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*National Center for Bioethics
in Research and Health Care*



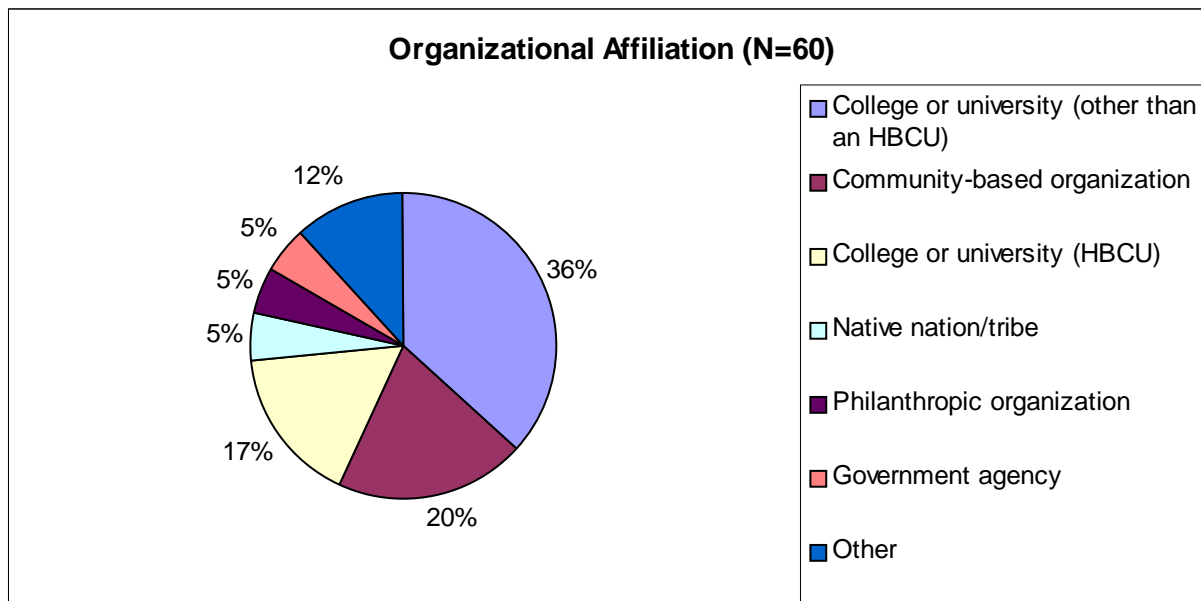
**Community-Campus
Partnerships for Health**
Transforming Communities & Higher Education



2007 Educational Conference Call Series on Institutional Review Boards & Ethical Issues in Research Evaluation Results

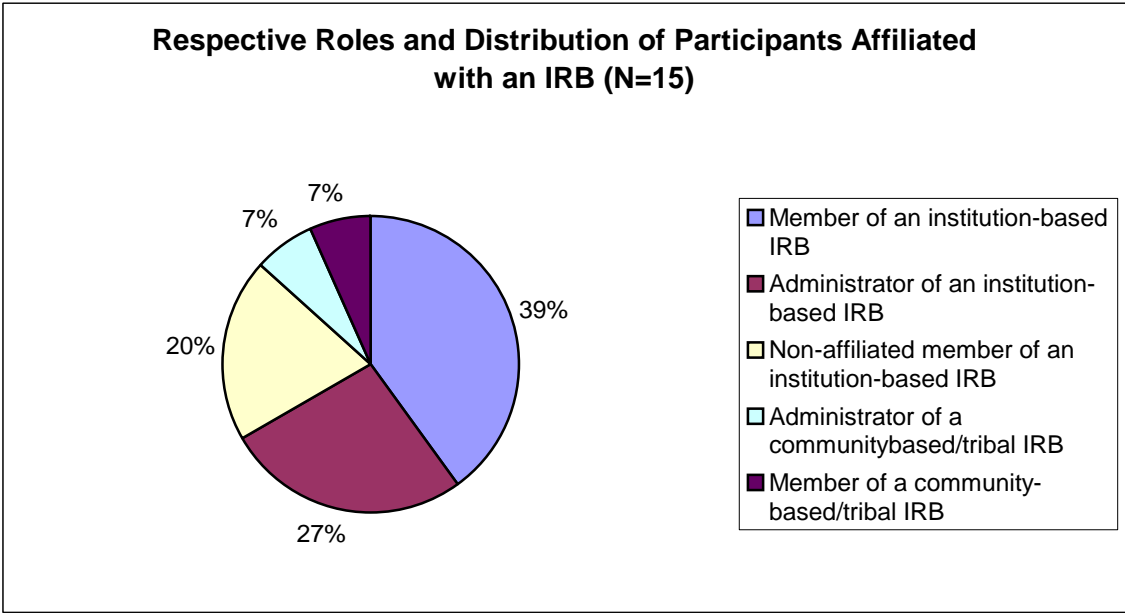
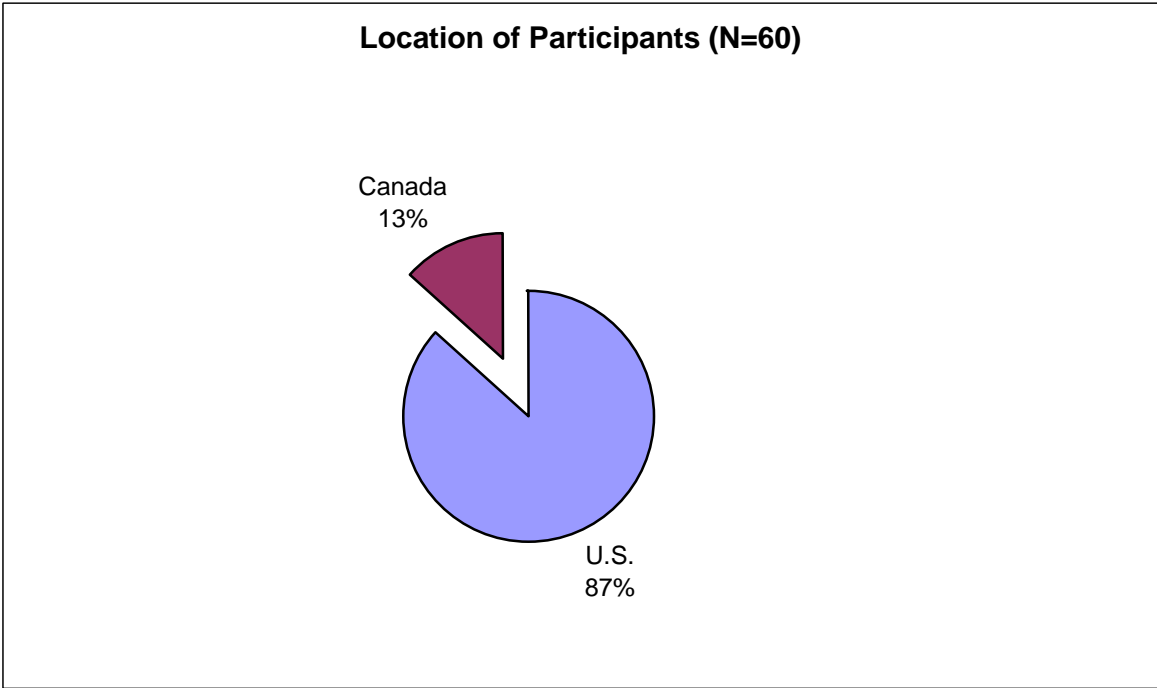
Compiled by Jessica Grignon, CCPH Graduate Research Assistant, November 2007

Purpose & Response Rate: A total of 467 participants in the 2007 Educational Conference Call Series were e-mailed a short survey to help determine next steps and get feedback on how future call series could be improved. Sixty participants responded to the survey, for a response rate of 12%.



Organizational Affiliation: Thirty-two (53%) respondents are affiliated with higher educational institutions, with 10 (17%) from Historically Black Colleges and Universities (HBCUs) and 22 (36%) from non-HBCUs. Twelve (20%) of respondents are affiliated with community-based organizations (CBOs).

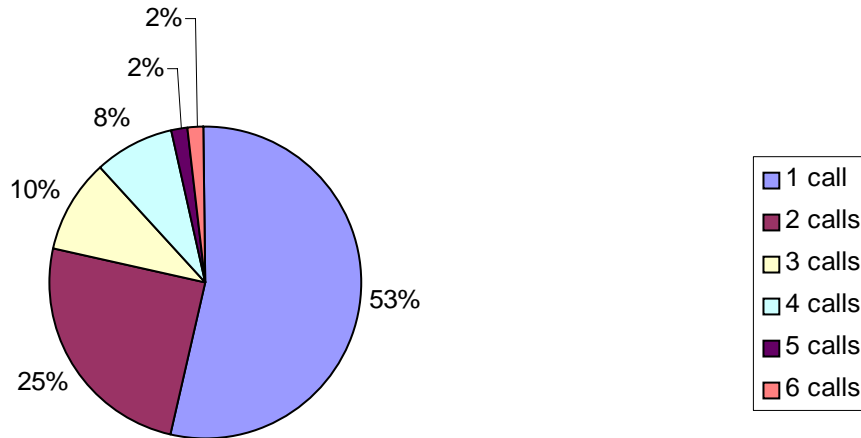
Seven (12%) respondents designated themselves as other and represented the following groups: academic hospital (1), clinical research institution (1), community-based teaching hospital (1), community-based nonprofit/Indian Health Service epidemiology center (1), medical institution (1), and national non-governmental organization (1). One respondent characterized him/herself as, “medical school volunteer faculty with community-based practice in applied research with non-profit clients (government, CBO, foundation).”



Roles of Participants Affiliated with an Institutional Review Board (IRB):

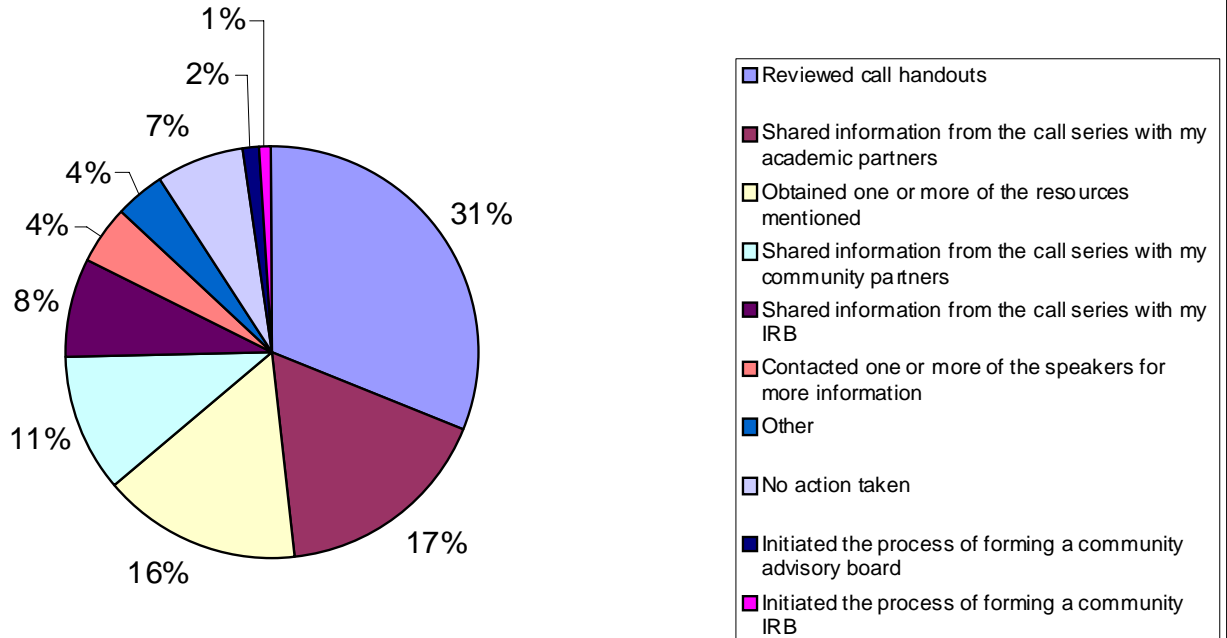
Fifteen of 60 respondents reported being affiliated with an IRB. Of those 15, six (39%) were members of an institution-based IRB. Four (27%) were administrators of an institution-based IRB, and three (20%) were non-affiliated members of an institution-based IRB.

Percentage of Participants Attending One or More Calls (N=60)



Number of Calls Participated: Thirty-two (53%) respondents to the evaluation survey indicated they participated in one call in the series. Fifteen (25%) respondents participated in two calls in the series, and six (10%) participated in three calls.

Reported Action as Result of Call Series (N=129*)



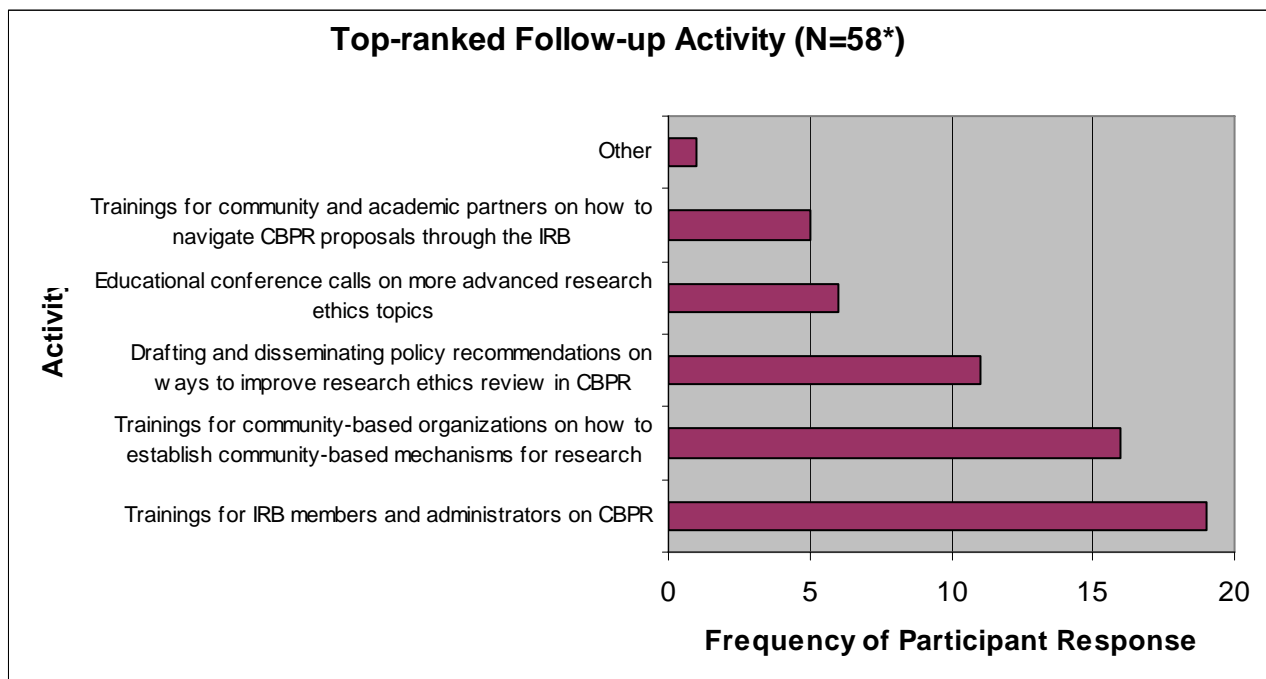
*N=responses. Survey respondents were allowed to choose more than one activity.

Reported Actions Taken: Survey respondents were asked, “What actions have you taken since the call series?” They were given a list of ten actions to choose from, including “other,” and were allowed to choose more than one action.

When asked what actions they had taken following the call series, there were a total of 40 (31%) responses for “Reviewed call handouts.” There were 22 (17%) responses for “Shared information from the call series with my academic partners,” and there were 20 (16%) responses for “Obtained one or more of the resources mentioned.” There were 14 (11%) responses indicating “Shared information from the call series with my community partners.”

There were five (4%) responses for “other” actions taken as follows:

- Made sure community-based participatory research (CBPR) was placed into the curriculum for Master's prepared nurses at Western Governor's University's new program
- Examined research policies used by various agencies
- Talked with a call participant about our presentation
- Will use as resource for future efforts
- Communicated with my IRB about CBPR; asked if CBPR was right for our hospital community



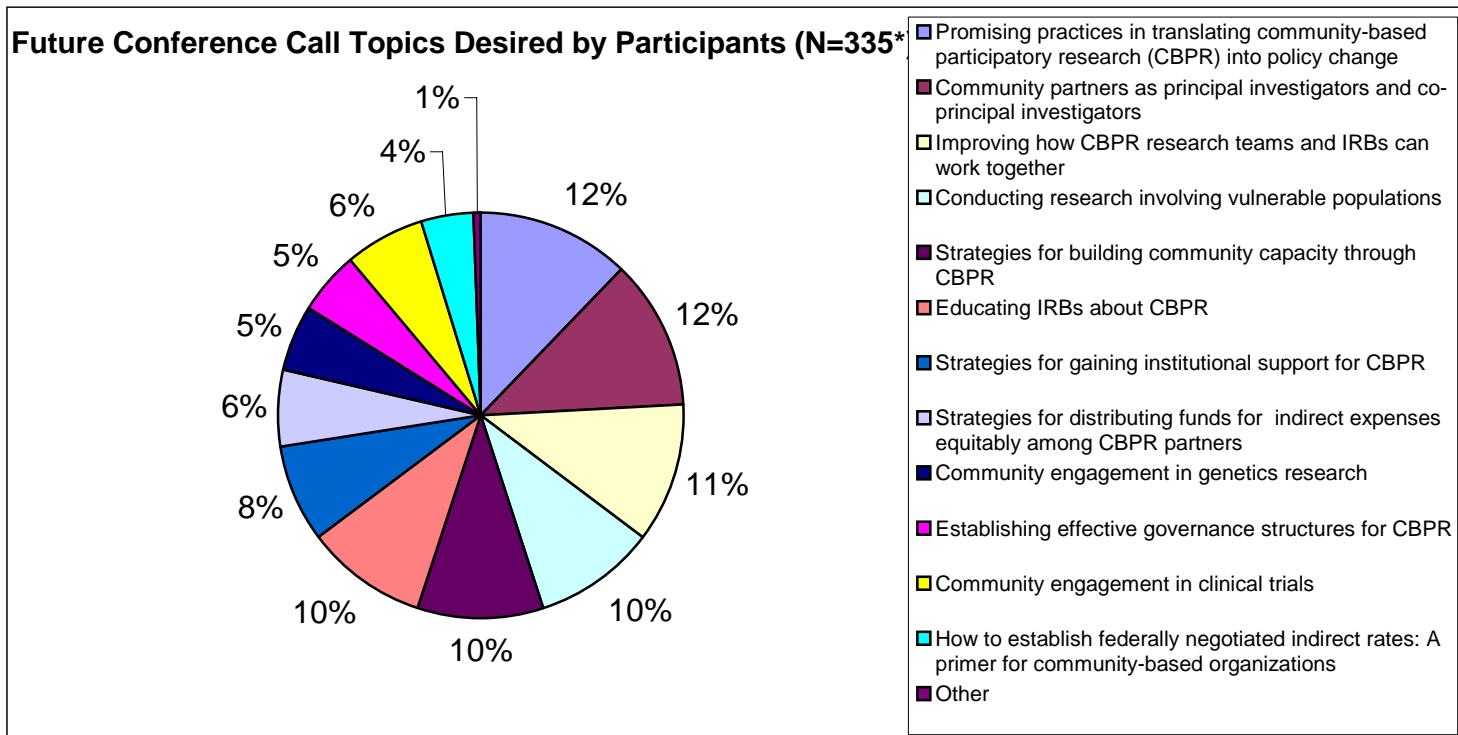
*N=responses. Survey respondents were allowed to choose more than one activity as top-ranked activity.

Top-Ranked Follow-up Activities: When asked, “What activities would you like to see us sponsor in follow-up to the call series?” respondents were asked to select from the following activities (listed in the order of their popularity):

- Trainings for IRB members and administrators on community-based participatory research (CBPR)
- Trainings for community-based organizations on how to establish community-based mechanisms for research ethics review (i.e., community research committees, community IRBs)
- Drafting and disseminating policy recommendations on ways to improve research ethics review in CBPR
- Educational conference calls on more advanced research ethics topics
- Trainings for community and academic partners on how to navigate CBPR proposals through the IRB
- Other

The "Other" follow-up activities respondents suggested were:

- Sponsor a call series or video conference where community members present their experience with CBPR
- Begin a dialogue on developing informed consent boilerplate language at both a "literate" and "low literate" reading level that is written into law as acceptable for nationwide use.
- Coming from out of the country, I would be interested in how one does cross-border work with the different research cultures and regulations. It is a real problem.
- Discussing the guide to determining when public health research does not require an IRB approval not even an exempt status (non research evaluation in public health)
- Forum for community IRBs to reflect on their experiences
- Sharing information and ideas about how CBPR could work at our hospital, from the perspective of IRB members.
- Developing workbook process guide and a mock IRB panel to “test” proposals and advise on whether projects might require an IRB review, or alternative protections.



*N=responses. Survey respondents were allowed to choose more than one conference call topic.

Future Conference Call Topics: Survey respondents were asked, “Which conference call topics would you be likely to sign up for (check all that apply)?” They were given a list of 13 topics to choose from, including “Other,” and were allowed to choose more than one action. The top three topics selected were:

“Promising practice in translating CBPR into policy change”: 41 (12%) responses

“Community partners as principal investigators and co-principal investigators”: 40 (12%) responses

“Improving how CBPR research teams and IRBs can work together”: 37 (11%) responses

“Other” conference call topics that were suggested included:

- Publishing CBPR research especially qualitative work
- Specific training for lay reviewers

Creating a Listserv: Forty-nine (78%) of the respondents believe a listserv devoted to IRBs and ethical issues in CBPR is needed, and 30 (61%) participants expressed interest in subscribing if such a listserv were developed.

Qualitative Results

The remaining section of this report presents findings from open-ended responses.

How did you benefit from participating in the call series?

General Knowledge/Learning (13 responses)

- I learned a lot but would like the series to be repeated.
- I came late to the series, but it raised my interest and understanding of the issues
- Learned information
- Information on how to approach problems
- I downloaded the whole series to study later.
- Validated my current knowledge
- Gained personal perspective
- Very informative!
- Learning about other community groups attempting to address similar issues.
- Learnt a lot about human consent and ethical issues regarding human studies
- Gained new knowledge
- Learned more on this topic
- Terrific opportunity to hear from diverse informants about a critical and timely issue.

Community-Based Participatory Research and IRBs (7 responses)

- The examples of specific CBPR programs was very enlightening.
- I learned more about CBPR, the challenges and the rewards. I also heard some good strategies for truly involving the community in research and found that very inspiring.
- Increase my understanding and knowledge about ethical issues and principles when initiating CBPR
- Learned more about how people doing CBPR are thinking about interactions with IRBs.
- Learned how others are handling CBPR and IRB
- Increased understanding of CBPR and ethics review in the US
- Learned a lot about the IRB process and about CBPR

Community IRB, CAB, or Similar Entity (6 responses)

- It was helpful to know that others have struggled with the question of whether or not and how to start their own IRB
- Provided valuable information as we form our tribal IRB

- Enhance understanding of the importance of community partners forming community IRB
- I learned more about community advisory boards.
- Learned more about how several other sites have handled IRB issues related to community-based initiatives
- It gave me more insight into community IRBs and access to online materials for me to review further.

Specific Actions Taken or Identified (5 responses)

- Made our informed consent document more participant-friendly
- I finally downloaded and read the Belmont Report. Although I have completed our institution's human subjects training, I had not read the actual report.
- I am able to apply the guidelines for a current project.
- I learned additional information about how to better assist our IRB community member.
- We're in the process of gathering information from stakeholders & gather information about current community partnerships (topic areas, neighborhoods targeted, types of partnerships, education and enrichment programs)

Community Partners, Member Involvement, and Collaboration (4 responses)

- Learned new ways of involving community partners and what some of the challenges may be in seeking to do so.
- Thinking about how to involve community members more in design process
- Excellent discussions re: different examples of successful community partnerships that have over come the IRB hurdles and barriers to produce significant research
- It was helpful to hear about other CBOs encountering problems and to hear about successful collaborations

Community Ethics (3 responses)

- Broadened the context of my understanding and thinking about Community ethics
- It is always good to hear what is going on for others and to learn how they are managing the ethics of community-based work.
- It reminded me of the complexity of community research even though I've been involved as both a researcher and a board member.

Networking (3 responses)

- More information and networking, ideas from what others are planning.
- Informed of other activities – network
- New ideas from different sources

General Understanding of IRB (3 responses)

- Obtained a clear understanding of what is an IRB, the importance of consent forms and how to obtain oral consent request from community participants.
- Getting information on what and IRB is and how it functions with the Human Subject that we serve.
- Learned new approaches to IRBs, etc.

Collection of Resources (3 responses)

- Collection of resources
- Learned about successful models from other groups and have a large collection of resources.
- I'm new to my position as an Academic-Community liaison, so was only able to participate in one call, but found it very informative and provided many resources.

Other (3 responses)

- It was enlightening to learn about CCPH because I knew nothing about it before.
- It was clear that there are many people interested in this area, and that many struggles and frustrations are common across the country. It really calls for leadership, potentially on the part of CCPH, to advance this issue.
- Awareness that others are struggling

Disappointment (One response)

- As I recall I was a bit disappointed. I had hoped for less ethics party line and more “lets reform the rules and make them workable for communities which have problems finding IRBs.” Getting real people other than ministers on IRBs, etc

How do you think the call series could have been improved?

Generally Positive (10 responses)

- Good format.
- Very well done
- Current format is good
- They were a good first step!
- I found it very effective and efficient.
- I think the call series are excellent, well organized with relevant and valuable materials and resources distributed to participants; questions and answers are helpful
- No suggestions. It seemed well announced and organized.
- In the one call that I was able to participate, I found it to be very valuable time spent.
- I think you all did as good a job as possible.

- Overall, the two calls that I participate in were ideal and well organized.

Time (5 responses)

- More time for Q & A
- Fewer speakers with more time for questions after their session
- Maybe the length should be reduced
- Perhaps only 2 presentations per call and more time for questions/discussion.
- Allow more time for questions.

Apparent Difficulties with Current System (5 responses)

- Difficult to log in
- I did not receive all handouts in a timely manner
- Perhaps send out presentations ahead of time and solicit questions in advance of the call.
- Have 2 questions ready for discussion that usually stimulate discussion about the issue rather than just depending on the participants alone. Back pocket questions.
- Provide participants with samples of the documents discussed.

Technological Suggestions (3 responses)

- Given the size of the call, I thought that it was managed well. I'm not sure how else one can have so many people on a call and facilitate discussion. As the technology improves, it might be worth considering webcasting the calls so “listeners” can “watch” the speakers!
- Not sure. It is hard to listen to multiple speakers in one solid block, but I don't have a good suggestion for an alternative. Video clips (of the speaker and/or to demonstrate a principle or point)? The Q and A portion of the call often yielded information that was excellent.
- Not that I have utilized all the available resources yet (indeed, there may already be something like this), but it seems like a blog associated with the series would help it be more interactive or give the opportunity to have listeners/lurkers post other thoughts, questions, resources.

Speaker Quality (2 responses)

- Speaker quality was inconsistent.
- Better informed speakers

Other Suggestions (6 responses)

- Opportunity to ask questions first to focus the call. More info geared toward community rather than academics in the community.

- In addition to here's the rules of the game, what changes would you like to see made to improve community involvement and approval of research ethics
- Canadian content as well as American
- I wanted to know whether there were common links and/or differences between the different presenters; from Dr. Yancy to the Waianae Coast Comprehensive Health Center; how does a community hospital differentiate between the models and create CBPR in one's own institution?
- I think there should be more calls; the more opportunities to learn, the better!
- Alternative times or rebroadcast for members who could not participated at the scheduled times.

Ambiguous (4 responses)

- I did not participate in enough of the calls to assess.
- I feel limited because I only participated in one [call]. Nothing comes to mind as far as ways to improve.
- Having access [to the call] from my office was key to my involvement.
- I didn't hear enough of them to comment.