

Brocher Foundation Workshop
'Severity' in the genomic age: Clarification and applications
June 13-15, 2023
Preliminary Programme

Day 1: Tuesday June 13th

9am-10am	Introductions, distribution of name tags documents
10am-10.30am	Opening address: co-applicants
10.30am-10.45am	Coffee Break
10.45am-12.45pm	<p>Panel Discussion: Health Theme</p> <p>Panellists</p> <ol style="list-style-type: none"> 1. Pascal Borry, University of Leuven, Belgium 2. Ruth Horn, University of Oxford, UK 3. Arzoo Ahmed, Newborn Genomes Project, UK <p>Chairs: Anne-Marie Laberge and Bartha Knoppers</p>
12.45pm-1.45pm	Lunch Break
1.45pm- 3.45pm	<p>Panel Discussion: Technologies and Genomic Futures</p> <p>Panellists:</p> <ol style="list-style-type: none"> 1. Samantha Leonard, Natera, France 2. Anna Middleton, Wellcome Genome Campus, UK 3. Lisa Dive, University of Technology, Sydney <p>Chairs: Ainsley Newson, Erika Kleiderman</p>
3.45pm- 4pm	Tea Break
4pm- 5pm	Panel Summaries, Framework Development and Conclusions
5pm-7pm	Informal networking/exploration of local area
7pm-8pm	Evening Meal

Day Two: Wednesday June 14th

9am-9.30am	Recap and Roadmap for day 2
9.30am- 9.45am	Coffee Break
9.45am-11.45am	<p>Panel Discussion: Lived Experience and Society Theme</p> <p>Panellists:</p> <ol style="list-style-type: none"> 1. Lucinda Freeman, University of Technology Sydney, Australia 2. Joel Reynolds, Georgetown University, USA 3. Jackie-Leach Scully, University of New South Wales, Australia <p>Chair: Felicity Boardman</p>
11.45am- 12pm	Summary
12pm-1pm	Lunch break
1pm-3pm	<p>Panel Discussion: Policy</p> <ol style="list-style-type: none"> 1. Edith Gross, Screen4Care, EuroDis, France 2. Mille Stenmarck, Akershus University, Norway 3. Catherine Joynson, Nuffield Council on Bioethics, UK <p>Chair: Vardit Ravitsky</p>
3pm-3.15pm	Tea Break
3.15pm-4.15pm	Panel Summaries, Framework Development and Conclusions
4.15pm- 7pm	Informal networking/exploration of local area
7pm-8pm	Evening Meal

Day Three: Thursday June 15th

9am-9.30am	Recap and Roadmap for day 3
9.30am-11.30am	<p>Framework Development</p> <p>All: Structured discussion drawing on previous panel themes</p> <p>Chairs: Felicity Boardman and Erika Kleiderman</p>
11.30am-11.45am	Coffee Break
11.45am-1pm	Summaries, Framework Finalisation and Conclusions
1pm-2pm	Lunch and Departure

Panel Questions

Health

- a. What do we mean by 'severity'/'serious' in health contexts? Are these distinct concepts?
- b. How has the concept been used in the domain of genomic health – reproduction (PGD, abortion, carrier screening, prenatal testing, newborn screening) v. treatment (gene therapy, somatic genome editing)?
- c. How has severity been measured/accounted for to inform clinical practice? (binning systems, expert panels, professional guidance, frameworks?)

Technologies and Genomic Futures

- a. Do understandings of severity vary across technological applications (draw on health theme)? (Newborn, carrier, prenatal, genome editing)
- b. How can measures/understandings of severity be future-proofed (i.e. responsive to constant changes in environment, treatments, social context, severity as evolving concept) (draw on all themes)?
- c. What role (if any) should contemporary understandings of severity have in determining the future directions of genomic medicine? (HGGE, novel gene therapies etc.)

Lived Experience and Society

- a. How has severity been understood through the prism of lived experience?
- b. What factors (distinct from clinical impacts) are important in mediating experiences of severity, e.g. social/environmental/economic etc.?
- c. How/do clinical accounts of severity (bringing in work from previous health theme) differ from experiential understandings?
- d. Whose perspective on severity matters?

Policy

- a. How should competing claims to expertise on severity be sorted through/weighted?
- b. Does severity have different meanings in a policy context than it does in clinical practice?
- c. What is the relationship of severity to mechanisms of funding at a policy level?
- d. Do systems used to measure/account for severity in clinical practice translate to policy contexts?

Framework Development

- a. What factors need to be taken into account when operationalising the notion of severity?
- b. How well are these captured within existing classification/taxonomy systems?
- c. How might a framework approach capture the complexity of factors that influence severity?
- d. Are different frameworks need across policy/practice contexts?