

IFPMA Data Ethics Principles

WEBINAR
June 25, 2021



With our experts/speakers:

- **Sobia Akram**
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- **Anna Dolinsky**
Novo Nordisk
- **John Olwal**
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- **Uma Swaminathan**
GSK
- **Jeffrey Scott**
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Housekeeping rules



Please mute yourself during the entire webinar.



If you have a **question**, please use the **chat box**. We will do our best to address all questions during the Q&A session. Unanswered questions will be collected to create a future Q&A document following IFPMA approval timelines.



When not speaking, please disable your video function to allow for maximum bandwidth.



The meeting will be recorded and distributed to the IFPMA Ethics & Business Integrity Committee members.

Expectations of today's webinar

- **Introduction:** Why focus on Data Ethics?
- **Overview:** What are the Data Ethics principles?
- **Considerations:** How to implement Data Ethics principles
- **Q&A and discussion**

The journey towards our Data Ethics Principles

Jan 2020

Brainstorming & drafting:

- Review of existing and proposed frameworks
- Input from regulators, advocates, other industries

Oct 2020

Feedback from internal stakeholders (R&D, IT/Digital, Markets)

Jan-Mar 2021

Internal socialization (eBIC, incl. EFPIA/JPMA/PhRMA)

Mar 2021

Road-tests in member entities

May 2021

External socialization (WHO, WMA, APEC)

Jun 2021

LAUNCH

UP NEXT

AI Ethics Principles

Extensive and diverse stakeholder input and feedback at every stage helped ensure pragmatic, risk-based approach with strong focus on protecting individuals and benefiting society



Trust is the core of the IFPMA Ethos...

But even the appearance of inappropriate use of data can damage trust...

We must do things right, preserving the trust at the core of our Ethos.

Why Data Ethics?



Data presents profound opportunities

At the same time there is increasing scrutiny and enforcement

University of California San Francisco

Big Data Powers Design of ‘Smart’ Cell Therapies for Cancer

FINANCIAL TIMES

UK competition regulator plans probe into Amazon’s use of data

benefitsPRO

How data science and personalization can transform the employee benefits experience

search The Guardian US edition
For 200 years

How US companies could use patients’ data from Covid vaccine drive

What is Data Ethics?



- Responsible and sustainable use of data in alignment with the *IFPMA Ethos of care, fairness, respect, and honesty*
- Doing the right thing for people and society, in the context of data security, privacy and integrity
- Respecting human rights and personal data protection



Data includes ALL types of data collected, analysed, stored, shared, and otherwise processed by pharmaceutical companies.

- *Individual data*
- *Data that did not originally relate to an individual* if processing such data can potentially harm/benefit individuals & society.

The 7 IFPMA Data Ethics Principles



Autonomy

Respect individuals' privacy, protect rights, & honour confidentiality.



Transparency

Individuals should be able to understand how personal data are used.



Data quality

Best quality data available used to make decisions.



Fairness and non-discrimination

Data acquisition to be inclusive, equitable & supportive of industry's mission of responding to needs of all patients.



Ethics by design

Controls to prevent risk/harm to individuals built into data architecture/processing design.



Responsible data sharing

Data sharing based on processes that consider, prioritize, protect individual rights.



Responsibility and Accountability

Data ethics principles operationalized through effective governance, clear standards, training, monitoring activities, disciplinary sanctions.

How to embed data ethics?



When you look to embed these Data Ethics Principles within your organization, here are **three thoughts** to consider:



Educating on and fostering **data ethics literacy**

- Creating **awareness** and communicating importance through top management narrative to build **a data ethics culture**.
- Offering **training and capability building** around data ethics through use cases & data ethics dilemmas.
- Communicating **company's position** on data ethics to suppliers, partners and customers.



Embedding data ethics into enterprise **ways of working** and **governance**

- Establishing **ownership and accountability** with (business) data owners
- Embedding data ethics into overall enterprise **data policies**.
- Viewing ethical data as an **asset**. Unethical data would be a **risk** and not in line with **Trust and Transparency values** with corresponding **risk assessment and mitigations** defined.



Enforcing data ethics **Risk Assessments** and **Controls**.

- Extending **monitoring** beyond standard controls to cover the **full spectrum** of 7 data ethics principles.
- Executing regular self-assessments / **health-checks** on data ethics (e.g., through internal audit).

Key considerations for implementation

- Continue to **diversify capabilities / skillsets**
- Integrate **executive sponsorship / buy-in from the top** in the ways we work
- Ensure **input from stakeholders** that are working with the data
- Include **third-party intermediaries**
- Apply **maturity model** to monitor progress
- Define **metrics** on Data Ethics that are relevant to track / report

Q & A

**Please raise your hand or send
your questions in the
chat box!**

Thank you!



Next steps: AI Ethics guidance



Ethics & Governance of Artificial Intelligence (AI) for Health: WHO Guidance and next steps

Effy Vayena & Partha Majumder (Co-chairs), on behalf of the WHO Expert Group



WHO publicly launches its AI guidance next week

Report Launch:
Ethics & Governance of
Artificial Intelligence for Health
28th June 2021 (12.00 – 13.30 CET)



Panellists:

- Dr E. Osagie Ehanire, Minister of Health, Nigeria
- Agnès Callamard, Executive Director, Amnesty Intl.
- Pushmeet Kohli, Head of AI for Science, DeepMind
- Stefan Winkler, Deputy Director, AI Singapore
- Partha Majumder, Indian Council of Science
- Effy Vayena, ETH Zurich, Switzerland

Moderator: Soumya Swaminathan, WHO Chief Scientist

Registration:

https://who.zoom.us/webinar/register/WN_eBapkEhBQluisMYizyl6ZQ