



## A Healthy Balance

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

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# Equity Reference Groups June 12 and 13, 2003 Halifax, Nova Scotia

## Report

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*The Healthy Balance Research Program is funded  
by the Canadian Institutes of Health Research and  
is supported by Dalhousie University, IWK Health  
Centre and Women's Health Bureau, Health  
Canada.*



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## Healthy Balance Research Program

The Atlantic Centre of Excellence for Women's Health (ACEWH), Dalhousie University and the Nova Scotia Advisory Council on the Status of Women (NSACSW) are providing leadership in the form of an innovative and collaborative program of research to better understand the connections between women's health and well-being, family life and earning a livelihood. The **Healthy Balance Research Program** is funded by the Canadian Institutes of Health Research (CIHR); other principal partners include the Nova Scotia Family Caregivers Association; the IWK Health Centre for Children, Women and Families; Mount Saint Vincent University; and the National Centres of Excellence for Women's Health Program.

It is well known that throughout their adult lives, women are more likely than men to experience stress and overwork as a result of their multiple care and work responsibilities. There is uncertainty, however, about possible health benefits to women in the paid workforce. We are only beginning to understand the extent and nature of women's unpaid caregiving work and its stress and health impacts -- whether this caregiving work is done on its own or combined with paid work.

This innovative partnership program will improve our understanding of the ways in which caregiving is now organized (e.g., unpaid caregiving shared between women and men), how caregiving affects people's sense of empowerment in their lives, and, in turn how that affects their health and well-being. Researchers will study different kinds of unpaid caregiving in Nova Scotia and will determine which unpaid caregiving situations -- on their own or combined with paid work, are associated with positive or negative health. The program will also examine how social and economic factors interact with paid work, caregiving, empowerment and health status -- for example how ethnicity, race and culture, as well as rural and urban location, income, age of the caregiver and other factors affect the health and well-being of care providers in Nova Scotia. On a practical level, the program will consider current policies and programs that address paid work and family life and how these can be improved.

The ultimate goal of this program 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. Specifically, we intend to: examine the relationship among unpaid caregiving work (performed on its own or in combination with paid work), empowerment and health status; foster "uptake" of new ideas and practices in policies; promote innovation in programs and health-service delivery that reflects new insights into the values and expectations we bring to caregiving and paid work; strengthen research capacity in Atlantic Canada by recruiting and retaining health researchers.

## Equity Reference Groups

**HBRP** 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, First Nations women, immigrant women, and women with disabilities. The ERGs have a powerful mandate to contribute to all aspects of the research program by recommending and approving culturally appropriate and respectful data collection methods and information sharing strategies in their communities. They have also accepted the challenge of facilitating the translation of research into better policy and practice.

## INTRODUCTION

The important contribution of the Equity Reference Groups to the unfolding of the Healthy Balance research is operationalized in several ways, the most visible being the joint meetings of all four reference groups on a regular basis. The most recent meeting took place in Halifax on June 12 and 13, 2003, an occasion for renewing friendships and cementing relationships as well as for learning about the progress of the research and grappling with the challenges of knowledge translation and policy impact.

This report details the presentations and discussions that took place during this gathering. It is organized somewhat differently from the meeting itself (see agenda, Appendix B), grouping general discussions first and then covering the reports from the research teams second. The agenda was developed to create a dynamic flow and to intersperse presentations with group activities and discussions. Removed from the conviviality of ERG interactions, a format organized around themes rather than around flow seems more appropriate.

## PROGRESS REPORT - WHAT HAS HEALTHY BALANCE ACCOMPLISHED SO FAR?

With the mid-way point of Healthy Balance drawing near, it seems opportune to review progress to date. Much has been accomplished and much remains to be done. Coming up with a list of accomplishments was not difficult for the Coordinator, who works full-time on Healthy Balance initiatives and is aware of the different facets of the project, and in fact, such a list was developed and shared with participants. First, however, participants reflected individually on their thoughts about accomplishments, hoped for outcomes, favourite parts of the Healthy Balance program, and missed opportunities. These thoughts were jotted down on pieces of paper and then displayed on the wall throughout the remainder of the meeting.

Ideas on these topics are included here, followed by the Coordinator's list of Healthy Balance achievements up to June 2003.

What is the biggest accomplishment so far?

- use of Equity Reference Groups throughout project
- speaking with MPs at Breakfast on the Hill (December 2002) and Dinner on the Hill (March 2003)
- highlight women's multiple roles, with unpaid caregiving being a major, taken-for-granted one
- Unfortunately, I am really only familiar with the Secondary Analysis Team. Our biggest accomplishment has been our research which has been recognized academically, in the media and with policy makers.
- including perspectives from diverse groups from the beginning

- taking (a) unique views on some fairly established issues - e.g. Secondary Analysis taking a new look at work, stress, health, gender; Team Q asking anew what we mean by caregiving
- The HBRP is part of the Province of Nova Scotia's business plan
- recognition of women's diversity, health, power, opportunities and challenges
- the ERGs were included from the beginning of study - giving the study validity
- bringing together people with diverse experiences and expertise which enables people to look at the issues through a very broad lens
- creation of a collaborative and functional research network, teams, ERG in Nova Scotia and across Canada (NRG)
- obtaining Susan as the Coordinator as she is excellent at moving us forward and facilitating the results we have achieved so far
- presentation - panel on "academic research and advocacy" - Congress of Social Sciences and the Humanities, June 2003
- GPI Atlantic linkage and data analysis - King's County and Cape Breton
- inclusion of ERGs as a major component of the overall program
- undertaking such a complex project
- emphasis given to the involvement of ERG
- interest/emphasis in knowledge transfer/policy implications

#### What is the outcome you would most like to see?

- finished report written in a language that is accessible to members of the ERGs and other community members
- an end product that includes policy development or other form of action
- national recognition of the research and its policy impacts
- the research completed and acted upon by the policy makers
- a coherent policy framework within which the issues of caregivers across the life cycle are addressed
- more recognition/policy of immigrant women's health takes place
- continuing the focus on the issue in a sustained, ongoing way
- policy and decision makers evaluate the info and make positive changes
- some meaningful outcome - such as policy direction, tangible action, continued action
- finished report ~ layperson's version ~ that we can take to various diverse communities (i.e. First Nations) and the content can be easily imparted and understood by community members
- finished report that can be easily shared with the different populations
- finished report that is acceptable to all groups
- policy development based on final report
- research results and analysis that resonates with women from diverse caregiving situations - First Nations women, African Nova Scotian women, women with disabilities, immigrant women, lesbians, mothers, daughters, sisters, friends, lovers, spouses - caregivers of people with a range of caregiving needs/requirements
- I want women to read/hear about our research and say "Yes!"

### What is your favourite thing about Healthy Balance?

- the way in which people work together and support each other, whether they're researchers, community people or government representatives
- opportunity to network, share information and research findings
- getting together in the 2-day workshops with the others in the ERGs (e.g. networking, discussing the project, learning from each other, having fun)
- bringing together different ERGs to share their diverse perspectives very educative and helpful for me
- look at different groups of women and gathering rich information from different cultures-for examples, focus groups
- getting to know and networking with such a diverse group and feeling that our group is providing valuable information that will assist in decision making at a higher level
- coming together with women from the reference groups and sharing information
- involvement of ERGs
- two-and-a-half day ERG meeting -
- bringing together the ERGs, hearing different perspectives
- project paid attention to diverse needs of various groups
- the blend of mixed methods in the research
- meeting members of other ERGs and the sharing of experiences/knowledge

### Name a missed opportunity - something Healthy Balance should have done but didn't

- should have a policy working group in place already - it's not "missed" yet, but we better get cracking!
- I worry that in trying to be very inclusive we may get breadth but lack depth, doing none of it as well as we'd like to
- not a lot of communication between ERG and research teams between meetings, but I'm not sure if this is expected
- circulate among ERG members some background papers on the issues discussed/presented at the meetings or make available data reports/analyses
- fridge magnets
- visit the Romanow report
- not a missed opportunity but maybe more diverse perspectives could be helpful - e.g. include at least one African immigrant or Muslim woman in the Immigrant Equity Reference Groups. These perspectives are unique.
- educate women to empower themselves, especially in financial level

### Healthy Balance accomplishment as described by the Coordinator

- Background paper - Thinking it Through
- Research teams recruited and working
- Four Equity Reference Groups recruited and working
- National Reference Group recruited and working
- Website developed and maintained

- Caregiver Information Bank developed and currently being updated
- Focus Groups organized and completed
- Focus Group data coded and analysed
- Census data (General Social Survey) analyzed by Secondary Analysis Team
- *Taking its Toll* submitted for publication in *Feminist Economics* - revisions requested
- *Taking its Toll* presented at luncheon in April - flurry of media coverage
- *Taking its Toll* presented at Canadian Economics Association conference and at an international conference
- Survey instrument drafted and revised after input from ERGs and respondents to a pre-test
- Overall plan for Caregiving Portraits developed
- Healthy Balance presented to MPs at a parliamentary Breakfast on the Hill
- Healthy Balance part of the Government of Nova Scotia business plan
- Presentation to the NS Public Service Commission
- Student placement - undergraduate student in Family Studies & Gerontology - MSVU
- Two Masters scholarships awarded in 2002; three applications received for 2003
- Paper on evaluation challenges presented at annual conference of Canadian Evaluation Society
- Healthy Balance represented in the planning of several initiatives (e.g. Policy Forum at MSVU; Striking the Balance breakfast for employers; PSC Employee Wellness Program)
- Display developed and put up two times - fine-tuned on each occasion
- Six editions of Update created and distributed

## WORKING WITH POLICY MAKERS - SOME TRICKS OF THE TRADE

Judy Hughes, Executive Director, Nova Scotia Disabled Persons Commission, talked with participants about things she has learned after years of working with policy makers. The overhead can be seen in Appendix C.

Judy's comments included:

- break policy goals down
- assess both direct and indirect impact
- figure out who is for, who is against and who is neutral about the policy you are proposing (Who is going to block the issue? What can you do about it?)
- calculate the likelihood of the policy being implemented - how do-able is it?
- don't bite off more than you can chew - incremental changes allow for a series of small successes - success keeps people at the table; failure does not
- don't build the roof before you build the foundation
- find champions
- develop a strategy and build momentum

- policy often arises from a crisis mode - this means there is no opportunity to build support, the response is not coordinated, there is no chance to get your ducks in a row or to thread the results with other initiatives
- policy should be coordinated for the public good

### **Discussion**

- neutrality - there are two aspects
  - those who have not yet made up their minds - they can be persuaded
  - those who are indifferent - they cannot even be approached
- power and influence of the media - the need for a coherent communication strategy
- we need to move policy makers from indifference to the point where they will pay attention to the issues we are bringing to them
- There seem to be two different levels of policy - on an abstract level, policy as a broad vision, a goal to achieve, and, on a more concrete level policy as rules and regulations. Policy makers would probably find policy advice that focuses on rules and regulations most helpful. The broad vision is often developed in the political arena.

## **KNOWLEDGE TRANSLATION**

We all have notions about what knowledge translation means. A straightforward explanation revolves around taking the findings of the various pieces of research that are being carried out and making sure that they are presented in language that is understandable and useful to the audience. There is also an acknowledgement that not all findings will be equally of interest to all audiences, and that effective knowledge translation means packaging the findings in ways that are tailor-made for the particular audiences.

The discussion began with a consideration of the definition of knowledge translation used by the Canadian Institutes of Health Research (CIHR):

*... the exchange, synthesis and ethically sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system*

This view of knowledge translation seemed not only daunting, calling upon Healthy Balance partners to bring about improved health status for Canadians, but also in need of some translation itself.

As a way of focusing on concrete steps that would contribute to knowledge translation, the following ideas found in the original proposal for the Healthy balance program were reviewed:



## Communications Plan

- To give researchers an opportunity to be heard by policy makers and practitioners in health and human resource professions
- To advise governments, in support of policies and programs that foster balanced living and positive health and well-being
- To engage the public in dialogue about public and private initiatives that support balance in paid and unpaid work, and consequent positive health and well-being

## Communication Avenues

- Academic publications
- Popular publications and media products (clear language research summaries, news releases, magazine inserts, interviews)
- Public lectures and speaking engagements, including presentations at conferences
- Workshops for policy staff, health practitioners and human resource professionals
- Annual Atlantic Canada forum
- International conference

Participants were then challenged to consider mechanisms, occasions and events that would be useful in helping Healthy Balance fulfill its knowledge translation mandate. Two discussion groups came up with the following suggestions:

### Group 1

- people in communities need to “get” how policy works
- the government only uses three key messages - each one should provoke deeper questions; these questions may be different for different audiences
- attach your messages to the work people are already doing
  - ▶ for government, link your message to the government business plan
  - ▶ for government, point out what other governments are doing; this taps into the competitive spirit that often characterizes governments (“In New Brunswick, they do this ...”)
  - ▶ for community health boards and district health boards - practical links to their mandates - e.g. caregiver training
- identify who is responsible for which pieces - e.g. who will fund what you are proposing
- train people to facilitate community development around policy; the FishNet format is a good example; there must be money allocated for training facilitators and producing community development materials
- link findings to each of the other studies so that policy development can be grounded in several studies
- link to the Caregivers Information Bank; watch for parallels with other literature to strengthen our findings
- need to know the capacity of your audience - don’t have expectations that they have no resources to meet
- handouts, pamphlets, etc at grocery stores, message on grocery bags, milk cartons

## Group 2

- explore the various vehicles for communicating the research findings
  - ▶ news conference - Province House would be a good venue
  - ▶ identify publications
    - women's magazines
    - trade magazines
    - Centres of Excellence network
    - Women's Health Bureau publication
    - Health Watch - available free at Lawtons
  - ▶ information sessions for service-providing agencies
  - ▶ handouts
  - ▶ speech/presentation model that presenters could follow
  - ▶ list of conferences where findings can be presented (Health Canada, Nova Scotia Department of Health)
  - ▶ a current, easy-to-navigate website
  - ▶ a calendar with caregiving information
- Healthy Balance business cards for ERG members
- keep clippings of media coverage of issues related to Healthy Balance
- look for grants that will cover the cost of dissemination materials and events

## SECONDARY DATA ANALYSIS TEAM

Team Leader **Shelley Phipps** and Team members **Lynn Lethbridge** and **Martha MacDonald** were present; Shelley Phipps gave the presentation. The PowerPoint presentation can be found in Appendix D.

To date, this team has produced *Taking its Toll: Implications of Paid and Unpaid Work Responsibilities for Women's Well-being*. The paper has been submitted for publication in and received favourable reviews from *Feminist Economics*; it was also presented at a *SPHERE* seminar at Dalhousie (Social Policy, Health and Economics Research Unit) and at the Canadian Economics Association meeting in Ottawa. It will also be presented at an international conference on feminist economics in Barbados later in June. The SPHERE seminar garnered a fair amount of both radio and newspaper coverage.

The Secondary Analysis Team talked about two new projects it is undertaking.

- **Atlantis**

Atlantis is a Women's Studies journal which has asked the Team to revise the *Taking its Toll* paper for publication. The revisions will expand the sample to include women 55 - 64 years (previously only 'prime age' women were included - 45 - 54 years) and will focus on a comparison between the Maritimes and the rest of Canada. In the Maritimes, women spend a significantly larger number of hours per week on unpaid work when compared to the rest of Canada, more hours on housework, childcare and, to a lesser extent, elder care, there is a higher percentage of women in the "sandwich generation" (caring for both children and elderly parents), and a higher percentage of low income women.

## Discussion

Participants came up with the following ideas about why women in the Maritimes do more unpaid work than women in the rest of Canada.

- family culture
- community orientation
- strength of the family
- the feeling that it is not acceptable for someone other than family to provide elder care
- low income - makes it less likely that women will pay someone else to do child care, elder care, and housework and other chores

It was suggested that it would be more relevant to compare Atlantic provinces figures (rather than Maritimes) with the rest of Canada.

There was a question about whether the child care variable includes unpaid childcare for children other than those of the respondent. Team members will look into this.

- **The Hours**

This is the working title for a new study, also using the GSS data on which *Taking its Toll* was based, that will explore the finding that both men and women under-report the number of hours their partners spend performing unpaid work and childcare. The research will look at the process of negotiation in couples, and try to determine factors associated with more equal sharing of reported hours of work. Age and educational level are thought to be considerations.

## Discussion

Participants suggested that this discrepancy might be due to different perceptions as to what exactly constitutes unpaid work and childcare work.

## SURVEY TEAM

Team Leader **Janice Keefe** gave a progress report on the survey. Graduate Student **Carla Johnson**, who is working on the survey was also present. The presentation can be found in Appendix E.

Janice began by reviewing the goals of the survey, which are:

- to provide insight into the scope of unpaid work in Nova Scotia
- to investigate perceived levels of empowerment
- to understand health outcomes related to unpaid work and caregiving
- to analyze the different forms of caregiving performed alone and in combination with paid work

She described the various mechanisms that were used to gather feedback on the survey instrument as it was being developed, including written feedback from a selection of ERG members and pre-tests with volunteers from among the Healthy Balance management and research team leaders.

The major revision that has taken place as a result of the feedback is the development of screening questions that will gather basic data from all respondents who agree to participate in the survey and then go into greater depth with those respondents who are providing care. The screening questions are:

- Work
- Provide receive care and unpaid work
- Health - physical and mental
- Balance between work and family
- Demographics - sex, age, ethnicity and postal code

This approach allows for a population-based survey of a substantial number of people (1500 – 3000) and a more detailed survey of a smaller number of caregivers identified through the screening questions (1000).

A significant methodological shift has also taken place. The plan now is to devise a sampling strategy that over samples those between 25 and 64 years of age and members of the Equity Reference Groups.

The Survey Team will be addressing the following issues as they analyze the data collected from the survey:

- identify proportion of individuals who left work for caregiving
- what is the impact of caregiving on health
- how levels of caregiving affect work and family balance
- what consequences caregiving has for work ( short-term effects, career effects, health outcomes)

Janice posed the question to the group - “What do you think we will be able to say at the end of the survey analysis?” Taking this question literally, one participant suggested that we should be able to say to policy makers: “We are aware that you have made cutbacks to social services. These cuts are not free - the cost is accorded to certain people - here is who these people are and here is how cutback have affected them.” Another participant expressed the hope that Healthy Balance would provide a better understanding of the relationship between care providers and care receivers, and another reinforced the importance of communicating with policy makers in language which was understandable to them.

Other points included:

- “Are you working for pay?” is an unambiguous way to phrase a question meant to elicit information about employment status.
- Care must be taken when discussing health issues concerning people with disabilities; a disability itself does not indicate poor health and many people with disabilities consider themselves healthy.

- Caregiver burden will be balanced with caregiver resilience.
- One aspect of reciprocity that will be explored is that between Work Interference with Family (WIF) and Family Interference with Work (FIW).

The Survey Team hopes to have the survey in the field (phone interviews being conducted by the selected survey company) in the fall of 2003.

## TEAM Q - FOCUS GROUPS

Team Q members sent their regrets - all were involved in other meetings and unable to participate in this ERG meeting. Susan reported on their behalf.

To set the scene, Susan first reviewed the research questions that Team Q had set out to address. These are:

- How do people become caregivers?
- Who cares for the caregiver?
- What resources are available for the caregiver?
- How do caregivers negotiate the utilization of these resources?
- What are the impacts of caregiving?
- What are the implications of caregiving for paid and unpaid work?

In addition to these 6 questions, team members want to identify "best practices".

The feedback from ERG members at the February 2003 meeting was also reviewed, in particular the concern that the category of "culture, race" seemed very broad and should be broken down if at all possible.

Team Q members are currently working on the final report. Susan reviewed the suggestions for the final report that ERG members had made at the February 2003 meeting. These included:

- The quotes are key to reporting on the focus groups; they enable readers to hear people's voices.
- **"Boiled eggs are easy"**...there was much discussion about this quote. Many of the participants found the quote 'said it all' and 'hit home'. People thought that this quote would be a good title for the final report.
- Final report:
  - ▶ written in plain language, language that is very understandable and accessible
  - ▶ not too long
  - ▶ catchy title
  - ▶ include coding tree, summary of report, schedule for focus groups, glossary of terms
  - ▶ should be dictated to a cassette tape or CD so people with visual disabilities and those with limited literacy skills can access it.
  - ▶ available on web site.
  - ▶ hard copy should be accessible in design - e.g. a binding that allows for easy photocopying

An examination of the proposed Table of Contents for the final report (see Appendix F) conveyed the message that these suggestions have been given serious consideration and in large part adopted.

Discussion centred on several suggestions for the final report, including:

- an upfront discussion of “what is caregiving?”, perhaps in the introduction
- glossary of terms
- analysis (perhaps this is captured in the Table of Contents item “Discussion”)
- message from the Healthy Balance co-chairs
- information about Team Q members - names, short bio, photos
- reference to/information about ERG members - names, short bio, photos - this will add credibility to the document when it is circulated in the various communities represented by the ERGs
- cross-reference to other Healthy Balance research being done
- recommendations
  - ▶ policy recommendations
  - ▶ practice recommendations - e.g. if a nutritionist reads the report, what might she/he do as a result
- a section on reflexivity - acknowledging that in qualitative research, the researchers themselves have an impact on the research in terms of the methodology, the interviewing or other form of interaction with participants, the analysis
- acknowledgments to CIHR, partners; also a disclaimer

#### Layout and design considerations

- readable font (style and size)
- sidebar for quotations
- binding that permits easy photocopying

#### Other suggestions

- create two versions of the report
  - ▶ one for policy makers; keeping in mind that there are different levels of policy making
  - ▶ one for community members
- Carol described the possibility of Healthy Balance publishing an edited book of readings based on the Healthy Balance research - there would be a call for papers and a peer review process. The Team Q findings could be included in one or more papers. Such a book could also include stories from the communities.

## TEAM P - CAREGIVER PORTRAITS

**Brenda Beagan**, Team Leader, reviewed the Caregiver Portraits component of the Healthy Balance Research.

The portraits provide the opportunity for an in depth look at people involved in caregiving situations. The number of caregivers involved is small, but the portraits will delve into the realities of caregiving to an extent not possible with other research methodologies. Research Assistants (RAs) will spend approximately 24 hours as participant observers. Formal interviews will also take place during this time. Caregiving households will be selected from the following communities:

- 2 African Nova Scotian
- 2 First Nations
- 2 immigrant
- 2 women with disabilities (where the caregiver has a disability)
- 2 gay/lesbian
- 2 rural white heterosexual

Participants - both caregivers and care receivers - will be given cameras and asked to take photos that show what giving care and receiving care looks like through their eyes. There have been concerns about this idea being perceived as an intrusion on people's privacy; Brenda explained that these concerns could be alleviated by thinking of photos that represent the realities of caregiving without having people in them. For instance, a caregiver might take a photo of a kitchen filled with dirty dishes to represent the overwhelming amount of work she is dealing with, or a care receiver might take a photo of the garden to represent a place where she/he can rest and be at peace. A potential research team member has experience in analyzing photographic data, and this will add to the richness of the finding from the portraits.

The RAs will be members of the community in which each particular portrait is being done. Their extensive training and careful supervision will contribute to capacity building in doing qualitative research in the communities.

The timeline for the portraits is:

- ethics approval - summer 2003 (or perhaps September)
- RA's recruited, selected and trained - Fall 2003
- data gathering (participant observation, interviews) - Winter 2004

Brenda posed two questions to the group:

- What are the distinctive caregiving issues in each of the reference group communities that need to be captured in the interview guides?
- How would the Equity Reference Group members like to be involved in the Team P research as it evolves over the next several months?

People discussed these questions in their separate reference groups. The ideas which emerged follow.

**Question: In constructing the interview guide for your community, what are the distinctive caregiving issues which should be highlighted?**

### **First Nations**

- on reserve/off reserve - one caregiver from each
- language
- jurisdictional issues re: accessing health care
- concept of community as family, especially on reserve, where there is more sharing and the pool of caregivers is broader
- the tensions of overcrowding, poor health status, poverty need to be separated out from the tensions of caregiving
- transportation
- age of caregivers - young girls as caregivers; expectations

### **Immigrant**

- language; translation services; interpretation
- caregivers' awareness of services available
- accepting services which might not be considered culturally appropriate, such as social assistance
- the rules and regulations governing access to long term care are difficult to understand and navigate even for non-immigrants
- the professional background of caregivers and how it differs from the caregiving role (e.g. an engineer not able to be employed in her/his profession and now providing care)
- no support system available if extended family is still in country of origin
- barriers presented by immigration laws
  - ▶ a family member who could assist in providing care is unable to get into Canada
  - ▶ income barriers - double whammy - individual already in Canada does not make enough to sponsor parents, but there are limitations on currency that can be sent overseas
- economic burden, such as sending medication to other countries or bringing someone to Canada for treatment; this is more marked in the immigrant community because of under- and unemployment
- child welfare/child protection concerns - newer immigrants do not understand child welfare legislation; fear that if they discipline their children, they might be reported to the authorities and the police might come and take their children away; this also causes a strange power dynamic between parents and children

### **Women with disabilities**

- not a homogeneous group
- accessibility of services, information, physical space
- an individual with multiple disabilities might have a support person/advocate - but that individual should still be able to speak for her/himself - dependency
- people with disabilities might have low self esteem and be non-assertive



- in the case of mental illness, consider the need for the caregiver to understand the illness of the person she/he is caring for on an ongoing basis as the illness runs its course
- power and control issues with mental illness, starting with the reality that the psychiatrist exercises power; patient compliance; advocacy
- family dynamics re: who provides care; resentment from other family members
- for the caregiver with a mental illness
  - ▶ care can be a bond if the care receiver also has a mental illness - the feeling of having been through the same thing
  - ▶ if the caregiver is depressed, for example, there will be significant challenges in dragging her/himself out of bed and caring for her/himself, let alone caring for another person
  - ▶ the system questions the capacity of the mental health consumer to be a caregiver
  - ▶ the caregiver can monitor her/himself and her/his symptoms
- potential for violence or abuse - person might strike out or inflict self-injuries; an older person with dementia might be abusive with family members but manage to pull it together when visitors are present and present a “normal” front
- there might be issues surrounding helper animals, such as guide dogs

#### **African Nova Scotian**

- economic
- language; dialect
- rural areas present unique challenges - grocery stores are far; medical service such as blood collection are far
- sibling rivalry which might already be present in a family can be accentuated in caregiving situations
- the broader community (where services and resources might be available) is not always perceived as a safe place to go
- education

#### **\*\*\* ASK IN ALL INTERVIEW GUIDES: How did you end up being the caregiver?**

- the sample should include a range of caregiving situations with a continuum of severity - not all portraits should be focused on situation in which there is 24-hour round-the-clock care being provided
- “routine” caregiving (parents caring for children without disabilities) will not be one of the portraits; this area is sufficiently covered in other aspect of the research; unusual caregiving situations will be over-sampled
- navigating the system will be a theme
- multiple caregivers/multiple care receivers

**Question: How should the ERGs be involved from here on in?**

The research team will have a representative from each community; the Research Assistants will be drawn from the communities being included; the team also needs some academics

- they should receive copies of the interview guides when they are developed and their feedback should be considered - each group will receive the guide relevant to its community
- monthly updates

## WRAP-UP

Closing comments focused on acknowledging the work still to be done in terms of knowledge translation and policy impact, but also on the solid foundation that has been built based on good working relationships, meaningful and effective research and creative ideas about how to proceed.

The next meeting will be a joint meeting with members of the National Reference Group; this will provide an exciting opportunity to move the Healthy Balance agenda forward with the combined efforts of diverse and committed supporters.

## FEEDBACK

Feedback on the meeting was positive. Participants commented on the connections they were able to make with other ERG members and with the researchers and HBRP staff, highlighting the enjoyment of renewed friendships. The reassurance of discovering that the feedback provided by ERG members to date has been taken into account was also expressed, along with satisfaction that the commitment to soliciting and considering the input of ERG members is continuing as the program continues.

Suggestions for improvement were procedural - clarifying mechanisms for asking questions and otherwise participating in discussions, and having dual streams in the agenda so that a participant who is not interested in policy, for instance, could take part in another option.

One participant was struck by both the uniqueness of the experiences of members of different reference groups and the similarities among groups when compared with the mainstream community.

The Feedback Form can be found in Appendix G.



# Appendices



## Appendix A

# Participants List

## Equity Reference Group Members

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Denise Moore  
Carla Moore  
Barb Oke  
Josephine Etowa  
Sue Edmonds  
Evangelia (Evie) Tastsoglou  
Youmei Chen  
Maria Yax Fraser  
Shanthi Johnson  
Marcie Shwery-Stanley  
Catherine Campbell

## Researchers

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Janice Keefe, Mount Saint Vincent University  
Shelley Phipps, Dalhousie University  
Martha MacDonald, Saint Mary's University  
Lynn Lethbridge, Dalhousie University  
Brenda Beagan, Dalhousie University  
Carla Johnson, MSVU Graduate Student

## Project Management

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Susan Nasser, Coordinator  
Carol Amaratunga, Co-Director  
Brigitte Neumann, Co-Director  
Nadine Chaulk, Admin. Assistant



Appendix B



Nova Scotia  
Advisory Council on  
The Status of Women

# A Healthy Balance

A community alliance for health research on

---

women's unpaid caregiving

## *Equity Reference Groups Meeting*

June 12 & 13, 2003

Four Points Sheraton Hotel

Navigator Room, Halifax

### A G E N D A, Thursday, June 12

- 12:00 - 1:00 p.m. Lunch
- 1:00 - 2:00 p.m. Progress Report - What has Healthy Balance accomplished so far?
- 2:00 - 3:00 p.m. Working with policy makers - some tricks of the trade
- Special Guest: Judy Hughes, Executive Director  
Nova Scotia Disabled Persons Commission**
- 3:00 - 3:15 p.m. Break
- 3:15 - 4:00 p.m. Secondary Analysis Team
- 4:00 - 4:45 p.m. Survey Team
- 4:45 - 5:00 p.m. Wrap-up
- 5:30 p.m. Please join us for supper at the Symposium

### A G E N D A, Friday, June 13

- 8:45 - 9:30 a.m. Team Q - Focus Groups
- 9:30 - 10:15 a.m. Team P - Caregiving Portraits
- 10:15 - 10:30 a.m. Break
- 10:30 a.m. - noon Knowledge translation - What is it? How do we do it? What mechanisms, occasions and events should we consider?
- 12:00 - 12:15 p.m. Wrap-up
- 12:15 Lunch together before heading off in different directions





## Appendix C

# PUBLIC POLICY

## POLICY THEORY

- Define the problem
- Gather the evidence
- Identify the causes
- Evaluate other policies
- Develop solutions
- Select the best solutions
- The prince system (accessing you support and opposition)
  - ▶ Identify the players for direct and indirect impact
  - ▶ Determine issue position for those who support, oppose or are neutral
  - ▶ Determine power - how effective each player is in blocking the decision, helping to make it happen or affecting the implementation of the decision
  - ▶ Determine priorities - How important the decision is to each player
  - ▶ Calculate the likelihood of the policy being implemented
- Develop Political strategies

## POLICY REALITY

Rather than an orderly sequence of events, what often happens in the policy world is:

- Reaction to a crisis
- Developed in isolation
- Not coordinated
- Incomplete/piecemeal
- Under resourced
- Not well evaluated, if at all
- Does not work well in practice
- Political will

### **Judy Hughes**

Executive Director

Nova Scotia Disabled Persons Commission

Halifax, Nova Scotia



**Appendix D**  
**Secondary Analysis Team PowerPoint presentation**

**Secondary Data Analysis**  
 Lynn Lethbridge, Martha  
 MacDonald and Shelley Phipps

**Progress since last year . . .**

- ✓ "Taking its Toll: Implications of Paid and Unpaid Work Responsibilities for Women's Well-being"
- ✓ Paper finished and submitted for publication to *Feminist Economics*
- ✓ Presented at 'Sphere' seminar at Dalhousie
- ✓ Presented at CEA meetings in Ottawa and will be presented at IAFFE meetings in Barbados

**New Projects**

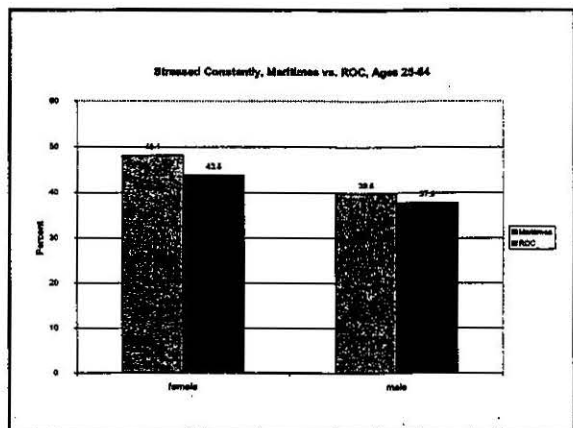
- ✓ "Atlantis"
- ✓ "The Hours"

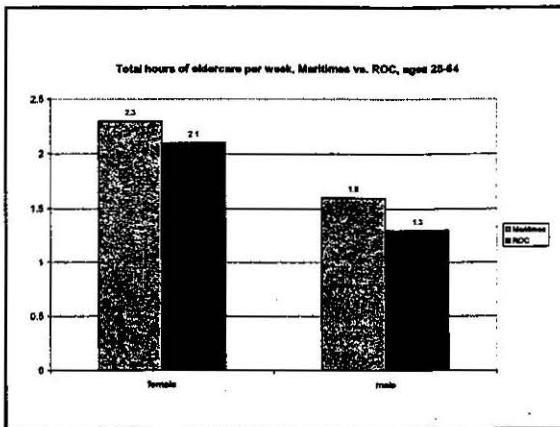
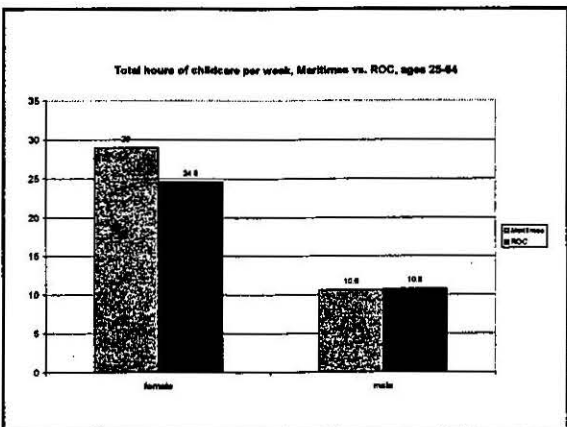
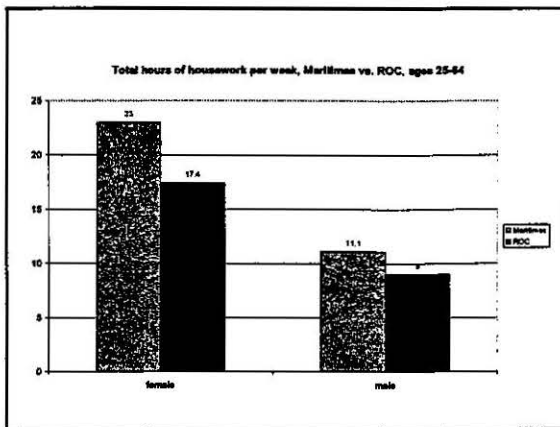
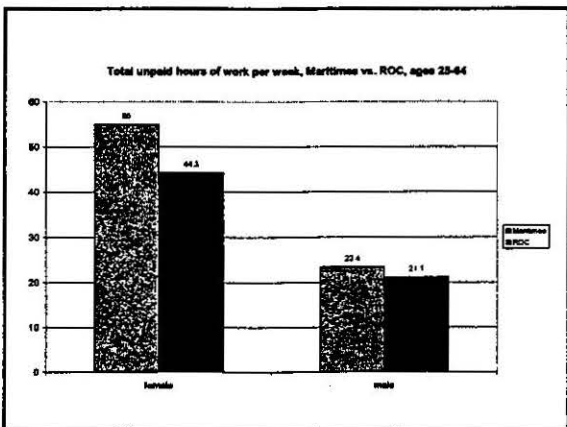
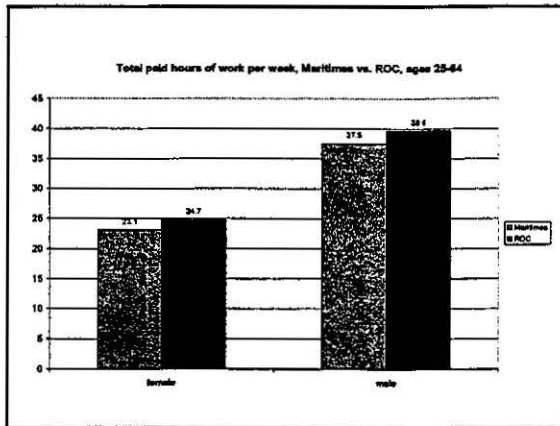
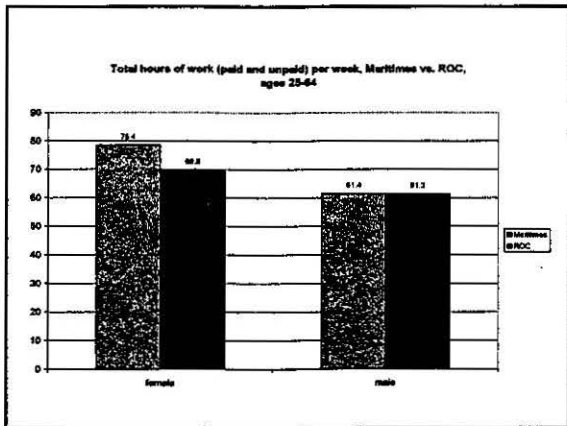
**New Project #1: "Atlantis"**

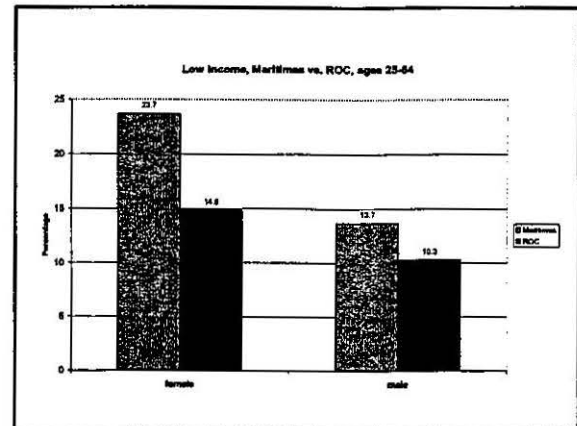
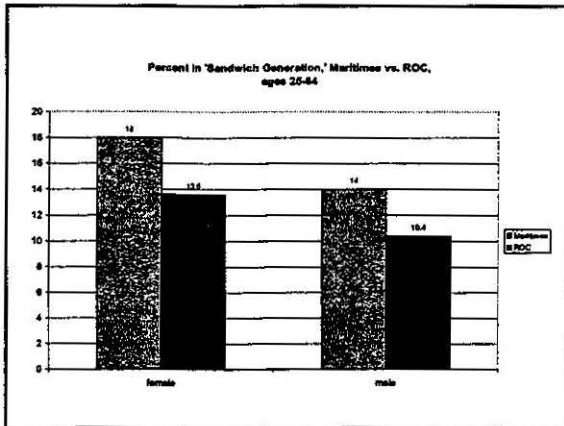
- ✓ Extension of "Taking its Toll"
- ✓ Study associations between paid and unpaid work responsibilities and women's reports of stress
- ✓ "Do you feel constantly under stress trying to accomplish more than you can handle"
- ✓ 1998 General Social Survey

**Differences from earlier study:**

- ✓ Expand sample to include 'older' women who are juggling both paid and unpaid work (25 to 64 years versus 25 to 54 in earlier study)
- ✓ Focus on comparison between Maritimes and rest of Canada (ROC)







**On-going research . . .**

- ✓ Multivariate analysis indicates that once we control for differences in work hours and poverty status, there is no significant difference in reported stress between the Maritimes and the ROC
- ✓ Can simulate implications for stress of reducing work hours to those reported for ROC; of reducing poverty

**Our question for you:**

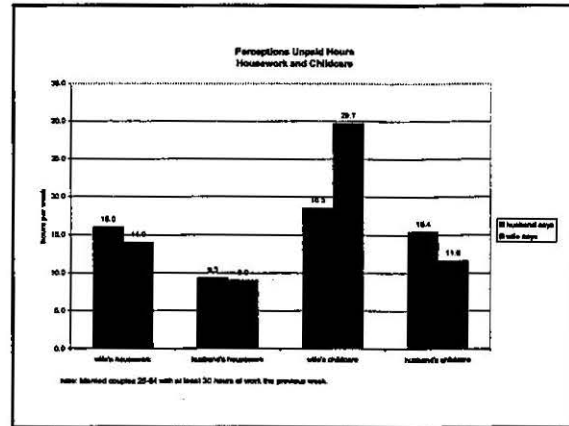
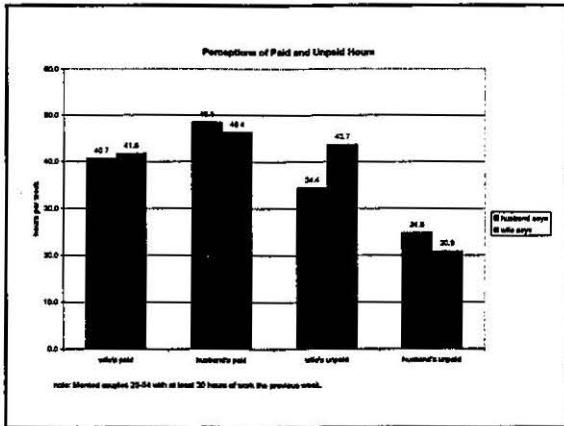
- ✓ Why do Maritime women do more unpaid work than women living elsewhere in the country?

**New project #2: "The Hours"**

- ✓ Beginning attempt to understand the process by which work hours are allocated in husband/wife couples
- ✓ Under what circumstances do husbands and wives do more equal total hours?
- ✓ Focus on couples in which both husband and wife worked 30+ hours for pay last week; both are aged 25 to 54

**"The Hours" (cont'd)**

- ✓ 1998 GSS asks husbands and wives to report paid and unpaid hours for themselves *and for their spouses*
- ✓ Note that *one* person answered for both partners
- ✓ Gives us a representative sample of all Canadian husbands compared to all Canadian wives



**Where do we go from here?**

- ✓ Multivariate analysis of factors associated with a more equal sharing of reported hours of work
- ✓ Attempt to understand differences in perceptions

**Possible Factors:**

- ✓ Education levels of both partners; family income; age, number and age of children, region, respondent/spouse disability; immigrant status
- ✓ 'Bargaining' variables: Higher education for him/her; Age differential

**Results thus far:**

- ✓ Not much explains share of unpaid work done by men (either as reported by themselves or by their wives) except that share is smaller in immigrant families

**Our questions for you:**

- ✓ Why do some men do a larger share of unpaid work?
- ✓ Why is total work shared more equally by some couples than by others?

Appendix E  
Survey Team PowerPoint presentation

## Phase 2: Population Survey

*June 12, 2003*

**Janice Keefe, Ph.D.**  
**Family Studies & Gerontology**  
**Mount Saint Vincent University**

Healthy Balance: a community alliance for health research on women's unpaid caregiving

## Outline

- ◆ **Goals of the survey**
- ◆ **Components of survey instrument**
- ◆ **Screening questions**
- ◆ **Sampling**
- ◆ **Analysis of variables**
- ◆ **Key messages**
- ◆ **Next steps**

Healthy Balance: a community alliance for health research on women's unpaid caregiving

## Goals

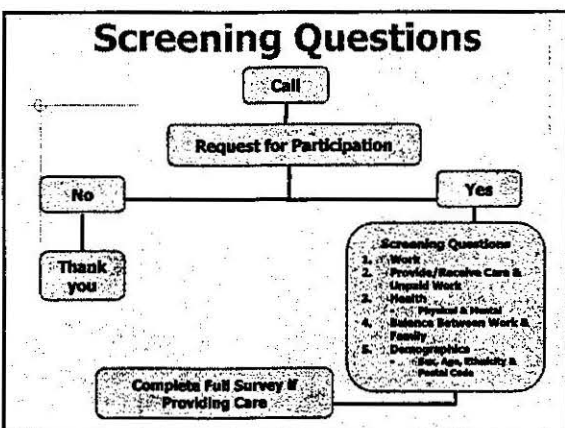
- ◆ **To provide insight into the scope of unpaid work in Nova Scotia**
- ◆ **To investigate perceived levels of empowerment**
- ◆ **To understand health outcomes related to unpaid work & caregiving**
- ◆ **To analyze the different forms of caregiving performed alone & in combination with paid work**

Healthy Balance: a community alliance for health research on women's unpaid caregiving

## Components of Survey Instrument

- 1. Caregiving**
  - Give & Receive Care
- 2. Indicators of Health**
  - Mental & Physical Health
- 3. Paid Work**
- 4. Balancing Paid Work & Caregiving**
- 5. Stress**
- 6. Demographics**

Healthy Balance: a community alliance for health research on women's unpaid caregiving

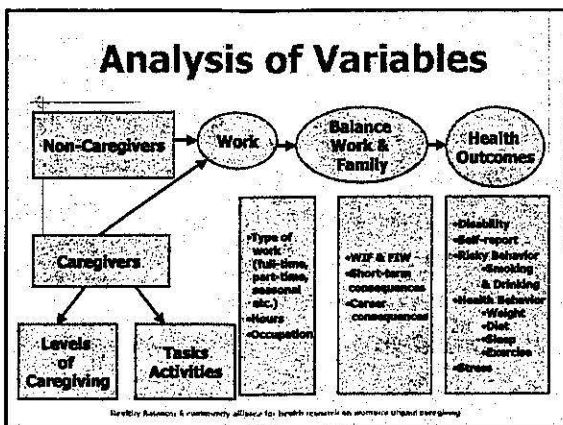


## Sampling

- ◆ **Over-sampling of those between the ages of 25 to 64 – work & care**
- ◆ **Over-sampling of Equity Reference Groups**
- ◆ **Include a comparison of:**
  - Non-caregivers
  - Non-employed (65+; 18 to 24)

Healthy Balance: a community alliance for health research on women's unpaid caregiving





- ### Key Messages
- ◆ Identify proportion of individuals who left work for caregiving
  - ◆ What is the impact of caregiving on health
  - ◆ How levels of caregiving effect work & family balance
  - ◆ How does caregiving effect consequences of work
    - Short-term effects
    - Career effects
    - Health outcomes
- Healthy Balance, a community alliance for health research on women's unpaid caregiving

## What do you think we will be able to say at the end of the survey analysis?

Healthy Balance, a community alliance for health research on women's unpaid caregiving

- ### Next Steps
- ◆ Survey revisions
  - ◆ Analysis review & discussion
  - ◆ Cost out survey collection
  - ◆ Conduct survey
  - ◆ Analyze data
  - ◆ Policy implications
- Healthy Balance, a community alliance for health research on women's unpaid caregiving

## Phase 2: Population Survey

*June 12, 2003*

**Janice Keefe, Ph.D.**  
Family Studies & Gerontology  
Mount Saint Vincent University

Healthy Balance, a community alliance for health research on women's unpaid caregiving

**Appendix F**  
**Table of Contents - Team Q Final Report**

***Boiled eggs are easy: The lived experiences of a diverse  
sample of caregivers in Nova Scotia***

**DRAFT REPORT**

**Prepared by:** Jacqueline Gahagan, Charlotte Loppie, Marlene McLellan,  
Laurene Rehman, Katherine Side

**June 30, 2003**

## **EXECUTIVE SUMMARY**

**Purpose**

**Findings and major themes**

**Gaps**

**Policy implications and recommendations**

## **TABLE OF CONTENTS**

### **1. INTRODUCTION**

### **2. PROCESS**

- 2.1. Purpose of the project
- 2.2. Team development
- 2.3. Partnerships
- 2.4. Methodology
- 2.5. Ethics
- 2.6. Instrument development
- 2.7. Focus group guide
- 2.8. Sampling
- 2.9. Recruitment
- 2.10. Meetings
- 2.11. Connecting to community
- 2.12. Interaction with Equity Reference Groups (ERGs)
- 2.13. Challenges and opportunities

### **3. FINDINGS**

#### **Demographics**

- 2.1 Research questions
- 2.2 Broad themes
- 2.3 Similarities and differences

### **4. DISCUSSION**

- 3.1 Policy implications
- 3.2 Best practices
- 3.3 Differential impact

### **5. RECOMMENDATIONS**

- 4.1 Uptake of findings
- 4.2 Process and limitations

## **APPENDIX**

## **REFERENCES**

Appendix G  
Feedback Form

**HEALTHY BALANCE RESEARCH PROGRAM  
EQUITY REFERENCE GROUPS  
JUNE 12 and 13, 2003**

1. **What did you like *most* about the meeting?**
  
2. **What could have been improved?**
  
3. **What are some of the things you learned?**
  
4. **What are some questions you still have?**
  
5. **Do you have suggestions for the next meeting? Remember, this will be a joint meeting with the National Reference Group.**
  
6. **What do you think of the facility? (If you have a suggestion for a better facility, please let us know - we will be happy to check it out!)**
  
7. **Final thoughts?**