

Translating Knowledge Directly to Childbearing Women:
A Study of Canadian Women's Preferences

W. A. Hall, RN, PhD

Professor

University of British Columbia School of Nursing

T. 201, 2211 Wesbrook Mall

Vancouver, B.C., V6T 2B5

J. C. Bandsmer, RN, M.Sc

Victoria General Hospital

K. Gregg, M.Sc.

Project Coordinator, University of British Columbia School of Nursing

C. Ebbelohj, RN, MScN

Lecturer, University of British Columbia School of Nursing

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Running header: Translating Knowledge for Canadian Mothers

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Abstract

Knowledge translation has relied on research products which take years to disseminate, losing relevance for intended users. We used a mixed-methods approach to determine women's preferences for research results and format, intention to share results, and potential benefits. We sampled healthy pregnant women who completed survey data during their third trimesters and wanted access to results. Mothers preferred results about sleep, fears, and anxieties during later pregnancy to benefit from reassurance their experiences were shared. Women mostly intended to share results with their social networks. Organizational contacts increased dissemination of the women's preferred information to non-study participants.

Key words: knowledge translation, maternal health, pregnancy

Running head: Translating Knowledge for Canadian Mothers

Background

Linking research to action is an essential component of the research process (Nuyens & Lansang, 2006). Most academic dissemination literature comprises theories, frameworks, models, and strategies, which address the complexity of the adoption of evidence-based interventions by organizations, health care practitioners, and policy-makers (Arrington et al., 2008; Baumbusch et al., 2006; Green, Ottoson, & Garcia, 2009., Ho et al., 2004; McBride et al., 2008; Tugwell, Robinson, Grimshaw, & Santesso, 2006). A model that is gaining support from funding agencies, such as the Canadian Institutes of Health Research (CIHR), is knowledge translation (KT). The CIHR (2004) defines KT as "the exchange, synthesis, and ethically-sound application of knowledge within a complex system of interactions among researchers and users" (p. 2).

The intent of the CIHR is to accelerate the capture of research benefits for Canadians through improved health (Strauss, Tetroe, & Graham, 2009). Graham and colleagues (2006) developed a model, adopted by the CIHR, specifically, the knowledge-to-action framework. Adapted to the health care context, the model incorporates knowledge creation and application; the action cycle of the model acknowledges the importance of identifying problems, selecting knowledge to implement, and adapting knowledge to local contexts (Strauss et al.).

The degree of engagement with a potential audience is an important element of KT. In this conceptualization, activities considered to be “pull” are focused on the needs of users, which create an appetite for research results (Tetroe et al., 2008). Our paper, rather than targeting policy makers and health care practitioners, presents a study aimed at translating knowledge directly to consumers, in this case, childbearing women.

Direct transfer of health knowledge to the general public has focused on making the community and the “consumers” of health care active participants in research; they are intended to contribute to the development of research projects and facilitate the use of evidence in decision making (Scharff & Mathews, 2008; Shea et al., 2005). Consumer involvement improves efforts to communicate research results to the community in a useable format (Green et al., 2009; Scharff & Mathews; Shea et al.); however, typical partnerships with consumers have involved existing consumer groups with identified health problems (Shea et al.) or communities have been described as stable entities with members available to engage in long-term partnerships with researchers (Scharff & Matthews).

Engaging with healthy, mobile, childbearing consumers offers a particular set of challenges to researchers who are interested in knowledge translation. Healthy childbearing women do not generally create consumer groups that coalesce around an illness condition. The current models of prenatal care delivery isolate women from other pregnant women (Baldwin, 2006). Women do not develop stable consumer groups that fit with consumer-based KT and dissemination descriptions in the literature (Scharff & Mathews, 2008). Consumers, such as childbearing women, usually have limited access to research, as well as limited time or expertise to extract relevant information when they do gain access (Eysenbach & Köhler, 2002).

Much of the focus in the KT literature has been on tested interventions to improve health (Green et al., 2009, Armstrong et al., 2007; Estabrooks, 2007; Graham & Tetroe, 2007). Green et al. argue the goal of evidence-based public health interventions is adoption by ‘free-living populations’. They highlight the reliance of research and

traditional knowledge translation on sources of evidence from randomized controlled trials in the confines of clinical research networks. Products involved with those approaches take years to make their way through the peer review process and lose timeliness and relevance for intended users. Attention to external validity requires consideration of sources of evidence, apart from randomized controlled clinical trials, that emphasize practical applications and up-take by intended users (Green et al.).

There has been minimal discussion of direct translation of research findings being an intervention in itself. In nursing practice, the delivery of health information has been viewed as an intervention (see for example, Nir & Weisel-Eichler, 2006). When individuals are informed about elements affecting their health or posing threats to well-being they may feel empowered to take increased responsibility for their health and well-being; psychosocial comfort and well-being can improve if people share experiences of concerns or common problems (Phinney, 2008). In other words, patients not only benefit directly from research findings about their everyday experiences, but also from learning from each other.

It is important to consider how researchers can move beyond traditional academic audiences to reach other target audiences, such as the public (Green et al., 2009; Tetroe et al., 2008). In this paper, we describe how we provided approximately 100,000 households across British Columbia (BC) and Canada with access to participant-driven, targeted information (a form of KT) arising from a four phase research process. We begin by briefly summarizing phase one of the research project and the results.

Phase 1: Summary of the Pregnant in BC Study

The first author conducted a cross-sectional survey-based study that examined healthy women's childbirth fears, expectations, sleep patterns and fatigue levels during their third trimester of pregnancy (Author, 2009). Eight hundred and seventy-two women throughout the province of British Columbia responded to recruitment efforts through posters, media reports, health professionals' offices, self-referral, community events for pregnant women, and professional organizations, academic institutions, and businesses. Women were provided with mail-out questionnaires.

The mean age of the sample was 31.5 years, with the majority (60%) being nulliparas. The women were well-educated, 98% had partners, and only 30.6% reported family incomes of less than \$60,000 CDN dollars per year. The majority self-identified as being Canadian (69.4%). In brief, 25% of women reported high levels of childbirth fear and 20.6% reported sleeping less than 6 hours per night. Childbirth fear, fatigue, sleep deprivation, and anxiety were positively correlated. ANOVA post-hoc comparisons indicated women with high childbirth fear were more likely to have more daily stressors ($F = 10.8, p < .001$), anxiety ($F = 88, p < .001$), and fatigue ($F = 27.5, p < .001$), as well as less help ($F = 12.7, p < .001$). Multiple regression analysis revealed higher family income, first time pregnancy, and higher levels of fatigue and anxiety predicted higher childbirth fear among women, accounting for 28% of the variance. Out of the final sample of 650 women, 254 women indicated they wished to be informed of the study results (39%).

To provide adequate funding for KT, the principal investigator applied for funding through the University of British Columbia. The grant supported a research

assistant to collect the qualitative and quantitative data and resources to develop formats for sharing the results.

Methods

The researchers used a mixed-methods approach to develop materials for KT; specifically we used mixed-methods for development, which is using qualitative data to inform questionnaire development (Molina-Azorin, 2011). Figure 1 describes the study design in four phases: 1) original mail-out survey; 2) qualitative study of participants' preferences for results and mode of access (n = 254); 3) on-line survey developed from phase 2 themes; and 4) broader dissemination of preferred information.

The extension to the study was approved by the University Behavioral Research Ethics Board. We used open-ended questions to generate qualitative data to determine women's preferences for information from the study results and format of the information. We also regarded accessing women's perceptions as creating an appetite for accessing research findings. Scharff and Mathews (2008) suggested qualitative research can help researchers take into account relevant community concerns and perspectives. The qualitative questions were as follows: 1) What kinds of information from the findings interest you; 2) What is the best format for you to access the study findings; 3) Do you intend to share the findings with other childbearing women or support persons? If yes, who; 4) How do you think the study findings could benefit other pregnant women and their families? Questions were shared with women by email.

Themes developed from our analysis of the qualitative data were used to develop a quantitative survey to determine the needs of users. The survey was an electronic

Internet survey (using the free Internet host Survey Monkey). The electronic internet survey questions are in Table 1.

Phase 2: Sample for the Qualitative Component

Of the women who had expressed interest in accessing the results, we randomly selected a subset of 60 women whom we contacted by telephone to determine interest in participating in the qualitative component. Thirty-nine women consented to respond to an email with open-ended questions. The women's mean age was 33, ranging from 22 to 41 years. Seventy-two percent of the women self-identified as Canadian with 5% self-identifying as Asian and 2.6% self-identifying as Chinese. It was a first pregnancy for 59% of the women. The majority (33%) had a university degree with 15% reporting less than a college education. Eighty-five percent of the women were employed with a median family income of between \$80,000 and \$99,999 Canadian.

Content Analysis and Findings

We used inductive content analysis to examine content to classify text into an efficient number of categories (Hsieh & Shannon, 2005). Content analysis has been deemed appropriate for text data that is in electronic form (Hsieh & Shannon). We developed general themes from email responses. We analyzed the emails sequentially until data saturation was reached ($n = 39$). Five themes were developed from the first question about kinds of information of interest: comparing personal experiences with other women, general overview of results, curiosity about study participants, requests for information not in the results, and inability to answer the question (See Table 2). When we analyzed the data from the second question the best format to access findings consisted of 6 routes, which were mostly electronic (See Table 3).

In response to the third question, 78% of women intended to share the findings with others, with the majority identifying other pregnant women, family, and friends as their intended recipients. The most common theme in response to benefits from findings was reassurance about being normal, followed by access to information, and identifying common problems with opportunities for improvement (See Table 4).

Phase 3: Sample for the Quantitative Component

After excluding women who participated in the qualitative component, we emailed a link to the internet survey to 143 participants who had provided an email address and indicated an interest in receiving the study results. Of those contacts, 11 emails bounced back and 3 produced an “Out-of-Office auto reply”. The research assistant delivered the survey by telephone for 5 participants who did not have access to the Internet and entered the results manually into Survey Monkey. A reminder email was sent three weeks after initial contact; 143 emails were sent, 16 bounced back as undeliverable. In total, 66 women completed the survey.

The online survey participants’ mean age was 31.3, ranging from 21 to 46 years. Sixty-eight percent of the women self-identified as Canadian, with 6% self-identifying as Asian, 8% as European and 5.2% as Chinese. It was a first pregnancy for 51% of the women. The majority (32%) had a university degree with 12% reporting less than a college education. All of the women had partners. Ninety-six percent of the women were employed with a median family income of between \$80,000 and \$99,999 Canadian.

Results and discussion

Our survey results indicated the women wanted information that would allow them to compare their sleep experiences with other study participants (77%), learn about

what interfered with sleep (73%), understand women's concerns, fears, and anxieties regarding pregnancy and labor (73%), access general information about later pregnancy and health (52%), and learn about participants' general demographic information (39%).

Comments written on the online survey and volunteered during the qualitative component indicated participants had specific questions. Some examples included: "Any information on pregnancies for women over 40; any information on pregnancies where women had an above-average weight gain; [did] any other women say anything about how their toddlers affected their sleep?; and what sleep aids could be used during pregnancy?" The nature of the questions indicated areas where women lacked knowledge, either because these areas have not received adequate research attention or KT from existing evidence has not been available to pregnant women.

Based on the qualitative themes, we offered women choices to indicate how the study findings could best benefit other pregnant women and their families. Their overwhelming choice was that the results could provide reassurance for pregnant women that sleep issues and feelings, such as worry and anxiety, are normal, commonly experienced, and could help women and their families to "not feel alone" (74%). In a telephone interview, one woman made this statement:

"In my experience pregnancy is an overwhelming time of information overload and studies such as yours could help ease some of the anxiety experienced because women would know if they are within the norm or if they should consult their physician for further assistance."

Another woman, from our online survey, wrote:

“It’s nice just to know that you are not the only one that is going through the experience. Although everyone’s experience is unique, we all usually have many things in common. It will give reassurance and peace of mind.”

Other responses about benefits included: general access to information for use by pregnant women (19%); and having factual data in the form of numbers, to back up their statements about concerns (8%).

Women also responded to the survey question about whether they would share the information they received; 64% indicated they might, while 15% did not intend to share the results. The remainder of participants did not respond to the question. When asked with whom they might share information, the majority of women indicated friends (68%), followed by family members (47%), other pregnant women or women wanting to start a family (44%), co-workers (14%), doctors (8%), doulas (8%), and midwives (5%).

We created a three-page summary of the survey results and saved it as a write-protected PDF file to maintain integrity of the results. We linked the file to the research website and emailed it as an attachment to all women who had provided email addresses and indicated they wanted results. The email also included a link to our website where the preferred information about results was posted. In total, emails were sent to 223 addresses, with 19 bouncing back. A further 39 paper summaries were mailed to participants who wanted results but had no functional email address. Four envelopes were returned to us as undeliverable. Two summaries were mailed to women who called about participation in our study after our data collection had already been completed. In total, we estimate that 241 participants in British Columbia received a copy of the results.

Phase 4: Broader Dissemination of Preferred Information

During recruitment, we used institutions to display recruitment materials and notify potential participants about the study. Our institutional connections included large and small businesses, province-wide professional groups, and an academic institution. To more broadly disseminate preferred information, we planned to build on our organizational relationships.

Through email communication, we requested representatives of our institutional partners to review a KT summary for its relevance to their constituents, indicate their preferred format for disseminating study findings, provide views about using the information, and suggest the most appropriate method of contact for future research results. When no responses were received to the email or a follow-up email request we contacted representatives by telephone and reached six contacts. One institution could not be reached by either email or telephone. When making contact, we were often directed to other individuals than the previous liaisons who facilitated recruitment for the study, as a result of changes in management structures. We built new relationships with institutional colleagues.

Some company representatives expressed hesitation about KT; barriers included concerns about organizations' appropriate roles. For example, a contact at a large institution did not want to be seen 'promoting one researcher's work'. Another company representative hesitated to engage in KT due to time and resource issues. Some contacts raised questions about the value of our findings for their employees and consumers.

To respond to barriers, we explained about the results we wished to disseminate and negotiated about methods to disseminate preferred information to suit available

technology and institutional tastes. Our actions proved beneficial to relationships because we tailored the format of our findings to fit with institutional requests. For example, we created a fact sheet hand-out for employees and customers of one organization rather than using their website. The outcomes are summarized in Table 5. By using organizations for broader dissemination of preferred information, we estimate approximately 124,350 households had access to our summary. Further diffusion of information (untargeted, unplanned) is also possible as a result of our targeted dissemination, through households sharing with others.

Conclusion

The intent of the CIHR (2004) is to accelerate the capture of research benefits for Canadians through improved health. Attending to engagement with a potential audience is an important element of KT; in our conceptualization we attended to the needs of users to create an ‘appetite’ for research results (Tetroe et al., 2008). We invited research participants and institutional recruitment partners to a conversation about KT and supported their appetite by determining participants’ perspectives about important elements of research results, ways in which they could most easily access them, intent to share results, and potential benefits from accessing results. We engaged with previous partner organizations to negotiate forms of dissemination that were most acceptable to them.

The strategies described are particularly important for a group of research participants who are healthy, relatively isolated from each other, and not easily accessible through illness-based consumer groups. Our difficulties re-contacting women using the original email addresses supplied for recruitment support our view of childbearing

women as a highly mobile population. The traditional definition of stable communities that are available for research partnerships (Scharff & Mathews, 2008) are difficult to apply to this group.

Complex processes of engaging community members in determining research priorities, undertaking peer review of systematic reviews, transferring knowledge to health care decision-makers, and promoting awareness and use of reviews have been taken up by groups linked with particular illness conditions (Shea et al., 2005). Those processes show attention to synthesis of research studies so that results can be assessed in the context of a larger body of knowledge and research and the judicious translation of research into practice and policy (Graham & Tetroe, 2007). It is important to state our approach to KT is not advocating practice or policy change. We have delivered targeted health knowledge in order to assist pregnant women to access research findings they regard as useful for their lives. It is possible that our findings will assist some pregnant women to act as advocates for themselves and each other, particularly because of their willingness to share the findings from this study with other pregnant women and the potential for women to demand effective services to deal with their concerns, as has been argued for other groups (Phinney, 2008).

Because our study findings were derived from a single, cross-sectional study of pregnant women's anxieties, fears, sleep deprivation and fatigue and extra resources were required for KT, we created a more flexible and rapid approach to KT rather than relying on building long-term relationships with community groups (Scharff & Mathews, 2008; Shea et al., 2005). We maximized the opportunity to engage women and organizations through internet access, on-line communities, and communication techniques associated

with BC-based, national, and international organizations. Ho and colleagues (2004) also emphasized the utility of modern information and communication technologies in the targeted distribution of information from which the public can benefit. We found some women preferred multiple approaches to accessing the findings. Engaging with research results in more than one mode (print reports, websites, and workshops) has been linked to increased utility of results and greater likelihood of sharing information with others (Mueller et al., 2008).

Our approach was limited by developing our internet survey based on responses from 39 women. The group of participants could have had particular interests in study findings, which were not shared by the larger group. A further limitation was our inability to access some of the original study participants. The number of emails that were not deliverable and the change in personnel in the institutional settings reinforced our view that a rapid approach to support KT that did not only rely on providing a published peer-reviewed paper was important for our participants.

Ethics applications generally require research participants to have access to study results. Moreover, the funding agency was supportive of our community-wide recruitment approaches and innovative efforts to share findings. Research funders want to know whether the research they are funding has an impact; it is important to have an idea of the target audience for findings and to take steps to reach this audience (Lavis, Ross, McLeod, & Gildiner 2003).

Traditional KT venues have relied on using health care practitioners to alter practice and disseminate research findings to their patients (Arrington et al., 2008; Baumbusch et al., 2007). The study participants considered themselves least likely to

share the information with health care professionals. In McKenzie's (2002) study of 'every day information seeking' communication between pregnant women and their physicians, patients reported withholding certain questions because they did 'not want to bug the doctor'; they assumed that their physicians would be too busy or the women assessed their concerns as trivial. It is possible that our participants chose not to mention the study findings to their health care providers because, as McKenzie suggested, they did not see themselves as valid providers of 'expert' knowledge. Studies of patterns of health care provision to pregnant women have suggested prenatal visits, with the most common forms of care providers, generally last an average of 15 minutes (Moos, 2006). Given the emphasis on surveillance for complications (Moos), it is possible that both women and health care providers would not view prenatal care as a useful venue for sharing research results about psychosocial areas. Moos suggests that women and their physicians would benefit from sharing psycho-social concerns in terms of relationship building.

The women's responses indicated they identified with the study participants as a group with a collective experience of later pregnancy, even though they were widely scattered geographically. They did not know each other, but were curious to know about each other.

Alternative venues to prenatal care could be developed for health care providers to share relevant psychosocial and sleep information with pregnant women, perhaps where they can be connected with each other to form support groups in their communities.

Institutions willing to assist with KT are valuable resources. By using institutional relationships, many households had the potential to be reached with targeted research

information with a minimal amount of expenditure and time. Including a simple question on a study contact form, “Are you interested in finding out the results of the study?” can be used by researchers as a base to build KT activities. Marketing techniques can be incorporated in KT. The 2000 Conference Report “Knowledge Transfer: Looking beyond Health” supports guidelines to assist researchers in effective transfer of research knowledge to the public (Canadian Health Services Research Foundation). The questions they raised are similar to the ways we approached KT, including: Who is it who wants to know what we know; What is it they care about; Is there something tangible they can hold in their hands; Is it delivered in a way that people trust, and can understand (Canadian Health Services Research Foundation)?

Our approach to KT suggests a number of other useful strategies. For example, monitoring website hits, having a feedback page on our results page, and including a question about how participants accessed the website, would increase understanding of the strategies’ effects. It is also important to determine whether participants shared the findings and with whom. Research could be conducted to determine why women were least likely to share research results with health care professionals. It would be useful to determine whether our summary adequately satisfied participants’ needs, or they had any suggestions for improvement.

In conclusion, our paper has described an innovative and relatively simple approach to KT with a group of healthy, mobile childbearing women and institutional liaisons. It describes KT approaches that are less sophisticated than systematic reviews and targeting practitioners and policy-makers, but the approaches used here have the

potential to increase women's understanding of shared concerns during pregnancy and increase their potential to serve as advocates for professional attention to their concerns.

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Figure 1: 4-Phase flow diagram of direct translation of knowledge (KT) to study

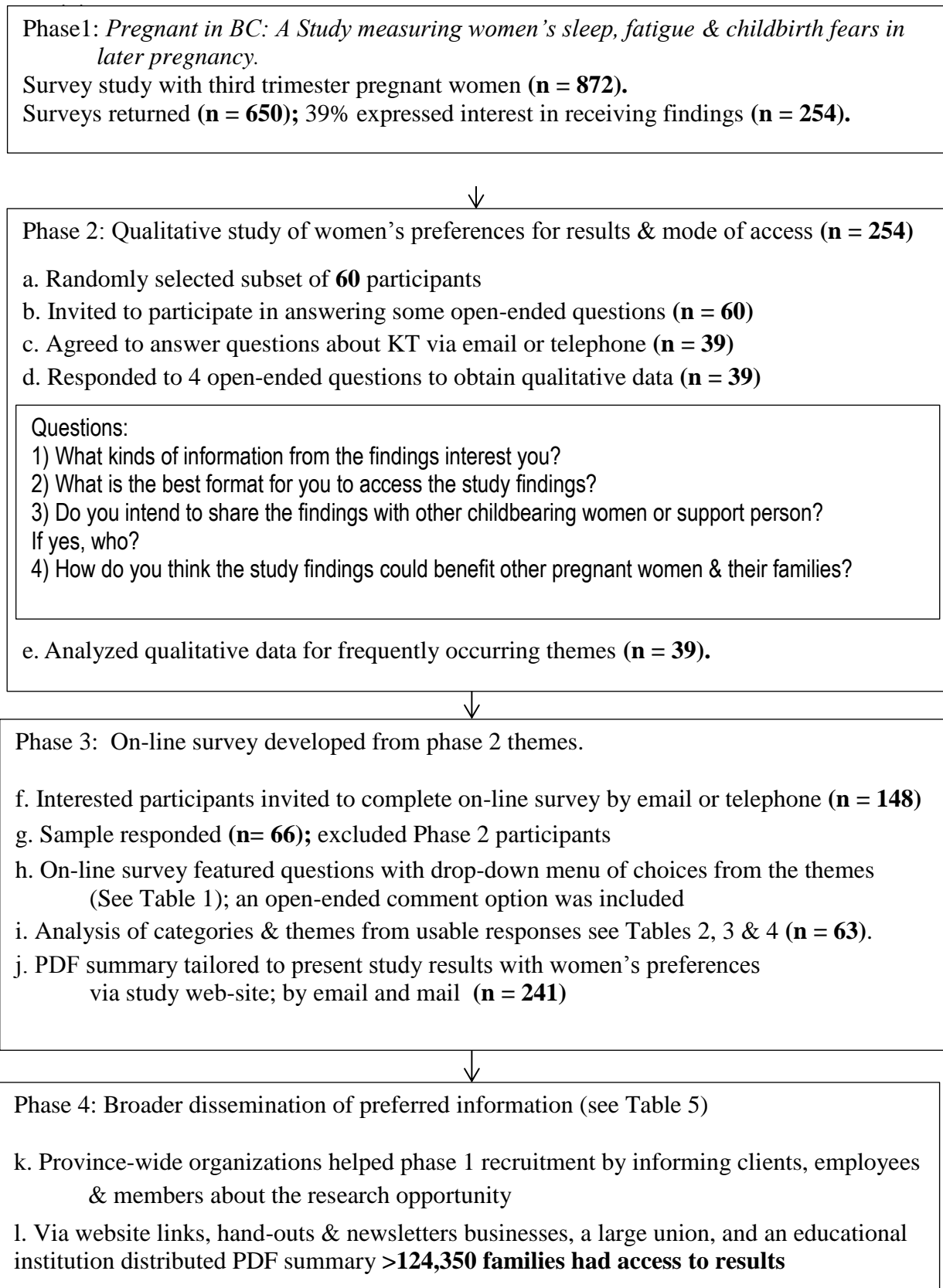


Table 1: *Survey Monkey Questions for the Study*

Question number	Question	Options
Q1	Tick the box that best identifies your preferred result format or access	<p>Enhanced summary</p> <p>Emailed link to Pregnant in BC website</p> <p>Paper copy mailed to my home address</p>
Q2	Tick the box beside the information themes to include	<p>Information about normal sleep patterns to compare my experience</p> <p>Information about other survey participants</p> <p>Information about the ‘average’ third trimester experience for women</p> <p>Information about what interferes most with sleep for women</p> <p>Information about women’s concerns, fears , and anxieties regarding pregnancy and labour</p> <p>General information about later pregnancy and health</p> <p>Information about whether sleep patterns and worry affect labour and delivery</p>
Q3	Please tell us about any other information you would like to receive in the box below	Open box
Q4	Do you intend to share the findings with childbearing women or support persons? If yes, who?	<p>No. I don’t intend to share results.</p> <p>Yes, I do intend to share results with:</p> <p>Friends</p> <p>Pregnant women, or women wanting to start a family</p> <p>Family members</p> <p>Co-workers</p> <p>Doctor, doula, midwife</p>
Q5	How do you think the study findings could benefit other pregnant women and their families?	<p>Reassurance sleep issues, and feelings (worry anxiety) are ‘normal’, commonly experienced,</p> <p>General need for access to information of use</p> <p>I want numbers to back up my information about the study.</p>
Q6	Please comment below on benefits of the study findings	Open box

Table 2: *Interest Categories*

Category	Thematic category	Characteristic responses
Compare with others		
C1	Average comparison and curiosity about others	It interests me to see if I fit into the 'average' as far as the pregnancy went and to see what other women's answers were. How many women are in the study? How many were pregnant for the first time?
C2	Sleep pattern comparison	Want to compare the results of other women with my experience. Are my sleep patterns on par? It was nearly impossible to sleep.
C3	Sleep interference comparison	What interferes with sleep the most for other women? Do toddlers affect sleep for others the way mine did?
C4	Fear and anxiety comparison	What are women's concerns, fears, and anxieties regarding pregnancy and labour? Did other women suffer from the same levels of stress that I did? Also how others feel about labor as it approaches.
C5	Age comparison	Is age a factor? I'm 41. Do older women have different patterns?
Improve sleep		
S1	Strategies to improve sleep	What might be able to help improve sleep comfort in pregnancy to avoid being exhausted as we head into labour?
S2	Herbal remedies	What herbs are safe?
Request results		
R1	Results summary	I am interested in the outcome of the findings just in general.
R2	Sleep and birth outcomes	I want to know does the lack of sleep result in higher percentages of C-sections?
R3	Recommendations	Will the information provided help future women have better birth outcomes?
Unable to answer		
U1	Summary needed	Need summary to answer questions.

Table 3: *Preferred formats for receiving results*

Formats
Email of pdf
Link to the Website
Both website link and email
Paper-based format
Research article
In lay terms
Graphs and summaries of research impressions

Table 4: *Perceived benefits of sharing information with others*

Category	Thematic Category	Characteristic Responses
Perceived benefits of sharing study information		
B1	Access	Need for access to information of use to pregnant women who have the right to know
B2	Reassurance	Reassurance, that it is normal to have sleep issues' 'Good to know you are not alone and what you are experiencing is normal; need to be reassured and comforted'
B3	Advocacy and areas for improvement	We need numbers to back up what is normal Women's need for rest during pregnancy is a neglected area Information to help women when they are most vulnerable from lack of sleep
Unable to answer		
U1	Summary needed	Need summary to answer questions.

Table 5

KT Outcomes using business, union, academic, and service collaborators

Collaborator	KT approach	Potential number of people reached
Large financial institution	Link to results on internal employee website.	Employs 2,800 in BC, 35,000 world-wide.
BC-wide professional organization	Publication of short summary with link to results website in a column of their news magazine.	Circulation is approximately 60,000 members. Magazine also available to public online
Large BC union	Dissemination at the Women's Committee booth at convention in form of handouts.	400 participants attended the convention
Large BC-wide medical business	Double-sided fact sheet created for distribution centers throughout BC; fact sheet circulated to employees as well.	100 locations across BC will have fact sheets for access by employees (~950) and clients (2 million patient visits per year).
Large BC and Canada-wide communication organization	Posting a link to our Preliminary Results website on their employee benefits webpage.	Approximately 8,500 employees in BC; 28,000 across Canada.
Academic organization	Posting a link to our Results website on their Environment, Health and Safety website.	Depends on website travel