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- Have a look at these website:
 - At UC http://www.canberra.edu.au/ucresearch
 - http://www.canberra.edu.au/ucresearch/ethics/human-ethics-manual
- It is very important to read all of the National Statement on Ethical Conduct in Human Research (2007 updated 2009)
 - http://www.nhmrc.gov.au/book/national-statementuser-guide-0
- You can look at the application form you will fill in and submit to the ethics committee here. You can register and have a practice
 - https://www.neaf.gov.au/default.aspx

- Why Ethics?
 - Identify good conduct
 - Protect welfare & rights of research participants
 - Ensure research benefits humanity
 - Build trust in research community

- History
 - Nuremburg trials after World War II
 - Widespread medical experimentation on humans in Nazi concentration camps
 - 1964 Declaration of Helsinki
 - · Set standards for medical research
 - Extended to behavioural & social research
 - Implemented by ethics committees

- Some basic ethical principles
 - Integrity/honesty of researchers
 - Commitment to contribute to knowledge
 - Commitment to use appropriate methods
 - Commitment to promote common good & avoid harm

- Some basic ethical principles
 - Respect for persons
 - Recognise, inherent dignity & rights of persons
 - autonomy
 - Special protection due to persons of diminished autonomy eg minors/marginalised

- ethical principles
 - Respect for community
 - Consider individual rights in context of community constraints
 - Weigh value to community with value to individuals
 - Avoid harm to communities
 - Eg Newcastle mining community health study

- ethical principles
 - Beneficence
 - · Maximize benefit minimize harm
 - Justice
 - · Distribution of costs & benefits
 - · Exclusion/inclusion of participant categories
 - Value
 - · Quality of methods
 - · Skill of researchers
 - Successful outcomes
 - merit

- ethical principles
 - Respect for law
 - Violence to persons
 - Privacy
 - Intellectual property
 - Consumer protection

- Ethics apply to all research involving humans where
 - Use of/collection of personal or collective data
 - Oral or observed testimony
 - $^{\circ}$ Testing of interventions
 - Informed cooperation in documenting local knowledge
 - Identification of individuals occurs at any stage

- Ethics involves balancing
 - · Harm vs good to individual
 - $^{\circ}$ Value to community vs welfare of individuals
 - Principle of privacy use of data for purpose it was given - vs. public interest

- Ethics in practice
 - CONSENT
 - Clearly establish <u>informed</u> & <u>voluntary</u> consent of each participant
 - Consent form
 - · Returned survey
 - Recorded agreement for interview
 - No deception

- Consent
 - · organisations & individuals
 - Take care of undue coercion/influence
 - Difficult in care/dependency settings take extra care in hospitals, workplaces
 - Freedom to withdraw consent

- Consent
 - · Use of data only for purpose for which it is given
 - De-identified data?
 - You do <u>not</u> need consent
 - · Observation in public places
 - Anonymous surveys

- Privacy & confidentiality
 - ∘ Freedom from intrusion & surveillance
 - · Report using aggregates or pseudonyms
 - · Not always possible
 - Respect personal information
 - Natural Justice
 - · 'right of reply'

Equity

- All people have an equal right to benefit from research & the advancement of knowledge.
 - $^{\circ}$ Sex disaggregated data
 - Intersecting analysis

Equity

- What identities are relevant to research context:
 - Woman/man
 - Gender intersects with
 - Race/ethnicity
 - · Income/occupation
 - · Caste/status
 - Experience of educated urban middleclass women different from uneducated poor hill-tribe woman
 - Enables targeting of resources to areas of need

Equity: use a research framework that allows differences between groups to surface. Beware averages, beware people speaking FOR others. eg Gender **Analysis Framework:** Issues **Enquiry** Roles/responsibilities Production (paid,self-employed, subsistence) What do men & women do? Reproductive (domestic, child-care, care ill/old) Where? (mobility Patterns) Community (voluntary work of benefit to community, participation in decision-making) When? (seasonal patterns) Assets Assets - men and women Livelihood assets/opportunities for Human (health, education, skills) men/women? Natural (land, labour, plants, water) Constraints faced by men/ women? Social (social networks, local radio, local gov) Physical assets (ICTs, transportation, clinic) Financial assets (income, capital, credit) Power & decisions Household level What decision-making do men/women Community level do control/participate in/? Needs Priorities & Perspectives What are women's/men's/children's practical needs? (eg closer water point) For men/for women What are women's/men's/adolescent's perspectives on choices, operation, management, Adapted from Institute of Development Studies UK maintenance

Equity

- Build in active accountability to communities likely to be impacted by policy changes
- Include members of target groups/people affected on research reference group
- Who is the research for?
 - · Check are we getting it right?
 - Don't expect one voice
 - Look for common interests