IFPMA Data Ethics Principles

WEBINAR June 25, 2021





With our experts/speakers:

- Sobia Akram
 Novo Nordisk
- Anna Dolinsky
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- John Olwal Novartis
- Uma Swaminathan
 GSK
- Jeffrey ScottPfizer











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

Brainstorming & drafting:	
 Review of existing and proposed frame 	works
 Input from regulators, advocates, other 	industries
Feedback from internal stakeholders (R&D, IT/	'Digital, Mai
Internal socialization (eBIC, incl. EFPIA/JPMA/Ph	RMA)
Road-tests in member entities	
External socialization (WHO, WMA, APEC)	Exten and fee
	 Review of existing and proposed frame Input from regulators, advocates, other Feedback from internal stakeholders (R&D, IT/ Internal socialization (eBIC, incl. EFPIA/JPMA/Ph Road-tests in member entities

LAUNCH

AI Ethics Principles

Jan 2020

Jun 2021

UP NEXT

Brainstorming & drafting

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

IT/Digital, Markets)







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

University of California San Francisco

Big Data Powers Design of 'Smart' Cell Therapies for Cancer

benefits **S**PRO

How data science and personalization can transform the employee benefits experience

At the same time there is increasing scrutiny and enforcement

FINANCIAL TIMES

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



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



Embedding data ethics into enterprise ways of working and governance



Enforcing data ethics
Risk Assessments
and Controls.

- 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.

- 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.

- Extending monitoring beyond standard controls to cover the full spectrum of 7 data ethics principles.
- Executing regular selfassessments / 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!





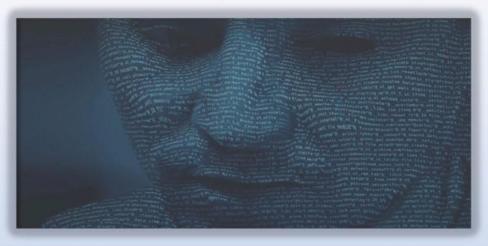
Next steps: Al Ethics guidance





WHO publicly launches its Al 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, Al 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_eB apkEhBQluisMYizyI6ZQ



