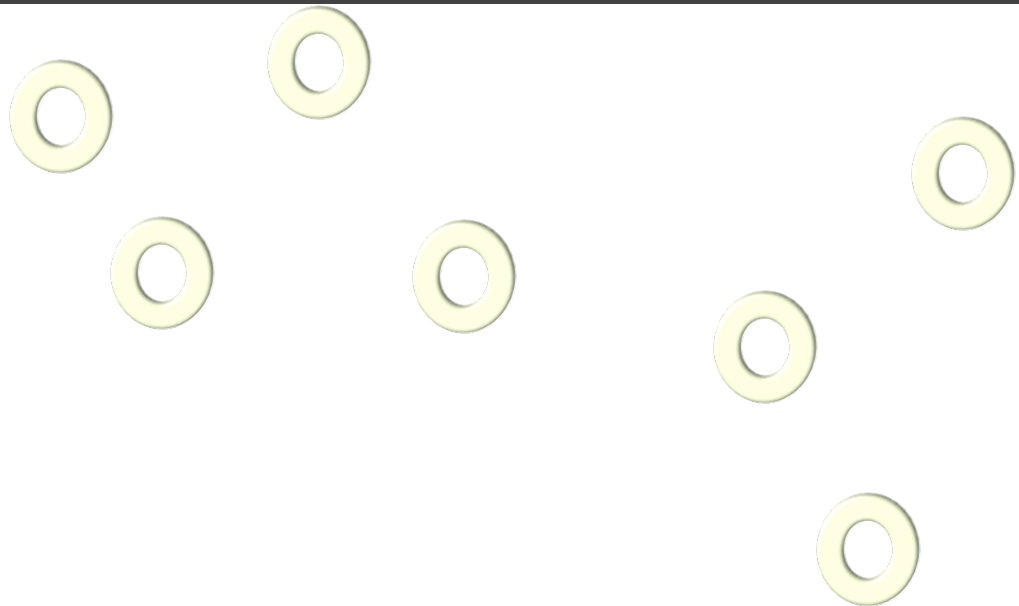


Ethical and Legal Issues in Personalised Medicine

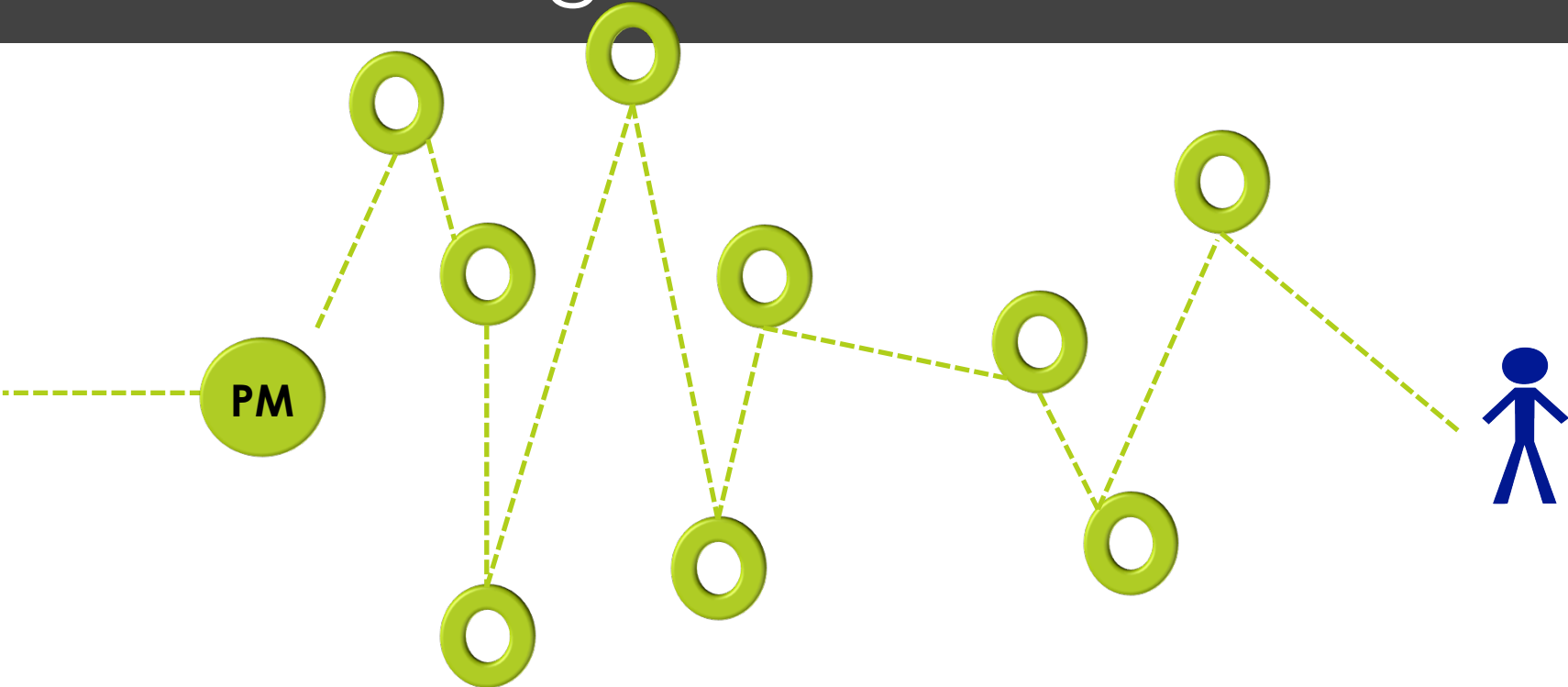
Effy Vayena, PhD

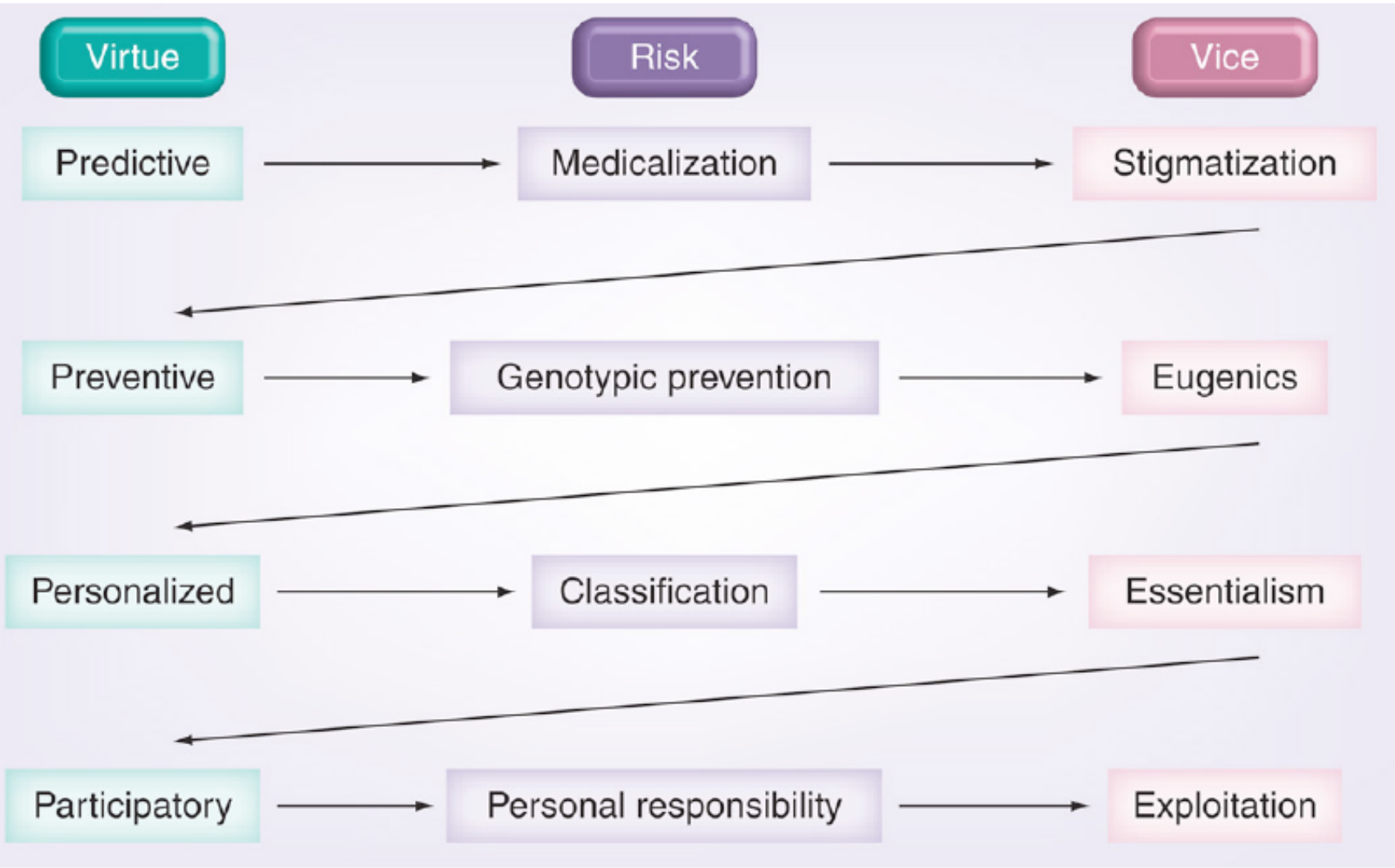
University of Zurich, Switzerland

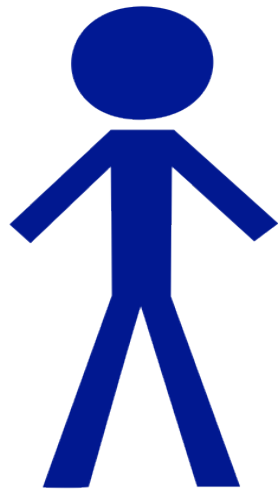
Challenges

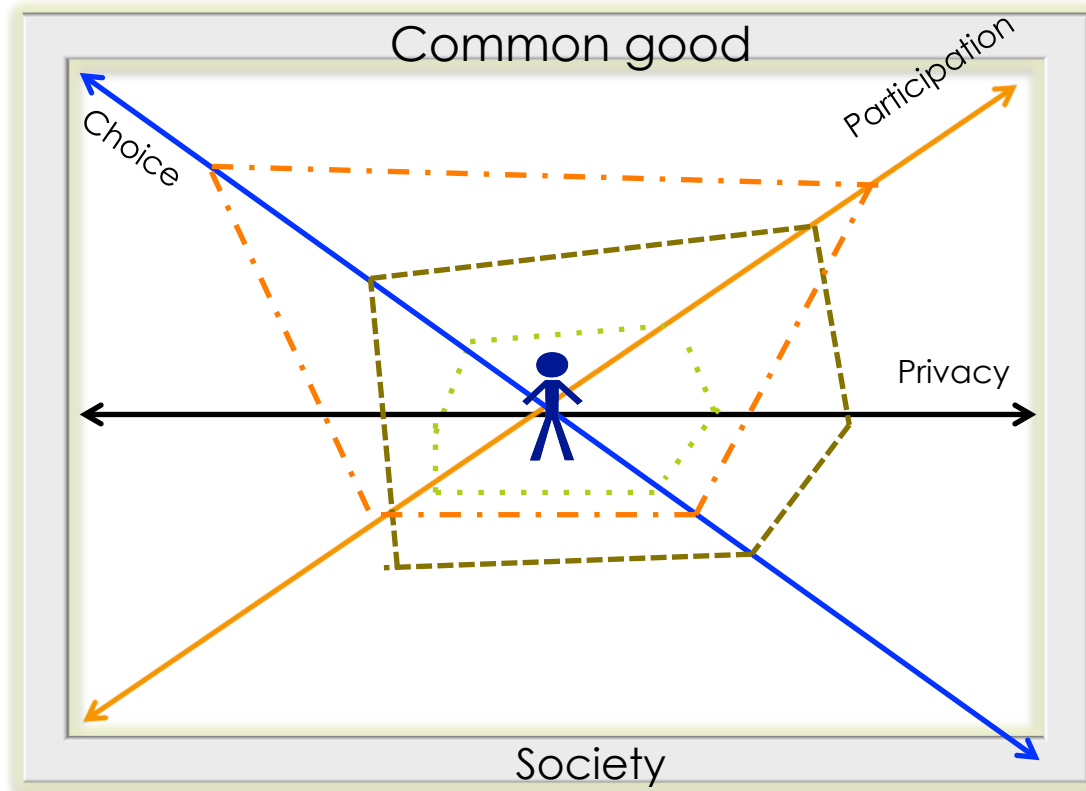


Challenges









Ethical Challenges

- Personal choice
 - How to respect choice?
- Participation
 - How to enable participation?
- Privacy
 - How to protect and respect privacy?

Common good

Uncertainty

Temporality

Ethics and law

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
 - Novel governance models
 - Participation
 - Person-centric
- ◆ (no conversation stoppers)
 - ◆ (one size doesn't fit all)
 - ◆ (bottom-up approaches, long term involvement)
 - ◆ (is good for the common good)