



# A Healthy Balance

A community alliance for health research on women's unpaid caregiving

## Evaluation of the Equity Reference Group

*June 2007*

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The Healthy Balance Research Program is funded by the Canadian Institutes of Health Research and is supported by Dalhousie University and the IWK Health Centre



## **Introduction**

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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 led by the Atlantic Centre of Excellence for Women's Health (ACEWH) and the Nova Scotia Advisory Council on the Status of Women (Advisory Council).

The 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 generating, transferring and transforming knowledge; taking up 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 Equity Reference Groups: African-Canadian Women, First Nation Women, Immigrant Women, and Women with Disabilities. At the request of the ERG members, the four Equity Reference Groups originally created were amalgamated early in the process into a single Equity Reference Group (ERG).

The ERG has guided the research teams in developing projects that are sensitive to the needs and norms of different communities and have helped to interpret research findings. The ERG has also provided a link between community and researchers in order to allow for the broad dissemination of research findings.

## **Terms of Reference of the Evaluation**

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In May 2006, an evaluation of the efficacy of the ERG in the Healthy Balance Research Program was undertaken by Hollett and Sons Inc., a market research firm based in Shoal Harbour, Newfoundland.

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

- Measure the effectiveness of the ERG for
  - increasing community participation in research
  - developing inclusive research
  - performing knowledge translation

- Identify the strengths and weaknesses of HBRP's use of an ERG, from both a process and a methods standpoint
- Produce recommendations for future research projects.

Hollett and Sons set up an ERG focus group (the ERG Focus Group) to conduct its evaluation. In June 2006 the ERG Focus Group requested a preliminary report of the firm's findings. This is the final report.

### **Evaluation Methods**

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The evaluation used the following methods: methods used for this evaluation included:

- Document review relating to the ERG for the HBRP as well as ERGs in other settings
- The ERG Focus Group
- Telephone Interviews with seven HBRP researchers, administrative personnel and advisors (HBRP Interviewees)

Dalhousie University granted research ethics approval prior to the undertaking of this research.

### **Findings from the Evaluation**

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Generally, members of the ERG Focus Group felt the ERG was a success and that this inclusive application is long overdue in community-based and academic sectors. However, they expressed the caveat that they wanted more involvement throughout the research process and more regular interaction with the researchers.

The staff of the HBRP found that the ERG made numerous and valuable contributions to their program. Researchers were able to gain a better understanding of the culture of ERGs. In addition, the ERG enabled HBRP staff to frame their research instruments and methods in a manner that drew on the knowledge represented by ERG communities. As one of the Research Co-Directors 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.<sup>1</sup>*

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<sup>1</sup>"Equity Reference Groups: Creating Linkages to Marginalized Communities for Research and Knowledge Translation." (Brigitte Neumann, undated).

HBRP staff hope that their research will benefit ERG members and their communities more directly due to the ERG's involvement in the knowledge translation process.

### **Equity Reference Groups as a Method in other Research Projects**

As use of ERGs in research is a new and evolving field, few applications of ERGs such as this were found. Similar applications of an ERG include

- Some Boards (such as the Saskatchewan Labour Force Development Board), who maintain ERGs to ensure the board deliberations and policy developments are relevant to and take into account the needs of their particular group
- Service Groups such as university recruitment offices, who 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
- Brisbane City Council in Australia, who has established ERGs to “provide support and [act as] a consultative mechanism for staff from culturally and linguistically diverse backgrounds.”<sup>2</sup>

### **Roles and Expectations of the Equity Reference Group**

All evaluation participants (the ERG Focus Group and HBRP Interviewees) agreed that the ERG's role included:

- Reviewing the HBRP's draft research instruments and processes
- Considering the appropriateness of proposed research instruments and processes, and ensuring respect for the communities represented therein
- Advising the researchers of the above

There were varying expectations of the roles of the ERG throughout the project. Some, but not all, ERG members had the following expectations within these roles:

- To advise the HBRP staff whether there were additional research questions or processes relevant to the ERG members' respective communities

To ensure the ERG's advice was incorporated into the final research instrument and processes

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<sup>2</sup>“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](http://www.brisbane.qld.gov.au/bccwr/community/documents/ocmc_strategy_document.pdf)

- To provide ideas and advice on how best to recruit research participants/targets
- To assist in the actual recruitment and selection of research participants/targets
- To provide ideas and advice on how best to present the HBRP research findings
  - to all audiences
  - to the HBRP's ERG communities (i.e., African-Nova Scotian women, Nova Scotia First Nation women, Immigrant women to Nova Scotia and Nova Scotian women with disabilities)
- To assist the HBRP staff with presenting research findings to the ERG's communities.

According to the Directors of Research,

*They [the ERG members] 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.<sup>3</sup>*

Results of this evaluation show that while the ERG's academic partners felt the ERG fulfilled its roles successfully, the ERG members felt they could have been more successful in this capacity.

### **ERG Members' Expectations (Within the Roles of the ERG) and Recommendations for Improvements**

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Differing viewpoints on the ERG's roles impacted on the evaluation participants' assessment of the success of the ERG. The following table presents the met and unmet expectations of the ERG as understood by the ERG Focus Group and the HBRP Interviewees. Because many of the recommendations for improvements were directly related to the expectations, these are also captured in this table.

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<sup>3</sup>“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>

<b>Expectations Within the ERG's Role(s)</b>	<b>Were Expectations Met or Unmet?</b>	<b>Improvements?</b>
Reviewing the HBRP's draft research instruments and processes	The ERG Focus Group and the HBRP Interviewees both agreed that this expectation was met.	
Considering the appropriateness of proposed research instruments and processes, and ensuring respect for the communities represented therein	The ERG Focus Group and HBRP Interviewees agreed that this expectation was met.	
Advising the researchers of the above	The ERG Focus Group was not unanimous that this expectation was met. HBRP Interviewees felt research methods were well explained and clearly understood by the ERG.	<ul style="list-style-type: none"> <li>• Ensure the ERG receives information sufficiently in advance.</li> <li>• Enable thorough dialogue between the ERG and the HBRP by conducting longer meetings.</li> </ul>
Advise the HBRP staff whether there were additional research questions or processes relevant to the ERG member's respective communities	This expectation, which was held primarily by the ERG Focus Group, was found by most of its members to be unmet.	<ul style="list-style-type: none"> <li>• Facilitate the opportunity for the ERG to provide advice regarding additional research questions or processes.</li> </ul>
Ensure the ERG's advice was incorporated into the final research instrument and processes	The ERG Focus Group indicated that this expectation was met or unmet depending on the research instrument and the Research Team Leader.	<ul style="list-style-type: none"> <li>• Improve communications between the HBRP and the ERG.</li> </ul>

*Evaluation of the Equity Reference Group*

<b>Expectations Within the ERG's Role(s)</b>	<b>Were Expectations Met or Unmet?</b>	<b>Improvements?</b>
Provide ideas and advice on how best to recruit research participants/targets	Some ERG Focus Group members felt this expectation was unmet.	<ul style="list-style-type: none"> <li>• Manage expectations better so the ERG does not feel underutilized.</li> <li>• Alternatively, enable the ERG to have more input into this process.</li> </ul>
Assist in the actual recruitment and selection of research participants/targets	Again, some ERG Focus Group members felt this expectation was unmet.	<ul style="list-style-type: none"> <li>• Manage expectations better so the ERG does not feel underutilized.</li> <li>• Alternatively, enable the ERG to have more input into this process.</li> </ul>
Provide ideas and advice on how best to present the HBRP research findings to <i>all audiences</i>	<p>As this expectation is directed towards the HBRP's end, which has not yet occurred, respondents largely forecast the meeting of this expectation.</p> <p>Most ERG Focus Group members were concerned they would not be enabled to meet this expectation; they were unsure of "what happens now" and unaware of plans for research dissemination.</p> <p>Most HBRP Interviewees indicated either that this was not one of their expectations or that they were confident of research dissemination before the project's end.</p>	<ul style="list-style-type: none"> <li>• Clearly communicate what is planned for this (and all) aspects of HBRP.</li> <li>• Enhance communications for the ERG, including the provision of a project overview, deliverables and timelines.</li> </ul>

*Evaluation of the Equity Reference Group*

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<b>Expectations Within the ERG's Role(s)</b>	<b>Were Expectations Met or Unmet?</b>	<b>Improvements?</b>
Provide ideas and advice on how to best present the HBRP research findings <i>to the HBRP's ERG communities</i>	See above. The ERG Focus Group held the expectation that its members were accountable to their communities for knowledge translation.	<ul style="list-style-type: none"><li>• See above.</li><li>• Ensure the ERG is actively involved in the presentation of research findings to their respective communities.</li></ul>



**Summary of Evaluation Feedback on the Efficacy of ERGs and Recommendations for their Use in Future Research Projects**

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Summary: All ERG members were drawn from the “community-based sector”. This sector is known for its ability to collaborate and is well-schooled in participation equity within processes. The research teams were all from the academic sector and their work processes tended to be more competitive and individualistic. These two cultures did not always work well together in the HBRP.

Recommendation: It is the responsibility of research teams from non-community-based sectors to give back to the community groups information on what was done with their advice. Better facilitation is necessary between community-based and academic sectors, as is an appreciation of what motivates and drives each of them and where these motivators and drivers intersect.

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



Summary: All evaluation participants indicated the participation of communities as represented by the ERG resulted in more inclusive research. The HBRP addresses multiple foci: an academic focus on publication in peer-reviewed journals and moving the body of knowledge ahead, the focus of the HBRP community partners on policy changes, and the ERG’s focus on knowledge translation.

Recommendation: Equal measures of planning, communication and sharing are necessary to ensure that the overall focus of the HBRP is unified, and that each group’s needs are included, balanced and perceived to be balanced.

*Balance the Goals of Publication, Policy Change and Enhanced Community-Knowledge*



Summary: Although ERG members approved of the ERG model and anticipate its broader use within research, overall the ERG members felt underutilized. They also indicated that their advice regarding the recruitment and selection of research participants/targets was not sought.

Recommendation: ERG members' abilities and willingness to provide more to the overall research process should be utilized. View the ERG as a partner in research rather than an advisory body.

***Better Utilize the ERG Members***



Summary: ERG members valued the evaluation of the ERG, as did several HBRP Interviewees.

Recommendation: Allow for a formative evaluation that engages the evaluator at the beginning of the program and provides a vehicle to incorporate observations in a timely fashion.

***Conduct an Early and Ongoing Formative Evaluation of the ERG***



Summary: The essential feedback loop between providing advice and seeing its incorporation (or non-incorporation) is key to the success of ERGs.

Recommendation: Employ a Communications Officer in order to improve the project's communication process between community-based sectors and academic partners and sectors.

***Implement Feedback Procedures To and From Community-Based Sectors***



Summary: The involvement of some of the ERG members as Research Assistants for the Caregiver Portraits team was widely regarded as a useful mechanism within the program.

Recommendation: Provide research opportunities for ERG members.

***Establish Research Assistantships for ERG Members***

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Summary: The qualitative research, and to a lesser extent, the quantitative research, took into account the ERG's advice regarding best practice for the recruitment of research participants/targets. Most of the ERG Focus Group determined that quantitative research absorbed fewer ERG recommendations than qualitative research. Additionally, most ERG Focus Group members and HBRP Interviewees felt the quantitative research was unaffected by the ERG's participation, yet the qualitative research was found to be positively affected by the ERG.

Recommendation: Monitor the ERG's advice for incorporation into quantitative research.

***Ensure ERG Recommendations are Accounted For in Quantitative Research***

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Summary: The ERG Focus Group members were excited to be involved in the process of giving advice on how best to present the HBRP research findings to ERG communities, but are unsure as to how or when this would occur.

Recommendation: Identify the means by which research findings are disseminated by the ERG members to their communities. Provide a schedule for this activity.

***Involve ERG Members in Discussion Regarding Research Dissemination to Their Communities***

**Evaluation Questions**

Similar questions were asked of the ERG Focus Group and HBRP Interviewees.

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