Establishing Open Science Policies for Data Generation and Sharing in Disruptive Situations

Beijing, China; 30 August 2022

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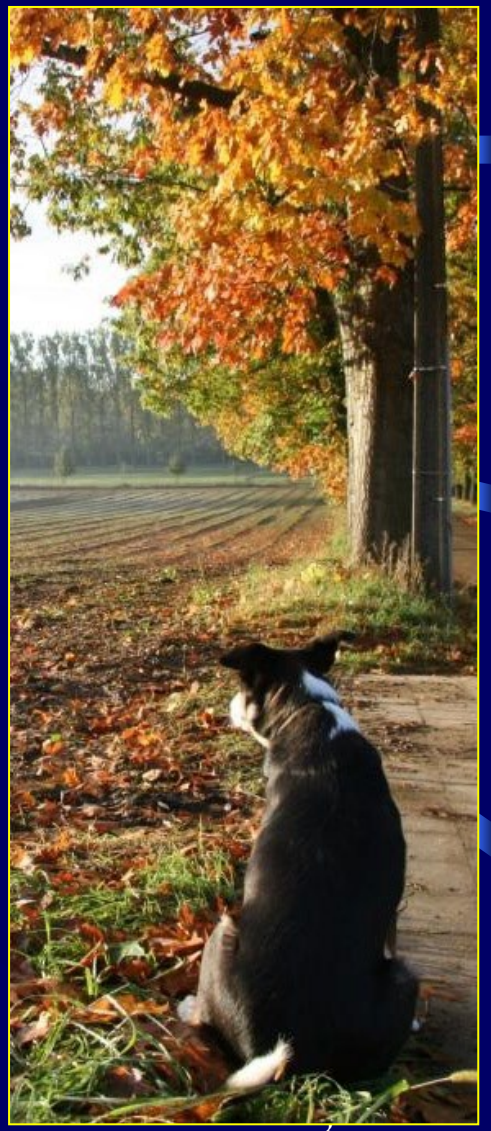
The views presented here are those of the speaker's. They do not necessarily reflect those of any organisation. Francis gratefully acknowledges the work of the membership of the International Science Council's CODATA International Data Policy Committee (IDPC) and the EOSC-Future / RDA Artificial Intelligence & Data Visitation Working Group (AIDV-WG). Francis' EOSC Future / RDA Ambassador for Ethics & Law and the EOSC-Future projects are co-funded by the European Union's Horizon Programme call INFRAEOSC-03-2020 - Project ID 101017536. CODATA is funded by the International Science Council (ISC) and Horizon Europe as well as by other funding organisations. The Research Data Alliance (RDA) is funded by Horizon Europe as well as by other funding organisations (see here). Francis is grateful for the support provided by CODATA and the EOSC-Future and the RDA communities, structures, and secretariats.

The Vantage Point

- EU GCP Dir/Reg and Paediatric Regulation
- Chair WG, *Guidelines and Recommendations for European Ethics Committees* (Brussels 1995/7)
- Past member UNAIDS ERC
- Chair, WHO WGs on Guidelines for Ethics Committees & DSMBs
- Co-founder, FERCAP & SIDCER
- CIOMS Member
- Past Member, WHO GCP & ICTRP Committees
- Past Member, EORTC IRB; Chair, INCTR EC
- Member, EWG, European Academy of Paediatrics
- Co-founder, European Network for Research on Alternating Hemiplegia (ENRAH)
- EUROSOCAP, ENCCA, nEUroped, RESPECT, EBC



Current Activities

- Established in 2000 'PREP - Preparedness Planning for Clinical Research During Public Health Emergencies' in response to the SARS-CoV-2 pandemic
- Ambassador for Ethics and Law, European Open Science Cloud (EOSC) Future
- Chairman, EOSC Future / RDA Artificial Intelligence and Data Visitation Working Group (RDA AIDV-WG) & Member, COVID-19 Legal & Ethics Sub-Working Group
- Chairman, International Data Policy Committee (IDPC) & Member, Executive Committee, International Committee on Data (CODATA), International Science Council (ISC)
- Member, Regulatory and Ethics Work Stream (REWS), Global Alliance for Genomics and Health (GA4GH)
- Research Data Publishing Ethics Working Group, FORCE11 & The Committee on Publication Ethics (COPE)
- Co-founder, Ukraine Clinical Research Support Initiative (UCRSI)
- Member of the Data Stewardship Working Group, Virus Outbreak Data Network (VODAN) GO-FAIR

Policy

- ‘a set of guidelines or rules that determine a course of action’
- ‘a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions’

Policy → Polis

Science Policy

'an area of public policy concerned with the policies that affect the conduct of the science and research enterprise'

Thus, two aspects of science policy

1. rules governing the conduct of science
2. rules governing the application of science to public policy (e.g., public health policy)

Science Policy ←→ Data Policy

Data Science

‘Data science is an interdisciplinary field that uses scientific methods, processes, algorithms and systems to extract or extrapolate knowledge and insights from noisy, structured and unstructured data, and apply knowledge from data across a broad range of application domains’

→Data is the currency of science
(the most highly valued commodity in today’s world)

→The value of data is determined through its utility

→ Data is science agnostic

Data Policy

2 Key Aspects

1. Purpose → determines goals (the why)
2. Framework (regulation/guidance) → determines conduct/actions (the how)

Data Policy provides a governance framework for why and how data is managed, within data science as well as for the use of data science.

Science & Data Governance

- How should we organise science (and data) within the sciences?
  - →to what purpose(s)
  - →within which framework(s)
  - →who is responsible? / who is in charge?
- How should we organise science (and data) within society?
  - →to what purpose(s)
  - →within which framework(s)
  - →who is responsible? / who is in charge?

Who Governs Science?
Who Determines Science Policy?

- Science governed from within

  → universities, scientific organisations, individual scientists

- Science governed from without

  → governments, inter-governmental organisations, funding organisations, communities, interest groups

Disruptive Situations & Science

Situations disruptive to 'normal life activities'

Situations disruptive to 'the activities of science'

- health-threatening events: e.g., epidemics, water and/or food scarcity
- natural events: e.g., storms, earthquakes
- human disasters: e.g., technology failures, poverty, political dishevel, conflict

→ Emergency situations that create threats

The Challenges of Science in Disruptive/Disaster Situations

- The vulnerability of persons affected by the disruption
- The lack of structure
- The lack of predictability
- The difficulty to organise
- Ongoing threats
- Angst

The Hesitancy of Science in Disruptive Situations / Disasters

- A tendency to respond with actions based on what we already know
- A view that science is a luxury
- A view that science (e.g., human experimentation) is unacceptable in disruptive situations
  e.g., Nuremberg Code, Geneva Convention

Science As Required During Disruptive Situations

- We must learn (including *in* situ) from disruptive situations to prepare for, and respond to, future disruptive situations that are similar
- We must learn (including *in situ*) from disruptive situations to respond to the situations themselves in real time

→ Requires data generation and data processing

→ Requires data policy

Why Science in Disruptive Situations

- Science is not a luxury
- Learning/Science, the quest for knowledge, belongs to the core of our humanity
- Science is a fundamental human right
- The scientific enterprise is fundamental to ensuring the good of society
  → science is a societal, national, community right

Science/Data Policy in Disruptive Situations / Disasters

- Science is only possible within well defined purposes and frameworks
- Preparing and responding to disruptive situations / disasters requires having clearly defined rules and practices → policy

Establishing Open Science Policies for Data Generation and Sharing in Disruptive Situations

Two critical frameworks

- 1. Sustainable Development Goals (SDGs)
- 2. Open Science Frameworks