



Epidemiology Workshop Summary

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OVERARCHING CONCEPTS

In the epidemiology workshop, participants identified six overarching concepts that should guide DOCTRID's research agenda in epidemiology. These overarching concepts are:

- The need to have a multi-disciplinary approach to research types of study
- Choose the study design best suited to the problem being addressed
- Have an awareness of the ethical issues involved in disability research
- Maintain communication with the public
- Training younger researchers is important
- Disability research requires a life span perspective

FIVE RESEARCH AREAS

Participants identified important research topics and this conversation generated over forty research ideas. They then analyzed the ideas and grouped them into five thematic areas. To facilitate collaboration, the group also identified DOCTRID team members interested in each thematic area. The five thematic areas, research topics, and team members are:

1. Clarification of the nature of the entities/phenotypes being studied

- a. Manifestational vs etiological diagnoses
- b. Studying traits across the spectrum of developmental disabilities

Working Group: Jodene Fine, MSU¹; Geraldine Leader, NUIG; Marisa Fisher, MSU; Lauren Beyer O'Connell; Kate Woodcock, QUB; Gràinne McLoughlin, KCL

2. Early detection

- a. Early identification of the clinical syndrome or disability
- b. Early biomarkers including genetic that predict the disability

Working Group: Gràinne McLoughlin, KCL; Jodene Fine, MSU; Keith English MSU

3. Searching for risk factors

- a. Nutritional
- b. Environmental
- c. Medical conditions in pregnancy
- d. Infections
- e. Socioeconomic
- f. Chemical toxins
- g. Genetics

Working Group: Jean Kerver, MSU; Lauren Beyer O'Connell, Nigel Paneth, MSU; Eda Yesilkaya, QUB; Bernard Dan, ULB

4. Secondary prevention of adverse outcomes after diagnosis of the disability

- a. Anxiety
- b. Mental health
- c. Challenging behavior
- d. Other health conditions in adulthood life span health conditions
- e. Using technology for prevention
- f. Medications and consequences

Working group: Niamh Mulryan, DOC; Geraldine Leader, NUIG; Kate Woodcock, QUB; Laura Collins; Lauren Beyer O’Connell; Marisa Fisher, MSU; Nigel Paneth, MSU; June Chen, NUIG/MSU

5. Attitudes and bioethical issues

- a. Relationship of research to the public
- b. Resistance against cultural eradication e.g. as in deaf culture
- c. Avoiding blaming mothers

Working group: Stacy Clifford Simpican, MSU/Vanderbilt; Laura Collins; Michael Gerald, UI; Lauren Beyer O’Connell; Geraldine Leader, NUIG; John Kosiulek, MSU; June Chen, NUIG/MSU

FUTURE FUNDING POSSIBILITIES

One next action step is to identify funding possibilities that are relevant to the five thematic areas. Potential funding opportunities include:

- EU Marie Curie ASSISTID Postdoctoral Fellows
- Hegarty Fellows
- RAIND MSU
- Horizon 2020 for 2016 calls
- NIH – especially NICHD, NINDS, NIMH, NIEHS
- Department of Defense
- Spencer Foundation
- Thrasher Foundation
- NCHB
- Simons Foundation
- Autism Speaks
- CP International
- Internal seed money from participating Irish & US universities
- Maternal and Child Health Branch of US DHSS

ⁱ University Abbreviations: MSU – Michigan State University; ULB - Université libre de Bruxelles; KCL – King’s College London; NUIG – National University of Galway, Ireland; DOC – Daughters of Charity Services Dublin; UI – University of Iowa; QUB – Queen’s University Belfast