Towards better sharing of data & samples collected during trials in resource-limited countries

Welcome from Inserm ethics committee

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on behalf of Hervé Chneiweiss

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Les Pensières
Our missions

- Impulse ethical awareness among Inserm staff on scientific medical research and health research;

- Anticipate new ethical challenges linked to research in life sciences;

- Contribute to the organization of public debates in emerging areas of biomedical innovation.
Our methods (1)

- Fifteen members appointed for a period of 3 years; diversity according to Gender (9/7), activities (Bio / SHS), institutional origin (Inserm / others), geographical origin (Belgium, Switzerland), 1 rep. patients assoc.;

- Interface with other Inserm bodies concerned with ethical issues: IRB, anim exp office, deontoly office;

- Interface with European research organizations (e.g. EUREC-Net).
Our methods (2)

- Monthly plenary meetings;

- Annual Inserm ethics committee Day
  - Gender in research (2015) R. Rapp, F. Ntoumi, G. Chêne
  - Research & Utopy (2016) M. Rodwin...
Some outcomes (1)

- *Working groups*
  - Human embryo & development
  - Unexpected/incidental research findings
  - Gender & health research
  - Perception of relationship with lab animal by the researcher
  - Ethics and health research in less developed countries
Some outcomes (2)

- Position papers (upon referral)
  - Policy for public research funding provided by non-public game operators
  - Marthe Gautier’s dispute over Down Syndrome discovery
  - Link/conflict of interest in public expertise
  - European Citizen Initiative One Voice (against anim exp)
  - European Citizen Initiative One of Us (against use of hESCs)
  - Use of CRISPER technology
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Why picking these issues?

- No research in human without collection of data and/or samples
- Ethical tensions (e.g. potential exploitation)
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What are we expecting from this workshop?

- Lessons learned from the field
- How to address the specific ethical tensions
- Setting guidances/good practices for stakeholders (researchers, REC members, key community representatives) and policy makers (ministries, reg. agencies)
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How to achieve in one day?

- Expert presentations
- Round table
- Breakout sessions
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A wish!
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But!
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Have a fruitful meeting!

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