

**A HEALTHY BALANCE:
A COMMUNITY ALLIANCE FOR HEALTH RESEARCH ON
WOMEN'S UNPAID CAREGIVING**

EVALUATION OF THE EFFICACY OF EQUITY REFERENCE GROUPS

October 2006



Introduction

The *Healthy Balance Research Program (HBRP): A Community Alliance for Health Research on Women's Unpaid Caregiving* is a five year program funded by the Canadian Institutes of Health Research (CIHR) and sponsored by the Atlantic Centre of Excellence for Women's Health and the Nova Scotia Advisory Council on the Status of Women.

The ultimate goal of the HBRP is to foster a "healthy balance" between women's health and well-being, family life and earning a livelihood. The interrelated and dynamic program objectives include knowledge generation, knowledge transfer and transformation, uptake of new ideas and practices, and strengthening research capacity.

HBRP includes a management team, four research teams, a post-doctoral fellow and four Equity Reference Groups.

The Healthy Balance Research Program has made a commitment to include the perspectives of historically disadvantaged and under-represented groups through its four Equity Reference Groups (ERGs): African-Canadian Women, Aboriginal Women, Immigrant Women, and Women with Disabilities.

The ERGs have guided the research teams in developing projects that are sensitive to the needs and norms of different communities and have helped to interpret the resulting research findings. The ERGs have also provided a link between researchers and community to allow findings to be broadly disseminated.

At the request of the ERG members, the 4 Equity Reference Groups originally created were amalgamated early in the process into one group.

Evaluation Terms of Reference

In May, 2006, an evaluation of the efficacy of the Equity Reference Groups (ERG) in the program was begun by Hollett and Sons Inc.

The Terms of Reference of the Evaluation included the following tasks:

- Measure the effectiveness of Equity Reference Groups for:
 - increasing community participation in research
 - developing research which is inclusive
 - knowledge translation
- Identify the strengths and weaknesses of HBRP's use of ERGs, both from a process and a methods stand-point

- Produce recommendations for future research projects.

A preliminary report was submitted in June 2006 at the request of the Equity Reference Group members who participated in their Focus group. This is the final report.

Methods for Evaluation

The methods used for this evaluation included:

- Document review relating to the Equity Reference Groups at HBRP and Equity Reference Groups in other settings.
- Focus Group with the Equity Reference Group
- Telephone Interviews with 7 of the researchers and administrative personnel and advisors of HBRP

Ethics approval to conduct the research was obtained from Dalhousie University in advance of the research being undertaken.

Overall Evaluation Findings

Equity Reference Groups have enhanced the research project in many ways. It has given researchers the opportunity to better understand the cultures of the ERGs. It has enabled them to frame their research instruments and methods to better capture the knowledge of all research participants. In addition, it is anticipated the research will better benefit the research participants as the ERGs assisted in the Knowledge Transfer process.

As one of the co-directors of research indicated:

The involvement and generous contribution of time and knowledge by the Equity Reference Groups has produced a situation in which research results can be “translated” into materials that are meaningful to the population that took part in the research.¹

From the perspective of the members of the ERGs, it was also a successful process, with the caveat they wanted more involvement and . They saw this process as long overdue, and they would have liked to have had even more interaction with the researchers.

Equity Reference Groups as a Method in other Research Projects

The use of Equity Reference Groups in applications such as this is a new and evolving field. The use of ERGs in HBRP was this and more. The ERGs were integrated into the advice on design of some research instruments, the research itself (as researchers) and as knowledge translators back into the equity group. Few applications of this sort were found. Some that were include:

¹“Equity Reference Groups: Creating Linkages to Marginalized Communities for Research and Knowledge Translation,” (Brigitte Neumann, undated)

- Some boards (such as the Saskatchewan Labour Force Development Board) maintain Equity Reference Groups to ensure the board deliberations and policy developments are relevant to and take into account the needs of their particular group.
- Research undertaken by the evaluator of other uses of ERGs show that many groups (university recruitment offices) for example use ERGs to test their marketing and messaging to the members of their specific equity group
- Participatory research, where the active involvement of the research subjects is critical to the success of the project, has also started to use Equity Reference Groups.
- Brisbane City Council in Australia has established Equity Reference Groups to “provide support and a consultative mechanism for staff from culturally and linguistically diverse backgrounds.”²

Expectations of the Success and Roles of the Equity Reference Groups

There were varying expectations of the roles of the ERGs throughout the project, which impacted on the assessment of success by participants. The evaluation results show the academic partners felt strongly the ERGs were a success in their role and the ERG members felt they could have been more successful.

All evaluation participants agreed the role of the ERG included:

- Review the draft research instruments and processes for HBRP
- Consider whether the proposed instruments and processes were appropriate and respectful to the communities they represent
- Advise the researchers of the above

Some, but not all, expected the roles to also include:

- Advise whether there were additional questions or processes which would be beneficial to the research within their communities
- See the advice provided by the ERGs being incorporated into the final research instrument and processes
- Provide ideas and advice on how to best recruit research participants/targets
- Assist in the actual recruitment and selection of research participants/targets
- Provide ideas and advice on how to best present the HBRP research findings:
 - to all audiences

²“One City, Many Cultures: Cultural Diversity Strategy for the City Council of Brisbane Australia” (October 2000) p.6 http://www.brisbane.qld.gov.au/bccwr/community/documents/ocmc_strategy_document.pdf

- to the communities of the ERG (African Nova Scotian women; NS women with disabilities; Immigrant women to NS and NS First Nation women)
- Assist with the presentation of research findings to their respective communities.

According to the Directors of research,

They are useful critics, pointing out the weaknesses in secondary data that do not reflect the realities of caregivers of various cultural backgrounds and ability status.

Furthermore, they are key players in developing ways to feed research findings back to their communities, who are then able to bring both concerns and potential solutions to the media, policy and program officials and elected representatives.³

The following table presents the findings of whether the two groups (interviewees and focus group) felt the expectations were met or unmet. Because many of the suggestions for improvements were directly related to the expectations, these are also captured in this table. Suggestions for improvements not directly related to the expectations are captured later in the table.

Expectations	Were Expectations Met or Unmet?	Improvements?
Reviewing the draft research instruments and processes for HBRP	It was agreed by all this expectation was met. ERGs were provided with the information on the research instruments and processes and were given the opportunity to review those research instruments.	
Consider whether the proposed instruments and processes were appropriate and respectful to the communities they represent	All agreed this expectation was met.	

³“The Healthy Balance Research Program: Knowledge translation for women's unpaid caregiving”, Canadian Institutes of Health Research (Carol Amaratunga, Ontario Women's Health Council Chair, University of Ottawa Brigitte Neumann, Nova Scotia Advisory Council on the Status of Women Barbara Clow, Atlantic Centre of Excellence for Women's Health, Dalhousie University) <http://www.cihr-irsc.gc.ca/e/30747.html>

Expectations	Were Expectations Met or Unmet?	Improvements?
<p>Advising the researchers of the above</p>	<p>The interviewees felt the methods were well explained and clearly understood by the ERGs; the ERGs were not unanimous that this expectation was met.</p>	<ul style="list-style-type: none"> • Ensure the information is given to the ERGs more in advance so they have adequate time to digest it. • Establish longer meetings between the ERGs and the researchers to enable them to have more dialogue
<p>Advise whether there were additional questions or processes which would be beneficial to the research</p>	<p>This was an expectation primarily of the Focus Group and most felt it was not met.</p>	<ul style="list-style-type: none"> • Future ERGs need the facilitated opportunity to provide advice on what additional questions might be appropriate
<p>See the advice provided by the ERGs being incorporated into the final research instrument and processes</p>	<p>Some felt this was met, but it seemed dependant upon the research instrument and the research team leader. The quantitative research (survey) was deemed by most to have absorbed less of the ERG recommendations than the qualitative research (focus groups and community portraits)</p>	<ul style="list-style-type: none"> • Communications between the HBRP and the ERG could be improved. The essential feedback loop between providing advice and seeing how it was incorporated or why it was not incorporated is essential to a body such as the ERG. • The suggestion of a communications officer or at least an improved communication process for the project was made several times by the Focus Group.

Expectations	Were Expectations Met or Unmet?	Improvements?
Provide ideas and advice on how to best recruit research participants/targets	Many felt this was accomplished, particularly for the qualitative research. Some focus group members felt they could have provided much more assistance in this area and felt underutilized.	<ul style="list-style-type: none"> • Manage expectations better so ERGs don't feel underutilized. • Alternatively, enable the ERGs to have more input into this process
Assist in the actual recruitment and selection of research participants/targets	Some focus group members felt they could have provided much more assistance in this area and felt underutilized. They also indicated the recruitment and selection may have been improved overall if their advice had been sought and heeded.	<ul style="list-style-type: none"> • Manage expectations better so ERGs don't feel underutilized. • Alternatively, enable the ERGs to have more input into this process
Provide ideas and advice on how to best present the HBRP research findings to <i>all audiences</i>	<p>HBRP is not yet complete and this activity is towards the end of the program, so respondents tended to discuss whether they <i>anticipated</i> this would happen.</p> <p>Most of the Focus Group members were very concerned they would not be enabled to accomplish this expectation, and considered it one of the most important roles they play with HBRP. They were unsure of "what happens now" and not aware of what, if any, plans had been made to accomplish this.</p> <p>Most of the interviewees indicated this was either not one of their expectations or it were confident it was going to be accomplished before the end of the project.</p>	<ul style="list-style-type: none"> • It is very important to communicate clearly what is planned for this (and all) aspects of HBRP. • ERG need to have enhanced communications on "where to from here" and a road map from the beginning on what is required of them and when.

Expectations	Were Expectations Met or Unmet?	Improvements?
<p>Provide ideas and advice on how to best present the HBRP research findings <i>to the communities of the ERG</i></p>	<p>Same as above, except focus group members felt accountable to their communities for the knowledge translation in particular.</p> <p>This seems to be an unanticipated dynamic and the Focus Group members are keenly awaiting the process to start where they will be involved in this piece.</p>	<ul style="list-style-type: none"> • Same as above • Ensure ERG are actively involved in the presentation of findings to their communities.

Impact of ERG on Research Participation

Most felt the participation of the communities in the quantitative research (survey) was unaffected by the ERG participation, but the participation in the qualitative research (community portraits in particular) was positively affected. Many of the focus group participants indicated they could have done more around the HBRP focus groups. The involvement of some of the ERGs as Research Assistants in the community portraits was taken by all as a good move for the program. All evaluation participants indicated this resulted in research that is more inclusive, with the only qualifier being it could have been even more inclusive.

Recommendations for Future Research Projects

Anticipate and Facilitate the Different Cultures of the Community and the Academy

All ERGs members were drawn from the “community-based sector”. This sector is known for its ability to collaborate and are well-schooled in equity of participation in processes. The research teams are all from the academic sector and their work processes tend to be more competitive and individualistic. These two cultures did not always seem to work well together in the HBRP. Community groups are constantly being asked for their input and advice. With that comes a responsibility to give back to the community groups what was done with that advice.

A recommendation for the future would be to better facilitate how the two cultures collaborate and appreciate what motivates and drives each of them; underlining where these drivers and motivators intersect.

Balance the Different Goals of Publication, Policy Change and Enhanced Community-knowledge

With the academic focus on publication in peer reviewed journals and moving the body of knowledge ahead; the HBRP partners focus on policy changes and the ERGs focus on knowledge translation, there is the potential for the overall focus of the project to not be integrated and all needs to not be met. Careful attention must be made to how the needs are balanced and perceived to be balanced. This requires equal measures of planning, communication and sharing.

Better Utilize the ERG Members

Overall the Focus Group members felt underutilized. While they are delighted with the model of the ERG and look forward with anticipation to it becoming more broadly used within research, they feel they could provide more to the process and would like to be more of a partner than an advisory body.

Have a Formative Evaluation

ERG members in particular like the idea of the evaluation, as did several interviewees. The suggestion was made that the evaluation would have been more useful if it had been a formative one, i.e., where the evaluator is engaged at the beginning of the program and provides observations in a timely manner that can be incorporated into the project at that point, instead of waiting until it is over and evaluating it at the end.

Research Questions

The questions for both the Interview and the Focus group were quite similar.

Focus Group Questions	Telephone Interview Questions
1(a) What were your expectations of your role in HBRP when you accepted the invitation to participate? (b) Have your expectations been met or unmet ?	Same
2 (a) Do you feel your contribution to HBRP has enhanced the participation of your community in this research? (b) In your opinion, has this resulted in research that is more inclusive?	Same
3 (a) Were you able to bring information back to your community that was of benefit to them as a direct result of your involvement in the ERG? Please describe. (b) How could this be improved in future research projects ?	Not asked in the Interviews (although often raised by interviewees)
4 (a) What is your overall opinion, thoughts and experience on ERG? (b) How could ERG structure / process / implementation be improved in future research projects?	Same
5. Other comments you would like to add?	Same