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#### ASSET

#### Bringing SiS issues in Pandemic Preparedness and Response Plans

Milan, 13<sup>th</sup> October 2016 SATORI WORKSHOP ON ETHICAL ASSESSMENT In Research and Innovation



co-funded by the EU. GA: 612236

ASSET Action plan on Science in Society related issues in Epidemics and Total pandemics



#### **SIS-RELATED ISSUES** in EPIDEMICS and TOTAL PANDEMICS

ASSET is a 48-months EU-funded project within 7th FP, which aims to contribute to incorporating SIS issues into the system of **RRI** related to pandemic preparedness by:

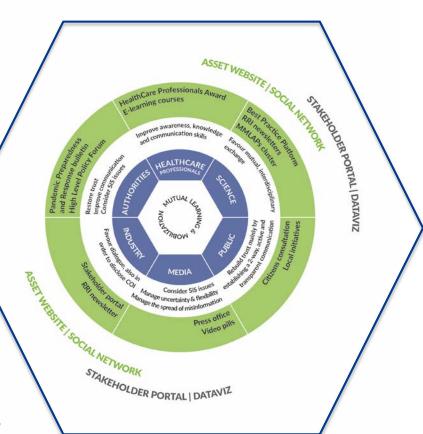
- exploring and mapping SiS-related issues in global pandemics (WP2);
- developing a partnership with complementary perspectives, knowledge and experiences to address effectively scientific and societal challenges raised by pandemics and associated crisis management;
- developing a participatory and inclusive strategy.



# ASSET Action Plan: a MODEL in 6

#### 6 MAIN SIS ISSUES

- 1. Governance
- 2. Open Access
- 3. Participatory Governance
- 4. Ethics, Law and Human Rights
- 5. Gender Issues
- Intentionally Caused Outbreaks



#### 6 TARGETS

Authorities
HCPs
Science
Industry
Media
Public





# Ethical Debate in Health

- IVF and other fertility/embryo treatments
- End of life issues
- Transplants
- Informed consent
- Gene testing and therapy

#### **INFECTIOUS DISEASES?**





# Areas of ethical tension in pandemic/epidemic events

- Restriction of personal freedoms
- Duty to provide care in pandemics
- Priority setting and resource allocation
- International cooperation and global governance







#### 2003 SARS

#### DIFFERENT STRATEGIES FOR QUARANTINE

- Hong Kong: barricades and tape to confine people;
  - Singapore: surveillance cameras and electronic monitoring devices;
    - China: penalties and jail
    - Canada: voluntary compliance





# 2009 A(H1N1) SWINE FLU















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#### 2015-2016 ZIKA













#### Vaccine hesitancy







# Vaccine hesitancy

- Individual right to refuse a treatment/Individual right to be protected
- Individual right for education of unvaccinated/ immunocompromised kids
- Individual minimal risk/Great public benefit (Sabin)



#### WP2 STUDY & ANALYSIS D2.4 ETHICS, LAW AND FUNDAMENTAL RIGHTS REPORT

- 1948: Universal Declaration of Human Rights (UDHR)
- 1950: European Convention on Human Rights (ECHR)
- 1981: WMA Declaration of Lisbon on the Rights of the Patient
- 2000 (2009 Lisbon Treaty): Charter of Fundamental Rights of the European Union (CFREU)
- 2005 International Health Regulations (IHR) provided guidance for WHO Member States to assess and manage serious health threats with a potential to spread beyond borders
- 2006: Universal Decl. on Bioethics and Human Rights





# 2005 International Health Regulations (IHR)

- Art 3: "...implementation of these Regulations shall be with full respect for the dignity, human rights and fundamental freedoms of all persons"
- Art. 42: "...implementation of health measures shall be [...]applied in a transparent and non discriminatory manner"
- Art. 23: public health authorities need to obtain an **informed consent** before implementing any protective (e.g. vaccination) or restrictive measures (e.g. isolation), except in circumstances where there is evidence of an "imminent public health risk" (Art. 30)





# 2005 International Health Regulations (IHR)

- Art. 30: public health authorities should carry out "[...] the **least intrusive and invasive examination** that would achieve the public health objective of preventing the international spread of disease"
- Art. 32: travelers must be treated with respect for their **dignity, human rights and fundamental freedoms**, and any discomfort or distress associated with implemented health measures should be minimized

#### **Good principles, no practical guidance**



# Ethical Considerations in Developing a Public Health Response to Pandemic Influenza (WHO,2007)

- Balance rights, interests & values
- Use best available evidence, but remain flexible
- Seek transparency, public engagement & social mobilization
- Inform, educate & communicate
- Justify resource constraints and allocations





Ethical Considerations in Developing a Public Health Response to Pandemic Influenza

- necessary,
- reasonable,
- proportional,
- equitable,
- nondiscriminatory,
- legal.

# 2009 WHO revised Pandemic

The revised guidance:

- highlights key principles when undertaking pandemic planning including:
- a) **application of ethical principles** to assist policymakers in balancing a range of interests and protecting human rights;

b) .....





### 2007/2009 WHO documents

 Develop an ethical framework to govern pandemic policy development and implementation (national level, Phase 1-3)





### **ASSET ANALYSIS**

#### 11 EU/EAA/EFTA Pandemic Preparedness and Response plans +



- 2009 PPRP, WHO
- 2004 EU Commission Working Document on Community PPRP





# **ASSET ANALYSIS**

ethic Switzerland **SWITZERLAND** • ETHIC WHO FREEDOM UK TRANSPARENCY CZECH REP. freedom **FAIRNESS** FRANCE World Health Organization **STIGMA** transparency EU HUMAN RIGHTS United Kingdom ITALY fairness EQUITY **SPAIN** Czech Republic stigma MINORITY France human rights LIBERTY European Union equity Italy minority



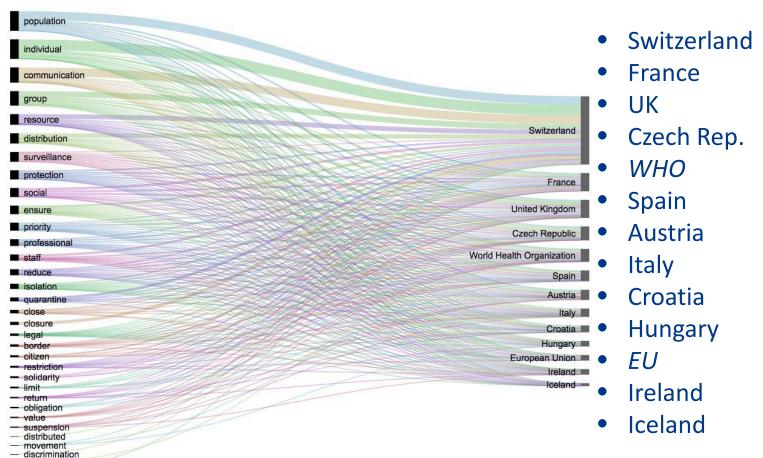
liberty

Spain



- Population
- Individual
- Communication
- Group
- Resource
- Distribution
- Surveillance
- Protection
- Quarantine
- Closure
- Legal
- Border
- •
- Discriminate
- Limitation

# **ASSET ANALYSIS**



discriminatory limitation



#### A lot of work to do!





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# **THANK YOU!**



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