

The International Community of Women living with HIV/AIDS

Guidelines on ethical participatory research with HIV positive women.

July 2004

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These guidelines have been adapted from those developed by the Royal Society of Canada regarding participatory research.

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Background

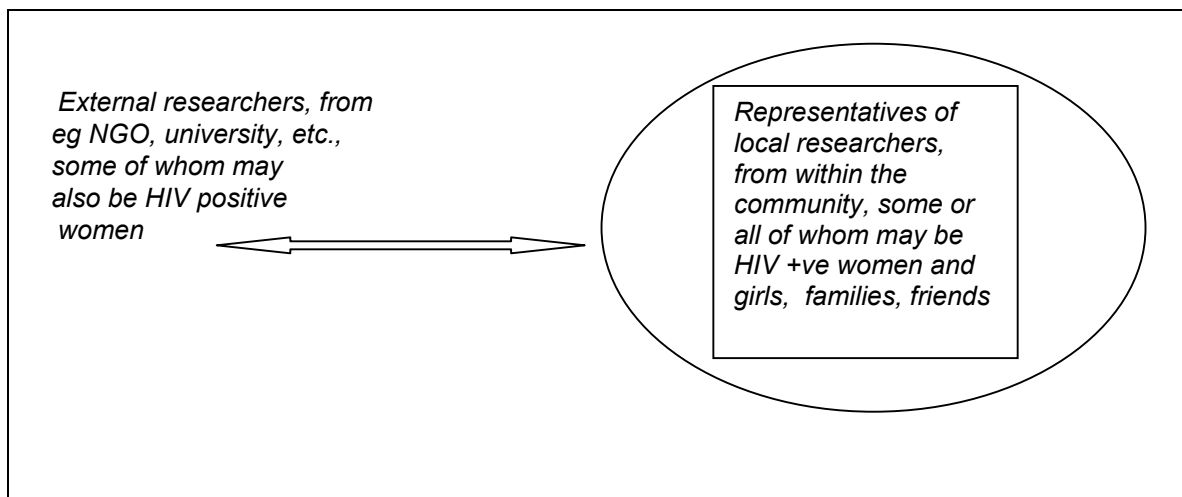
- ICW believes that, as far as possible, *all* HIV positive women should be offered meaningful opportunities to be actively involved in all medical, socio-economic or other research which is undertaken concerning women living with the virus, regardless of our age, religion, culture, socio-economic background, parental status, length of knowledge of HIV positive status, or sexuality.
- As women living with this virus, we are uniquely placed to contribute our knowledge, skills and experience to all research conducted on this issue, as well as to all research which explores more effective ways of preventing acquisition or further transmission of the virus.
- Much current research on HIV ignores gender-related differences with regard to transmission, the effects of the virus on the individual concerned, and appropriate forms of care or treatment for that individual. Much current research also ignores the effects of the research process itself on the psychological and economic well-being of the individual women concerned.
- Below we present some guidelines and categories for classifying participatory research protocols for your consideration in developing socio-economic research programmes. We have not had room here to consider issues regarding biomedical research programmes also, although there are many similar issues to address. (Readers interested in ethical considerations in biomedical research are encouraged to read the two articles on the websites below. The first outlines the pros and cons of the proposed amendments to the Helsinki declaration. http://www.mja.com.au/public/issues/172_06_200300/stockhausen/stockhausen.html The second document is on the CIOMS website http://www.cioms.ch/frame_guidelines_nov_2002.htm and is long and comprehensive.)
- We believe that only through involving HIV positive women in all stages of research will a clearer picture emerge of the issues facing HIV positive women. This information is long overdue. It is also critical, if we are together to find a way of reducing the effects of the virus on women in the future, and ultimately to eradicate the spread of the virus to future generations.

Instructions

The following guidelines can serve to appraise the extent to which research projects align with principles of participatory research.

We propose that you set up a “stakeholders’ research advisory group” which consists of diverse members of the community(ies) concerned and others who wish to conduct the research with them. The idea is that *all* those concerned should be viewed as researchers. You should seek to ensure that different interest groups in the community are properly represented on the stakeholders group.

Stakeholders Research advisory group, made of external researchers and representatives of community researchers



Together you could then agree to meet regularly and you could start by going through these guidelines. This process may enable you to identify areas where your opinions differ and will, we trust, enable you to discuss and resolve them, before proceeding further.

You could also use these guidelines as a monitoring tool, to check the *process* of your research on a regular basis together.

For each guideline, check only one box. Some of the guidelines may not be applicable to the research project, in which case no boxes should be checked. Alternatively, a box labeled "not applicable" could be added to all the guidelines for users to check when appropriate. The categories identified by boxes for most guidelines increase in appropriateness to participatory research from top to bottom, but the most appropriate level for some projects on some guidelines might be more toward the middle of the row of boxes.

Guidelines

1. Research participants and the nature of their involvement in the research:

a) how have the researchers arrived at their definition of the community/ies concerned in the research?

no consultation between external researchers and potential local researchers	
inexplicit/general consultation	
general but explicit consultation	
general/detailed consultation	
detailed consultation	

b) Are different sections of the community and the likely diversity of their experiences and viewpoints (their “issues of difference”) going to be acknowledged and upheld during the research process (on the basis of eg age, parental status, socio-economic well-being, ethnicity, religion, sexuality, awareness of positive HIV status, length of time of knowing HIV positive status, death of children, etc)?

no acknowledgement of issues of difference	
little acknowledgement of issues of difference	
moderate acknowledgement of issues of difference	
much acknowledgement of issues of difference	
high acknowledgement of issues of difference	

c) Do members of the defined community participating in the research have concern or experience with the issue to be investigated?

no concern or experience with the issue	
little concern or experience with the issue	
moderate concern or experience with the issue	
much concern or experience with the issue	
high concern or experience with the issue	

d) Are interested members of the defined community provided opportunities to participate in the research process?

no opportunity to participate	
little opportunity to participate	

more than one opportunity to participate	
several opportunities to participate	
many opportunities to participate	

- e) Is attention given to barriers to participation, (such as timing, meeting places etc) with consideration of those who have been under-represented in the past? (eg women in general, women who don't belong to existing groups, younger, women, grandmothers etc.)

no attention to offsetting barriers	
low degree of attention to offsetting barriers	
moderate degree of attention to offsetting barriers	
moderate/high degree of attention to offsetting barriers	
high degree of attention to offsetting barriers	

- f) Has attention been given to establishing within the community an understanding of the researchers' commitment to the issue?

no attention to the researchers' commitment	
low attention to the researchers' commitment	
moderate attention to the researchers' commitment	
high attention to the researchers' commitment	
explicit agreement on the researchers' commitment	

- g) Are community participants enabled to contribute their physical, or financial and/or intellectual resources to the research process?

no enabling of contribution from participants (external researchers do it all)	
mostly external researcher effort; some support for contribution from local participants	
about equal contributions from local participants and external researcher	
mostly resources and efforts of local participants; external researchers have some direct input	
full enabling of local participants' resources (external researchers act only as facilitators)	

2. Origin of the research question(s):

a) Did the impetus for the research come from the defined “community”?

issue posed by external researchers or other external bodies	
impetus originated mainly from external researchers; some input from community	
impetus shared about equally between external researchers and community researchers	
impetus originated mainly from community researchers; some impetus from external researchers	
issue posed by the community researchers	

b) Is an effort to research the issue supported by members of the defined community?

support for research from very few, if any, community members	
less than half of the community supports research on this issue	
community is roughly divided on whether the issue should be researched	
more than half of the community supports research on this issue	
support for research from virtually all community members	

3. Purpose of the research:

a) Can the research facilitate learning among community participants about individual and collective resources for self-determination?

no provision for learning process	
low provision for learning process	
moderate provision for learning process	
moderate/high provision for learning process	
high provision for learning process	

b) Can the research facilitate further collaboration between community participants and other resources external to the community?

no potential for collaboration	
low potential for collaboration	
moderate potential for collaboration	
moderate/high potential for collaboration	
high potential for collaboration	

c) Is the purpose of the research to empower the community to address determinants of health and well-being?

purpose devoid of empowerment objective	
low priority empowerment objective	
moderate priority empowerment objective	
moderate/high empowerment objective	
high priority empowerment objective	

d) Does the scope of the research encompass some combination of gender-related, age-related, political, social and economic determinants of health?

no consideration of political, social or economic determinants	
only one or two determinants are considered	
limited consideration of combined determinants of health	
moderate consideration of combined determinants of health	
comprehensive consideration of combined determinants	

4. *Process and context - methodological implications:*

a) Does the research process apply the knowledge of community-based researchers in the phases of planning, implementation, and evaluation?

no use of community knowledge in any phase	
use of community knowledge in one or two phases only	
limited use of community knowledge in all three phases	
moderate use of community knowledge in all three phases	
comprehensive use of community knowledge in all three phases	

b) Are the methods used for research data collection accessible by non-literate as well as literate community members (eg “participatory learning approaches” (PLA) including role-play and drawing etc.)?

no use of PLA methods	
low use of PLA methods	
moderate use of PLA methods	

moderate/high use of PLA methods	
high use of PLA methods	

- c) For community researchers, does the process allow for learning about these research methods?

no opportunity for learning about research methods	
low opportunity for learning about research methods	
moderate opportunity for learning about research methods	
moderate/high opportunity for learning about research methods	
high opportunity for learning about research methods	

- d) For external researchers, does the process allow for learning about the community's visions and potential barriers to achieving those visions?

no opportunity for learning about the community visions and barriers	
low opportunity for learning about the community visions and barriers	
moderate opportunity for learning about the community visions and barriers	
moderate/high opportunity for learning about the community visions and barriers	
high opportunity for learning about the community visions and barriers	

- e) Does the process allow for flexibility or change in research methods and focus, as necessary?

Methods and focus are pre-determined; no potential for flexibility	
mostly pre-determined methods and focus; limited flexibility	
about equal blend of pre-determined methods and focus with flexibility	
high flexibility; some pre-determined methods and focus	
complete flexibility; methods and focus not predetermined	

- f) Are procedures in place for appraising experiences during implementation of the research?

no procedures for appraising experiences	
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few procedures for appraising experiences	
some procedures for appraising experiences	
many procedures for appraising experiences	
comprehensive procedures for appraising experiences	

g) Are community researchers involved in the three analytical issues: interpretation; synthesis; and the verification of conclusions?

no involvement of community in any analytic issue	
involvement in one or two analytic issues only	
limited involvement of community researchers in all three analytic issues	
moderate involvement of community researchers in all three analytic issues	
comprehensive involvement all three analytic issues	

5. Opportunities to address and take forward the issues of interest:

a) Is the potential of the defined community for individual and collective learning reflected by the research process?

research process not aligned with potential for learning	
limited alignment of research process with potential for learning	
moderate alignment of research process with potential for learning	
moderate/high alignment of research process with potential for learning	
comprehensive alignment of research process with potential for learning	

b) Is the potential of the defined community for taking subsequent action, based on the research findings, reflected by the research process?

research process not aligned with potential for action	
limited alignment of research process with potential for action	
moderate alignment of research process with potential for	

action	
moderate/high alignment of research process with potential for action	
comprehensive alignment of research process with potential for action	

c) Does the process reflect a commitment by external researchers and community researchers to social, individual or collective actions consequent to the learning acquired through research?

no commitment to action beyond data collection and analysis and writing report for funding agencies	
low commitment to social actions based on learning through research	
moderate commitment to social actions based on learning through research	
moderate/high commitment to social actions based on learning through research	
comprehensive commitment to social actions based on learning through research	

6. *Nature of the research outcomes:*

a) Do members of the wider community benefit from the research outcomes?

research benefits external researchers only	
research benefits researchers/ external bodies primarily; community benefit is secondary	
about equal benefit of research for both internal and external researchers/external bodies, and community	
research benefits community primarily; benefit is secondary for researchers/ external bodies	
explicit agreement on how the research will benefit the community	

b) Is there attention to or an explicit agreement for acknowledging and resolving in a fair and open way any differences between external researchers and community researchers in the interpretation of the results?

no attention to or any agreement regarding interpretation issues	
low attention to interpretation issues	

moderate consideration of interpretation issues	
high attention to interpretation issues; no explicit agreement	
explicit agreement on interpretation issues	

c) Will HIV positive women in the community be able to review any written or oral reports, for content, language and style, before any public presentation?

no opportunity for HIV positive women in the community to review the reports	
low opportunity for HIV positive women in the community to review the reports	
moderate opportunity for HIV positive women in the community to review the reports	
high opportunity for HIV positive women in the community to review the reports; no explicit agreement	
explicit agreement for HIV positive women in the community to review the reports	

d) Is there attention to or an explicit agreement between external researchers and community researchers with respect to ownership of the research data?

no attention to or any agreement regarding ownership issues	
low attention to ownership issues	
moderate consideration of ownership issues	
high attention to ownership issues; no explicit agreement	
explicit agreement on ownership issues	

e) Is there attention to or an explicit agreement between researchers and community participants with respect to the dissemination of the research results? (For instance, is it planned that HIV positive women from the community should present the research at public fora? Is it planned that HIV positive women from the community should be included as co-authors of any published documents relating to the research? Is it intended that other HIV positive women should be included amongst the recipients of the publications and at presentations regarding the research?)

no attention to or any agreement regarding dissemination issues	
low attention to dissemination issues	
moderate consideration of dissemination issues	
high attention to dissemination issues; no explicit agreement	
explicit agreement on dissemination issues	

ADAPTED FROM L.W. Green, M.A. George, M. Daniel, C.J. Frankish, C.P. Herbert, W.R. Bowie, M. O'Neill, Study of Participatory Research in Health Promotion. Royal Society of Canada, Ottawa, Ontario, 1995, pp 43-50. Reproduced with the kind permission of the Royal Society of Canada and the authors.

Appendix – Exercise for introducing ethical guidelines

In July 2004 at the International AIDS Conference in Bangkok, ICW organised a Skills Building Workshop to introduce these ethical guidelines for involvement of HIV positive women in research (see www.icw.org <<http://www.icw.org>>). The workshop was facilitated by Alice Welbourn and Violeta Ross. We wanted to design an exercise which would enable people who had never met each other before to engage quickly for themselves and with each other in the issues which we were trying to address in the workshop (we only had 90 minutes for the WHOLE workshop)

So we asked people to divide into groups of 5 (in each group there were people from different continents and a mixture of backgrounds (eg academic, NGO, positive woman, lawyer, pharmaceutical staff) and to read together and discuss some quotes which we had printed out for them on strips of paper in advance. We gave each group 5 minutes to discuss each quote, and gave them a new quote to consider every 5 minutes - though they could go on discussing the earlier quotes if they preferred. For each quote, we asked them as a group to define what the problems were and, from their own experiences, to come up with suggested solutions to ensure that these problems wouldn't happen again.

Altogether we had prepared 7 quotes, one each covering a different aspect of the issues which we wanted to cover in the workshop. In the end (what with people arriving late etc.) there wasn't time to discuss all the quotes. But the first 5 were discussed by all the groups. The discussion in each group was intensive and lively and this process seemed to work really well in bringing the issues to life for the participants. At the end of the time available, each group was asked to summarise 2 key learning points from the discussions which they had had within each group.

Several participants - even several seasoned participatory practitioners - commented on having had "aha" moments with these quotes. The quotes that we used are below, but of course they could be adapted for different contexts, from quotes which trainers have themselves heard from their own experiences.

Summary: this exercise seemed to work really well in putting flesh on the bones of the issues being discussed; it quickly broke down barriers between participants who were strangers, produced lively discussions amongst them and appeared to shift the thinking of quite a few of those who took part.

1) “She interviewed me in a room with the door open, so people could hear what I was saying if they wanted to when passing in the corridor. But I was too scared to complain, in case she wrote something down about me being a trouble maker. She wrote down everything I said, and she offered to show it to me afterwards, but I can’t read, so I said no, that’s fine thanks.”

2) “I was feeling really scared about the interview, but was determined to help. But then when I got there, there was a student with her which I hadn’t reckoned on. She did ask if that was OK and I said no, I just want to talk to you. But then the student was obviously cross and didn’t close the door behind her when she left the room. No, no-one apologised.”

3) “All the questions were focusing on the bad stuff I’m going through. I felt so depressed by the end of the interview, when I was on the bus, I just started crying. It thought it would be good to have the \$20 but afterwards I felt drained for days and just shouted at the kids. Life’s hard enough without that.”

4) “What do these people do with all these questions they ask us? They come in in their smart vehicles, ask us loads of questions and then they disappear again and you never hear anything more from them. I used to stop and help them, in the hope that they might help us but I never bother now.”

5) “You could tell that they didn’t know the first thing about our lives. They kept on asking us about how long it takes us to get to the health centre and what we think of how the staff treat us there. When did we last have the time or money to get to the health centre? The trouble is you daren’t tell them that because then our district chairman might get cross with us if he hears you haven’t answered their questions correctly.”

6) “Yes, they always ask our leaders the questions. No, they never ask us anything. But you see they are very important people from the university, so I know they haven’t got time to ask us all.”

7) “Well I tried to explain that if I didn’t already have a child that I would have wanted to go ahead with the pregnancy, no matter what, just in the hope that the baby might be OK. But she said there wasn’t room on the form for that answer, so I’m not sure what she wrote.”

Acknowledgement: the write-up of this exercise appears in PLA Notes 50, 2004, published by the International Institute for Environment and Development (IIED). It is reproduced here with IIED’s kind permission.

NB For more information on participatory research processes, please view <http://www.ids.ac.uk/ids/particip/research/index.html>

We welcome any comments or feedback which you have on these guidelines.

Please contact us on info@icw.org