

Ethical implications of the use of Longitudinal Studies

Iara Coelho Zito Guerriero, PhD
Chair of the working group on Social Science and
Humanities/ National Commission on Research
Ethics (CONEP)

This presentation:

- Research and its applications in social policies: an ethical issue
- Ethical aspects in longitudinal studies

Research and its applications in social policies: an ethical issue

Commitment

Benefits return to the population who agree to participate in research, and sometimes to the research participants themselves.

How to translate research results
in public policies?

- Academic publication: the least important to inform policy makers
- Books: used widely used by undergraduate and graduate students. Research can be lived on when they graduate and have a job.
- Technical reports can be useful, specially if available on line
- Professional meetings

Strategies

- Identification of what's important to each specific audience
- Use appropriate language to present research results to different audiences
- Definition of the best way to communicate to each audience: meetings, online meetings, reports etc.

Knowledge Translation - Definition

Knowledge Translation (KT) is defined as a dynamic and interactive process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.

This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user (CIHR).

(CIHR available at: <http://www.cihr-irsc.gc.ca/e/29418.html>)

Ethically-sound application of knowledge

Ethically-sound KT activities for improved health are those that are consistent with ethical principles and norms, social values, as well as legal and other regulatory frameworks – while keeping in mind that principles, values and laws can compete among and between each other at any given point in time. The term application is used to refer to the interactive process by which knowledge is put into practice.

Ethical aspects in longitudinal studies

Right to participate

- A broad dissemination to ensure the right to participate of potentially eligible individuals.
- It is fundamental to clearly explain the eligibility criteria and the exclusion criteria (if applicable).

Volunteers

Ensure that only those who received proper information and decided to participate in the study are going to be included. For example: never ask bosses to indicate employees to participate in the study.

Secondary use of data

- Data produced in a context of health assistance, for example, or any other than research
- Is it ethical to use them for other purposes (ex. research), different from the one in which people shared their data?

Secondary use of data

- Justify the relevance of the study
- Protect confidentiality of individuals and groups
- The protocol must be approved by a Research Ethics Committee

Confidentiality

The guarantee of data confidentiality is a crucial aspect of protection of research subjects due to the risk that third parties access personal information and the consequent possibility of stigmatization and social or economic losses. Ensuring confidentiality is essential in longitudinal studies because it can include a very large number of participants, the research team can be large and it can produce a huge amount of data of a private nature. (Aquino et al, 2013)

Confidentiality

Special care is needed to avoid the research team to have direct access to private information from colleagues, neighbors etc.

Confidentiality

Only a restricted group of researchers (coordinators, supervisors) has access to the data obtained in confidence, specially if this data is linked to personal information, allowing identification.

Confidentiality

The team members are not allowed to make any comments about the interviews' content with people in the community, because they know each other. It can only be discussed with the field supervision to clarify doubts (Aquino e col, 2013).

Confidentiality

The data system of Brazilian Longitudinal Study for Adult Health (ELSA-Brasil) includes routines that aim to preserve data secrecy and security and guarantee information integrity. The system has the following features:

- use of a safe connection (HTTPS),
- access to the system is restricted to registered users with passwords,
- specific profiles of access according to distinct functionalities,

- use register system, and
- timeout after a period without interaction.

The participants' personal identifiers are stored separately from the system's other data (Aquino e col, 2013).

Confidentiality

The identification numbers on the bases distributed to the researchers are different from those used in data collection (Aquino e col, 2013).

Confidentiality

Data security and confidentiality is a great challenge in studies that produce data continually, in which the inclusion of individual identifiers, such as name and address, is indispensable to follow up them.

Ethics as a process

Both data production and analysis have a continuous nature, and some future analyses cannot be anticipated. The genuine challenge would concentrate, therefore, on the understanding that each peculiar situation that emerges requires the identification of new questions to debate. Therefore, ethical sensitivity is needed to identify and answer them with the most informed interventions (Aquino e col, 2013).

The right to refuse

Changes can occur in the participants' motivation concerning both a definitive and a temporary abandonment of the research, which poses the question: to what extent can researchers insist in the invitation to participation without harming the right to refuse (which sometimes is not expressed in an explicit way)? (Aquino e col, 2013)

Research Ethics Committee doesn't allow to follow up those who have expressed do not have interest in continuing in the study (Tinker e col, 2009).

Brazilian guidelines on research ethics

Resolutions approved by National Health Council:

http://conselho.saude.gov.br/web_comissoes/conep/aquivos/resolucoes/resolucoes.htm

References

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Thank you for your attention!

iara.guerriero1@gmail.com