ETHICS AND HUMAN RIGHTS UNDERPINNING DATA POLICY FOR OPEN SCIENCE IN CRISIS SITUATIONS

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Open science as an open common

- OS
  - Open access: making scholar interactions available to public and scientific community (free, reusreusable data, preprints, and reviews.
  - Open source-open data: collected data, meta-data and source code sharing to foster replication, enhance data- reuse and facilitate review process.
  - Open peer review: publicly available review reports and author answers to increase review quality and reduce COI risks.
  - Open Science (OS) is an open common (OC) in which all scientific data is accessible to everyone.
- OC is grounded on a cluster of rights of people and institutions whose main interest is to support PUBLIC GOOD.
- The need for OS is emphasized during public health emergencies (PHE) such as pandemics because of the urgent need for fast science and intervention.
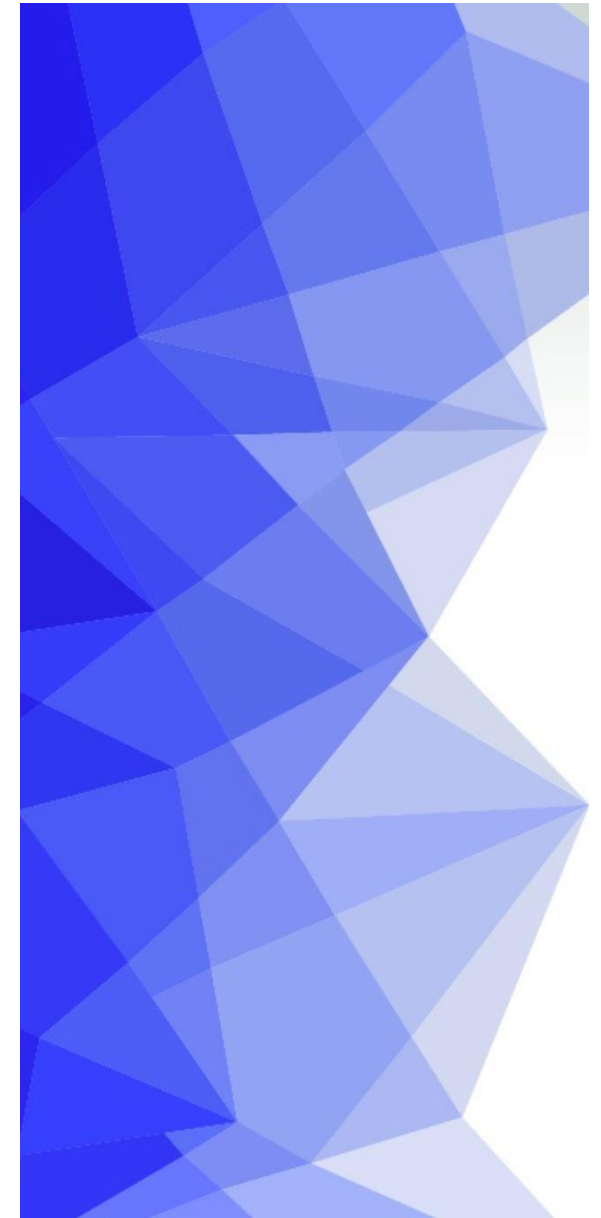
OS DURING THE PANDEMIC

- Publishers made new COVID-19 articles Open access

- Reviews and pre-prints shared more systematically

- Retractions

- News agencies/ social media posts disseminated unreliable/ unchecked results vastly

The pandemic

- fostered accessible, transparent OS

- highlighted the need for accountability and adaptation of sturdy mechanisms to avoid unvalidated results. "Infodemics"

OS provided important insights about research integrity during the pandemic:

- Over-recruitment in trials
- Conduct of human trials before animal trials
- Overlooking adverse effects of medical interventions to find a "cure" ASAP.
- Duplication of research
- Effectivity of pre-registration sites (IRB approval, reduce duplication, assuring that the research is conducted as it is planned, mitigating the risk of falsifying, fabricating results,

Why do we need "openness" during PHE?

1. A way to enhance transparency and accountability of the research

2. To promote accessibility and reusability of research outputs within and beyond the scientific community

The Pandemic proved once more that OS is a technical and social, cultural, and moral issue.

Therefore, we need a broad perspective while addressing the ethical issues

Pros & Cons of OS as an OC during PHE

- Pros: accessible, real-time big data, the enhanced possibility of scientific intervention, avoiding duplication of research and enabling prudent use of resources.

- Cons: Hurried, sloppy publications becoming available to the scientific community and public, overlooking RCR principles

These are not necessarily the cons of OS, but expectable results of unpreparedness to PHE.

OS is just a tool that is being misused because of this unpreparedness.

ETHICS of OS

- Research ethics:
  - RCR
  - Principal based approach
- Data ethics:
  - Big data, real-time data, AI and ML
  - FAIR data
  - Risk mitigation
  - Consent
  - Privacy
- Institutional ethics
  - IRB/ ECs and RIO
  - Transparency
  - COI
- Science and society ethics
  - Fair, justified surveillance
  - Promoting the common good/ public good
  - OS/ interventions made possible by open science results social moral change (SMC)
  - Core concepts like privacy, and confidentiality are subject to SMC
  - The balance/ tension between individual rights and the common good

Users (researchers, institutions, and agencies) should be aware of the fact that

They are sharing private data (subjects data) with theAI system

The AI system is generating private data by profiling/ processing the avaliable data

The AI system is using/ making this private data avaliable to third parties

The third parties may/ may not be using this data for their own ends

These ends may be various and not defined at the time data is collected or generated

The risks about AI & big data exceeds the contend and context of GDPR

That's why we need Trus

- Consent (respect for autonomy)
- Privacy
- Confidentiality
- Risk mitigation
- Fairness and justice (in terms of sharing risks and benefits)
- Data ownership and IPR

- Defining public good as the main and only moral value risks ignoring other essential values and principles.

- Defining value only in terms of economic or interventive capacity to do good to public is too narrow.

- We should develop and sustain a broader constellation of values to embrace **individual rights (autonomy and the right to determine the good and valuable for oneself, ownership and property rights), diversity, cultural values, and vulnerabilities**.

PROBLEMS TO CONSIDER

ISSUES ABOUT DATA AND RIGHTS

1. IPR: Whose data is it? Who owns the data?

2. the competence of the people who will use or have access to data?

3. For what ends the data and results will be used?

4. Consent?

5. Commercialization of data? Base/ annotated data and the labor required to generate data in reusable format?

OS as a tool for Surveillance

- Real-time data and immediate access to research results make effective surveillance and intervention possible.

- Surveillance may be/ has been a tool for social control and profit.

- Scientification of political decisions- using science as a ground for political decisions to overlook individual rights.

The shared results or data may be fraud because of rush/ incompetence or lack of research integrity. (the grounds may not be as stable as we think and the consequences of ignoring individual rights may not cause the expected benefits for the public)

It is not OS that makes unethical surveillance possible, It is the misuse of big data and AI.