Capacity: Digital Data and Information Systems

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Moderator: **Maimuna Majumder**, (Member), Harvard Medical School and Boston Children's Hospital

Panelists:

David Lazer, *Northeastern University*

Rahul Bhargava, *MediaCloud and Northeastern University*

Agata Ferretti, *Health Ethics & Policy Lab, ETH Zurich*

Elaine Nsoesie, *Boston University (virtual)*

Media Cloud

as a critical piece of public data infrastructure

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Online Communication Environment

broadcast

public social

private social

DATA CULTURE GROUP

We need public data infrastructure to understand media amplification of messages across the online communication environment.

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What is Media Cloud?

A comprehensive database of global online news.

A set of online analysis tools and methods.

An interdisciplinary team of technologists and researchers.

A cross-sector research service.

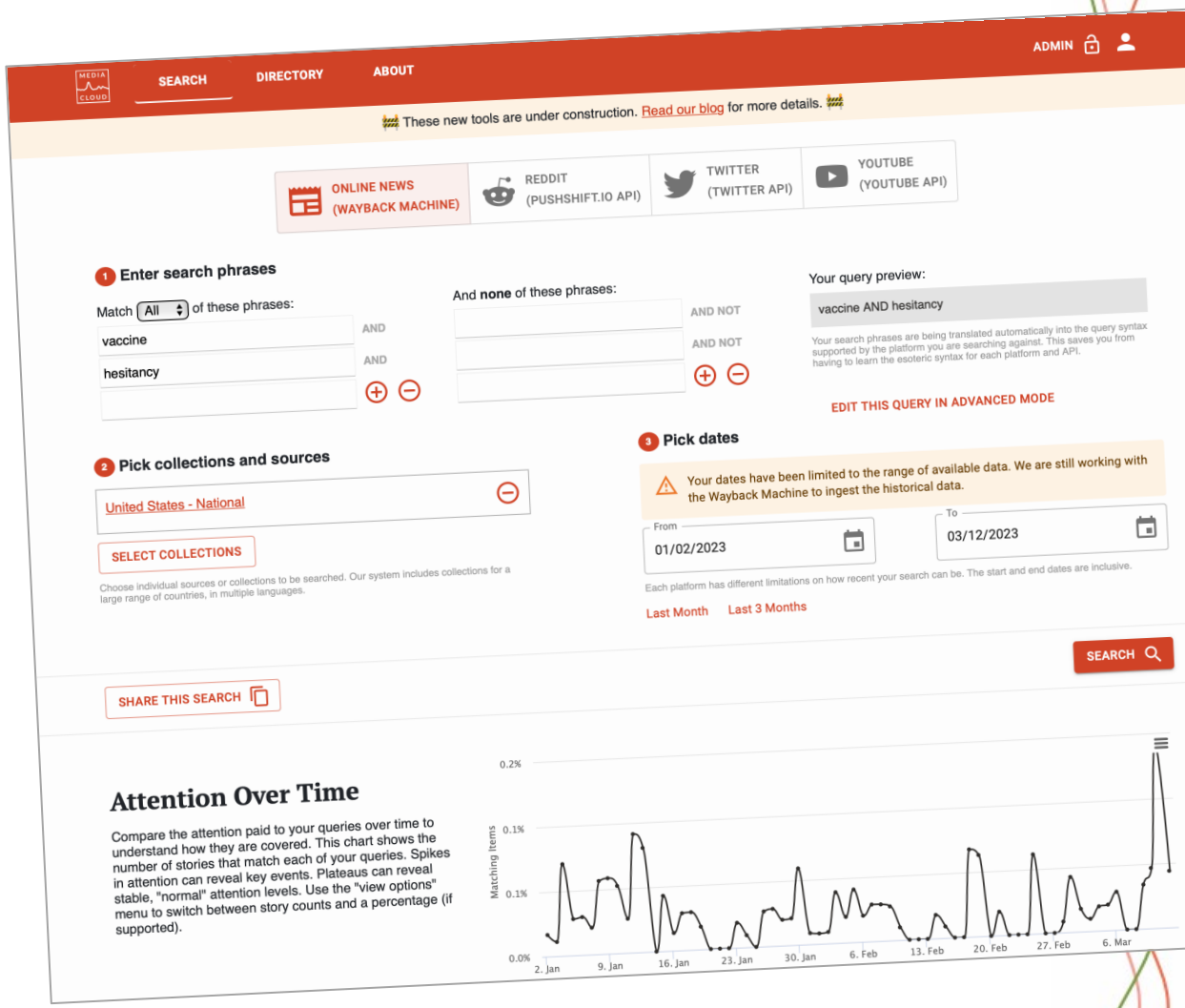
DATA CULTURE GROUP

Search Tools

Investigate media attention, language, representation and influence.

Search against geographic sets of media sources from our directory

search.mediacloud.org



DATA CULTURE GROUP

For Digital Public Health Communicators?

content quantity → perceived susceptibility

“what happened” content → perceived severity

“here’s why” content → perceived benefits

“here’s how” content → call to action

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Health Ethics & Policy Lab

Capacity: Digital Data and Information Systems

A path toward more ethical digital health

Dr. Agata Ferretti
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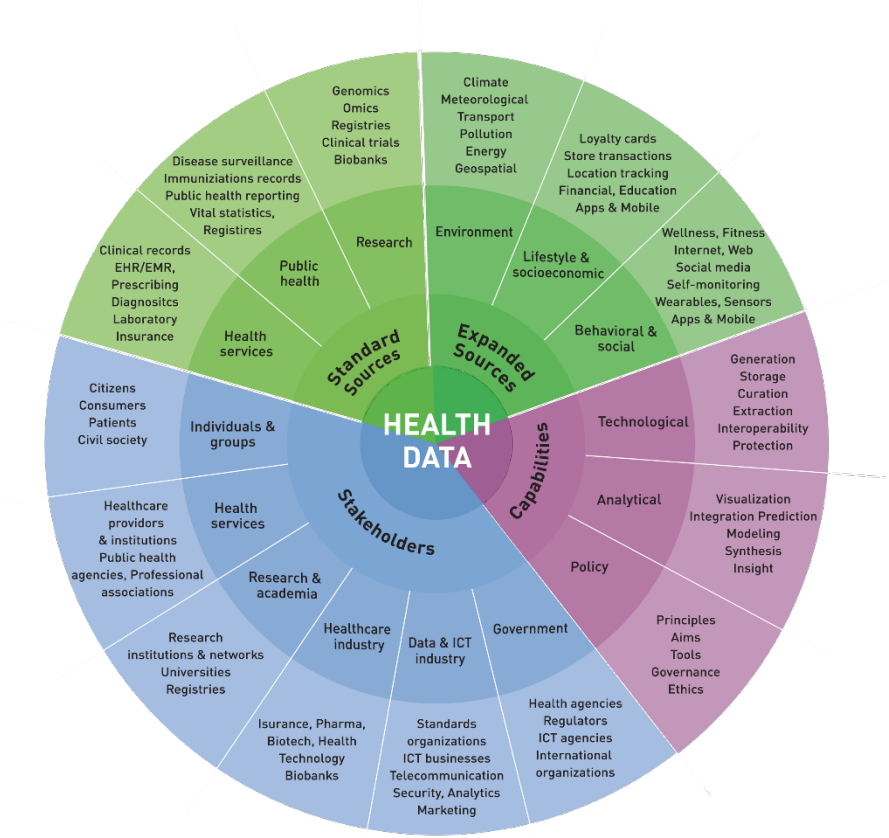
1. The health data ecosystem

- Medical big data + other data sources
- New powerful analytics tools
- New stakeholders



Vayena et al. Bull World Health Organ. 2018 Jan 1;96(1):66-68.

2. Privacy focus in digital health and health data governance

- **Availability of real-time big data** allows to build scientifically sound and reliable technologies

BUT

- Data collection, use and storage increase **risks for privacy**

- Privacy as the **most debated** ethical concern in big data governance and digital health ethics

- **Swiss contact tracing case**: Low adoption rates (25% / ~2M) despite privacy friendly design and the scientific efficacy

Ferretti, A., Vayena, E. (2022) . Epidemics.
Blasimme, A., Ferretti, A., Vayena, E. (2021). Frontiers Digital Health,

3. Unaddressed ethical issues

Problematic to consider privacy and data protection as **ethics panacea in digital health and data governance** because:

1. **Inadequate access to the technology**
   - BIAS & SCIENTIFIC EFFICACY issues

3. Unaddressed ethical issues

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3. **Inadequate meaningful public engagement**
   - TRUST & SOCIAL LICENCE issues

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3. **Inadequate meaningful public engagement**
   - TRUST & SOCIAL LICENCE issues
4. **Inadequate ethical monitoring and oversight**
   - JUSTICE & BENEFIT DISTRIBUTION issues

4. A path toward more ethical digital health

Develop PRIVACY PRESERVING and TECHNICALLY ROBUST tools

+

Ensure REPRESENTATIVENESS of datasets and SCIENTIFIC EFFICACY

- Tackle issues of technology accessibility at social/cultural level
- Invest into digital infrastructures, digital interoperability, digital literacy and digital health training

Increase tech ADOPTION and fight MISINFORMATION

- Provide clear, transparent, and reliable communication about data and its (re)use
- Inform the public about any involvement of (private) partners in the development and deployment of technologies

Build TRUST and SOCIAL LICENCE for digital health use

- Carry out public engagement while developing technologies
- Integrate people's perspectives into tech development and data governance

Ensure FAIR BENEFIT DISTRIBUTION among stakeholders

- Strengthen ethics oversight and accountability mechanisms
- Monitor for conflict of interest arising from collaborations among private/public actors

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Thank you

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