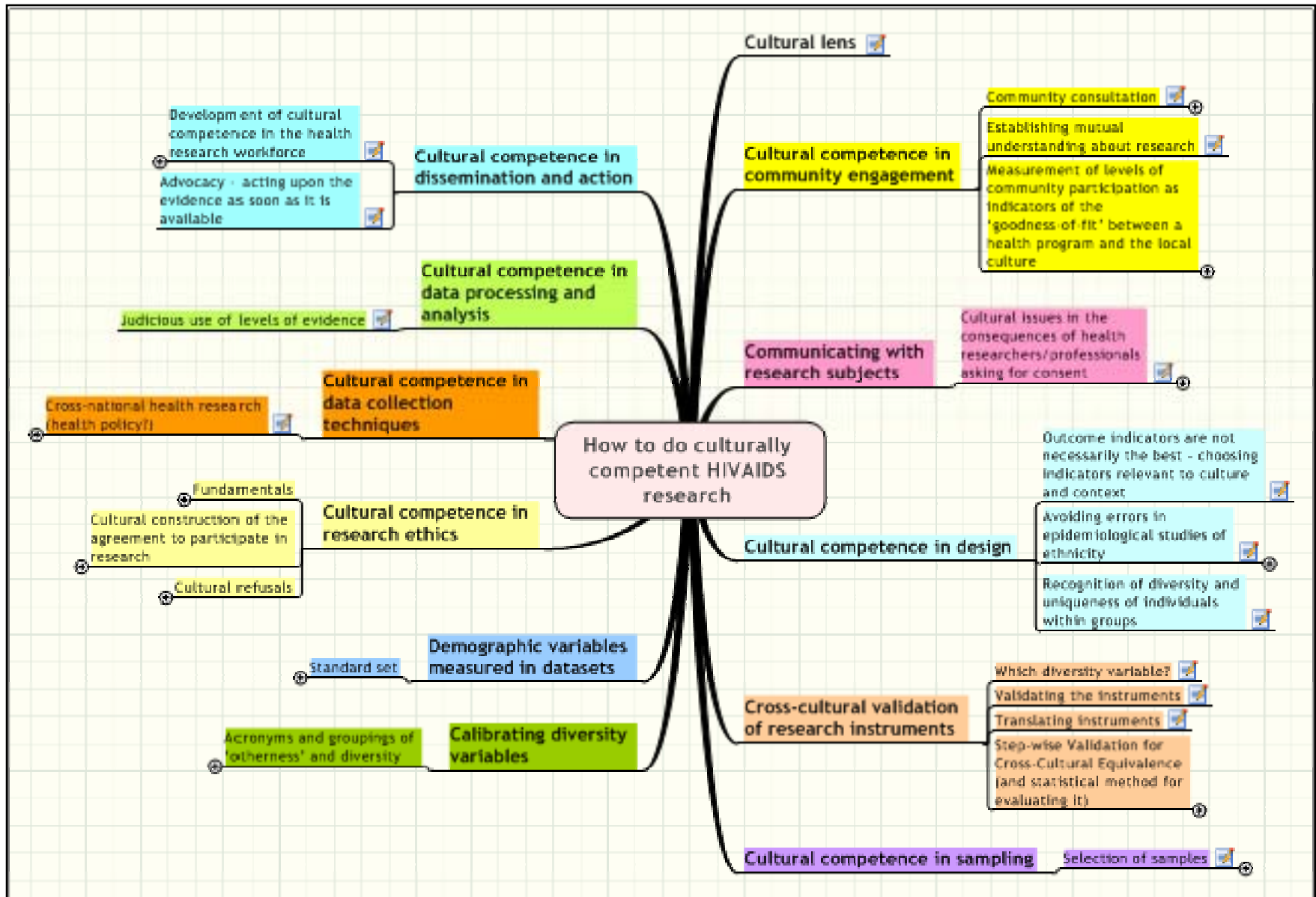


How to do culturally competent HIV/AIDS research





Cultural competence in community engagement

Cultural competence in community engagement

Community consultation 

Ongoing reciprocal and respectful dialogue among scientists, prospective participants, their families, and other community stakeholders

Require researchers establish relationship with community long before study commenced 

Establishing mutual understanding about research 

Measurement of levels of community participation as indicators of the 'goodness-of-fit' between a health program and the local culture

Dimensions 

Require researchers establish relationship with community long before study commenced

Require researchers establish relationship with community long before study commenced

This relationship can inform study's goals and aims and engage community members as true collaborators.

Consultation is not means of obtaining blind acceptance of an already worked-out protocol.



This relationship can inform study's goals and aims and engage community members as true collaborators.

This relationship can inform study's goals and aims and engage community members as true collaborators.

Consultation is not means of obtaining blind acceptance of an already worked-out protocol.

Depends on relationships of trust established early in research design phase and continued through data interpretation, implementation, and dissemination phases

Measurement of levels of community participation as indicators of the 'goodness-of-fit' between a health program and the local culture

Measurement of levels of community participation as indicators of the 'goodness-of-fit' between a health program and the local culture

Dimensions

1. needs assessment
2. leadership
3. organisation
4. resource mobilisation
5. management

Communicating with research subjects

Communicating with research subjects

Cultural issues in the consequences of health researchers/professionals asking for consent



The very act of asking for consent may, for cultural reasons, place potential participants in a shaming, embarrassing or otherwise difficult situation. Complicated where differences in understanding and expectations around the role of health professional and patient, and request for consent may be interpreted as disorienting or else difficult to refuse.

Cultural issues in the consequences of health researchers/professionals asking for consent

Cultural issues in the consequences of health researchers/professionals asking for consent



The very act of asking for consent may, for cultural reasons, place potential participants in a shaming, embarrassing or otherwise difficult situation. Complicated where differences in understanding and expectations around the role of health professional and patient, and request for consent may be interpreted as disorienting or else difficult to refuse.

Must be in language understood and preferred by prospective participants and their guardian or guardians



The very act of asking for consent may, for cultural reasons, place potential participants in a shaming, embarrassing or otherwise difficult situation. Complicated where differences in understanding and expectations around the role of health professional and patient, and request for consent may be interpreted as disorienting or else difficult to refuse.

Must be in language understood and preferred by prospective participants and their guardian or guardians

Children and adolescents may have different language competencies and preferences than adult members of their families.

Consent forms translated using procedures that ensure equivalency

Cultural competence in design

Cultural competence in design

Outcome indicators are not necessarily the best - choosing indicators relevant to culture and context



Avoiding errors in epidemiological studies of ethnicity



Errors in cultural epidemiological studies



Recognition of diversity and uniqueness of individuals within groups



Avoiding errors in epidemiological studies of ethnicity

Avoiding errors in epidemiological studies of ethnicity



Errors in cultural epidemiological studies



Inventing ethnic groups



Not comparing like with like

Lumping groups together

Not adjusting for confounding factors

Errors in cultural epidemiological studies

Errors in cultural epidemiological studies



Inventing ethnic groups

A study labelled a group as Urdu on the basis of the language spoken, thus inventing an ethnic group

Not comparing like with like

Lumping groups together

Not adjusting for confounding factors

Cross-cultural validation of research instruments

Cross-cultural validation of research instruments

Which diversity variable? 

Validating the instruments 


Translating instruments 

Step-wise Validation for Cross-Cultural Equivalence (and statistical method for evaluating it)

Content Equivalence 

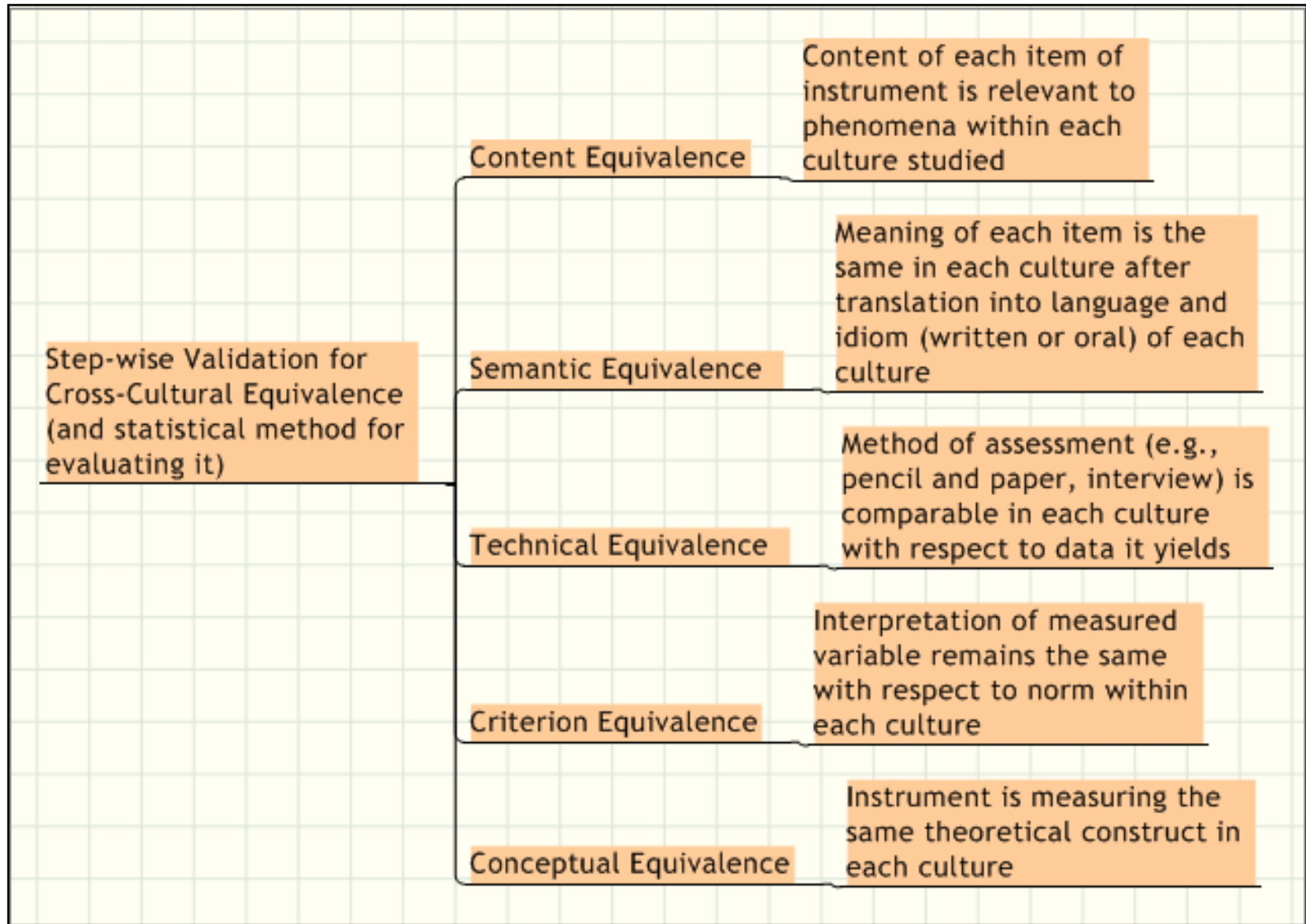
Semantic Equivalence 

Technical Equivalence 

Criterion Equivalence 

Conceptual Equivalence 

Step-wise Validation for Cross-Cultural Equivalence (and statistical method for evaluating it)



Cultural competence in sampling

Cultural competence in sampling

Selection of samples 

Sample bias 



The case of clinical trials 

Selection of samples

Selection of samples 

Sample bias 

Culture/ethnicity as inappropriately studied - the wrong variable

Culture/ethnicity as understudied - the missing variable

The case of clinical trials 

Calibrating diversity variables

Non-English Speaking
Background (NESB)



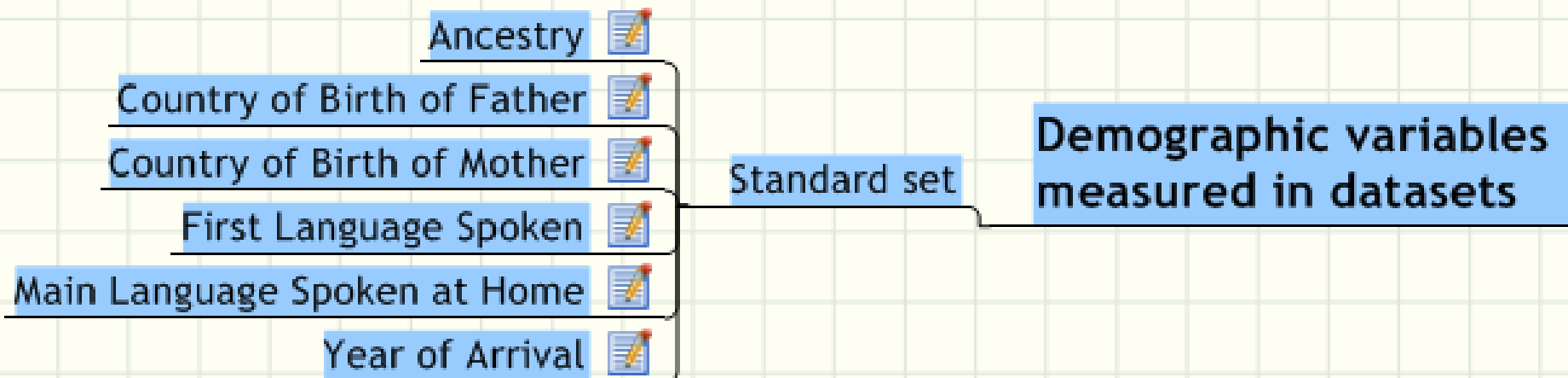
Culturally and Linguistically
Diverse (CALDB)



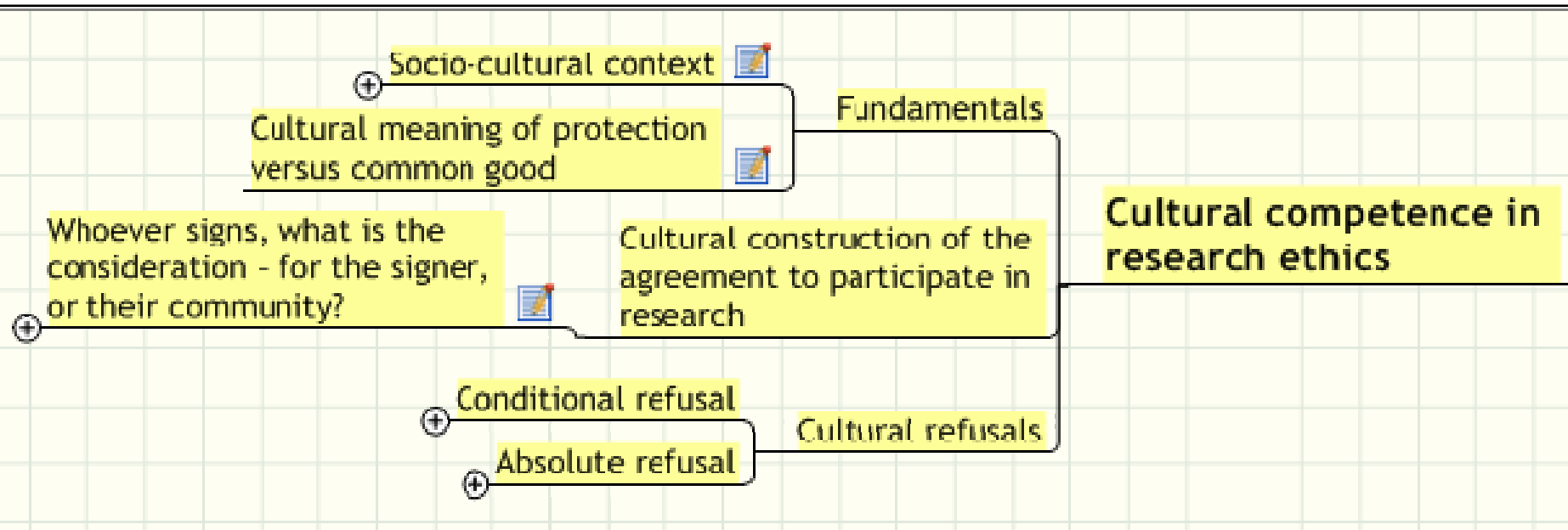
Acronyms and groupings of
'otherness' and diversity

Calibrating diversity
variables

Demographic variables measured in datasets



Cultural competence in research ethics



Fundamentals

Is there a universal research ethical ethics?



Socio-cultural context



Fundamentals

Cultural meaning of protection versus common good



Socio-cultural context

Christakis (1992) posits whether, instead, an empirically based approach based on examining systems of medical ethics cross-culturally might identify universal principles. Based on his examination of Asian systems of medical ethics, believes it is unlikely to derive common principles. Medical ethics might, on one perspective, be viewed as 'local knowledge'

Is there a universal research ethical ethics?

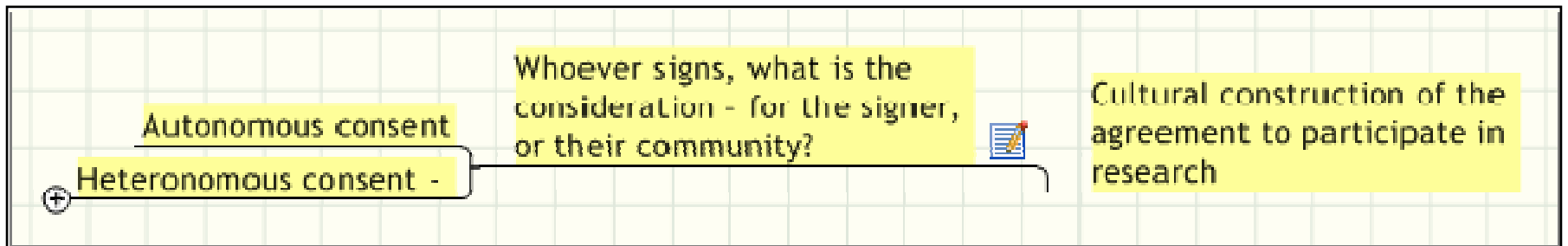
Socio-cultural context 

Cultural meaning of protection versus common good

Cultural meaning of protection versus common good




Cultural construction of the agreement to participate in research



Whoever signs, what is the consideration - for the signer, or their community?

⊕ Cultures that place emphasis on the role of family in making collective decisions about the best courses of action for the individuals therein

Autonomous consent

Whoever signs, what is the consideration - for the signer, or their community? 

Heteronomous consent -

Heteronomous consent -

e.g. Parker and Barrett recruited Iban from Borneo to take part in research who attached little significance to immediate risks posed to individuals involved but were greatly concerned by what they saw as unpredictable longer term danger posed to group as a whole

Cultures that place emphasis on the role of family in making collective decisions about the best courses of action for the individuals therein

Heteronomous consent -

Cultural refusals

e.g. Jehovah's Witness who considers any study involving blood transfusion as unethical only insofar as Jehovah's Witnesses might be taking part. Conditional refusals might refer to the 'topic' of the study (the procedure involved) or the design itself (e.g. a randomized control trial might be interpreted as gambling, a practice frowned on for followers of some religious codes).

Conditional refusal

Cultural refusals

From religious perspective that holds given procedure to be contrary to natural or divine law and therefore unethical for anyone to be involved with, regardless of their religious or cultural

Absolute refusal

Conditional refusal

Moral difference -
Participant's decision not to
take part in given study

e.g . Jehovah's Witness who considers any study involving blood transfusion as unethical only insofar as Jehovah's Witnesses might be taking part. Conditional refusals might refer to the 'topic' of the study (the procedure involved) or the design itself (e.g. a randomized control trial might be interpreted as gambling, a practice frowned on for followers of some religious codes).

Conditional refusal

Absolute refusal

Moral difference - Questions ethics of study taking place at all

From religious perspective that holds given procedure to be contrary to natural or divine law and therefore unethical for anyone to be involved with, regardless of their religious or cultural

Absolute refusal

Cultural competence in data collection techniques

Summary Measures of Population Health (SMPH) need to be compatible across nations and cultures to serve as comparable measures for global health policy making

Cross-national health research (health policy?)

Cultural competence in data collection techniques

Cross-national health research (health policy?)

To serve as inputs for global SMPH, for reasons of comparison and policy relevance, these instruments need to be cross-culturally relevant and sensitive to measuring comparable constructs across cultures

Summary Measures of Population Health (SMPH) need to be compatible across nations and cultures to serve as comparable measures for global health policy making

Cross-national health research (health policy?)



Cultural competence in data processing and analysis

Judicious use of levels of evidence



Cultural competence in data processing and analysis

Cultural competence in dissemination and action

Investigators must provide all members of research team with training in cultural competencies necessary to conduct research in order to ensure the highest quality of data collection

Principal investigators should encourage staff to provide ongoing feedback about participants' responses to recruitment practices, experimental procedures, instruments, and all aspects of the research

Development of cultural competence in the health research workforce



Cultural competence in dissemination and action

Advocacy - acting upon the evidence as soon as it is available



Development of cultural competence in the health research workforce

Feedback will allow investigators to evaluate effectiveness of procedures and need for culturally appropriate methodological adjustments

Investigators must provide all members of research team with training in cultural competencies necessary to conduct research in order to ensure the highest quality of data collection

Principal investigators should encourage staff to provide ongoing feedback about participants' responses to recruitment practices, experimental procedures, instruments, and all aspects of the research

Development of cultural competence in the health research workforce

