



Contribution of citizens to the development of plans for combatting an influenza pandemic

Echoes of a deliberative experience

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Review of the past

- 2007-2008
 - fear of an avian flu pandemic
 - SARS episode
 - ⇒ need for a rigorous, streamlined strategy that is effective
- foresight and prevention
 - WHO leadership (1999)
 - national plans
 - what could not be done in the past



The spirit of research by GREB

- ≠ specialist in experimentation and in consultation methods
- = bioethics research
- ⇒ showing the rich perspectives of ordinary citizens discussing difficult questions, considered outside the scope of their comprehension
- a critique of bioethics



The citizen workshop project

- Title
 - *Contribution of citizens to the development of plans for combatting an influenza pandemic*
- Objective
 - ≠ establishing priority access lists...
 - ≠ having plans evaluated by citizens
 - what would they contribute if invited to take part in their development?
 - *the contribution of non-expert knowledge*



Upstream of the workshop

- study of plans for combatting a pandemic
- preparation of citizen dialogue workshop



Plans for combatting a pandemic (1)

- study of 20 national plans for combatting a pandemic from 2006
- selection criteria
 - French or English and online
 - all continents represented
 - plan of the country's highest level of authority
- analysis grid
 - overall structure of plan
 - use of genomics
 - ethical issues addressed
 - the public's role



Plans for combatting a pandemic (2)

- ethical issues
 - no ethical framework
 - except for: Canada, Switzerland, New Zealand
- the public's role
 - unidirectional communication
 - two exceptions: United Kingdom and Brazil



Preparation of citizen workshop

- advisory committee
 - oversee integrity of process
- introductory material
 - familiarize participants with subject
- recruit 15 citizens
 - newspapers, posters, emails
 - neither experts nor militants
 - diverse backgrounds



The citizen dialogue workshop

- term borrowed from the European Commission
- the format draws on various methods
- small number of participants: 15
- a moderator guides the discussion
- formal presentations \Rightarrow promote dialogue between citizens



The April 11-13, 2008 workshop

- introductory session
 - the project
 - pandemics
- 4 topical sessions
 - 30m: an expert gives a presentation followed by a short exchange period
 - discussion among citizens
- synthesis of discussions
 - draft recommendations presented during the last session
 - final document is approved at a session in June



Topics of sessions

- topics
 - decision-making process and communication
 - state power and freedom of citizens
 - organization of care and services
 - role of genomics
- topics chosen subsequent to:
 - analysis of various national plans
 - agreement of advisory committee



Why genomics?

- the first three topics:
 - closely concern citizens
 - raise many ethics-related questions
- the forth:
 - the source of funding
 - a prospective approach to ethical questions
 - in coming years, public health may make greater use of genomics to better target interventions



Results

- at the start, the paucity of knowledge was clearly apparent
 - citizens want to be informed, they are unable to contribute
 - quickly assimilate the various aspects (scientific, ethical, social and legal) of the issue
 - this leads to the desire to make available their collective knowledge as citizens; even if they are not specialists on the topic
- Citizens do not wish to replace experts
 - even accept priorities established from "above"
 - are partners in a more collegial decision-making process
 - possess *complementary* knowledge that they wish to share
 - do not want to be reduced to the role of simple executants



Results

- in certain cases, emergency measures are necessary
 - the plans have a very general scope and aim, but their effective application depends on
 - citizens from various socioprofessional groups
 - consideration being given to specific contexts and situations
 - "Between the plan and the field lies a world of difference"
- concern for more vulnerable communities,
 - more difficult to reach through ordinary means of communication
 - "democratize" the information



Results

- aim to increase sense of responsibility among citizens through the establishment of a *culture of civil safety*
 - move decisional power closer to the place where problems emerge
- this culture requires citizens to be aware:
 - of risks present in their environment
 - of the need to protect against and prepare for these risks
 - of the importance of investing human and financial resources
 - of the need to take responsibility for managing these risks
 - of the need for solidarity among people



Evaluation

- strong points
 - quick grasp of issues
 - original proposals for action
- weak points
 - experts want to have their plans evaluated
 - lack of diversity among citizens
 - short duration ≠ maturation of thought



Added ethical value

- a central tenet of plans: public health must respect the autonomy and dignity of individuals
 - usual sense = negative; i.e. avoid coercive measures
 - ⇒ positive sense: promote the responsible and mutually supportive actions of all citizens, whether or not they are experts.
- strategies for communicating plans ⇒ trust and transparency
 - communication that is too "formulaic" and that is sent too exclusively from "above" ⇒ mistrust and bureaucratization
 - solidarity and dialogue between experts, decision makers and the public
 - add ethical value to public health interventions
 - respond to practical interest in the health, governance and lives of affected communities



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