«What is really important? What matters for real?»

An international study on COVID-19 **patient's** experiences
Status update and future perspectives

The DI COVID-19 research community
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Institute of Biomedical Ethics
and History of Medicine

AIMS

University of Zurich UZH

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and History of Medicine

DIPEx International

1. Present the progress of the DI COVID-19 project;
2. Present the dataset and its structure;
3. Poke into the data;
4. Discuss about future perspectives.
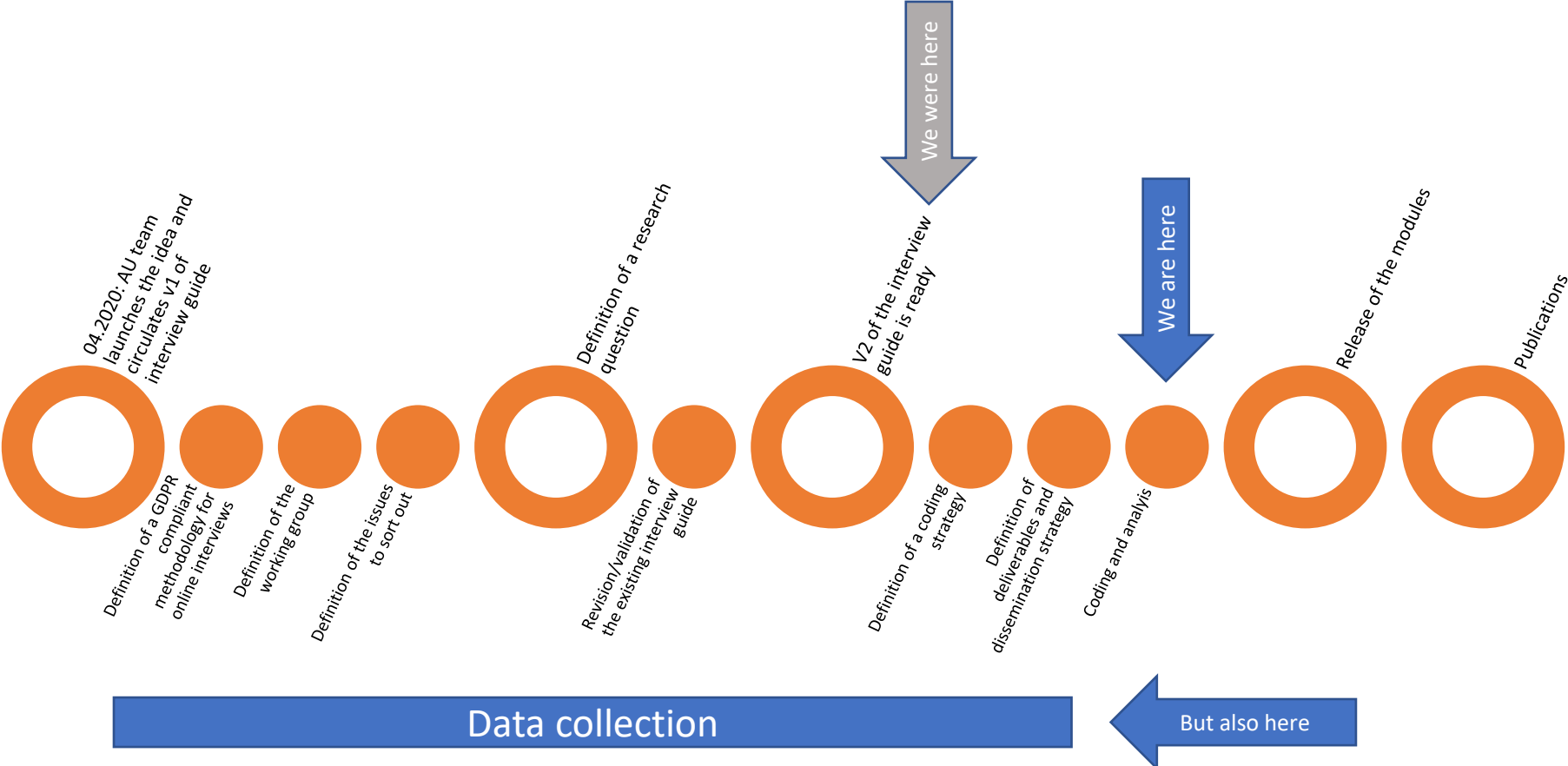
Some preliminary questions

Global events happen (also) locally. So **what's** the right perspective to understand them?

Cultures shape the interpretation of phenomena. So how can we build a common analytical framework?

Diversity is richness. So how can we preserve it, but keep the analysis manageable?

1. Status update

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04.2020: AU team launches the idea and circulates v1 of interview guide

Definition of a GDPR compliant methodology for online interviews

Definition of the working group

Definition of the issues to sort out

Definition of a research question

Revision/validation of the existing interview guide

V2 of the interview guide is ready

We were here

Definition of a coding strategy

Definition of deliverables and dissemination strategy

Coding and analyis

We are here

Release of the modules

Publications

Data collection

But also here

1. Status update

Country	People	Status	ITW guide used	Target population
USA	Rachel Grob, Jane Alice Evered, Madison Wynn	7 interviews recorded	standard plus additions	Recovered patients (including healthcare workers)
the Netherlands	Nienke Verheij, Manna Alma	20 interviews coded (short, by phone)	different guide, will use the standard for new interviews	Recovered patients
Brazil	Alicia Navarro de Souza, Maria Inês Gandolfo Conceição, Ana Claudia Germani, Juliano Luna Ivone Cabral	32 interviews recorded, coding in progress	standard plus additions (spirituality, social inequality)	Recovered patients (including healthcare workers); at least 2 with long covid
Germany	Martina Breuning, Christine Holmberg, Anne Thier	15 existing itws with different itw guide (useful for comparisons) + 4 with long covid patients (standard itw guide)	different guide + standard	Recovered patients + healthcare workers
Switzerland	Nikola Biller-Andorno, Susanne Jobges, Corine Mouton Dorey, Giovanni Spitale	13 interviews recorded; coding in progress.	standard plus additions (icu)	recovered patients (including healthcare workers) (with a focus on ICU for a related project)
Japan	Rika Sato, Akiko Sawada, Rie Toyomoto, Emiko Wada	11 interviews recorded; coding in progress, target: 50.	standard	For COVID-19 interviews: recovered patients (9) and family members (2) (including 1 bereaved)
Spain	Vinita Mahtani, Emilio Sanz, Elisa Torres, Alicia Mora, Víctor Expósito	13 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers) and one caregiver
Australia	Lorraine Smith, Renata Kokanovic, Kate Johnston-Ataata, Anna Urbanowicz	8 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers when available)
UK	Lisa Hinton, Annelieke Driessen, Sue Ziebland, Tanvi Rai, Anna Dowrick, Kaveri Qureshi, Kate Hunt, Ashley Brown, Louise Locock	61 interviews recorded, coding in progress, target: 150	standard plus additions	Three studies: 1 - recovered ICU patients and relatives of deceased patients, 2 - seldom heard groups in the UK, particularly Black, Asian and other minority groups, 3 – patients with long covid
Canada	Susan Law, Ilja Ormel, Michelle Marcinow, Linda Rozmovits	15 interviews recorded, 1 transcript not returned, 14 interviews coded	standard plus additions (covid and pregnancy)	recovered patients (including healthcare workers)

195 interviews!

… and more are coming!

(from December 2020) SUMMARIZING:

1. What about linguistical and contextual complexity?
   Is there anything we are not factoring in and might prove a bad surprise?
   The idea is to conflate complexity without losing detail. Does it work on paper?

2. What about our coding strategy?
   Any previous experience?
   Risks and benefits? Strengths and opportunities?

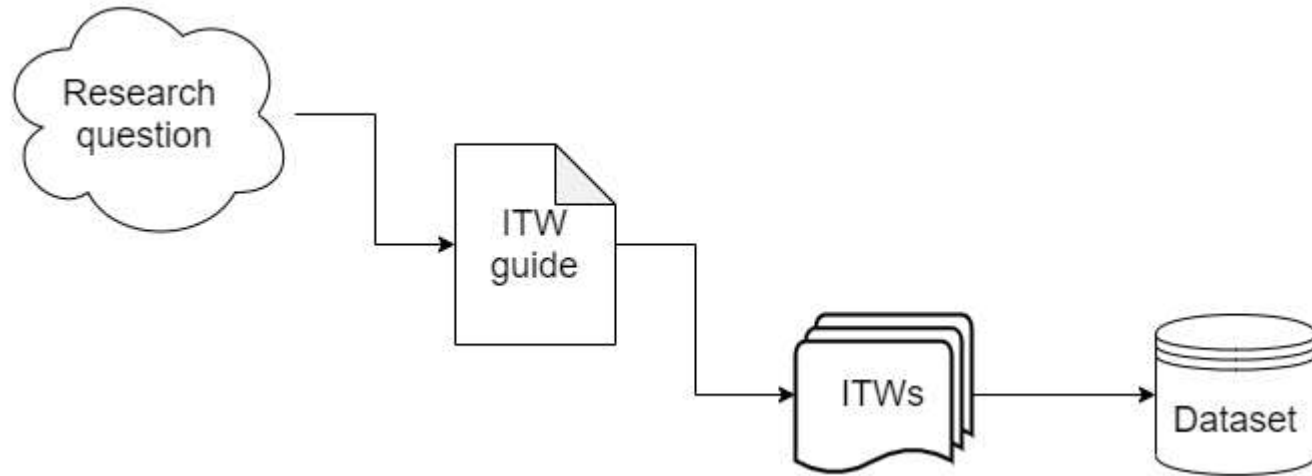3. What about deliverables?
   Would you use the intermediate deliverables?
   Would you share them on open data platforms like Zenodo or OSF?
   Any clever ideas for focusing publications? What would you ask to these data?
   Module(s): where shall we publish this material? DI website? National websites?

2. Dataset and data structure

1. Dataset and data structure

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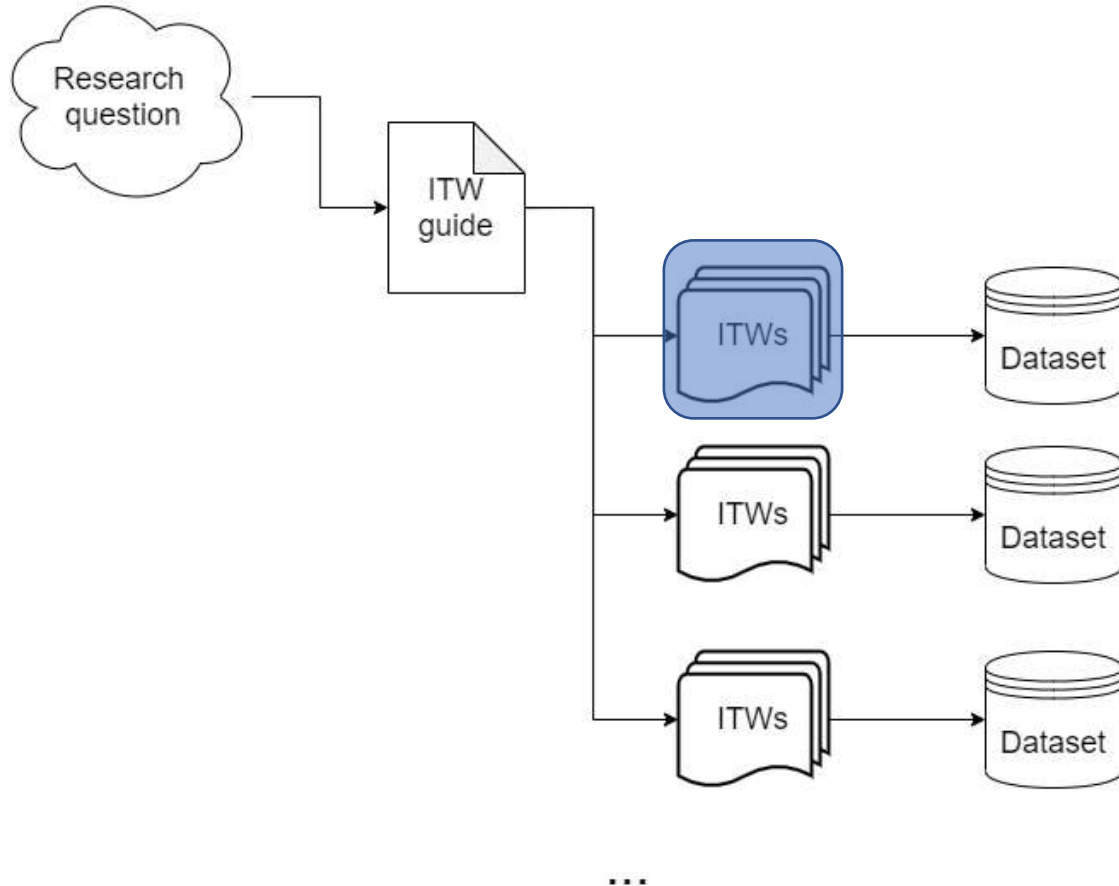
Properties
- **Metadata** (language, duration, time of the recording, file type, kind of consent) - **Variables** that describe the **interviewee** (itw code, age, country, region, gender, relational status, has children, ISCED, occupation, level of employment, living arrangement, ethnicity, disability) - **Variables** that describe the **experience** (setting of health care, time of diagnosis, long covid) - **Codes**

3. What we are doing, where we are standing

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https://rattocloud.hopto.me/index.php/s/pgN7xNkcaFEJm7R?path=%2Fcoding%2Fcommon%20coding%20system%20-%20v4%5Bfinal%5D

But how did we get there?

Well, with a lot of collective effort.

3. What we are doing, where we are standing

But we had wonderful neighbours who -- and a granddaughter who lives close, who picked up food for us. So we were in a good position. …
(AU, social support)

even today I was talking to a preceptor at the Clinic, "hey, I got a call from a friend of mine who is using chloroquine, it looks crazy! She cannot have chloroquine, there is no evidence." Then I was very quiet. Until today. My fellows don't know I used it. […] But the media and medical literature started not to provide information at a speed that we needed to generate this discussion there at the Clinic. So, we started receiving a lot of information via WhatsApp.
(BR, Local political conflicts/contexts)

wife: What I can add, and I won't add anymore uh (we had) a friend who is a medical doctor, he asked if I (could ask if they're using) I guess it would be the ((unintelligible)) and when I asked them, it was a different name, under a different name, he said no, we (don't think) it's effective. But I had to specifically ask.
I: Ok.
wife: Yeah, I wasn't getting a lot of information.
(CH, lack of information)

E: And some guy came in and said you need to be intubated right now, and that's the last thing I remember. <<laughs>> Until I woke up like about two weeks later. In the ICU and the hoses in me everywhere and strapped down. (CH, urgency and (lack of) consent)

Keep asking yourself:

Why do I think / feel it is important?

What are my own cultural biases in interpreting this (fragment of) a narrative?

Are there any other possible interpretations?

Can this experience be transversal, or it is intrinsically connected to the context in which it happened?

What do others see here?

134 codes in the shared branch
(to have comparable data)

Complete freedom to work in the local branch
(to capture local or specific phenomena)

Next steps:

- Protocol/methods paper

- Coding and analysis

- OSOPs

- Topic-specific papers

3. Into the data!

3. Into the data

…And now, the cool part of this session
- Watch selected clips;
- Note down what is interesting or surprising from your point of view, and what you see in the clip;
- Discuss your perspective in the breakout rooms (20')

https://drive.switch.ch/index.php/s/5obXSZca4K3Xfvo
P: DI2021v

Country	Topic	Moderator
Brazil	On the edge: solidatiry dilemma	Alicia
Brazil	On the edge: solidatiry dilemma	Ines
Switzerland	COVID in ICU	Corine
Switzerland	Existential outcomes	Giovanni
UK	Testing and precarious employment + Negotiating risk of transmission when caring for others	Anna and Sue
USA	Long COVID	Jane
Japan	Social integration after recovery	Rika

4. Future perspectives
(or: what we are learning from the process)

4. Future perspectives

COI disclaimer:
I do have a strong
commitment to
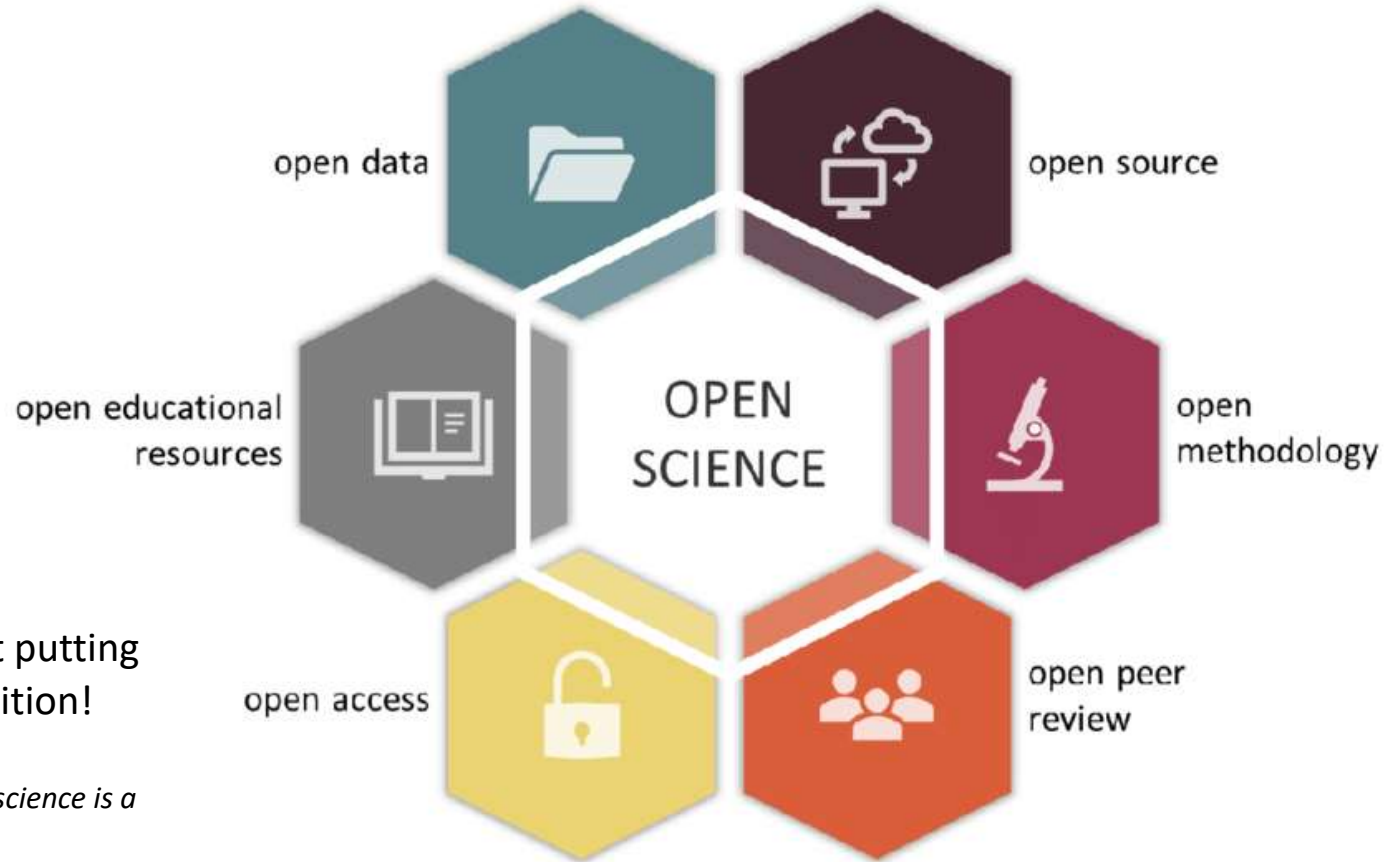open science!

We're open.
Are you?

openscience.uzh.ch

4. Future perspectives
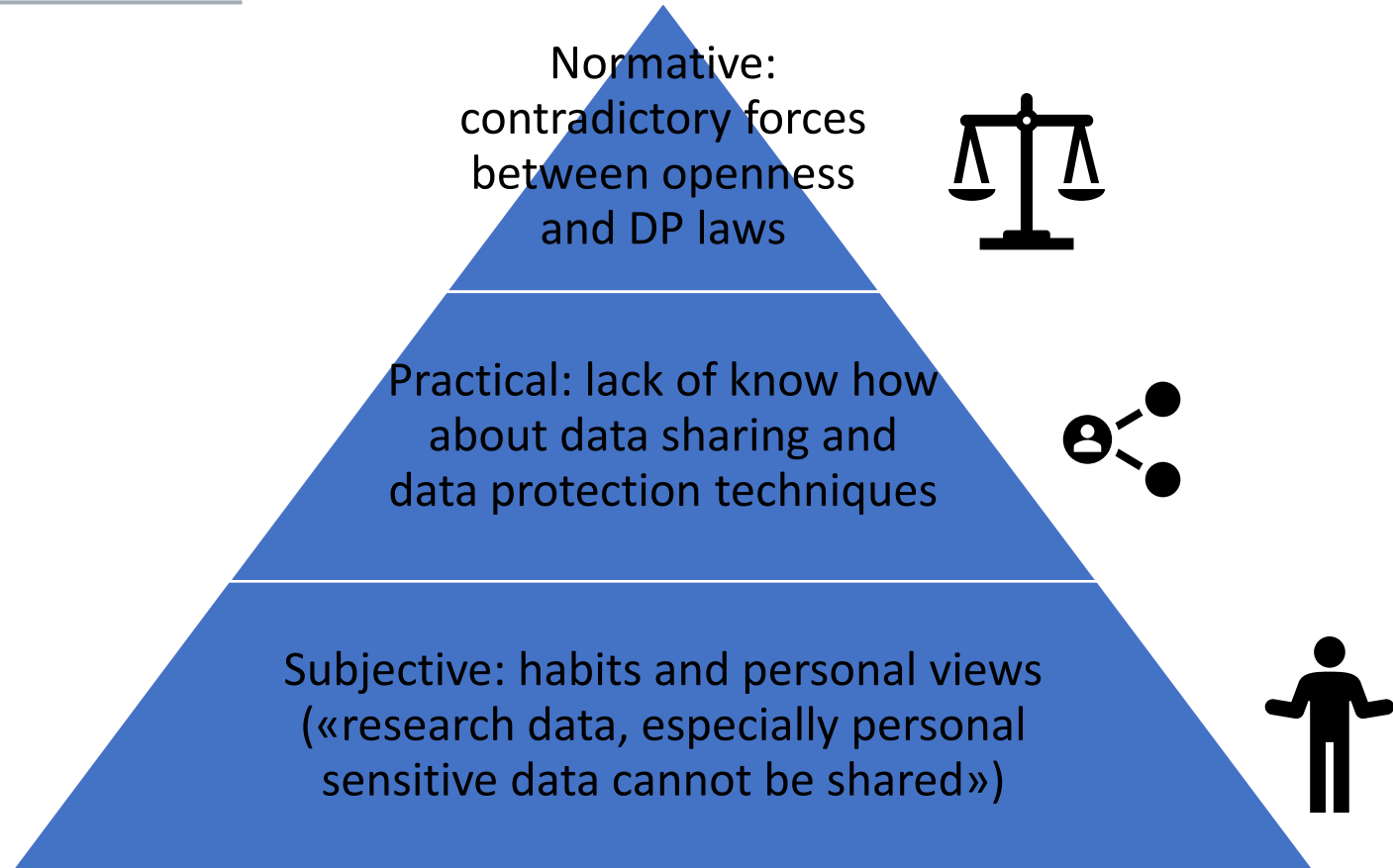
Open science is better science:
- It's more accessible
- It's more fair
- It's more transparent
- It's more efficient
- It has a wider impact

+ many universities or funders start putting open science approaches as a condition!

Woelfle, M., Olliaro, P. & Todd, M. 2011, Open science is a research accelerator.

open data

open source

open educational resources

OPEN SCIENCE

open methodology

open access

open peer review

4. Future perspectives

Challenges to data sharing
- Special status of sensitive data
- Harmonization issues
- Technical issues
- Legal issues

Normative: contradictory forces between openness and DP laws

Practical: lack of know how about data sharing and data protection techniques

Subjective: habits and personal views («research data, especially personal sensitive data cannot be shared»)
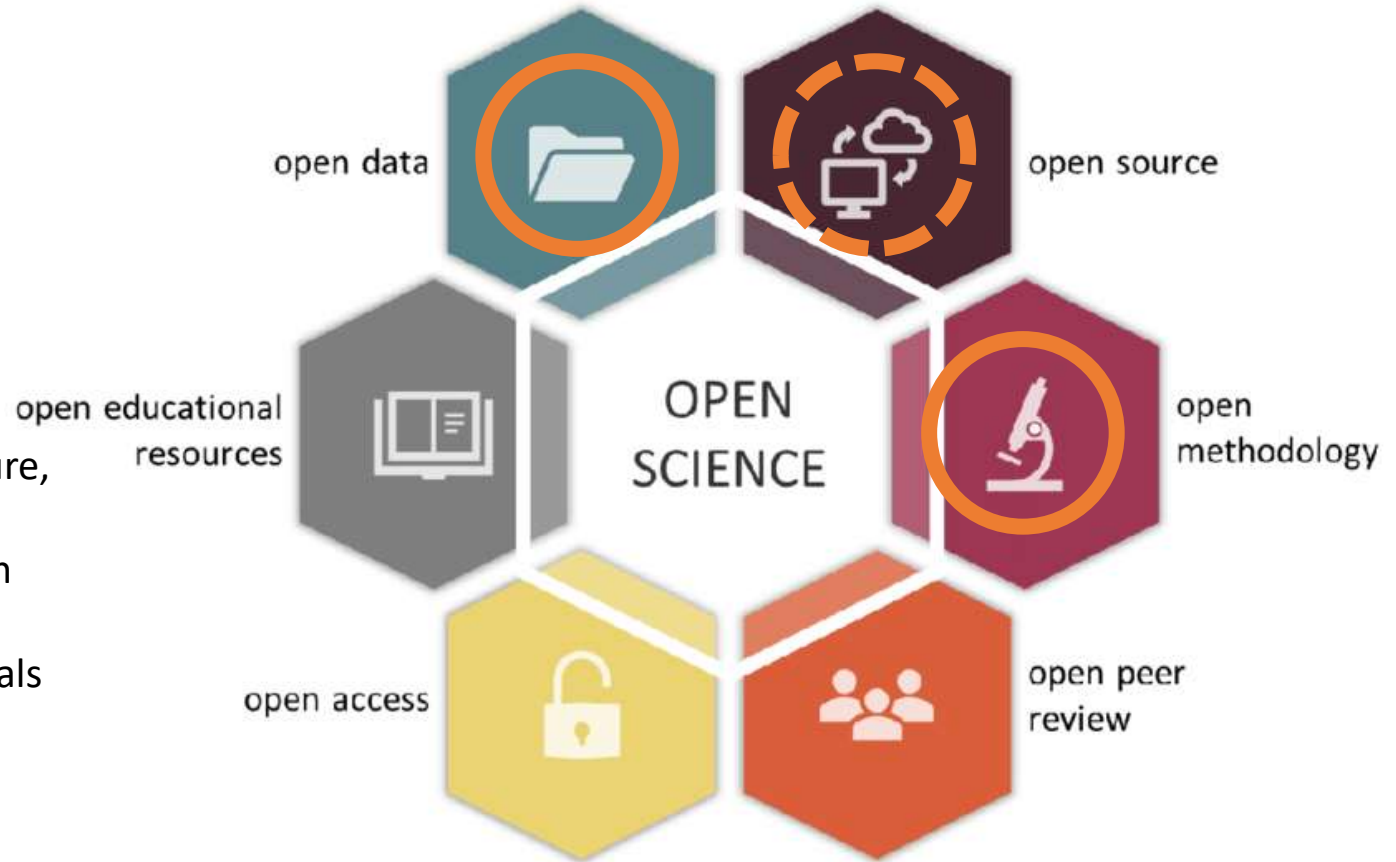
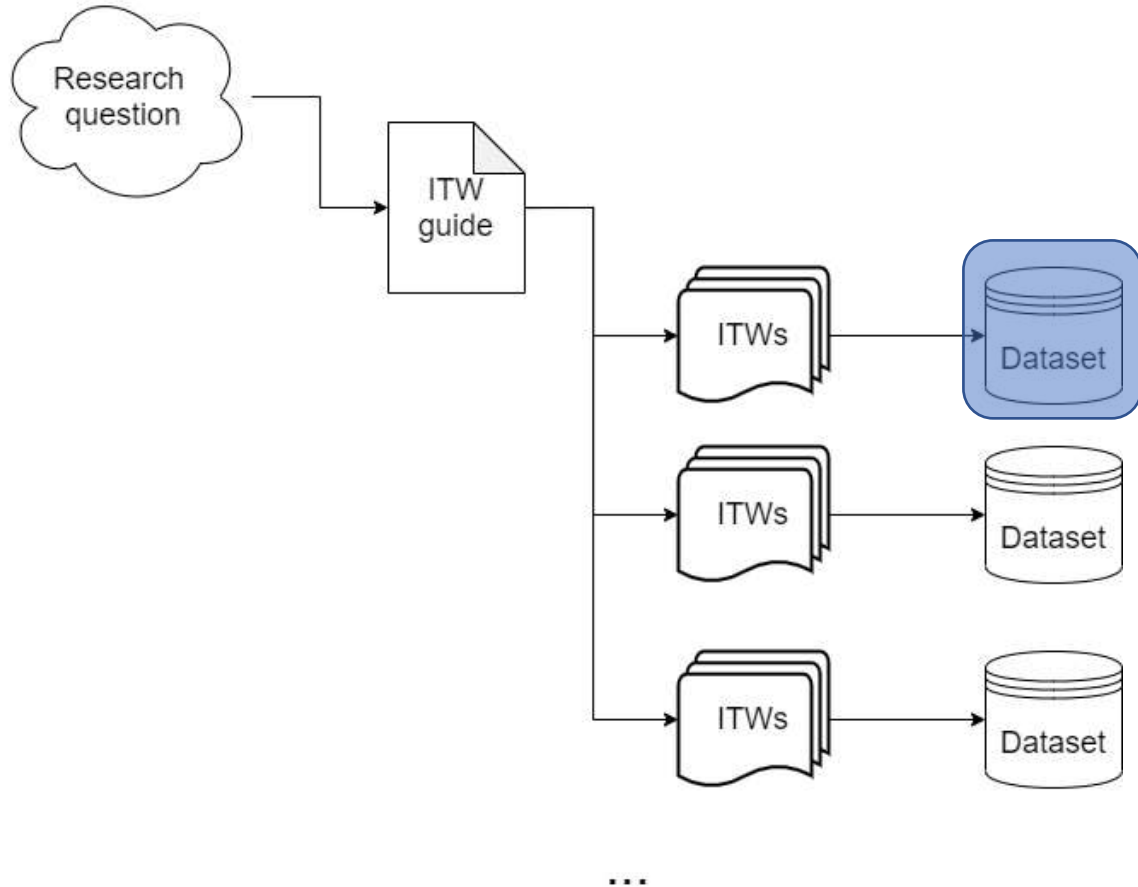# 4. Future perspectives

But we can share some data:
- Interview guides
- Variables
- Coding trees
- Metadata

All of this, put in a coherent structure, would allow:
- Improved compliance with open science principles
- Resources for preparing proposals
- Fast project piloting
- More international projects

4. Future perspectives

Properties
- **Description of the study** (target condition, target population, research question, researchers involved)
- **ITW guide** (and eventual translations)
- **Variables** used in the analysis
- **Coding trees** and descriptive memos
- **OSOPs**
- ...

Proposal:

Open a discourse on the data access model, keeping in mind cost of the data collection, possible exploits for commercial purposes, and infrastructure;

Start to reason on the feasibility of an international **"meta-database",** i.e: an harmonized catalogue of existing datasets and a set of rules for developing new datasets;

Reflect on the criteria for retrospective harmonization;

Leverage on existing experience - from the COVID study but also from other fields, e.g the Maelstrom catalogue (epidemiology)
https://www.maelstrom-research.org/page/publications

Give a scientist a tool and you feed science for a day.

Teach a scientist to be open and you feed science for a lifetime.

Graham Steel (@McDawg)
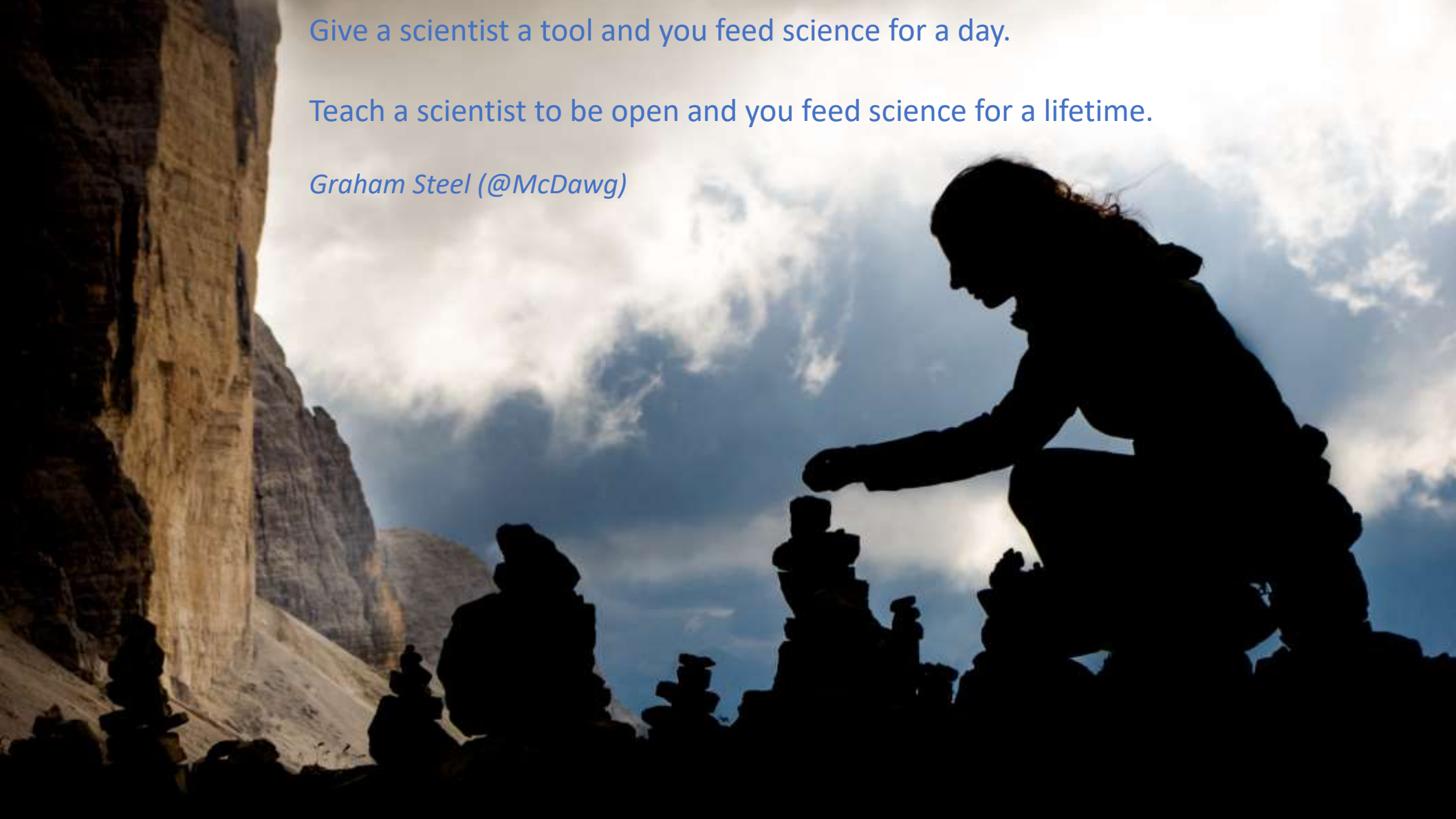
THANKS FOR YOUR TIME!

Still the same owl from last time, but upside down it's even weirder

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