



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



**Welcome from  
Inserm ethics committee**

**François Hirsch**

*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, deontology office;**
- ❖ **Interface with European research organizations (e.g. EUREC-Net).**

# Our methods (2)

- ❖ **Monthly plenary meetings;**
  
- ❖ **Annual Inserm ethics committee Day**
  - ✓ **Neuroethics (2014) J. Montgomery, J. Illes, P. Amouyel**
  - ✓ **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!**

[francois.hirsch@inserm.fr](mailto:francois.hirsch@inserm.fr)

