How to do culturally competent HIVAIDS research

- Cultural competence in community engagement
- Communicating with research subjects
- Cultural competence in data processing and analysis
- Cultural competence in dissemination and action
- Cultural competence in research ethics
- Cross-cultural validation of research instruments
- Cultural competence in sampling
- Demographic variables measured in datasets
- Cross-national health research (health policy)
- Cultural referrals
- Cultural construction of the agreement to participate in research
- Advocacy - acting upon the evidence as soon as it is available
- Development of cultural competence in the health research workforce
- Judicious use of levels of evidence
- How to do culturally competent HIVAIDS research

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

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

Avoiding errors in epidemiological studies of ethnicity

Recognition of diversity and uniqueness of individuals within groups

Which diversity variable?

Validating the Instruments

Translating Instruments

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

Selection of samples

Acronyms and groupings of ‘otherness’ and diversity

Calibrating diversity variables

Standard set

UNESCO Expert Consultation 'Promoting standards for socio-cultural research on the issues of HIV/AIDS and trafficking', Bangkok, September 19-21 2005
Cultural competence in community engagement
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.

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
Communicating with research subjects

The very act of asking for consent may, for cultural reasons, place potential participants in a shaming, embarrassing or otherwise difficult situation. Complicated here 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

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

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

Avoiding errors in epidemiological studies of ethnicity.

Recognition of diversity and uniqueness of individuals within groups.

Errors in cultural epidemiological studies.
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

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

- Content Equivalence: Content of each item of instrument is relevant to phenomena within each culture studied.
- Semantic Equivalence: Meaning of each item is the same in each culture after translation into language and idiom (written or oral) of each culture.
- Technical Equivalence: Method of assessment (e.g., pencil and paper, interview) is comparable in each culture with respect to data it yields.
- Criterion Equivalence: Interpretation of measured variable remains the same with respect to norm within each culture.
- Conceptual Equivalence: Instrument is measuring the same theoretical construct in each culture.
Cultural competence in sampling
Selection of samples

Culture/ethnicity as inappropriately studied - the wrong variable

Culture/ethnicity as understudied - the missing variable

The case of clinical trials
Calibrating diversity variables
Demographic variables measured in datasets

- Ancestry
- Country of Birth of Father
- Country of Birth of Mother
- First Language Spoken
- Main Language Spoken at Home
- Year of Arrival

Standard set
Cultural competence in research ethics
Fundamentals

Is there a universal research ethical ethics?

Socio-cultural context

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?
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?

Cultural construction of the agreement to participate in research

Autonomous consent

Heteronomous consent -
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

Heteronomous consent -

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

- Cultural refusals
  - Conditional refusal
    - 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 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

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

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Absolute refusal

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 ethics of study taking place at all.

Moral difference - Questions
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.
Cultural competence in data processing and analysis

Judicious use of levels of evidence
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.

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

Cultural competence in dissemination and action.
Development of cultural competence in the health research workforce

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

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

Development of cultural competence in the health research workforce.