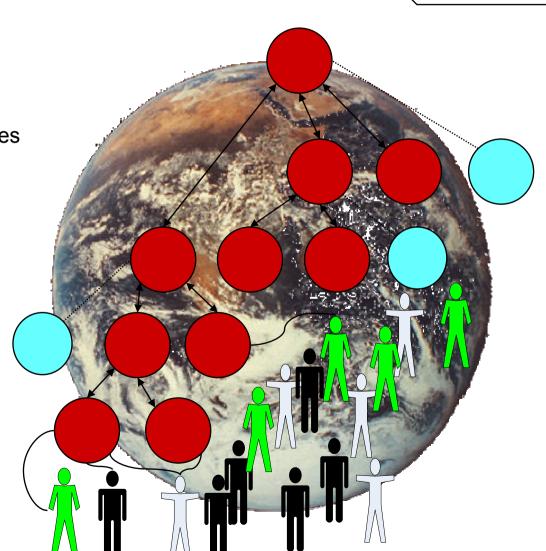
Cooperation sans frontières



Central outbreak response service

Regional / national command centres

- Public Health services
- Private Health Services
- Voluntary sector
- Employers
- Citizens



ssues?

Atos Origin

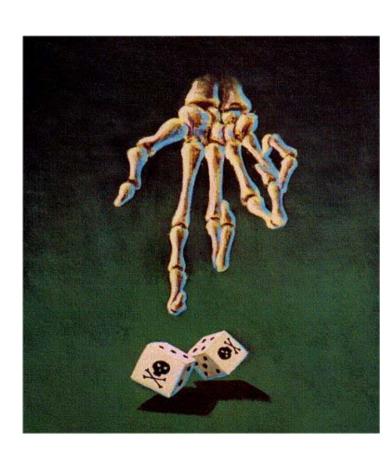
- Improved detection and diagnostic procedures
- Getting commitment from governments, organisations and citizens
 - Agreeing when to start sharing data about which conditions?
 - » after some agreed threshold (infections or deaths)?
 - » at the first sign of danger?
 - » routinely?
 - Allowing personal health data to be shared globally?
 - » Anonymised?
 - » Pseudonymised?
 - » Fully identifiable?
 - Timeliness and completeness of information
- Valid statistical / probabilistic models to support decision-making
- Two way communication focused on prevention of (further) infection
 - » semantic interoperability
- Information and Communications Technology infrastructure unlikely to be the biggest challenge

The future?

Data Sharing sans frontières?



- Were we (relatively) lucky with HIV/AIDS and SARS?
 - » and meningitis, yellow fever, ebola, cholera ...
- Will the threat from Avian Flu materialise?
 - Is there a real danger of a pandemic from bio-terrorism?
 - GOARN is excellent, but ...
 - ... can we do more and better?
- Should we put Global Good before Personal Privacy?







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