



EU Big Data Stakeholder Forum 2024

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Session 3

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Anchoring ethics at all steps – Remembering ethics is as much questions as answers

Vision, **agreed values and diversity in their implementation**

Integration at all steps (from research to policy)

Openness and documentation of points of views/positions (these aspects are DATA to consider)

Ethics by design for tools

Real world ethical challenges : case studies in training

Example 1: **genomic data**

- sequencing data, representativity (genetic diversity), sharing policies and processes
- **choice** of data to use, share, (re-analyse)
- address incidental/secondary findings policies (no consensus)
- not only pharmacogenomics aspects
- genomic data encompass health related and non health related aspects

Example 2: **Social media data** (3 keywords: research, transparency, point of view)

Content

Thank you for listening

Further information

See websites for contact details

Heads of Medicines Agencies www.hma.eu
European Medicines Agency www.ema.europa.eu

The European Medicines Agency is
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