



ASSET

share and move to face nasty bugs

Tools and Strategies for PARTICIPATORY COMMUNICATION

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Participatory governance and
science education

The ASSET FINAL EVENT

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www.asset-scienceinsociety.eu



IS COMMUNICATION A SCIENCE?

EVIDENCE
BASED
MEDICINE

EVIDENCE BASED
COMMUNICATION





INFORMATION

EDUCATION

COMMUNICATION





COMMUNICATION



ONE SIMPLE RULE

LISTEN AS MUCH AS YOU TALK





PARTICIPATORY COMMUNICATION

- guarantees **full involvement** of participants
- provides them with **communication channels**
- enables them to **participate freely and equally** in dialogue and debate.





PARTICIPATORY COMMUNICATION

- Approach based on **DIALOGUE**
- which allows **SHARING** of information, perceptions and **opinions** among stakeholders
- **to facilitate their EMPOWERMENT;**
- not just the exchange of information and experiences, but **exploration and generation of new knowledge**
- aimed at **addressing situations** that need to be improved.



World Bank, 2009





Patients and Public Involvement (PPI)

- Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.
- Within RRI, Responsible Research and Innovation



SEE ASSET D3.2 ROADMAP TO OPEN AND RESPONSIBLE RESEARCH AND INNOVATION IN PANDEMIC





SOME RECOMMENDATIONS

- Participation of patients should be considered in the overall process of research to provide experiential knowledge that can improve the quality, relevance and validity of the research process
- Minimum of two patient research partners
- Definition of the expected contribution
- Consider communication skills and motivation
- PI must facilitate and encourage the participation of patient partners and consider their specific needs
- PI must insure appropriate information and training
- Contribution of patients should be officially recognized.

By The European League Against Rheumatism



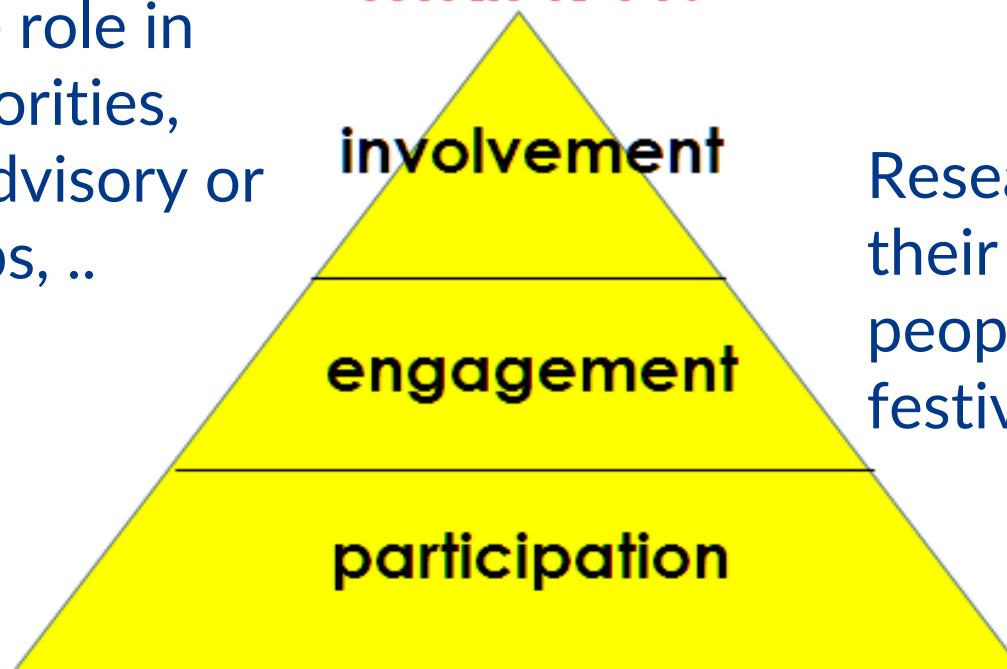


INVOLVE, UK

(by National Institute for Health Research)

Patients and/or public have an active role in identifying priorities, members of advisory or steering groups, ..

What is PI?



Researchers describe their results to lay people (science festival, open day,...)

People have research done on or to them





TOOLS OF INVOLVEMENT

- Deliberative democracy
- Citizen science (i.e. gathering data, videogames, ecc...)
- Patient Associations in Editorial Committee of BMJ
- Preparing Professionals for Partnership with the Public (4Ps)
- [EUPATI Academy of patients](#)
- EURORDIS
- RARECONNECT
-





EURODIS SURVEY 2009

- Of the 309 patient organizations that responded
 - 37% had **funded** research in the last 5 years;
 - 76% created **links** patients, researchers and doctors;
 - 57% **found patients** for clinical trials;
 - 49% gave CT participants **info and counselling**;
 - 48% **assisted in the design of research projects and clinical trials** (45%) by highlighting patients' needs and expectations
 - 28% were involved in promoting **the collection of biological samples** (28%).





WHAT ABOUT INFECTIOUS DISEASES?

- Acute
- Sudden Outbreaks
- No Patients' Associations
- Spread
- Societal impact





LESSONS LEARNT BY H1N1

- “...in the past the **main challenge was in dealing with the perception and communication of risks.**
- In future, we need to develop ways of better **involving** the scientific community and civil society.
- The aim must be that risk is properly understood and **trust maintained**”.

*ECDC The 2009 A(H1N1) pandemic in Europe
A review of the experience*





WHY do we need a «PARTICIPATORY» COMMUNICATION?

Spread of infectious diseases often depends on people's behaviour



People's behaviour depends on their beliefs, attitudes, habits, values, fears

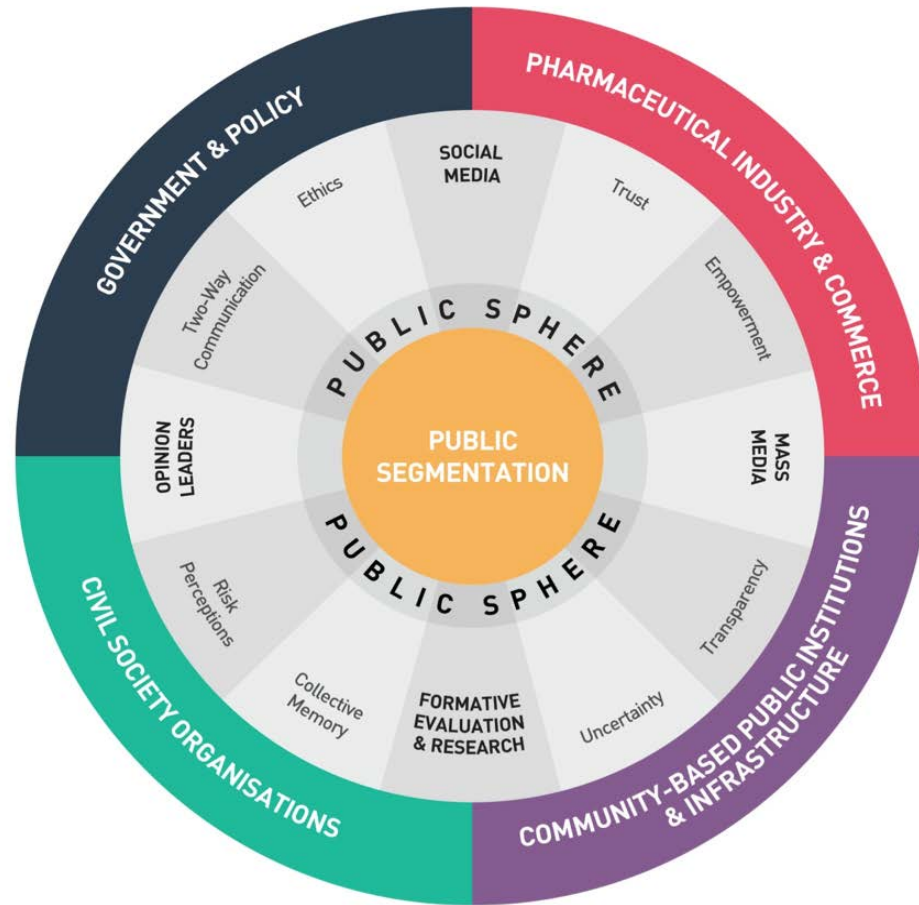


A top-down information that does not take this into account can be ineffective





WHO ARE THE «STAKEHOLDERS»?



TELL ME PROJECT FRAMEWORK MODEL BY THE UNIVERSITY OF HAIFA





GOBBLEDYGOOK?





“In the next influenza pandemic, be it now or in the future, be the virus mild or virulent, the single most important weapon against the disease will be a **vaccine**.

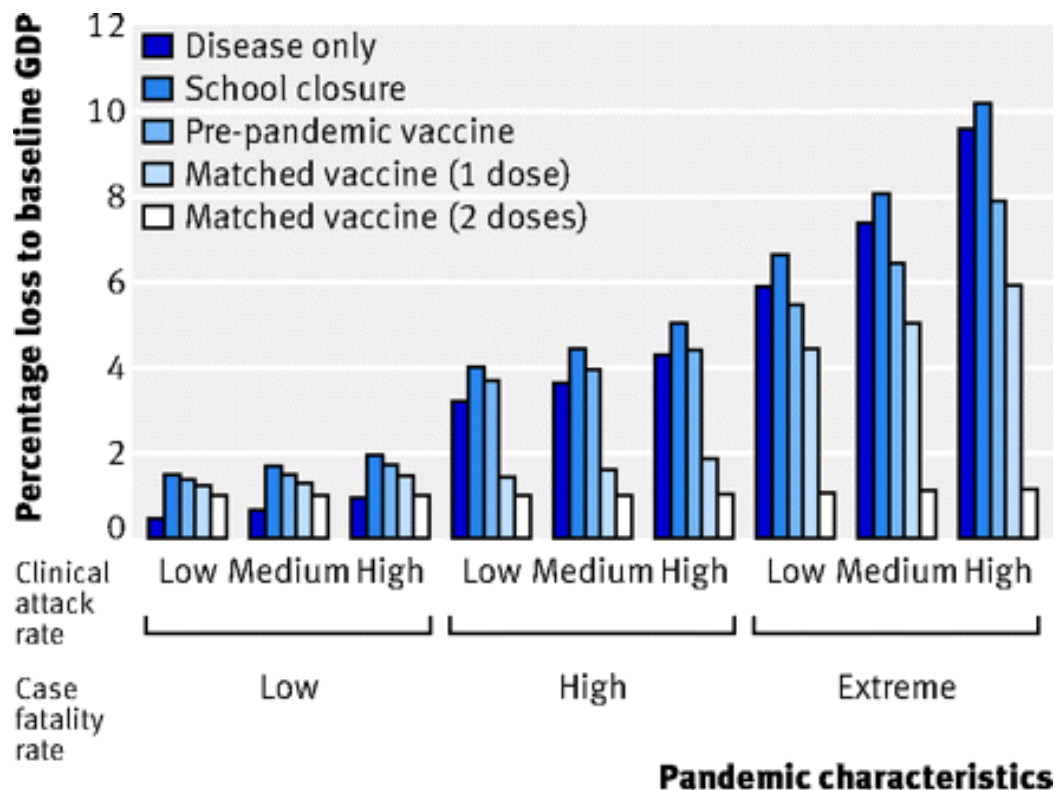
The second most important will be **(PARTICIPATORY) communication.**”

John Barry. The Great Influenza in Nature, 2009





Big societal issues





QUARANTINE



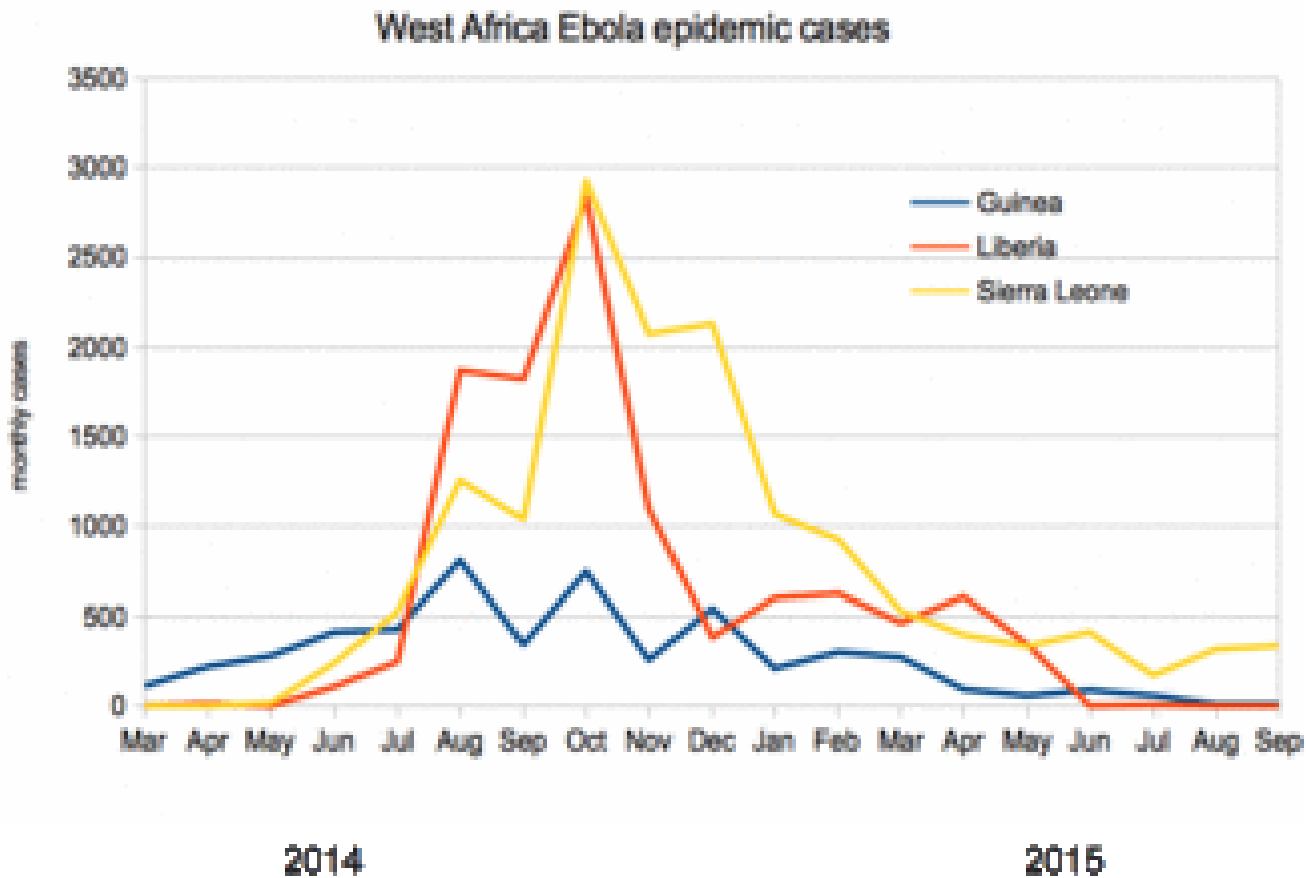


- Bush-meat
- Contact with patients
- Burial practices
- Suspect towards government
- Suspect towards western people





EBOLA IN WEST AFRICA





EBODAC



<https://www.youtube.com/watch?v=hzb4LtTZ2Bg#action=share>





Participatory communication can save lives!



THANK YOU!
Roberta Villa, ZADIG

