IFPMA
Data Ethics Principles

WEBINAR
June 25, 2021
With our experts/speakers:

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- Anna Dolinsky
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- John Olwal
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- Uma Swaminathan
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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

<table>
<thead>
<tr>
<th>Jan 2020</th>
<th>Brainstorming &amp; drafting:</th>
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<td>• Review of existing and proposed frameworks</td>
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<td>• Input from regulators, advocates, other industries</td>
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<td>Oct 2020</td>
<td>Feedback from internal stakeholders (R&amp;D, IT/Digital, Markets)</td>
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<td>Jan-Mar 2021</td>
<td>Internal socialization (eBIC, incl. EFPIA/JPMA/PhRMA)</td>
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<td>Mar 2021</td>
<td>Road-tests in member entities</td>
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<td>May 2021</td>
<td>External socialization (WHO, WMA, APEC)</td>
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<td>Jun 2021</td>
<td>LAUNCH</td>
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<td><strong>UP NEXT</strong></td>
<td><strong>AI Ethics Principles</strong></td>
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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

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

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

How data science and personalization can transform the employee benefits experience

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
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_eBapkEhBQluisMYizyI6ZQ