# Ethical Issues in Collaborative Research

Eva Maria Cutiongco-de la Paz, MD, FPPS Executive Director, National Institutes of Health Vice Chancellor for Research, UP Manila

#### Outline

- I. Collaborative research defined
- II. Enhancing research collaborations
- III. Ethical issues in collaborative research
- IV. Summary

### Genetic Research in Developing Countries

#### "Postal Research"

 Developing countries courier biological materials to the west

#### "Parachute Research"

 Western researchers travel to developing countries to collect biological samples



#### Collaborative Research

- Collaborative research can be defined as researchers working together to achieve the common goal of producing new scientific knowledge
- It is an umbrella term for methodologies that actively engage researchers, communities and policy makers in the research process from start to finish.

### Why do people collaborative?

- Science has been increasingly dependent on collaborations.
- No single person has the skills, knowledge, and resources to address all research problems.
- Research has been significantly configured by the idea that researchers should work in collaboration, rather than in isolation.
- Global health research collaborations have the potential to play a significant role in addressing global health disparities

## What drives the increasingly collaborative nature of research?

- 1. The push from funding agencies to do research within and across disciplines and industry.
- 2. The need for complementary skills in research.
- 3. The availability of ICTs that support communication process.
- 4. Technology transfer from academia to industry has provided incentives.
- 5. The evidence that collaborations improve progress.

### What researchers look for in collaborations

- Active involvement in cutting-edge, interesting science
- Effective Leadership
- Competence in and commitment to good scientific practice
- Capacity building
- Respect for the needs, interests and agendas of all partners
- Opportunities for discussion and disagreement
- Trust and confidence
- Justice and fairness in collaboration

# Enhancing Research Collaborations

### Preempting Discord: Prenuptial Agreements for Scientists

"Nothing should be taken for granted when researchers decide to collaborate."

**Howard Gadlin** 



# Six Key Components of Successful Collaborations

Macrina, F. Scientific Integrity: An Introductory Text Second Edition. American Society for Microbiology Press. 2000.

# #1 Communicate first, second and throughout

# #2 Discuss in advance who will do what in a project, while understanding that the research may evolve

### #3 Discuss authorship in advance

## #4 Discuss data and material management in advance

## #5 Discussing intellectual property issues in advance

### #6 Manage Accountability

# Ethical Issues in Collaborations

### Authorship

- It has been recognized that collaborative partnership initiatives have shown promise and attracted growing interest
- However, there has been little attention given to fair distribution of authorship credit within these partnerships
- Several reports show that unethical authorship occurs in more than 10% of cases
- Zachariah et al. describes difficulties associated with distributing authorship in re- search teams conducting operational research in low and middle-income countries
- Guidelines on authorship often excludes recognition of important actors who have made essential contributions to research in LMICs

### Authorship

- 1. Authorship guidance not adequately applying to global health research because it requires authors to write or substantially revise the manuscript.
- 2. Current guidance on authorship order does not address or mitigate unfair practices which can occur in global health research due to power differences between researchers from high and low-middle income countries.
- 3. The potential for real or perceived editorial bias in medical science journals in favor of prominent western researchers, and the risk of promoting misplaced credit and/or prestige authorship.
- 4. Diverse cultural practices and expectations regarding authorship may create conflict between researchers from low-middle and high income countries and contribute to unethical authorship practices.

### Addressing Issues on Authorship

- 1. Undertake further empirical and conceptual research regarding authorship in global health research;
- 2. Raise awareness on authorship issues in global health research; and
- 3. Develop specific standards of practice that reflect relevant considerations of authorship in global health research.

### **Ethical Data Sharing**

- Value of data sharing
- Minimizing harm
- Promoting fairness and reciprocity
- Trust

### Value of Data Sharing

- Attitude were typically more cautious
- Support for data sharing often grew as researchers became familiar with the concepts involved, the potential advantages of sharing, and safeguards that could be implemented to address concerns.

### Minimizing Harm

- De-identification of data was not necessarily considered sufficient in itself to minimize the risk of harm.
- Risks of harm were associated both with the sensitivity of the data sets collected and with the uses that could be made of the data.
- There was also concern about secondary research with deidentified data contributing to the stigmatization of identifiable communities, populations, and even countries.

### Promoting Fairness and Reciprocity

• The importance of ensuring that data-sharing practices did not increase existing inequalities was considered fundamental - the need for data sharing to be ethical and equitable.

#### **Trust**

- The importance to researchers, communities and the wider public of ensuring that data were shared in both a trusted and trustworthy manner
- Data sets, primary researchers, secondary data users, and data-sharing policies and processes all needed to be trusted for effective and ethical data sharing
- Researchers highlighted the need for data-sharing policies and processes that would permit them to fulfill their obligations to research participants.

### Ethical Data Sharing: Ways Forward

- 1. Seeking consent to data sharing
- 2. Governing data sharing
- 3. Data sharing policies
- 4. Capacity building

### Summary

- Collaborative research allows researchers to work together to achieve the common goal of producing new scientific knowledge
- There are key factors that can lead to successful collaborations that should be discussed way before the collaboration starts.
- Challenges posed by collaborative research can be overcome by formulating guidelines, processes and policies that address ethical issues.
- Successful international collaborations are possible within the framework of guidelines.