### **Research ethics**

Malin Eriksson PHD, Senior lecturer Epidemiology and Global Health Umeå University, Sweden Malin.eriksson@epiph.umu.se ISS Training Workshop: Gadjah Mada University Yogyakarta, Indonesia, February 20-24, 2012



## 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"?

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



#### Discussion

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