

# Focus Groups in Health Services Research at the Institute for Clinical Evaluative Sciences



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# TECHNICAL REPORT

## Focus Groups in Health Services Research at the Institute for Clinical Evaluative Sciences

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## Introduction

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Health services research applies research methodologies in innovative, creative ways to probe the interface of clinical practice, health services delivery and health policy. The overall goal is to improve the equity, efficiency, effectiveness and quality of health care, and to create a blueprint for a better health care system. One of the specific goals is to enable patients to achieve optimal care and, in the new era of informed consent, take a much greater role in treatment decisions.<sup>1</sup>

The Institute for Clinical Evaluative Sciences (ICES) specializes in health services research. Many of the research projects completed to date have helped to “shift the goal posts,” and set new standards for the quality and efficiency of care. The provision of evidence-based information for clinicians, managers, policy-makers and the public—with a view to protecting and improving the quality, accessibility and affordability of health care—is one of the most important components of ICES’ mandate.<sup>1,2</sup>

ICES employs diverse methodologies—both quantitative and qualitative—to provide high-quality information to physicians and the public. Noticeably, more and more projects which involve components of informing the public or the medical profession may include methods that augment traditional quantitative methodologies. Health care evaluation research now frequently features a component that reflects the opinions of consumers of care. Particularly in the development of decision tools and decision aids, investigators are using qualitative manoeuvres—specifically focus groups—in new and creative ways.

Focus groups are group interviews conducted by a facilitator, with or without the assistance of an observer or recorder, which capitalize on discussions with a small group of people (usually six to ten) on a specific topic from the perspective of their individual experience or opinion. Typically, a group interview runs anywhere from half an hour to two hours.

Focus groups can be used for a variety of research purposes:<sup>3,4</sup>

- ◆ as basic research, to contribute to fundamental theory and knowledge
- ◆ as applied research, to illuminate a societal concern
- ◆ as summative research, to determine program effectiveness
- ◆ as formative evaluation, for program improvement
- ◆ as a method to facilitate or evaluate provider/consumer relations or services
- ◆ as a method to deconstruct a routine cycle of care or service to generate new insights.

Historically, the quantitative community of researchers has been somewhat unsympathetic to the use of the opinions of the lay public to inform providers of care. They question: 1)

their ability to objectively evaluate care received (in part because of their lack of knowledge of the technical aspects of care); 2) how much influence or weight should be placed on the views of the small number of people which typically constitute a focus group; and 3) the variety of types of bias introduced.

The use of focus groups in soliciting the views of the public when the subjective viewpoint is of interest can be valuable. It has been our experience that focus groups can provide an excellent method for obtaining particularly rich information within the social context. This methodology can be used quite successfully conjointly with and to inform other research approaches, which can provide a broader perspective for the investigator. Soliciting the opinions of the public has the potential to enhance the quality of some types of research projects, by providing fresh perspectives on process, context and experience.

Originally, focus groups were used as a marketing strategy to test responses to the way a product was positioned to enter the market and its desirability as a commodity.<sup>5</sup> In their importation to health research, focus groups have been used to assess health education messages and manoeuvres, and to examine the public understanding of illness, various health behaviours and health programs. Focus groups can be used to explore how patients have experienced various health care services, or what their experience of a specific illness or disease process has been.

Focus groups provide a venue for data collection that capitalizes on group interaction and usually yields rich experiential data. Participants can choose the vocabulary of their discussion and issues important to them within the framework of the research question, providing a source of valuable information. It is the dynamic of the group process—stimulating the thinking processes of and provoking conversation among participants on a topic of interest or in response to specific questions posed by the researcher—that can provide researchers with details and perspectives they could not obtain using other methodologies.

Consensus is not the reason for focus group discussion. Because focus groups encourage talk between participants in the group—asking each other about experiences, reacting to each other's statements, and discussing potentially differing points of view—this process provides an opportunity for participants to explore and to clarify values which would not happen in a one-on-one interview. In quantitative analysis, data points are arranged in relation to the norm. In qualitative analysis, the range may also consider the outliers—which contributes to the richness of the data obtained. If a researcher wants to explore an individual perspective or a sensitive topic in depth, focus groups may not be the most appropriate method.

This document has been developed to report specifically on the use of various types of focus groups – and the way ICES as an agency has used them in health services research. In this context, focus groups have included interviews with the lay public, panel discussions of stakeholders providing input on proposals, and a facilitated multi-physician discussion.

The document is also intended to provide an in-house template for future research involving focus group activity by chronicling the use of these methods on a project-by-project basis. Sample consent forms, check lists, budgets, a reference bibliography, and a list of manuscripts and deliverables to review are included in the appendices.

In addition to statements made earlier in this report, there were several questions that arose from attempts to analyze, define and make sense of what is “different” about the use of focus groups within the context of the health services research done at ICES, as compared to their use in traditional qualitative work. They are presented here with our thoughts and “decisions” to further inform the reader.

### **Focus Groups – Some Preliminary Questions and Answers**

**Q - *Do we use the term ‘focus groups’ too lightly?***

**A -** By definition, bringing together a group of individuals for discussion about a pre-specified topic is called a focus group. Usually focus groups are constructed—persons with a common disease, a group of people who work together—to capitalize on participants’ shared experiences. It can also be useful to pull together a very diverse group to explore the range of responses within the group (i.e. a group of teachers). When we pull together groups of physicians, in some contexts we call them “focus groups,” but in others we call them “expert panels” or “consensus panels.” In each of these cases we are seeking expert (informed) opinion.

**Q - *How do we differentiate between “focus groups” and “expert or consensus panels”?***

**A -** The answer lies in the *objective* of the discussion meeting. If we are aiming for consensus (as in delphi processes concerning urgency ratings for bypass surgery), we cannot call them focus groups. If we are discussing usual parameters of care or prescribing patterns with a group of physicians, we can, because we are looking for a range of behaviours that may further direct, for example, guideline development.

We use focus groups for a very wide range of research activities and we acknowledge that we have been very flexible and quite informal in our development and approach to using focus groups in these contexts.

**Q - *Does that informality characterize ICES focus groups or does that describe a characteristic of focus group use in health services research?***

**A -** ICES focus groups are sometimes used in evaluation as well as fundamental research. We would argue for an expanded definition of rigour in the research process that includes care and adherence to data collection rules, but allows for flexibility and modifications to research processes reflect the demands of the project and the field.

**Q - *Is this flexibility a characteristic of doing focus groups in health services research? In evaluation research?***

**A - Yes.**

**Q - *We also use focus groups as process in researching topics. Is that a characteristic?***

**A - Possibly.**

**Q - *Because we use focus groups for such a variety of information-seeking projects with equally various aims and objectives, and have certain characteristics articulated above, are we in fact developing a new construct for focus groups within health services research? Are we, in an unplanned fashion, generating theory?***

**A - No.**

**Q - *Do we need to modify the definition of focus group use in health services research?***

**A - No.**

**Q - *Do we need to concern ourselves with concomitant development of a guideline or criteria or something of that nature to carve out how one conducts focus groups in health services research?***

**A - This document's original intent was to be descriptive and experiential; should another document be a "methodology" review considering (and comparing and contrasting) formal qualitative methods? No. There are many methods papers available in the literature.**

## Why focus groups in health services research?

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The general goal of health services research is to improve the equity, efficiency, effectiveness and quality of health care.<sup>1</sup> Many of the activities of health services research have traditionally relied on data which is amenable to statistical analysis and generalizable to entire populations, indicating which health services are efficient and effective. Projects done at ICES are planned to provide a wide and varied audience including the public, health care practitioners, other stakeholders and/or policy makers with the best evidence available. Many of the projects are quantitative analyses that inform many of these stakeholders.

Qualitative techniques such as focus groups can alternately provide data that offer important information we cannot access with traditional quantitative or epidemiological approaches—such as information about needs, beliefs, attitudes and values of various individuals or population sub-groups, and insights into new or complex public issues. These data, when analyzed, provide fertile ground for hypothesis generation or concept clarification. The data enable a “real life” rather than an experimental or controlled view of past phenomena. The information can be used to identify potential areas of enquiry, to explore issues that are not amenable to quantification, to augment understanding of one or more dimensions of a study, as first steps in exploration/description of a particular problem, and potentially as a basis for hypothesis development.

Some of the applications for focus groups in health services research are:

- ◆ to serve as a tool in strategic or long-range planning
- ◆ to learn about information needs of specific groups (e.g. men needing information about prostate cancer screening)
- ◆ to develop and assess the usefulness of educational materials (e.g. breast cancer decision aid)
- ◆ to evaluate programs (e.g. prostate specific antigen project)
- ◆ to provide opinion on policy creation or revision (e.g. wife abuse/abuser project)
- ◆ to supplement professional services (e.g. physician feedback study)

They are also useful:

- ◆ in testing the construction, utility or validity of questionnaires or when trying to focus on the most important variables in a planned study
- ◆ when survey results are ambiguous or suspect and require clarification or more elaborate explanation

## Issues to resolve when contemplating focus group use in health services research

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There are a number of steps, as in any research project, to review when considering the use of focus groups:

- ◆ ***Why choose focus groups for this project?*** Consider them when planning to discuss service utilization, program or tool/instrument development and evaluation, for defining issues or deficiencies in health care delivery, to assess health knowledge and health care behaviour, to evaluate effectiveness of educational materials, to recognize incongruencies and disparities in needs and perceptions of need.
- ◆ ***What is the research objective?*** Having a clearly articulated research question and questions to be answered will help provide a framework from which to consider topics, criteria and question development for the group. Questions must be open-ended to encourage discussion and debate among participants, rather than just *yes* or *no* answers or simple statement responses.
- ◆ ***Who is the target population?*** This decision is based on the research area or questions to be addressed. Typically, focus groups are homogenous. Issues to consider include sample size; variation, homogeneity or heterogeneity of participants; and sampling strategy (convenience, random, stratified).
- ◆ ***Where, when, how?*** Organization and facilitation should all be prearranged in a repeatable fashion. Location (when possible), time allotted for the group and the questions to be asked should all be standardized.
- ◆ ***What's the plan for the data? Manual or computer-assisted analysis?*** At the outset, notes should be typed and tapes transcribed to facilitate the chosen method of analysis. In transcription analysis one identifies themes and patterns within the notes. There are several types of content analysis including: rating of themes or issues by independent raters who then compare and contrast observations through aggregate analyses; tabulation of word or phrase frequencies; developing grids which summarize the themes/patterns of the language of the focus group; and coded mapping of transcripts.<sup>4</sup>
- ◆ ***How to disseminate? Oral presentation? Written report?*** One of the most common problems with qualitative research is not communicating the findings to audiences who could benefit from hearing them. Publishing research findings formalizes and legitimizes the data and its analysis, moving it from the sphere of *anecdotal* and *informal* findings. It also provides access to the information for other researchers. Quantitative researchers have traditionally had difficulty with qualitative methodologies in that reliability and validity of this type of data can't be measured in the same way that quantitative data can. There are, however, other ways to evaluate and methodologically ensure rigour that are more appropriate for this type of data. In general terms, researchers can make data collected in this

fashion credible by carefully preparing questions, choosing participants, encouraging vigorous discussion, repeating the process among several groups convened for the same purpose and analyzing the data obtained rigorously. Within the context of this methodology, the results obtained have the potential of being as reliable and useful to inform researchers as those obtained through quantitative methods.

## From the trenches: General suggestions for running focus groups

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A general bibliography has been included in the appendices to help with project planning. Some examples of ICES projects, lists of working papers/journal articles, documentation and consent forms, and actual time spent on various projects to help with budget projection have been included.

### Sampling/Group composition

Kitzinger<sup>6</sup> points out a couple of advantages to focus groups: they don't discriminate against people who can't read or write, and they encourage participation from those who feel they may have nothing of importance to say or that are reluctant to be interviewed on their own. This potential for inclusiveness rather than exclusivity is very attractive when soliciting opinion.

Most focus group studies involve only a few groups, numbers depending mainly on what the aims of the project are, the available resources, and the heterogeneity of the population of interest. Most use a *convenience and/or purposive model* in which participants are selected to reflect a range of the total study population rather than a representative sample of the population.

In purposive sampling, researchers draw on their knowledge of the subject under investigation to identify those characteristics that are likely to influence variability in the responses from the focus group participants. The respondents are then selected on the basis of these characteristics. For example, if social class and ethnicity are important considerations, researchers might choose to conduct focus groups among ethnic minorities or among those who are societally disadvantaged. Usually the use of a *theoretical sampling model*<sup>7</sup> is neither possible nor warranted unless the purpose of the project is explicitly to generate theory, which is not the *raison d'être* of focus groups used in health services research.

To capitalize on participants' shared experiences, most researchers recommend homogeneity of the group as a goal. People may be more comfortable talking when surrounded by like individuals. Conversely, it can also be useful to pull together a very diverse group to maximally explore the range of responses within the group (e.g. a group of teachers). However, a hierarchy based on seniority within that group may occur which may inhibit the exchange of ideas and provision of information (for example, a principal with a junior teacher). Additionally, little may be gained from a focus group where lack of common ground results in heated arguments or distrust.

Groups that work well can be ones that occur naturally (persons with a common disease, a group of people who work together) or ones that can be drawn together specifically for the project. When participants know each other as friends and colleagues, they share and relate to each other's comments but may also challenge each other on contradictions between what they say they believe and how they actually behave. Groups of strangers can

work equally well – the anonymity of the situation can provide an atmosphere where complete honesty can take place without fear of reprisal.

The literature varies on the optimal size of a focus group. Researchers have commented that when groups are larger, participants can be competitive, inconsiderate, too aggressive and impulsive, but may generate more ideas. Conversely, when groups are smaller, participants can be tactful, constrained, passive and tense, but may not necessarily generate fewer ideas.<sup>8</sup> Critical factors to consider when considering the size of focus groups include the nature of the study and the complexity or sensitivity of the topic to be discussed; the diversity of the group and participant ability to converse effectively and collectively; the needs and abilities of the participants themselves; and the skills of the facilitator<sup>8</sup>.

Ideal group size ranges between four and twelve people. If there are more participants than that, not everyone will get an opportunity to talk on all issues, and the facilitator and recorder cannot keep track of body language and background conversation; if there are fewer participants, it may be difficult to invoke group interaction. Many researchers prefer groups of no more than six or eight participants. Many qualitative researchers feel that the size of a focus group should be based on the research topic or purpose. But when discussing sensitive or highly intense issues, forming a group with fewer numbers may prove more useful because group cohesion may be more easily established. Highly charged debate or expression of feelings can be harder to moderate when the group is large.

There is no “right” answer to how many focus groups are “enough” in order to be confident that one has good and adequate data. It will always depend on the subject/phenomenon of interest and its complexity, and the purpose of the study. The literature is quite contradictory in this area, suggesting a range from one to ten groups is usually adequate for most projects. The content of group discussions begins to repeat itself and there is no new information when nearing the point of “enough”—in our experience, about four to eight focus group encounters.

Anonymity of group participants (or first name only) should be maintained whenever feasible. This can be achieved when facilitators are not the recruiters or responsible for sign-in/expense reimbursement of participants. Anonymity may not always be possible within the group but confidentiality should be assured (see Ethics section).

Some suggestions on how to contact the target population for the focus group include: disease-specific advocacy groups; Community Services; cultural community clubs; authors who have worked in specific areas of interest (and can provide contacts); specific physicians or surgeons for referral of disease- or experience-specific patients; and professional colleges.

An important caveat was learned from the breast cancer decision aid project (See Appendix 2): when involving persons with a specific disease in focus groups, it's important to remember that you are participating in a point-in-time discussion. The beliefs that persons hold at that time can and often do change. Validate the findings by repeating the focus group at a later date, if possible.

## **Facilitating focus groups**

The role of the facilitator is to establish rapport with the participants, ask the questions of interest to the researcher, encourage all participants to share their thoughts and to keep the discussion on track. Whenever possible, sessions should be held in relaxed and comfortable surroundings. The room used for a focus group should match the size of the group; too large or too small makes people uncomfortable. Avoid rooms full of windows, with telephones, or that are high traffic areas as these can be distracting—as can rooms with elaborate furnishings. The surroundings need to be perceived by participants as “safe;” as a place where they can express opinions and views without fear (fear of giving the “wrong answer” as well as fear of sanction or retribution). Refreshments should be provided. Sitting in a circle or around a table seems to work best; people feel less exposed and this arrangement seems to increase interaction and participation.

Each session should last an hour or an hour-and-a-half, and no more than two hours. Take into account the differences of the group—language, cultural, normative and value differences. Group dynamics must remain utmost in mind. Confidentiality should be assured. If audio- or videotaping is planned, consent must be obtained. Most researchers now ask participants to sign a consent form, whether proceedings are being taped or not. Many researchers also ask participants to provide some anonymous personal demographic data, such as age, gender, education or those facts which have an impact on the focus of the research (see Ethics section).

Facilitators should plan a welcome, introducing themselves and any colleagues, and explaining their role to the group. It is important to outline the purposes of organizing the group and what is to be accomplished. Facilitators might start the process with general questions that “warm up” discussion. This activity of introductions and making participants comfortable generally takes about 10 to 15 minutes. If the proceedings are to be taped and the facilitator is concerned about the participants' comfort zone, taping everyone's voices sequentially and then playing the tape back may help diffuse apprehension.

It is important to structure things so that the data will be unbiased and reflective of the group's thoughts. Expect surprises. Listen carefully. It is important to appear neutral and non-judgemental. Validate what is being said, acknowledge comments from individuals and encourage expansion and discussion by other group members. Encourage participants to respond to the questions by discussing them with each other rather than the facilitator. At the outset, be a listener and observer; stimulate interaction by drawing participants into the discussion who haven't yet spoken. Later on in the discussion, intervene when necessary to nudge debate to a natural conclusion and to encourage discussion around

inconsistencies. Within-group disagreement can be used to encourage participants to elucidate and clarify their specific point of view. Above all, keep the discussion on track.

The questions developed for the group's consideration are not meant to be all-inclusive or restrictive; rather, they should reflect the general areas to be covered. The facilitator should be very familiar with the topic area and able to pose supplementary questions, using probing comments/questions or prompts which will facilitate understanding of opinions and beliefs of the participants, enabling exploration of the group's opinion.

The selection of facilitators should take into consideration more than just training or background. It is important to have facilitators or moderators (or recorders) who have special expertise or credibility or some feature that is essential to the success of the study, such as being of the same gender, age, occupational group or ethnic background.

## **Recording**

Working in groups of two—one staff member facilitates and another records or transcribes—is ideal. While the facilitator keeps the group focussed and on topic, the recorder should take detailed notes and observe the dynamics of the group, such as verbal and non-verbal cues, body language, and how and with whom participants interact. Noting the match between verbal and non-verbal behaviours is important to understanding the data obtained from the focus group and determining the presence of any bias. The recorder should watch for discordance, for comfort levels with specific topic areas, for obvious cases of social desirability response bias and responses to controversial or sensitive issues. Moreover, what *is* and what *is not* said is of equal importance. (Some researchers prefer to hold focus group meetings in specially-designed rooms with two-way mirrors, so that observers can monitor the body language and interactions of the group members, who, though informed of the observation, usually lose any initial inhibition as they respond to the task of answering questions). These observations become an important part of data collection, revealing subtleties that may be missed.

It is important that the recorder not draw any conclusions while listening to the discussion, but remain open-minded. The recorder should then type up his/her field notes and record any overall impressions as soon as possible after the conclusion of the interview. The facilitator and recorder should then discuss their impressions of the information gathered to identify those parts of the process that were strong (or weak), using this information to improve subsequent focus groups and possibly modify or provide supplementary questions for the planned research question sequence.

## **Recording the data**

Most usually, focus group discussion is captured by audiotaping the proceedings and transcribing the tape to allow good quality analysis and to conserve the data in a fashion that is usable by other members of the researcher team (or even other researchers in other contexts). Some researchers prefer to videotape focus group discussion. Both of these

modalities *can* be perceived as intrusive by some participants and *may* affect the free expression of thoughts and feelings about the issues under discussion (see sections on Facilitating and Ethics). Videography equipment is expensive, and audiotape transcription is also costly (transcription services charge approximately \$25-50/hour and up; transcribing a 1.5 hour tape can take 6-8 hours).

Audiotaping is the most frequently used method for most focus groups. For best quality, clarity and evenness of recording, place the machine in the centre of the table where possible. Accessory microphones will provide better clarity than the microphone built into the machine. Use good quality 90-120 minute tapes so tape changes are limited during the discussion. Use “normal bias” tapes as they capture the human voice better than metallic tapes. Many researchers recommend using fresh batteries for the recording device with each use as one does not always keep an eye on the progress of the tape and might not notice battery failure. Others have reported that current-operated machines may slow or stop for no apparent reason, which may be attributable to power surges that tape recorders are rarely designed to handle. Researchers also report difficulties with voice-activated recording equipment that can fail to pick up low voices or those of soft-spoken persons.

Using a research team member as recorder offers some benefits; this person may be especially attuned to the group dynamics and body language of participants through familiarity with the research question and its sensitivities. Debriefing after a focus group when two research team members have heard and observed the group allows comparison of perceptions and understanding of the important messages of the group. People can differ in their interpretation of a discussion and may pick up nuances that the other missed, so this function can be very valuable.

Some researchers develop data collection tools (pre-designed sheets) for recording purposes; some take free hand notes. These methods can be cost-conserving if budgets and/or timelines are tight. Choice should depend on which is most appropriate for the specific project.

Some researchers also find it useful to record participant views and issues on a flip chart, which summarize important messages and can be taken away for transcription.

### **Attrition and Participant Compensation**

Even though group candidates assure researchers that they will attend, routinely one or two participants will not show up. Confirmed commitment does not always ensure attendance. Oversubscribing an attendee list by 20 per cent is a good rule of thumb. Attendance can often be encouraged by offering an honorarium, reward or stipend. Travelling expenses (transit costs, parking costs, taxis) should always be covered. A flat rate for travelling expenses (regardless of travel modality) is preferred by some research teams, but be sure that it is equitable. Some facilitators have also used lottery tickets as gestures of gratitude or good will for focus groups of the general public. Be sure to tell attendees the time commitment up front.

If contemplating focus groups of physicians, remember that pulling physicians away from their workday is very difficult. Those that are paid on a fee-for-service basis are reluctant to give up time seeing patients. Evening groups also prove difficult to arrange; the pharmaceutical industry dinner and talk has upped the ante (the honorarium rate and the number of possible commitments of physicians). Dinner or refreshments and honoraria are usually necessary for recruitment of physicians for evening focus group participation. The standard honoraria suggested by the Canadian Medical Association/Ontario Medical Association is \$200 - 250 for half-day meetings (see [www.cma.ca/inside/policybase](http://www.cma.ca/inside/policybase) or [www.oma.org](http://www.oma.org)). Early morning breakfast meetings can be an option if they can be held at or near a hospital.

## **Group Dynamics**

As previously mentioned, it is very important to observe the interactions of the group participants to each other, as well as their reactions to the questions and opinions of others. Identify verbal and non-verbal cues, how the individuals participate and with whom, and whether or not the verbal statements match the non-verbal behaviours.<sup>9</sup> The innuendo and interpretation by participants of the opinions of others can inform the research as much as spoken statements, as can observation of comfort levels with the topic areas and sensitive or controversial issues. The best way to observe all of this is by using two person teams (facilitator and recorder/observer) or observers behind two-way mirrors.

## **Analysis and writing**

Analyzing focus group data is comparable to analysis of self-report data. This can be accomplished in a number of different ways. One method is for researchers to examine the material derived from the focus group discussions, “code” or group the material into themes, and then review them to identify common themes and any interrelated concepts. It is important to try to distinguish individual opinions expressed in spite of the group from the actual consensual statements of the group. And although consensus statements may be important, researchers should consider minority opinions and those examples which may not appear to fit hypothetically with the rest of the data before labelling them as outliers. Kitzinger suggests that when coding a transcript of a focus group, create special categories for different types of narrative (including things like jokes and anecdotes) and types of interactions between participants (questions, deferring to others’ opinions, changing of mind).<sup>6</sup> She also suggests presenting some of the transcribed dialogue between focus group participants, rather than just presentation of isolated quotations from the transcript. When analyzing focus group data, it’s important to incorporate and discuss the dynamics of the group, consider the intra-group comparisons and evaluate the impact of interaction with the research staff.

There are a number of things to consider in the analysis: the language used and the context of usage, internal consistency of ideas, the frequency of comments and the intensity of their articulation, the specificity of the comments, and the seminal findings that come out of the discussion. Other issues to be considered: personal perceptions and beliefs of the

participants, whether the verbal statements match the non-verbal behaviours, and intra-group dynamics and reactions.

Some researchers prefer to use qualitative software programs such as NUD\*IST™ or The Ethnograph™ for analysis. It is important to remember that these software programs sort and manage data, enable data links and cross-group links, but they do not do the intellectual work of analysis. This type of software analysis requires a word-processed transcript that still needs to be coded manually. It is a formal process and methodologically as defensible as many quantitative analyses when done well by trained and experienced analysts. Data can be analysed in the usual numeric sense with word and phrase counts.

Krueger<sup>10</sup> has recently written that using transcripts in some situations may be overrated and impractical. If there are time constraints or less in-depth analysis is necessary, using “abridged” transcripts that “contain only the most pertinent data” or “real time” transcripts of notes taken by hand or using a laptop computer during the focus group, may serve equally well. Moreover, this approach will certainly cost less.

## **Biases**

The usual biases reported in qualitative literature include volunteer or selection bias, social desirability response bias, and systematic bias, among others.

## **Ethics: issues, considerations and confidentiality**

Many researchers now submit qualitative project plans to local hospital- or university-based Ethics Review Boards for approval. Although participants of focus groups are not subject to typical interventions (procedures, investigational drug treatments etc), most researchers now agree that discussing problem-specific health issues is a type of intervention, and patients should be made aware of their rights within this context. Participants should be informed that they may decline without prejudice to answer any questions with which they are not comfortable; that they may leave at any time; that their identity and responses will be kept confidential (audiotapes typed by a person unaware of the identity of the participants in the room); that any identifying information will be removed from the written transcripts; and that reports of the research will not identify participants or anyone mentioned during the discussion. It is reassuring to the participants that their confidentiality is assured and formally acknowledged. This helps make them feel safe in sharing their opinions and beliefs with the group. Having participants sign a consent form which indicates an understanding of these principles is now a standard procedure and connotes active rather than passive participation (see Appendix D for examples).

Participants should be told that there are few direct benefits to themselves in focus group participation (other than teleological or communitarian benefit). However, some feel that there can be risks in participating in a focus group.<sup>11</sup> Participants may appreciate being given the opportunity to express their views and informing the researchers in a way that

may benefit others, but some may feel troubled by information provided or discussed, particularly if the research topic is sensitive or other participants express opinions which they find offensive or unacceptable.

Researchers have an obligation to ensure that the research process, as affirmed in the Helsinki Declaration, does not harm focus group participants physically or psychologically. Of the four principles within the framework of research ethics (respect for autonomy, beneficence, justice and nonmalficence), the fourth principle, nonmalficence—allowing no harm to come to participants—is the major influence in this context. The new tri-council joint policy statement on ethical conduct for research involving humans (available at [www.mrc.gc.ca](http://www.mrc.gc.ca)) also provides an excellent guideline to supplement material from individual Ethics Review Boards.<sup>12</sup>

Three ideas for assessing and reducing the stress/distress of participants include: 1) allowing a “debriefing” component at the end of the focus group session. This allows participants an opportunity to discuss their reactions to the research topic and the conversation in which they have participated with the facilitator; 2) encouraging an interactive informal debriefing among the participants themselves; and 3) making available or providing educational briefs or literature that participants can take away with them. These strategies will help reveal discomfort or stress. Facilitators should optimally monitor the stress levels of the participants throughout the course of the focus group, and intervene or diffuse tension as needed. When discussing sensitive topics it can be useful to have a facilitator with clinical experience monitor the group “comfort” level.<sup>11</sup>

Confidentiality needs to be maintained *throughout the project*, with access to the transcripts, demographic data and recorder notes restricted to the investigator and the research team. Data should be kept in locked files.

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## Conducting Focus Groups: Some Caveats <sup>13</sup>

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### **Don't overlook the herd mentality**

One can't be absolutely positive that what people say in the group genuinely represents his/her *individual* experience. To ensure researcher confidence that all group members freely participated, watch for censoring of comments by others and for conformity of comments (social desirability response bias). Everyone wants to *belong* to a group—it's instinctual human social behaviour. Some folks can be led, will say what they think others want to hear, will play devil's advocate or confabulate. Explicitly ask "does this reflect each/all of your opinions?" whenever there is concern or doubt.

### **Participants want to be good research subjects**

Some participants may not contribute much to the discussion, and it can be difficult to understand what this lack of contribution means. Silence can mean agreement (or not having anything substantial to add), but it can also mean that they disagree and just don't want to say so. Facilitators should be sure to ask direct questions of these participants without being confrontational to ensure that everyone participates and that the data is not biased.

### **Qualitative data and quantitative data aren't the same thing**

Focus groups aren't just surveys conducted orally, and they shouldn't be "counted" or taken out of the context. The interaction of the group and the opinions expressed are important dimensions of focus group methodology, and Ashbury suggests that if this isn't to be considered and incorporated into the analysis, perhaps the choice of this methodology was incorrect.<sup>13</sup>

### **Focus groups aren't cheap**

They are time-intensive and require certain skill sets. Time-wise, the actual focus group activity is a "visible" activity; however, much of the considerable amount of time it takes to do focus groups well is in the planning and analysis stages, which are often less "visible." We append some time allotments in Appendix E as examples.

### **You don't always get what you want**

Researchers may be surprised by focus group findings, which may take a research project in a different direction from the original plan.

## **Take the time to do it well**

We can't stress enough the importance of planning and vetting question guides before starting a project. Run your choice of questions through other experts in the research area and/or with other research coordinators with experience in this field. Often the subtle revisions suggested are a great help. Question guides often require revision after the first or second focus group is conducted, based on what has been learned from the discussion. This is usual and expected, as long as the questions and expanded areas of inquiry build on what has been learned. It's often useful to ask participants to clarify comments, which may lead to new strings of thought on the research at hand.

## **Trained or not?**

Facilitators should know the topic area well so that they can respond to questions (or clear up misconceptions of participants), as well as pose supplementary or probing questions to maximize the information obtained from the participants. Most of the ICES Research Coordinator group has had some exposure to a focus group role (either as facilitator or recorder), and all agreed that being trained was highly important to the success of the project.

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## Appendix 2: Examples of focus groups

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### ICES projects using focus groups as a component

1. Guidemap for the Early Detection of Breast Cancer in Ontario
2. Breast Cancer Decision Aid Project
3. Hereditary Breast Cancer Project
4. PSA educational material for material (1994)
5. PSA educational materials around new LPTP Guidelines for physicians and patients
6. Prescribing Feedback Study
7. Hyper/hyper project
8. Sore Throat Score
9. Wife abuse - when woman and abuser are patients of the same physician

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**Title of project:** *Guidemap for the Early Detection of Breast Cancer in Ontario*

**Purpose:**

- i. To develop an ICES Working Paper, a set of annotated clinical practice paths for breast screening explaining both the areas of consensus and those where interpretation of the evidence differs.
- ii. To develop a physician information package.
- iii. To develop a client/consumer information package providing women in Ontario (40-75 years old) a useful guide to:
  - (1) current guidelines on breast screening for women 50-75 years old.
  - (2) factual guide through controversial area of breast screening for women 40-49 years old.
  - (3) potential for disagreement with their physician regarding breast screening in the 40-49 years old.
  - (4) options to consider if they are in conflict with their personal physician's position.

**Research Team Members:** ICES: Dr. A.S. Basinski, Virginia Flintoft  
Insight Canada Research: Shirley Simo

**Are the focus groups part of a research project also using other methods or stand alone?**

Purpose (iii.) Involved the two focus groups as well as a telephone survey of 121 women conducted within the same week as the focus groups by Insight Canada Research.

**Number of Focus Groups Planned/Conducted:** Two planned and completed.

**Time Frame:** Toronto Focus Group held February 15, 1995  
Chatham Focus Group held February 16, 1995

**Where Done:** Insight Canada Research office - 101 Yorkville Avenue, Toronto.  
Holiday Inn Meeting Room - Chatham, Ontario

**Who were the participants (in general terms):** Two groups of 8 women; 40 to 75 years old (50% within 40 to 49 year age group); no history of breast cancer; no enhanced knowledge of breast cancer issues (not nurses, employees or activists in breast screening or breast cancer programs associations or centres); hadn't participated in a research group in the previous 6 months.

**How did you access your participants?** Insight Canada professional recruiters recruited participants. In order to ensure each session had an appropriate number of participants thirteen women were recruited for each session.

**How Done:** Toronto session: The Research Coordinator (VF) met the facilitator approximately 30 minutes prior to the focus group to discuss the process and perform a final review of the Discussion Guide. The Research coordinator was positioned in a private observation room fitted with a window into the focus group room and a telephone linked to the facilitator. The participants met at 6:00 p.m. at the Insight Canada offices and were brought into the room upon arrival. Sandwiches and coffee and juices were provided. When all had arrived the facilitator introduced herself, and explained again the purpose of the group. At the end of the session (approximately 2 hours) the facilitator came to the observation room to ensure all issues had been adequately addressed - the participants were then thanked and allowed to leave. The research coordinator was asked if she would be willing to meet the participants to answer any of their questions - which she agreed to do.

**Facilitator:** Yes. Insight Canada trained facilitator conducted both sessions.

**Recorder:** Audiotape - no recorder. Both the Toronto and Chatham sessions were audiotaped, and the Toronto session alone was videotaped, no independent transcription by recorder was performed. Audiotape was not transcribed.

**Interview:** Semistructured

**Questionnaire/ Guide:** a Focus Group Discussion Guide was prepared and is available.

**Type of Analysis planned:** Open-ended responses were coded and the data analyzed using SPSS - when more than one answer was accepted from each participant the percentages were calculated as a proportion of the respondents who gave each response.

The results of the Focus group are reported in an integrated manner with the Teleresearch results. The latter provides the foundation of the report and the Focus Group results buttress the quantitative findings.

**Expenses/honoraria provided:** Each participant was given \$25 for participating

**Were facilitator & recorder previously trained or given training:** Yes

**List of Deliverables:** Final report of Teleresearch and Focus Group.

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**Title of project:** *Development of Breast Cancer Surgery Information/Decision Aid [1995-98]*

**Purpose:** To determine the effectiveness of augmenting treatment information delivered to women with newly confirmed breast cancer at the time of their post biopsy surgical consult using a decision aid (booklet and audiotape). This patient decision aid for the surgical treatment of early stage breast cancer will include explicit presentation of probabilities, photographs and graphics and a values clarification exercise.

In Phase I, focus groups were held with women living with breast cancer, to determine what information they *would have wanted at the time of diagnosis*. In Phase II, the draft aids were developed based on the 1996 Ontario Cancer Treatment Practice Guidelines Initiative and incorporated the focus groups' suggestions. In Phase 3, the decision aid were evaluated in a community based randomized controlled trial by women with newly confirmed breast cancer. Main outcome measures of the trial were breast cancer knowledge, decisional conflict, decisional regret and anxiety.

**Research Team Members:**

Dr. Carol Sawka, Dr. Vivek Goel, Dr. Annette O'Connor, Dr. Glen Taylor Dr. Catherine Mahut, Dr. Ida Ackerman, Dr. Pam Chart, Janet H. Burt [lay member]

Research Coordinators: Virginia Flintoft, Elaine Gort, Elaine Thiel, Pam Slaughter

**Are the focus groups part of a research project also using other methods or stand alone?** Inform the entire planned project. Multi-phase project.

**Number of Focus Groups Planned/Conducted:** Five focus groups with women living with breast cancer [WBCa]; 2 focus groups with oncology nurses [Ns].

**Time Frame:** [WBCa] focus groups: July - September 1995. [Ns] focus groups: May - June 1996

**Where Done:** ICES boardroom, Canadian Cancer society offices in Metro Toronto and in Ajax, private homes.

**Who were the participants:** Twenty-three women living with a breast cancer; most affiliated with breast cancer support groups. Seven oncology nurses. All were volunteer participants.

**How did you access your participants? [WBCa]:** Focus Group 1 consisted of five women recruited by a working member of one of the support groups for women with breast cancer. Focus Group 2 consisted of four women recruited by a member of a support group. Focus Group 3 consisted of three women recruited by a breast cancer survivor. Focus Group 4 consisted of six women recruited by a volunteer member of the Ajax Chapter of the Canadian Cancer Society. Focus Group 5 consisted of five women recruited by staff and volunteer members of the Metro Toronto Chapter of the Canadian Cancer Society.

**[Ns]:** Notice was posted at Toronto-Sunnybrook Regional Cancer Centre [TSRCC] inviting oncology nurses to evaluate decision aid on two specified dates.

**How Done: [WBCa]:** Facilitator defined twelve open ended questions to be asked re “What type of information was given to you during your consultation with the surgeon?” and the particular time of interest - the interval between diagnosis and surgery. Guided by these questions, women were asked to recall and share their experiences regarding what information they were given. What information was used in the decision making during consultation with the surgeon? Did they have a choice in their breast surgery? Did the women look for other sources of information? What should be included in a decision aid? What should be its prime focus?

For Groups 4 & 5 sessions began by the facilitator showing the group the blank "frame" of the decision tool. She asked them to make suggestions at any time during the discussion regarding what should be included in the tool and the type of language to be used in it. Group 4 evaluated the draft version of the booklet and photos to be included in the pilot study.

**[Ns]:** The oncology nurses listened to the audiotape which guided them through the workbook (pilot version: 27 minutes). They noted any comments on a brief evaluation form as they reviewed the aid and then rated the colour, content, artwork, photos, and scales used in the Aid at the conclusion of the tape. The facilitator then asked the following questions: “Can you tell me what your emotional reaction is to this decision aid? Would you say that this decision aid gives you a positive or negative feeling? Can you think of any areas that might be troublesome for other women reviewing this decision aid? Were there any area’s that were unclear? Do you have any other suggestions for improvement?”

**Facilitator:** [WBCa]: Pam Slaughter Recorder: Patti Pinfold

[Ns] Joint Facilitator/Recorders: Elaine Thiel and Virginia Flintoft

**Record of Focus Group: [WBCa]:** audiotaped; notes from recorder. **[Ns]:** transcription by recorder; additional written comments by nurses.

**Transcribed: [WBCa]:** Yes. **[Ns]:** No

**Structure: [WBCa]:** Semistructured **[Ns]:**Semistructured

**Questionnaire Guide planned:** Yes **available:** Yes

**Type of Analysis planned:** content analysis

**Expenses/honoraria provided:** transportation expenses, refreshments

**Were facilitator & recorder previously trained or given training:** qualitative methodology course in Master's program; clinical training; worked with more experienced facilitator.

**List of Deliverables:**

1. *Making Decisions about the Removal of My Breast Cancer: What do I Prefer?* ICES 1998: Decision Aid & Audiotape - printed by the Canadian Cancer Society and Ontario College of General Surgeons.
  2. Slaughter PM, Pinfold SP, Sawka C, Goel V. Information needs at diagnosis: Messages from focus groups of breast cancer survivors. *Cancer Prevention & Control* 1999 (provisionally accepted).
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**Title of project:** *Hereditary Breast Cancer Information Aid project [1996-1998]*

**Purpose:** The general objective of this project is to evaluate the feasibility and acceptability of the information aid in women with a family history of breast cancer.

**Study objectives:**

1. To develop an information aid for women with a low to moderate risk of carrying a hereditary breast cancer susceptibility gene who are currently ineligible for molecular genetic testing.
2. To develop a knowledge scale specifically relevant to this group of women.
3. To pilot test the information aid on the appropriate target group of women and measure its effect on:
  - a) patient satisfaction
  - b) knowledge and comprehension of hereditary cancer risk, inappropriateness of genetic testing, and screening recommendations.
  - c) patient anxiety levels
4. To ensure that the information aid can identify high risk women inadvertently misclassified as being lower risk.

**Research Team Members:** Dr. Ellen Warner, Dr. Vivek Goel, Dr. Lavina Lickley, Dr. June Carroll, Dr. Brian Doan, Dr. Wendy Meschino, Dr. Kathryn Taylor, Dr. Pam Chart, Dr. Ruth Heisey. Collaborators: Dr. Steven Narod, Dr. Allan Swayze, Dr. Phil Wyatt.

Lay members: Ms Anne Parker, Ms Margaret Rao, Ms Bonnie Bassett-Spiers.

Research coordinators for the focus groups: Jane Edwards (Boyle), Nancy Ondrusek

[Elaine Thiel and Nancy Ondrusek for Pilot 1--evaluation of the information aid by women waiting to be seen at TSRCC Familial Breast Cancer Clinic.] Collaborators divided into two groups:

- ◆ content committee to discuss current literature and determine content of the information aid
- ◆ knowledge scale committee to discuss ideas for the scale to be used to evaluate women's knowledge of hereditary breast cancer before and after using the aid.

**Are the focus groups part of a research project also using other methods or stand alone?** Focus groups were only used in the developmental phase of the information aid.

**Number of Focus Groups Planned/Conducted:** We felt that four focus groups of 8-10 women would provide us with the information we required. These groups were large enough to encourage active discussion without seeming intimidating or overwhelming to the women participating.

**Time Frame:** Spring of 1996

**Where Done:** ICES, YMCA Toronto, TSRCC Familial Breast Cancer Clinic, U of T Women's Club.

**Who were the participants?:** Women with low, moderate and high risk for developing breast cancer. The research coordinator contacted various cancer treatment centres, support groups and community groups to find suitable women to participate in the focus group discussions. Each group of women was from a specific risk category: average risk women ages 17 through 45 (1 group), women with a mothers and sisters who had breast cancer (1 group), average risk women ages 30 through 70 (1 group), and women who had experienced breast cancer themselves (1 group). There was no selection criteria, other than an interest or concern about breast cancer and women's health and a desire to participate in a group discussion. All the women who participated did so in their own interest in learning about breast cancer and aiding the research project

**How did you access your participants?** Volunteers from following groups:

- ◆ ICES admin staff [preliminary focus group]
- ◆ U of T Women's Club [Most had indirect experience with cancer in family or friend.]
- ◆ Breast Cancer Survivors [recruited through Alliance of Breast Cancer Survivors and Medulla (Bayview Support Network)]
- ◆ Sisters and daughters of Breast Cancer Survivors [recruited through Alliance of Breast Cancer Survivors]
- ◆ YMCA Toronto [ women recruited through flyers at YMCA ; self-rated as having average or below average knowledge of breast cancer]
- ◆ Observed Individual Interviews of 7 patients attending TSRCC Familial Breast Cancer Clinic for assessment for hereditary breast cancer.

**How Done:** A list of discussion topics was generated by the research coordinator (JE) and the facilitator (BD), and was used to direct the group discussion. The main ideas behind each question remained constant throughout all four groups, yet the questions were flexible enough to allow certain tangential discussions to take place, depending on the specific background and risk level of the individual group. The questions were designed to encourage women to talk about what they knew about breast cancer and breast cancer risk. The intention of the discussion questions was to encourage women to reveal

personal experiences and stories about family and friends and thereby communicate to the research group their knowledge level, opinions and actions in regard to breast cancer.

Focus group participants were seated at tables, or in comfortable chairs, with refreshments and snacks. Each woman was given some information about the study, the goals of our research and the importance of their input and ideas into the project. The sensitive nature of our discussion was mentioned and the women were made aware of the fact that they could leave at any time, and use the contact numbers for a counselling psychologist and a psychiatrist which we provided in the event that they felt they wished to discuss any issues further. They were introduced to the members of the research team, given a list of the discussion topics and a pen in case there were thoughts, questions or experiences that they were not comfortable asking or mentioning out loud to the group.

The same facilitator, (BD) ran each of the four sessions, and two recorders (JE) and (NO) took notes. Each session was attended by one other member of the research group (PC, EW, WM, LL). Each physician was introduced to the focus group as “a member of the research team” in order that the discussion did not focus around questions directed to the doctor, and evolve into an information session. There was some time at the end of each group session for the doctor to answer some of the questions that were brought up and address some of the issues which women seemed confused or anxious about.

**Facilitator:** Dr. Brian Doan [psychologist at TSRCC]

**Recorder:** Jane Edwards, Nancy Ondrusek

**Record of Focus Group:** written transcription by recorders only.

**Transcribed:** The two sets of notes were transcribed immediately, and combined into one document that was checked by both recorders for consistency.

**Structured/Semistructured/unstructured:** Semistructured

**Questionnaire Guide planned:** Yes      **Available:** Yes

**Type of Analysis planned:** informal summary; suggestions from groups were incorporated into information aid. [Focus group paper was to be written/text included here].

**Expenses/honoraria provided:** Refreshments provided to participants.

**Were facilitator & recorder previously trained or given training:** Facilitator had formal training. Recorders read texts and had instruction from facilitator.

**List of Deliverables:**

1. Warner E, Goel VG, Ondrusek N, Thiel E, Edwards J, Lickley L, Meschino W, Chart P, Carroll J, Doan B, Taylor K, Rao M, Parker A. Development of an information aid and knowledge scale for women at low to moderate risk for hereditary breast cancer (HBC). 20th annual San Antonio Breast Cancer Symposium, December 3-6, 1997 (poster presentation) 1997.
  2. Warner E, Goel V, Thiel E, Ondrusek N, Doan B, Carroll J, Chart P, Meschino W, Lickley L, Taylor K, Parker A, Rao M. Pilot study of an information aid for women at low to moderate risk for hereditary breast cancer (abstract). American Society of Clinical Oncology [ASCO] conference in Los Angeles, California, May 19, 1998.
  3. Ondrusek N, Warner E, Goel V. Development of a knowledge scale about breast cancer and heredity (BCHK). *Br Ca Res Treatment* 1998 (in press).
  4. Hereditary Breast Cancer information aid: [Includes booklet & audio tape: Hereditary Breast Cancer: "Someone in my family has had breast cancer." "Am I at increased risk?" "Will I get it too?"] The aid will be used in Pilot 2 study January 1999 in the community with low/moderate risk women and their family physicians.
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**Title of Project:** *PSA educational package for the public (1993-4)*

**Purpose:** to develop an educational brochure for the public regarding the use of the PSA blood test to screen for prostate cancer.

**Research Team Members:** Dr Vivek Goel, Dr. Neill Iscoe, Shawna Mercer, Pam Slaughter

**Are the focus groups part of a research project also using other methods or stand alone?** Part of a planned educational package. Needs assessment for inclusion.

**Number of Focus Groups Planned/Conducted:** Four

**Time Frame:** over 1 month period

**Where Done:** ICES boardroom, Field locations in Toronto

**Who were the participants:** maintenance housekeeping staff and mangement (males) from Sunnybrook Health Science Centre; male members of Masonic Lodge lunch program; mixed group of lawnbowlers.

**How did you access your participants?** Telephone recruitment via department managers, phone contact with Lodge and Club—volunteers requested.

**How Done:** recruited men from several sources. Two focus groups from Sunnybrook: male housekeeping staff, male management from maintenance/housekeeping department. All-male group at the Masonic Lodge, mixed male-female group in lawnbowling league.

**Facilitator:** Shawna Mercer (x3); Pam Slaughter

**Recorder:** Pam Slaughter (x4)

**Audiotaped:** Yes x3 Tapes available Transcribed

**Structured/Semistructured/unstructured:** Semistructured

**Questionnaire Guide planned:** Yes

**Type of Analysis planned:** Responses used in development of educational brochure

**Expenses/honoraria provided:** Transportation expenses, refreshments.

**Where facilitator & recorder previously trained or given training:** Had done qualitative methodology course in Master's program, clinical training, worked with more experienced facilitator.

**List of Deliverables:**

1. "PSA and Prostate Cancer" ICES/Canadian Cancer Society sponsored brochure, 1994
2. "To be screened, or not to be screened" *informed* Vol 1(2) March 1, 1995
3. ICES fax-back service articles "PSA and Prostate Cancer" for physicians and for the public
4. Mercer SL, Goel V, Levy IG et al. Prostate cancer screening in the midst of controversy: Canadian mens' knowledge, beliefs, utilization and future intentions. *Can J Pub Health* 1997;88(5):327-32.

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**Title of Project**      *PSA educational package for the public and for MDs* (1997-98)

**Part I**

**Purpose:** 1) to evaluate newly-developed educational materials about the new Ontario Prostate Specific Antigen (PSA) Clinical Guidelines for Testing published in September, 1997 for physicians; 2) to evaluate an implementation/dissemination strategy that philosophically incorporates the notion of informed consent and responsible testing using the new provincial guidelines from the LTPT of the MoH; and 3) to develop educational packages for physicians and the public.

**Research team:** Dr. Jack Williams, Dr. Vivek Goel, Pam Slaughter, Cathy Cameron, Shawna Mercer, Carole Estabrooks, Tami Axcell, Patti Pinfold, Elaine Gort

**Where done:** Stratford, Mississauga, Thunder Bay, Toronto

**How done:** Using new LPTP/MoH PSA guideline materials developed in-house (using expert review with modifications), then mailed out to participants for review prior to focus groups. Total groups: physicians (3) and the public (6). See package of attached materials. See also s:\mohpsa files for all documentation.

**Expenses/honoraria:** travel expenses, physician honoraria, hotel room rental and refreshments

**Trained/given training:** on-the-job for some, course work/previous training for others, clinical training.

## Part II

**Purpose:** To evaluate newly-developed educational materials about PSA testing for patients to help facilitate their discussion with their family physician and decision-making around the new Ontario Prostate Specific Antigen (PSA) Clinical Guidelines for Testing published in September, 1997.

**Research team:** Dr. Jack Williams, Dr. Vivek Goel, Pam Slaughter, Cathy Cameron, Shawna Mercer, Carol Estabrooks, Tami Axcell, Patti Pinfold, Elaine Gort

**Where done:** Community Centres in Peel (Brampton) and Toronto (Danforth); Canadian Cancer Society office in Stratford and Thunder Bay; Access Alliance Community Health Centre; ICES Boardroom (Prostate cancer support/ advocacy group Man-to-Man).

**How done:** Groups of 4-12 men with facilitator + recorder. Participants reviewed the materials ahead of time and discussed strengths and weaknesses, suggestions for change.

**Expenses/honoraria:** Transportation expenses, refreshments.

**Trained/given training:** Qualitative methodology course in Master's program, clinical training, worked with more experienced facilitator.

### Deliverables:

1. *PSA: the new Expert Panel Recommendations*. Information for physicians about prostate cancer screening. Ministry of Health project. Spring 1998.
2. *PSA: the new Expert Panel Recommendations*. Information for patients about prostate cancer screening. Ministry of Health project. Spring 1998.

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**Title of project:** *Prescribing Feedback Study*

**Purpose:** To evaluate the impact of confidential prescriber feedback on antibiotic use in primary care and to assess its acceptability to physicians

**Research Team Members:** Dr. Jan Hux, Michele Melady, Don DeBoer, Francine Duquette

**Are the focus groups part of a research project also using other methods or stand alone?**

Part of project - program evaluation

**Number of Focus Groups Planned/Conducted:** One

**Time Frame:** 2 hours duration, held six weeks after completion of program

**Where Done:** Holiday Inn at Cambridge (Hwy 24 and 401). This was a central location for participants and the hotel is visible from the 401 so was easy for attendees to find.

**Who were the participants:** Cambridge was selected as the site of the focus group for convenience reasons. PFS participants within 50 km of Cambridge were eligible for the focus group and were randomly selected for invitation until 10 positive responses were obtained. An unanticipated problem with this approach was that there were no women on the list. (16 to get 10)

**How did you access your participants?** They were participants in the PFS

**How Done:** Faxed letter from PI with follow-up phone call from coordinator.

**Facilitator:** Michele Melady, Research Coordinator. Jan Hux also present.

**Audiotaped.** Transcribed. Copies available

**Structured/Semistructured/unstructured:** Structured; samples of program materials were provided during the process to facilitate recall and elicit more specific comments.

**Questionnaire Guide planned:** Yes. Available: yes

**Type of Analysis planned:** No formal analysis done yet. We had planned to do a full program evaluation with quantitative and qualitative components but due to difficulties with the quantitative data, this work has been sidelined.

**Expenses/honoraria provided:** Yes

**Were facilitator & recorder previously trained or given training:** No formal training

**List of Deliverables:** may still do further content analysis of the focus group data and write up for a medical education journal.

1. Hux JE, Melady MP, DeBoer D. Confidential Prescriber Feedback and Education to Improve Antibiotic Use in Primary Care: A Randomized Trial. CMAJ (under review)

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**Title of project:** *Development and evaluation of a coronary risk self-assessment workbook and guide*

**Purpose:** To obtain practitioner and consumer reaction to a newly-devised workbook for the self-assessment of coronary risk, to revise it accordingly, and to seek advice regarding its implementation.

**Research Team Members:** Hilary Llewellyn-Thomas; Michael Paterson, David Naylor, Gordon Hardacre

**Are the focus groups part of a research project also using other methods or stand alone?** This study also involved semi-structured interviews with participants (both physicians (n=20) and patients (n=40)) at the conclusion of the field trial.

**Number of Focus Groups Planned/Conducted:** 2 x 5 family physicians

**Time Frame:** Focus Groups: May and June 1996 Field Trial: September 1996-March 1997

**Where Done:** ICES Conference Centre

**Who were the participants (in general terms):** Focus Groups: 10 members of the SHSC Department of Family and Community Medicine (including Courtesy Staff)

Field Trial: 20 family physicians and 40 patients of their choice. Physicians were members of the University of Toronto Department of Family and Community Medicine Teaching Practices Network.

**How did you access your participants?** Invitation by mail

**How Done:** Mail

**Facilitator(s):** Michael Paterson, Hilary Llewellyn-Thomas

**Recorder:** Proceedings audio taped. Audiotape record supplemented by hand-written notes.

No verbatim transcript made.

**Structured/Semistructured:** Semi-structured. Guide used and available from investigators (MP).

**Type of Analysis planned:** Frequency counts and verbatim extracts.

**Expenses/honoraria provided:** Honoraria

**Were facilitators & recorder previously trained or given training?** No

**List of Deliverables:**

1. Risk assessment workbook prototype
  2. Study report
- 

**Title of project:** *Sore Throat Score*

**Purpose:** to design a useful scoring tool to help physicians rate the likelihood of patients presenting with sore throat having group A streptococcal (GAS) pharyngitis and thus improve the accuracy of antibiotic prescribing.

**Research Team Members:** Dr. Warren McIsaac, Dr. Vivek Goel, Pam Slaughter with the help and collaboration of 4 family physicians from Stratford Ontario including Drs. Wayne Parsons, Joe Ennet, Paul Weir, and Van Woolnaugh.

**Are the focus groups part of a research project also using other methods or stand alone?** Initially informed the project (topic choice) and reviewed findings collaboratively.

**Number of Focus Groups Planned/Conducted:** One

**Time Frame:** 1994/95

**Where Done:** Stratford, ON

**Who were the participants:** Volunteer family physicians

**How did you access your participants?** Through one opinion leader colleague

**Facilitator:** Warren McIsaac      **Recorder:** Pam Slaughter

**Transcribed:** No

**Structured/Semistructured/unstructured:** Unstructured review. Two group meetings. At the first meeting the ideas and background of the project were discussed. The Stratford physicians then met to draft a series of questions to which we could respond through the research of the literature. At the second meeting, we presented our written

findings, and then discussed how best to move this forward working through the questions and responses.

**Questionnaire Guide planned:** No                      **Available** No

**Where done:** Stratford and ICES

**How done:**

**Expenses/honoraria:** OMA recommended reimbursement; review done in the evening on a voluntary basis.

**Trained/given training:** qualitative methodology course in Master's program, clinical training

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**Title of Project:**            *When the wife abuse victim and offender are patients of the same primary care physicians: a study to establish clinical guidelines for primary care physicians*

**Purpose:**

- 1) To use the information from a previous study to examine the kinds of care practicing physicians, medical ethicists, and family medicine experts believe are appropriate for the victim and offender in cases of dual relationships and to identify barriers to dealing with victim and offender in these cases;
- 2) To develop clinical guidelines concerning dual relationships which provide recommendations to primary care physicians on how to provide abused women with appropriate assistance (e.g. referral to women's shelters and other social and community services) and how to deal with the offender when he is also a patient

**Research Team Members:**                      Lorraine E. Ferris, PhD. C.Psych,  
Peter Norton, PhD. MD, CCFP, Earl V. Dunn, MD, CCFP, Elaine H. Gort, MSc

A multi disciplinary group of consultants who had direct involvement with women living in abusive situations supported the team. This group consisted of 5 practicing primary care physicians representing urban rural practices and a sexual assault clinic, an academic psychologist, a clinical nurse specialist, a social worker, and two consumer representatives who had been abused.

**Are the focus groups part of a research project also using other methods or stand alone?**

The focus groups were one component of the project. Another component was using the information obtained from the focus groups, and from a Delphi panel convened in a previous phase of this work, to draft the guidelines in conjunction with the consulting

group. The final phase of the project was pilot testing the draft guidelines by eliciting feedback from focus group participants and from a convenience sample of primary care physicians.

**Number of Focus Groups Planned/Conducted:** Nine agencies agreed to participate by screening and recruiting individual participants, providing the space and assigning a staff member to attend and act as follow-up support to participants if required.(copy of letters etc., attached)

**Time Frame:** groups lasted 1 to 2 hours

**Where Done:** At the participating agency

**Who were the participants (in general terms):** Women who were clients of community agencies supplying support services to women who **had been** in abusive relationships. Women still living in abusive situations were screened out to ensure that a women's participation in the group did not escalate the abuse.

**How did you access your participants?** Seventeen community agencies, identified through our network of community connections and a directory of community agencies, were asked to participate. Agencies were initially approached by phone, faxed background information including a request for a face-to-face meeting with agency staff. Staff at each agency recruited individual participants.

**Facilitator:** Elaine Gort

**Recorder:** Admin Support Staff - Susan Campbell or student volunteer

**Record of Focus Group:** audiotaped, recorder-transcribed

**Semistructured with planned Questionnaire Guide** Available **Yes**

**Type of Analysis planned (ie content analysis):** content analysis for common theme generation

**Expenses/honoraria provided:** \$100 per agency, \$50 per individual

**Where facilitator & recorder previously trained or given training:** Previous experience for both but no formal training

**List of Deliverables:**

1. Report to Health Canada - funding agency
2. Ferris LE, Norton PG, Dunn EV, Gort HE, Degani N for the Delphi Panel and the Consulting Group. Guidelines for managing domestic abuse when male and female partners are patients of the same physician. *JAMA* 1997; 278 (10):851-7

## Appendix 3: List of Deliverables from Focus Group Projects done at ICES 1994-99

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### Breast Cancer

#### A. Guidemaps for the Early Detection of Breast Cancer

Report: includes analysis of responses, copy of discussion guide and teleresearch survey (held by Virginia Flintoft)

#### B. Breast Cancer Decision Aid

1. *Making Decisions about the Removal of My Breast Cancer: What do I Prefer?* ICES 1998: Decision Aid & Audiotape - printed by the Canadian Cancer Society and Ontario College of General Surgeons.

2. Slaughter PM, Pinfold SP, Sawka C, Goel V. Information needs at diagnosis: messages from focus groups of breast cancer survivors. *Cancer Prevention & Control* 1998 (under review).

3. Sawka CA, Goel VG, Mahut C, Taylor G, O'Connor A, Ackerman I, Burt J, Thiel EC, Slaughter P. Pilot study of a decision aid for locoregional management of breast cancer. 19th Annual San Antonio Breast Cancer Symposium. Dec 1996 (abstract).

4. Sawka CA, Goel VG, Mahut C, Taylor G, O'Connor A, Ackerman I, Burt J, Thiel EC, Slaughter PM. Pilot Study of a decision aid for locoregional management of breast cancer. *Br Ca Res Treat* 1996;41:258 (abstract).

5. Sawka CA, Goel VG, Mahut C, Taylor G, Thiel EC, O'Connor A, Ackerman I, Burt J, Gort EH. Development of a patient decision aid for choice of surgical treatment for breast cancer. *Health Expectations* 1998;1:23-36.

#### C. Hereditary Breast Cancer Project

1. Warner E, Goel VG, Ondrusek N, Thiel E, Edwards J, Lickley L, Meschino W, Chart P, Carroll J, Doan B, Taylor K, Rao M, Parker A. Development of an information aid and knowledge scale for women at low to moderate risk for hereditary breast cancer (HBC). 20th annual San Antonio Breast Cancer Symposium, December 3-6, 1997 (poster presentation) 1997.

2. Warner E, Goel V, Thiel E, Ondrusek N, Doan B, Carroll J, Chart P, Meschino W, Lickley L, Taylor K, Parker A, Rao M. Pilot study of an information aid for women at low to moderate risk for hereditary breast cancer (abstract). American Society of Clinical Oncology [ASCO] conference in Los Angeles, California, May 19, 1998.

3. Ondrusek N, Warner E, Goel V. Development of a knowledge scale about breast cancer and heredity (BCHK). *Br Ca Res Treatment* 1998 (in press).

4. Hereditary Breast Cancer information aid: [Includes booklet & audio tape: Hereditary Breast Cancer: “Someone in my family has had breast cancer.” “Am I at increased risk?” “Will I get it too?”] The aid will be used in Pilot 2 study January 1999 in the community with low/moderate risk women and their family physicians.

## **Prostate Cancer**

### **D. PSA Project 1994**

1. “*PSA and Prostate Cancer*” ICES/Canadian Cancer Society sponsored brochure, 1994
2. “To be screened, or not to be screened” *informed* Vol 1(2) March 1, 1995
3. ICES fax-back service articles “*PSA and Prostate Cancer*” for physicians and for the public
4. Mercer SL, Goel V, Levy IG et al. Prostate cancer screening in the midst of controversy: Canadian men’s knowledge, beliefs, utilization and future intentions. *Can J Pub Health* 1997;88(5):327-32.

### **E. PSA Project 1998**

1. *PSA: the new Expert Panel Recommendations*. Information for physicians about prostate cancer screening. Ministry of Health project. FALL 1998.
2. *PSA: the new Expert Panel Recommendations*. Information for patients about prostate cancer screening. Ministry of Health project. FALL 1998.

## **Other**

### **F. Prescribing Feedback Study**

1. Hux JE, Melady MP, DeBoer D. Confidential Prescriber Feedback and Education to Improve Antibiotic Use in Primary Care: A Randomized Trial. *CMAJ* (under review)
2. May still do further content analysis of the focus group data and write up for a medical education journal

### **G. Hypertension/hypercholesterolemia Projects**

1. Risk assessment workbook prototype
2. Study report

### **H. Sore Throat**

1. *Sore Throat Score: Decision Aid for Physicians* ICES 1996. Developed to reduce inappropriate antibiotic prescribing in viral illness.
2. McIsaac WJ, Goel V, Slaughter PM. "Sore Throat": Reconsidering the clinical approach. *ICES Working Paper #37*, April 1995.
3. McIsaac WJ, Goel V, Slaughter PM, Parsons GW, Woolnough KV, Weir PT, Ennet JR. Reconsidering Sore Throats: I. Problems with Current Clinical Practice. *Can Fam Phys* 1997;43:485-93.
4. McIsaac WJ, Goel V, Slaughter PM, Parsons GW, Woolnough KV, Weir PT, Ennet JR. Reconsidering Sore Throats: II. Alternative Approach and Practical Office Tool. *Can Fam Phys* 1997; 43: 495-500.
5. "Sore Throat Management: Who needs antibiotics anyway?" *informed* Vol 1(4) September 1995.
6. McIsaac WJ, Goel V. Effect of an explicit decision support tool on decisions to prescribe antibiotics. *Med Decision Making* 1998;8: (in press)

#### **I. Wife Abuse**

1. When the wife abuse victim and offender are patients of the same primary care physicians: A study to establish clinical guidelines for primary care physicians. Report to Health Canada - funding agency
2. Ferris LE, Norton PG, Dunn EV, Gort HE, Degani N for the Delphi Panel and the Consulting Group. Guidelines for managing domestic abuse when male and female partners are patients of the same physician. *JAMA* 1997; 278 (10):851-7

## Appendix 4: Samples of consent forms for focus group participants

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### Consent to Participate Focus Testing of a Pamphlet for the General Public entitled

“ \_\_\_\_\_ ”

**Purpose:** To receive feedback on written materials that have been developed for the general public in order to present and explain the \_\_\_\_\_.

**Procedure:** You will first be asked to take some time to read through the pamphlet. Then you will be asked for your comments about the pamphlet. We are interested in such things as whether the information is clear and easy to understand, and whether there any specific words or terms that are unclear. You will be asked about the format and layout of the pamphlet. Lastly, you will be asked about the kinds of information and assistance you feel are important for you to have when you are asked to consider complicated health care issues.

The interview will last about 90 minutes. You may refuse to answer any specific questions. The interview will be recorded on an audio tape so that we can analyse the group's responses and prepare a report. *Please do not photocopy these materials at any time and to return them to the facilitators at the end of the session; these are DRAFT copies and their revision will reflect the comments and suggestions of the group.*

**Confidentiality:** All information will be kept confidential. The audiotape will be typed by a typist who is unaware of the identity of all the people in the room. All identifying information will be removed from the written transcripts. Any reports of this research will not identify you or anyone whose name you mention.

**Benefits/Risks:** There are no direct benefits or risks to you in participating in this focus group, except that you may appreciate being given the opportunity to express you views. In so doing, you will help us to develop a pamphlet that will be truly interesting and informative for men and their friends and families.

**I have read this statement and I agree to participate in this focus group. I understand that I am free to withdraw at any time without any consequence to me. The information I provide will not affect my health care in the future at any institution. I also understand that I will not be told what I personally should do regarding my health care. Instead, I understand that if I have any questions related to my own personal health and health care, I should discuss these with my family doctor.**

**I understand that I may contact the focus group leaders at any time at (416)480-4055 if I have questions about the study.**

Name: \_\_\_\_\_

Witness Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

## Consent to Participate Focus Testing of a Pamphlet for Physicians entitled

“ \_\_\_\_\_ ”

- Purpose:** To receive feedback on written materials that have been developed for Ontario physicians in order to present/explain the \_\_\_\_\_.
- Procedure:** You will first be asked to take some time to read through the pamphlet. Then you will be asked for your comments about the pamphlet. We are interested in such things as whether the information is clear and straightforward, and whether anything is missing or ambiguous or inadequately addressed. You will be asked to comment on the format and layout of the pamphlet. Lastly, you will be asked whether the information would be helpful to you when dealing with your patients, and whether you would use the patient pamphlet in your own practice.
- The interview will last about 90 minutes. You may refuse to answer any specific questions. The interview will be recorded on an audio tape so that we can analyse the group's responses and prepare a report. *We ask you to refrain from photocopying these materials at any time and to return them to the facilitators at the end of the session; these are DRAFT copies and their revision will reflect the comments and suggestions of the group.*
- Confidentiality:** All information will be kept confidential. The audiotape will be typed by a typist who is unaware of the identity of all the people in the room. All identifying information will be removed from the written transcripts. Any reports of this research will not identify you or anyone whose name you mention.
- Benefits/Risks:** There are no direct benefits or risks to you in participating in this focus group, except that you may appreciate being given the opportunity to express your views. In so doing, you will help us to develop a pamphlet that will be truly informative and helpful for Ontario physicians.

**I have read this statement and I agree to participate in this focus group. I understand that I am free to withdraw at any time without any consequence to me.**

**I understand that I may contact the focus group facilitators at (416)480-4055 at any time if I have questions about the study.**

Name: \_\_\_\_\_

Witness Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 5: Timeline/Budget/Checklist Examples

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### Example Budget - Pilot Testing Material\*

Distribution of Materials to Participants (approx. 100)  
(including postage, envelopes, letterhead)

Physician Focus Groups

- Honorariums
- Catering

Consumer Focus Groups

- Lottery Tickets (thank-you gift)
- Travel Expenses for Participants
- Catering

Facilitator's Travel Expenses

- Airfare
- Car Rental
- Mileage
- Parking
- Hotel
- Meals

Tapes

\* does not include staff time

### Example: Budgeting Staff Time - Varies by project

#### Personnel Costs re: Focus Groups

Faculty

Research Coordinator

- project development time
- conducting focus groups/analysis/writing \* time
- coordinator as facilitator
- coordinator as recorder

Administrative Support

\* writing includes activities such as protocol development, ethics application, preparation of questions for focus groups, transcript review, preparation of educational packages, drafting of reports and manuscripts.

## Appendix 6: Checklist for Focus Groups

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- Copies of consent forms
- Copies of demographic sheet (bottom question sheet)
- Focus group guide
- Extra materials (booklets, detailers and brochures)
- Tapes
- Tape recorder
- Note pad and pens for recorder
- Lottery tickets for public's groups
- Sign-in for physician's name/address for honorarium
- Name tags for participants
- Confirm room arrangements
- Confirm catering arrangements
- Confirm participant attendance