

Development of an Ethical Framework for Infodemic Management

International Conference on “Governing Social Listening in the context of Serious Health Threats”,
22-24 August 2023, The University of Hong Kong, HK

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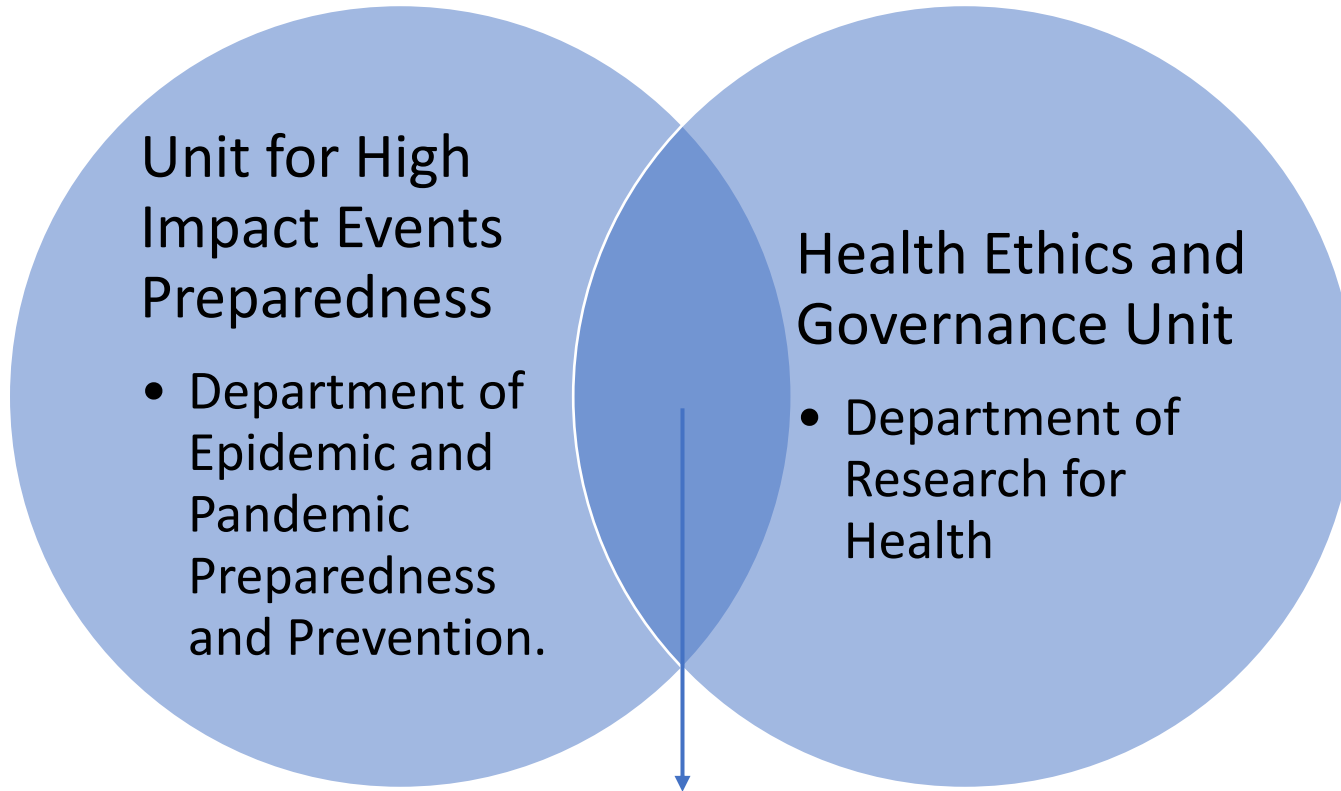


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This process

WHO Secretariat: Katherine Littler, Co-Unit Head of Health Ethics & Governance in the Department of Research for Health in the Science Division of the World Health Organization, Sylvie Briand, Director of Pandemic and Epidemic Preparedness and Prevention in the Health Emergencies Programme, Tina Purnat, Team Lead for Infodemic Management in the Unit for High Impact Events Preparedness of the Department of Pandemic and Epidemic Preparedness and Prevention, John Reeder, Acting Chief Scientist and Director of Research for Health Department in the Science Division, Andreas Reis, Co-Unit Head of Health Ethics & Governance in the Department of Research for Health in the Science Division, and Sandra Varaidzo Machiri from the African Field Epidemiology Network in Zimbabwe.

Co-chairs of the group: Isabella Ballalai from the Brazilian Immunization Society and Calvin Ho from the Centre for Medical Ethics and Law at Hong Kong University.

Experts involved: Najeeb Al-Shorbaji from the Jordan Library and Information Association, Thalia Arawi from the American University of Beirut, Cherstyn Hurley from the Health Security Agency in the UK, Dimitra Lingri from the European Healthcare Fraud & Corruption Network (EHFCN) and the Department of Law at the Faculty of Law at Aristotle University of Thessaloniki in Greece, Stefan Mandic-Rajcevic from the Infodemiology Lab at the School of Medicine at the University of Belgrade in Serbia, Lisa Talia Moretti from AND Digital in the UK, Syed Nakazat from the DataLEADS Foundation in India, Claudia Pagliari from The Usher Institute at the University of Edinburgh in the UK, Alejandro Posada from Internews in Bogotá, Colombia, Ana Lorena Ruano from the Center of Studies for Governance and Equity in Health Systems in Guatemala, David Scales from the Weill Cornell Medical College at Cornell University in the USA, Max Smith from the School of Health Studies at Western University in Canada, Theresa M Senft from Macquarie University in Australia, Harry Sufehmi from MAFINDO in Indonesia, Ross Upshur from the Dalla Lana Faculty of Public Health at the University of Toronto in Canada, and Fatou Wurie from Harvard University in the USA.

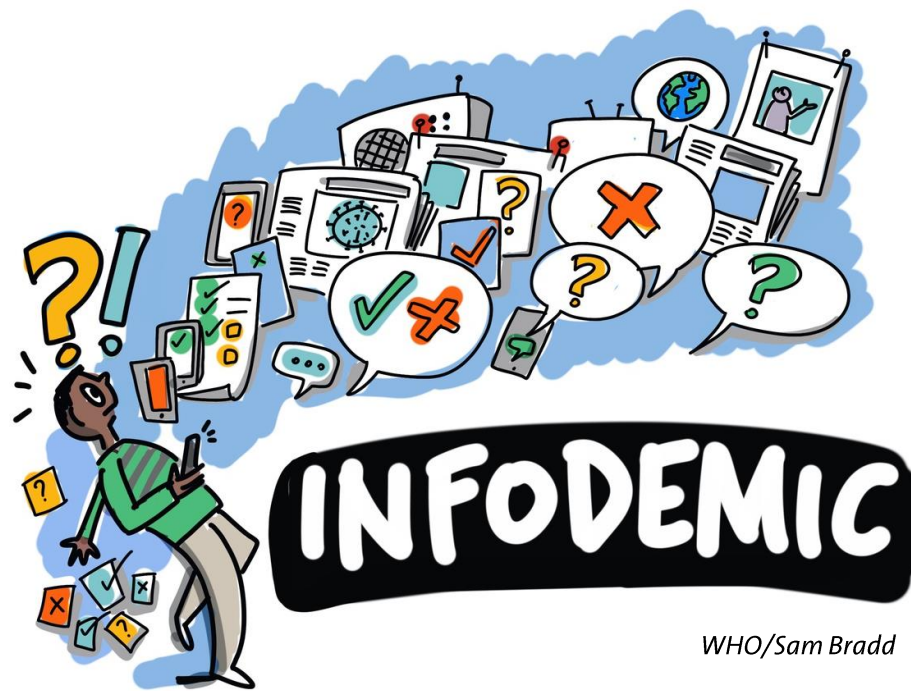
Observers: Surangani Abeysekera from UNICEF, Guilherme Canela De Souza Godoi from UNESCO, Timothy K Mackey from the University of California, San Diego, Lee Hibbard from the Council of Europe, and Betsy Mitchell from the US Centers for Disease Control and Prevention.

1. Defining the problem

2. The process

3. Architecture

1. Defining the problem



WHO/Sam Bradd

Too much information, including false or misleading information, in digital and physical environments during a disease outbreak.

- causes confusion and risk-taking behaviours that can harm health;
- leads to mistrust in health authorities;
- undermines the public health response;
- can intensify or lengthen outbreaks.

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Infodemic management

the systematic use of risk- and evidence-based analysis and approaches to manage the infodemic and reduce its impact on health behaviours during health emergencies.

- Listening to community concerns and questions;
- Promoting understanding of risk and health expert advice;
- Building resilience to misinformation;
- Engaging and empowering communities to take positive action.

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Defining the problem



1. **Effectiveness/Efficacy/public good/usefulness:** ability to produce benefit in real life conditions
2. **Autonomy** (understood differently in different cultures): the combination of intentionality, understanding and non-control
3. **Fairness/justice:** a comprehensive set of basic rights and liberties that can coexist with similar rights for all

Vulnerability of individuals and communities

Active and passive freedom of information

Trust, transparency, and trustworthiness

Privacy, confidentiality, and consent

Aims

- To guide **organizations and individuals** seeking advice on how to **ethically engage in social listening**,
- In concordance with the **protection and respect for human rights**,
- As part of an **infodemic management protocol**,
- **Before and during health emergencies.**

= Navigate the tensions detailed before and (try to) strike that balance.



2. The process

The process

Infodemics? IM?

Moral values to pursue?

How do we get there?

Define the activities and the context



Identify risks and challenges



Define aims



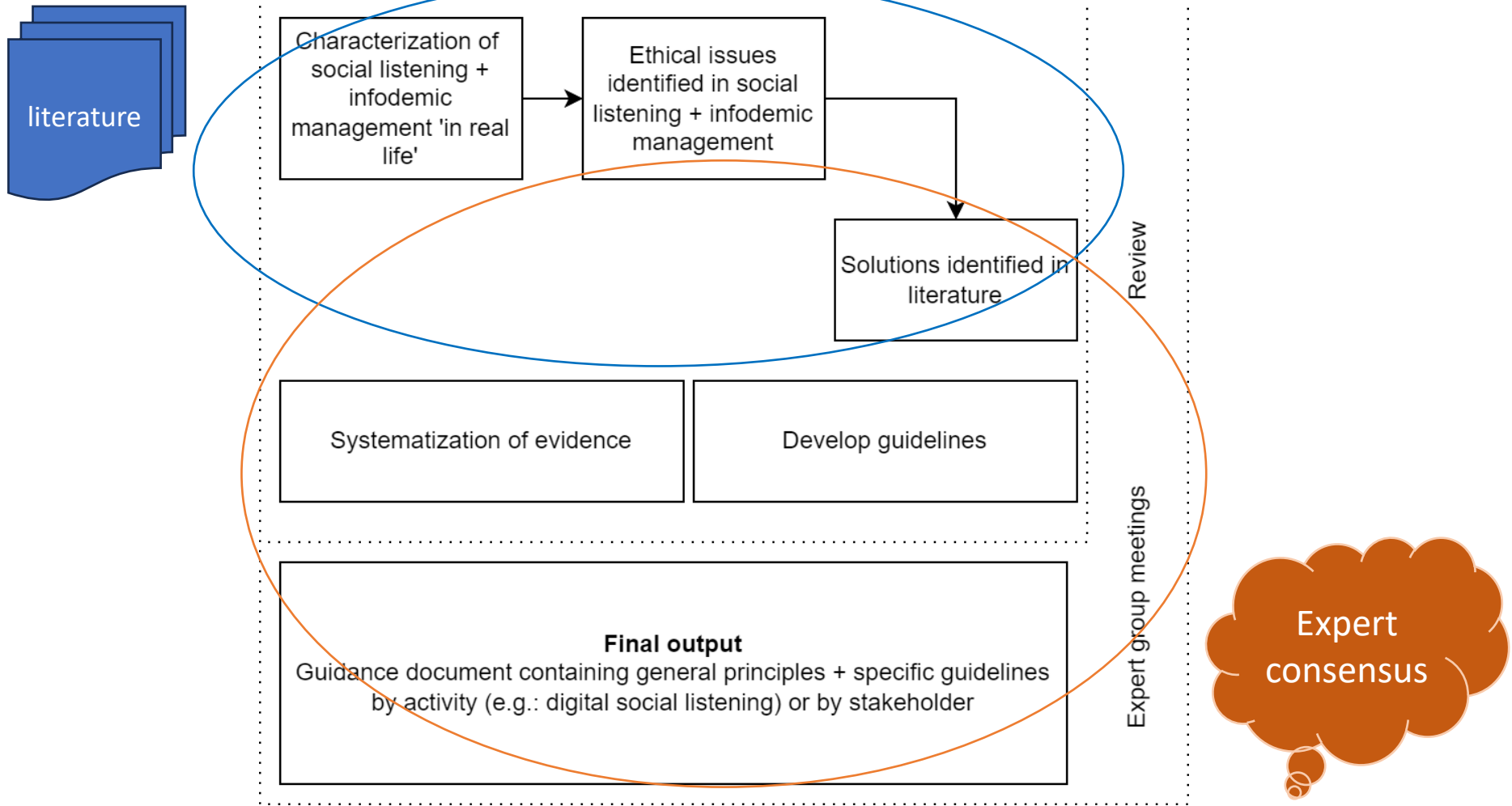
Define guiding principles



Develop implementation guidance

Potential harm?

Where do we want to go?



3. Architecture

Foundations

Aims and scope	What the document is about and what issues it addresses
Target audience	Who this document is for
General introduction	Contextualization: health emergencies and preparedness, prevention and response, impact of infodemics
Definitions	Definitions of relevant concepts used in the document (e.g.: health emergency, public good, public interest, infodemics, ...)

Justification and raison d'etre

Importance of ethical guidance for SLIM	Contexts of use, 'peace time' (monitoring, signal detection) and 'war time' (response to acute events)
Risks of unethical practices in SLIM	Harm to people (esp. in vulnerable situations); erosion of trust; ineffective response of health systems; data misuse, dual use, or other unintended use

Process

Methodology and approach	How the document is being developed (and by whom)
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Alignment

Findings of review (alignment)	Challenges: managing power imbalance; working with uncertainty; legitimacy of actors; ensuring effectiveness
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Ethical significance

Striking a balance	Challenges: managing power imbalance; working with uncertainty; legitimacy of actors; ensuring effectiveness
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What makes it difficult

Where we want to go

Process aims	'Where we want to go with SLIM' - protection of and respect for human rights; epistemic justice; trust; fair and inclusive decision making; integrity; ...
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Our overall plan

Principles	Or: guiding concepts to translate process aims in practice, avoiding or reducing the risks.
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Theory to practice

How we get there

Implementation tools	Practical guidance, specific for stakeholders and context of application
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4. Core content

Challenges



Managing **power imbalance** and **guaranteeing good governance**



Working in conditions of **uncertainty** (epistemic underdetermination, truth, revisability, reliability, certitude)



Ensuring Infodemic management **effectiveness**



Identifying **legitimate actors**

Process aims (1)

Still work in progress!



Protection of and respect for human rights



Pursue epistemic justice



Preserve and build trust, reciprocal trust, trustworthiness



Apply fair, equitable and inclusive processes of decision making



Guarantee integrity of actors and actions

Process aims (2)

Still work in progress!



Value community engagement



Pursue understandability



Driven by beneficence, effectiveness, and community benefit

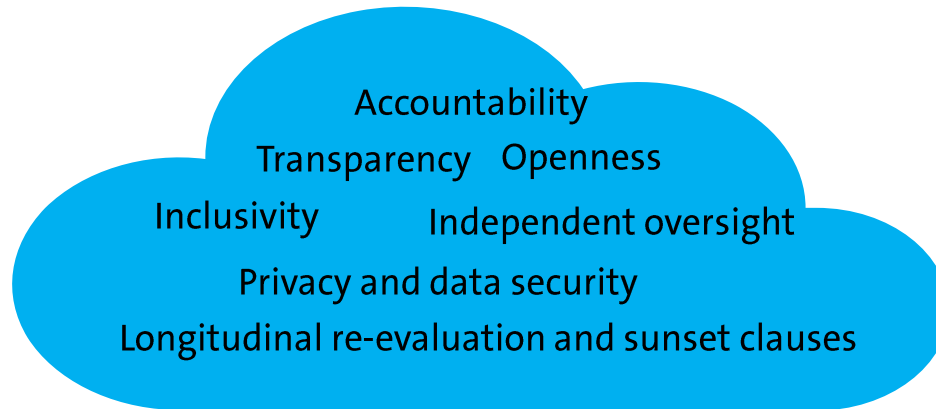


Balanced by necessity, utility, proportionality, and least intrusive approaches

Principles

Still work in progress!

Principles help translating challenges and aims which exist in abstract (i.e.: what we want to avoid and where we want to go) into codified processes to be incorporated into the guidance.



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Guidance/recommendations

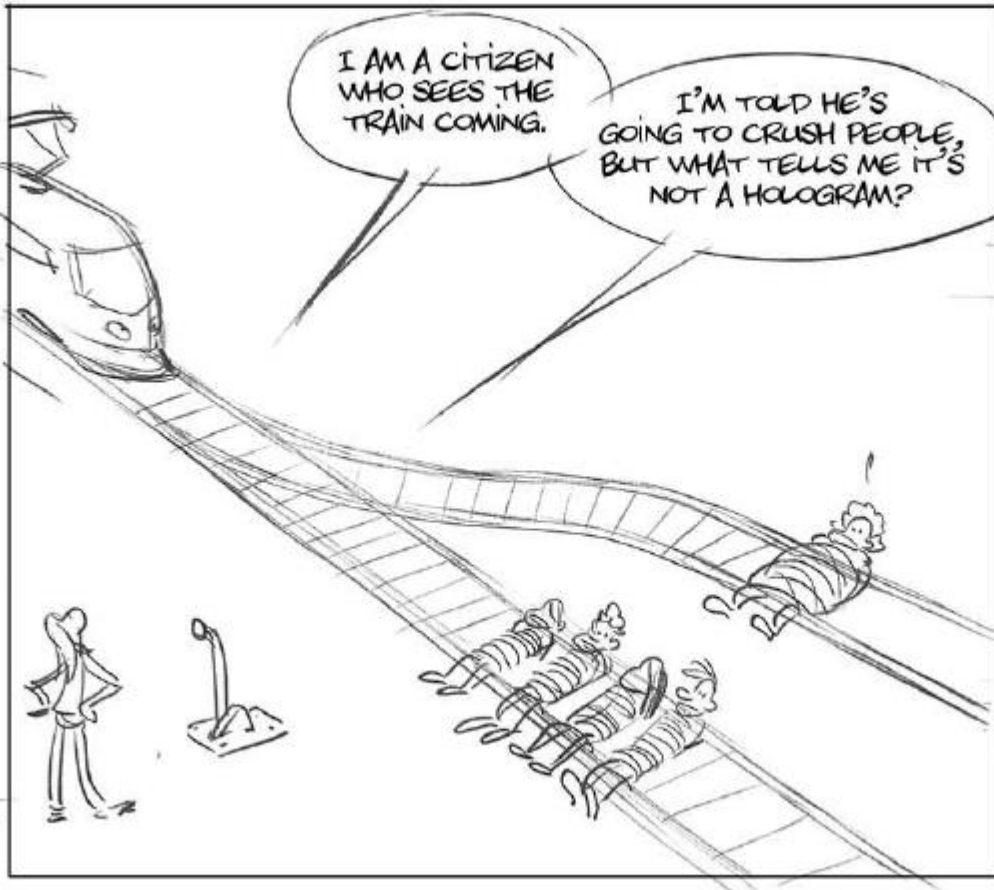
Still work in progress!

Recommendations help shaping concrete actions according to ethical desirability.

Recommendations target specific stakeholders (e.g.: International health organizations; national governments; public health officials, ...) and specific infodemic management activities (e.g.: capacity building; planning infodemic response procedures; collecting infodemic insights; ...) with a pragmatic life cycle approach.

SUMMARIZING:

- Infodemics and infodemic management pose significant challenges.
- An **ethical framework** is necessary for effective infodemic management.
- The development process is based on both **literature and experts' views**.
- The architecture includes **definitions, ethical challenges, process aims, principles, and stakeholder-specific guidance**





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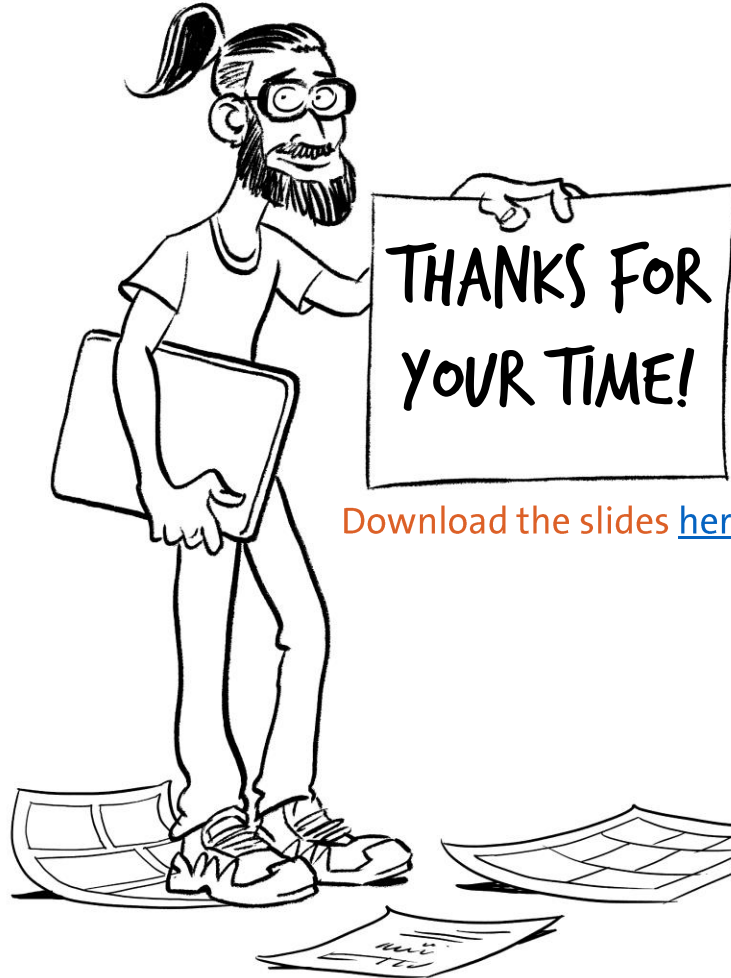


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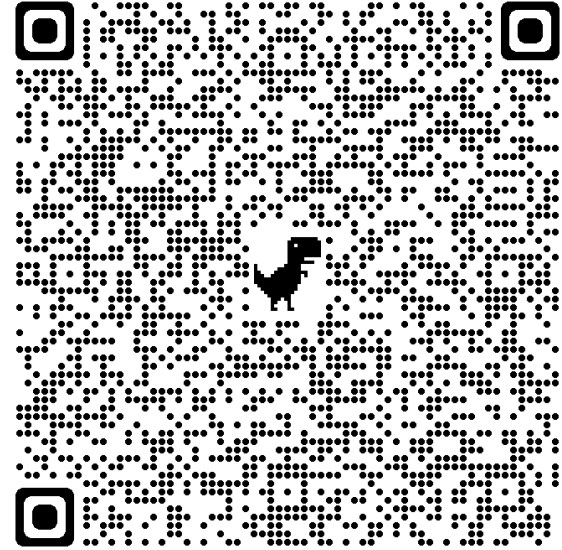


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