Research ethics

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International codes for research ethics

- Declaration of Helsinki (World medical Assembly 1964 – 2008)
- WHO Guidelines for Biomedical Research involving Human Subjects (CIUMS, 1993)
- Guidelines for Good Epidemiological practise (IEA, 2003)



Basic ethical principles

- Principle of autonomy
 - Openness
 - Self-decision
 - Informed consent
- Principle of beneficence
 - Maximize benefits
 - Minimize the risks
 - For general population and for individuals
- Principle of no harm
 - Prevent all possible harm for participants
 - Confidentiality
- Principle of justice
 - Treat all human beings equally (unless strong
 Datum ethical justification for treating them differently)



Informed consent

 "Enough" information about the study to make a voluntary decisions to participate or not

– How much is enough?

- Right to withdraw at any stage in the study
- Written or verbal consent?



Confidentiality

- Report data in such a way that respondents could not be identified
 - Eliminating/disguising identifying information
 - How to handle with high level actors?
 - Discuss possible consequences of problems with confidentiality

• Data handling

- Transcripts safely stored
- Only accessible by involved researchers
- Avoid use of real names etc. in transcripts



Ethical considerations in qualitative research

- Beneficial consequences of the study?
 - Will the study improve human conditions?
 - What are the potential benefits for the participants?
 - Benefits for the group? For general knowledge?
- Informed consent?
 - Obtained orally or in written?
 - Obtained by subjects or their superiors?
 - How much information and when?
- Confidentiality?
 - What can we promise?
 - How can identities be disguised?
 - Any legal problems?

Dahlgren, L., Emmelin, M. & Winkvist, A. (2007). *Qualitative methodology for international public health.* Umeå: Umeå University. 6



Ethical considerations in qualitative research, cont

- Consequences?
 - Potential harm?
 - Balance between harm and beneficence?
 - Consequences of publishing, for subjects and for groups?
- Researchers role?
 - How will quality be ensured?
 - How will researcher avoid "going native"?

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Discussion

- Ethical considerations for
 - INTREC as a whole?
 - WP1?
 - Literature- epidemiological and curricula reviews?
 - Interviews with decision maker and other stakeholders?