Ethical and Legal Issues in Personalised Medicine

Effy Vayena, PhD

University of Zurich, Switzerland
Challenges
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Common good

Choice

Participation

Privacy

Society
Ethical Challenges

- Personal choice
  - How to respect choice?

- Participation
  - How to enable participation?

- Privacy
  - How to protect and respect privacy?

Common good

Uncertainty

Temporality
Foundational issues:
- What is the normative approach?
- e.g. Global Alliance for Genomics and Health
  - “Framework for responsible sharing of genomic and health-related data”

Human Rights
Article 27: “to share in scientific advancement and its benefits”

“To the protection of the moral and material interests resulting from any scientific production of which a person is an author”
Ethics and law

“Support research on the adequacy of current regulatory pathways and the development of new regulatory and legal framework for personalised medicine/health care”
- PerMed recommendations

- What format they will have?
- How national laws will converge?
- Good Governance Framework
  - Caution about legislation (limits of law)
  - Reflexive governance
Ethics, law and good governance

- Reflexive approach
  - Deliberation, communications and partnership
  - Broader participation in governance

G. Laurie. Hum Gen, 2011
Innovative ethical thinking

- (no conversation stoppers)

Novel governance models

- (one size doesn’t fit all)

Participation

- (bottom-up approaches, long term involvement)

Person-centric

- (is good for the common good)