Incentivizing Sharing of Stakeholder Health Data – What Works?

CIOMS Perspective

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What is CIOMS?

Foundation:

By WHO and UNESCO in 1949

Members:

44 member organizations, representing many of the biomedical disciplines

26 international members including organizations such as World Medical Association (WMA), International Union of Basic and Clinical Pharmacology (IUPHAR), International Society of Pharmacovigilance (ISoP) and International Society of Internal Medicine (ISIOM)

18 national members mainly representing national academies of sciences and medical research councils

Major areas of work:

1) Ethics in healthcare, mostly research ethics, especially research involving humans

2) Product development with the focus on ensuring medicines and vaccines safety - *Pharmacovigilance*

- More information at www.cioms.ch

Future of healthcare – stakeholders joint efforts of better sharing of data for better (patient) health

Dealing with two disincentivizing issues

1. All agree “the rationale”, but people are not rational but **emotional** – fears …

2. Several layers of **ethical concerns** about sharing and using health data linked with research involving humans

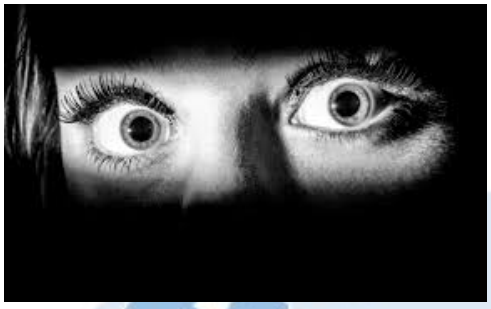
   - although “good science” is usually also ethical research ethics is also increasingly challenging due to changing environment (R&D +)

Fear

Definition of fear … an unpleasant often strong emotion caused by anticipation or awareness of danger (Merriam-Webster)

An unpleasant emotion caused by the threat of danger, pain, or harm (Oxford Dictionary)

Several **fears** likes the fear of loosing privacy*, fear of mis-using data etc.



*http://www.ituudised.ee/uudised/2017/06/19/uuring-euroopas-on-eeldused-terviseandmete-piiriuleseks-liikumiseks-olemas

CIOMS New 2016 Ethical Guidelines

1 – Scientific and social value and respect for rights

2 – Research conducted in low-resource settings

3 – Equitable distribution of benefits and burdens in the selection of groups of participants

4 – Potential benefits and risks of research

5 – Choice of control in clinical trials

6 – Caring for participants' health needs

7 – Community engagement

8 – Collaborative partnership and capacity building

9 – Individual informed consent

10 – Modifications and waivers of informed consent

11 – Collection, storage and use of biological materials and related data

12 – Collection, storage and use of data in health-related research

13 – Reimbursement and compensation for research participants

14 – Treatment and compensation for research-related harms

15 – Research involving vulnerable persons

16 – Research involving individuals who are incapable of giving informed consent

17 – Research involving children and adolescents

18 – Women as research participants

19 – Pregnant women and lactating women as trial participants

20 – Research in disasters and disease outbreaks

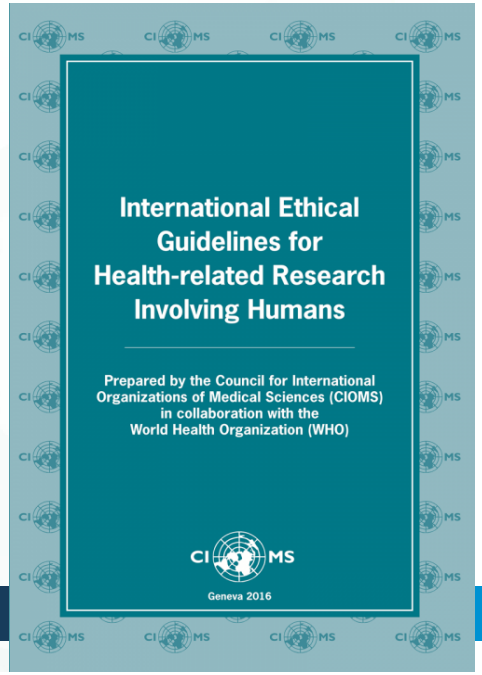
21 – Cluster randomized trials

22 – Use of online environment and digital tools

23 – Research ethics committees and review

24 – Public accountability

25 – Conflicts of interest



Instead of Conclusions

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