# Summary of Feedback Regarding the Qualitative Research Document Circulated by SSHWC

*Submitted by the*

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# Introduction

This document provides a summary of feedback received in response to the call for consultation on Qualitative Research in the Context of the TCPS: A Follow-up to the *Giving Voice to the Spectrum* Report and a Discussion Paper.  The consultation period was originally from February 16 to April 16, 2007 but was subsequently extended to April 30, 2007. In the end it offers an understanding of how qualitative research approaches differ, from the more positivistic/ quantitative approaches that underlie most work in biomedicine, natural sciences and engineering, and in many of the social sciences as well. If there is a guiding objective that is to be conveyed to REBs and the research community overall, as well as to the Canadian public, it is the need to recognize the different assumptions that guide more qualitative forms of research, to appreciate the differing interrelationships that are characteristic between researchers and participants, and to understand the implications these differences have for research ethics and the research-ethics review process. Qualitative research has a long history in anthropology, sociology, education and many other well-established disciplines in the social sciences and humanities, as well as many areas[1] in the health sciences (e.g., nursing). This document is intended to include these perspectives (and disciplines) in the broader dialogue about research ethics in Canada.

Ninety-four submissions were received; however, one submission actually contained 3 individual responses so the final total was 97 responses. Submissions were made by individuals, REBs, educational institutions, hospitals/health authorities, professional/discipline associations, and government organizations.  There was a good geographic distribution of responses including two international responses. Submissions were made by both those with research ethics affiliation and those without. Disciplines that were represented included but were not limited to: Sociology and Anthropology, Social Work, Urban Studies, Pharmacy, Library and Information Science, History, Education and Environmental Studies. In most instances of submissions by an REB or REB members, the type of REB was not specified. The committee received 85 of the submissions in English and 12 in French.

The working committee would like to thank all the individuals and organizations that took the time to respond to the consultation. The thoughtfulness and completeness of the responses serves to underlie the importance of this topic to the research community in Canada.

## 1.  Community Feedback

The following is an outline of the responses received from our consultation call undertaken on the *Qualitative Research in the Context of the TCPS* document, from February 16 to April 30, 2007. These are the issues that the participants deemed to be of utmost importance vis-à-vis the issue of qualitative research and the TCPS.  They form the basis for our recommendations, which have been integrated into a new chapter on "Qualitative Research" that we have recommended be included in the next version of the TCPS.

There were 15 questions relating to qualitative research in the context of the TCPS along with 6 questions in an appendix focusing on the relationship between REBs and issues related to qualitative research. The feedback received from all of these questions has been grouped thematically into 13 sections.

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[1] *The Social Sciences and Humanities in Health Research: A Canadian Snapshot of Fields of Study and Innovative Approaches to Understanding and Addressing Health Issues*, CIHR and SSHRC, 2000. See http://www.sshrc.ca/web/about/publications/ahprc_e.pdf

## 1.1 Visions of Qualitative Research

The vast majority of respondents (86%) felt that the vision of qualitative research outlined in our 2007 discussion paper resonated with their understanding/experience of qualitative approaches.

As one respondent said: "I am beyond delighted that a panel of experts has finally outlined the innumerable ways in which the suppositions inherent in the [ethics applications/processes] we have been using are totally incongruent with the realities of the kind of research that qualitative researchers carry out."

There were some caveats about terminology and a few respondents felt that the vision was too closely tied to the Social Sciences and Humanities research context. These issues have been addressed in the final version of the document.

## 1.2 Separate "Qualitative" Section vs. Integration of Perspective

There was a clear consensus for the need to include a separate section on qualitative research into the revised TCPS *and* to integrate examples and a clear qualitative perspective throughout the body of the TCPS document. 41% of respondents supported this approach, while 11% supported having only a separate section and another 11% supported having only integration.

There was some concern that a separate section, alone, would reinforce the idea that qualitative research does not fit the "norm" or that it would further marginalize qualitative approaches and divide research disciplines. "There is a danger of assuming that only specific approaches can be used for specific types of questions if qualitative research is secluded into its own chapter."

The rationale for providing both options was described by respondents as a need for:

- A separate section, for quick reference and education about qualitative approaches; and,

- Integration of the qualitative perspective in the body of the work, to normalize qualitative research approaches.

A few respondents did not see a need to change the TCPS fundamentally, but rather suggested better education of the REBs and the inclusion of better examples within the TCPS. There was a fear that changing or adding to the TCPS would make the document more cumbersome than that it is already perceived as being.

Finally, a few respondents were not in favour of adding a qualitative research section. Among these, many acknowledge problems but do not think that adding a new section is the solution. The following are some of the reasons provided.

- The TCPS as is offers sufficient flexibility, it is its overly rigid interpretation that is the problem.

- It is the lack of consistency among REBs both between and within institutions that is the issue, which can be solved by including illustrative examples rather than a whole new section.

- REBs need to be discipline specific not institution specific.

- "The harm-assessment approach is problematic, the model is often incommensurate with qualitative research approaches."

- One respondent suggests a move towards professionally recognized codes of conduct.

These comments form the basis for our recommendations that additional examples and references be incorporated into the main body of the TCPS, in addition to the inclusion of a separate chapter on Qualitative Research.

## 1.3 Revisions to REB Processes

Respondents mentioned a number of possible revisions to REB processes and procedures that would ameliorate existing problems for qualitative researchers. The most commonly mentioned recommendations (almost 50% of responses) include:

- Ensuring that qualitative researchers serve on all boards that review research using qualitative methods, by requiring such membership;

- Providing educational sessions or training to REB members about qualitative research approaches;

- Consulting with qualitative research experts, as needed, when individual board members do not have the necessary expertise.

Respondents noted discrepancies and inconsistencies in decisions made by different REBs (within and across institutions; or, with the same REB, over time) as examples of the problems with the existing interpretation model used by institutions in Canada.

Finally, the need to develop procedures for REBs based on qualitative researchers' experiences (including the need for better documentation developed by and for qualitative researchers) is mentioned. Improved documentation (such as REB application forms) is often described as being more flexible in nature and more reflective of qualitative practices (e.g., provisions for oral and/or written consent procedures, not just a single "consent form").

### 1.3.1 What Can Qualitative Researchers Do?

Respondents also provided suggestions regarding steps that qualitative researchers can undertake to improve the current ethics review process. Recommendations included:

- Serving on REBs;

- Providing training in research ethics appropriate to qualitative research methods to Board members (e.g., workshops);

- Engaging with REBs in one-on-one dialogue about their personal research projects , to educate members about specific approaches;

- Providing clear and detailed documentation about methodology/methods and ethics procedures in research ethics applications; and,

- Referencing the TCPS, ethics and methods texts, or other appropriate material when writing ethics applications, to assist REBs in interpreting the TCPS when reviewing qualitative research practices.

"Having a real conversation where REBs came together with researchers as colleagues to brainstorm solutions might be a good way of doing education, problem solving and assist with the methodological reviews."

### 1.3.2 The Need for Flexibility

The need for flexibility is an ongoing theme in the responses to the consultative document; for some respondents the current TCPS documentation is viewed as too rigid, while for others, it is the REBs' interpretations of the TCPS that are too rigid. The only consensus is that somewhere there needs to be more flexibility.

Respondents also provided suggestions regarding steps that REBs can take to improve the current ethics review process for qualitative researchers. Recommendations included:

- Showing some flexibility when dealing with research with which they may be unfamiliar;

- Seeking expert advice from researchers external to the REB, when necessary;

- Educating themselves about the diverse research approaches used by researchers in various disciplines;

- Maintaining open dialogue with researchers about specific research proposals; and,

- Encouraging researchers to reference the TCPS, ethics and methods texts, or other appropriate material when writing ethics applications, to assist the REB in interpreting the TCPS when reviewing qualitative research practices.

Requiring qualitative researchers to be represented in the membership of REBs and providing education to REB members about the diversity of research approaches, are two specific ideas that can be translated into policy recommendations for changes to the TCPS. These suggestions need to be implemented to fulfill the mandate of rendering the ethics review process more open to and inclusive of qualitative research in all disciplines.

## 1.4 Field Contact and Research Plans/Programs

### 1.4.1 Field Contact

In response to the question about how REBs should deal with the need for many qualitative researchers to engage in field contact before a research plan can be fully developed, two common themes emerged:

- That REBs must have the flexibility to deal with this type of scenario;

- That researchers should present a preliminary outline of what they will be doing in the field, with the understanding that this might change as contact in the field progresses.

There was a third theme that emerged from the responses, which is that many respondents indicated that they feel that early field contact and field notes are not in the purview of the REB because they are preliminary to research.

An example of how this issue might be addressed in practice can be found in the following quote: "As long as data is not being collected, it is accepted to visit the field site, interact with people, and establish relations with members of the community. Before 'official' data collection begins (and this is primarily interviews or exercises where text or numerical data will be collected and used for analysis), ethics approval must be obtained. This approach allows for preliminary visits, the determination of research questions and methods, without overly taxing the REB too early in the process. It also permits the inclusion of community-based concerns into the project design and data collection process."

### 1.4.2 Research Programs

Respondents also addressed the emergent nature of qualitative research, particularly in longitudinal or other long-term projects. They noted that:

- Individual research projects that extend over a long period of time (and may be marked by periodic data collection) should be asked to submit annual reports to REBs, rather than having to submit new ethics applications for each phase of the research. Many institutions already include such reports as part of their procedures, although there is little consensus regarding the appropriate timing for this type of review; and,

- Specific research projects that form part of a researcher's program of research, but which are distinct in nature, should be seen as individual "studies" with separate ethics review applications – even where these projects build on previous work.

Respondents reinforced the current practice of informing REBs about any significant change to research plans; however, the question of what constitutes a "significant change" remains unclear for many REB members and qualitative researchers. Respondents recommended:

- That decisions be made on a case-by-case basis;

- That REBs provide lists of examples regarding what might constitute a "significant change" to provide guidance to researchers (i.e., almost 60% of respondents suggested this); and,

- That REBs understand that emergent design in qualitative research does not constitute a "change" to the research plan, but reflects the intention of this approach to research. For example, while the addition of a new method to a study may well constitute a "change" requiring additional review by the REB, the specific interview questions asked of a participant typically cannot be known in advance of the start of the interview. This approach to interview design is one example of the emergent design that is found in qualitative research projects.

## 1.5    Field Notes and REB Review

The question of how best to manage field notes, and whether researchers need ethics approval to take such notes, showed a diversity of approaches in how these notes are used by qualitative researchers. As one person noted, "it is important to distinguish between interactions with individuals that inspire a research idea and interactions that are used as data." Respondents referred, for example, to the following categories of notes, which demonstrates the complexity of making ethics approval judgments based on the type of method (or data collection tool) used in qualitative research:

- "Idea notes" (or "researcher journals") are general observations or ideas that a researcher gathers informally, often after interacting with other individuals; although some of these ideas will mature into research projects (which may require review), others will not. These types of notes are not "data" and do not require ethics approval;

- Traditional "field notes" are used/gathered in ethnographic/observational approaches and do contain data that will be used in the research project. The decision to collect these types of notes (like other data collection methods) typically requires ethics approval.

### 1.5.1    Special and Expedited Review Procedures

#### 1.5.1.1  Special

60% of respondents favoured some form of special review procedures for "emergency or disaster" research, with the following suggestions or observations:

- Researchers could get a blanket approval, in advance, in their areas of expertise, for such situations; for example, researchers could submit general research intentions regarding their procedures during an emergency, which could be reviewed and approved "in principle" by the REB;

- Researchers could get approval after the fact, where emergencies warrant immediate decisions without access to the REB for consultation;

- Respondents at smaller institutions, however, expressed concerns about having access to "emergency" review, at all times, given the small size of their institutions; and,

- Respondents noted that any "emergency" process must mitigate concerns that rigorous review processes may be short-circuited for expediency, particularly as participants might be very vulnerable in certain circumstances.

There were some respondents who were completely opposed to the idea of "emergency" procedures. They noted the following concerns:

- That this would be time-consuming for Board members;

- That this could lead to "emergency research" claims in attempts to short-circuit the review process;

- That such a process is not needed, as these requests can be handled on a case-by-case basis; and,

- Some respondents questioned researchers' roles in trying to conduct research in an emergency situation (i.e., rather than offering assistance to people).

### 1.5.1.2 Submission of General Research Intentions

Respondents did note a number of benefits to the idea of submitting "general research intentions" to REBs for approval "in principle," 74% were in favour of such an option. They noted:

- The ability to submit general intentions would be particularly helpful in an international context;

- Researchers could pass an online ethics tutorial and submit general intentions to start a project (e.g., when a grant is first awarded), and then later submit a full application when the project is fully developed;

- That this should only be used in projects involving minimal risk;

- That this should only be used where researchers will return for a full review at a later date;

- That reporting on progress would need to be more frequent; and,

- That researchers would need to demonstrate that they have rigorously considered possible ethical issues that might arise and how they would deal with them.

Those respondents who did not support this process provided the following ideas/reasons:

- That this step would not be needed if the current ethics review procedure were more flexible and better reflected emergent research design;

- That this would encourage too much bureaucracy; and,

- That this would be an undue time constraint for Board members and researchers.

## 1.5.2 REB Reviews

The review process is another area of concern for qualitative researchers.  Currently, it appears to mostly be based on a biomedical paradigm which, for example, views research as having a well-defined beginning and end. Qualitative research, particularly if it is emergent is not so easy to categorize. Thus when to submit a proposal for review and how that review should be conducted are important points. The responses that were received generally made the following points.

### 1.5.2.1 When to Review

- REB reviews should take place before data collection, upon formalization of the project. Some respondents noted that because the "beginning" and "end" of qualitative research projects can be unclear, particularly in emergent designs, the TCPS needed to clearly address this issue; and,

- As one individual noted, it is important that REB processes address the problem that "researchers may not be able to submit a neatly packaged research proposal prior to their

involvement in the setting." That is, REBs should be counselled to expect differently packaged types of research proposals from researchers who are working with different methodologies in diverse contexts.

### 1.5.2.2    How to Review

- Review should be iterative or ongoing throughout the life of the project. There should also be graduated or flexible levels of review (i.e., minimal/nonexistent for minimal risk projects, etc.)

## 1.6    Researchers' Roles and Relationships

Respondents' opinions diverged on how best to manage researcher-participant relationships after specific projects come to a close. Some respondents believe that managing multiple roles between researchers and participants is outside the purview of the REB, while others believe that the REB should require full disclosure of such multiple relationships. Half of the respondents agreed, however, that it is not the REBs' responsibility to monitor relationships that the researcher might maintain; however, some respondents recommended providing a formal acknowledgement to participants, stating that the project was concluded, as a useful strategy for delineating roles and activities.

"One of the biggest concerns with qualitative research is the embedded power relationship that can exist in this research and so we would like more discussion on how to deal with these relationships…. The REB should acknowledge that power exists in different roles but it is how these roles are lived and not how they are perceived as a hierarchy that determines whether or not there is power within the relationship. The term coercion can easily be considered too broadly and this can unnecessarily limit qualitative research."

## 1.7    Consent

The issue of consent is of the utmost importance in human-centered research; however, there were conflicting opinions on the subject of managing the consent process. Some respondents believed that REBs should develop precedents for how consent should be managed by, for example, cataloguing a variety of "good practices" as demonstrated by researchers in their submissions; while others believed that researchers should decide on their own process for acquiring and recording consent. Some respondents believed that establishing a set of standard procedures was not a good idea, as this would be too rigid for most research projects.

"This is a tough one. I think that participants come in many forms and with many different sets of power relationships – what is appropriate for one group may not be appropriate for the other. So I suggest that the onus is on the researcher to identify the nature of the power relationship with potential participants and why one particular 'consent' process is the best way to go."

## 1.8    Conflict of Interest

Respondents raised a number of concerns about conflicts of interest, including:

- When the researcher could accrue professional/personal gain (e.g., financial gain); and,

- When the researcher does not declare potential conflict of interest.


Respondents considered conflicts of interest to be particularly serious when highly imbalanced power relationships existed between participants and researchers; however, they noted that such conflicts are only an issue if they pose a potential danger to participant. Respondents provided mixed commentary on how best to handle conflicts of interest:

- Some felt that it was up to the researcher to handle this type of issue;

- Others felt that the ethical responsibility was the REB's;

- Respondents agreed that, regardless of consent procedures used, participants must be free to withdraw from a study;

- Respondents noted that ongoing consent processes are preferred, compared to the current "one-time" consent process that is used with written consent forms;

- Overall, respondents preferred improved education on the nature and implications of conflict of interest rather than TCPS modification on this issue.

## 1.9    Managing, Storing, and Retaining Qualitative Data

70% of responses favoured addressing aspects related to the management, storage and retention of data in the TCPS.  Respondents noted a number of issues related to data storage and management that are particularly important (and problematic) for qualitative researchers. They noted:

- Qualitative data typically need to be stored for longer periods than quantitative data, often with no expectation that data will be destroyed;

- Plans for management, storage and retention should be included in researchers' ethics review submissions;

- Consent processes could include explanations of how data changes over time, possible uses it can be put to, its ultimate disposition and how (if at all) participants can access it;

- Issues related to the management, storage and retention of data are best addressed by practices of the discipline in question; or,

- One respondent thought that a more pressing issue was the new privacy legislation that could prevent the sharing of data among researchers.

## 1.10   Publishing Qualitative Data

Only a few respondents commented on the issues related to publication. They noted that free and informed consent processes are key to the ethical publication of qualitative data (e.g.,  in some studies participants are involved in data analysis and writing). Some respondents noted that this issue fell outside of the REB's purview, while others noted that existing processes are sufficient in addressing the ethics of publication practices.

## 1.11   Fundamental Intersection of Research & the TCPS

- Informed consent, confidentiality/anonymity, and risk were considered to be the most fundamental elements needed in research in order that the principles of the TCPS are integrated into the research process to the potential benefit of the community at large.

- Several respondents also mentioned community involvement in research design particularly in the cases of vulnerable groups.

## 1.12   Pedagogical Exercises and REB Reviews

Respondents noted that REBs should play no role in approving student pedagogical exercises for the purpose of learning about research and data collection, as they felt that this would lead to REB overload. Rather, they provided a number of suggestions for reviewing ethics procedures in these types of projects:

- REB sub-boards (e.g., departmental boards) could review such projects;

- Professors should be responsible for teaching ethics to their own students; or,

- Require only that the course be reviewed, where professors address the assignment, ethics training, etc. (i.e., not individual students).

Further, respondents noted that some guidelines could be provided as to when review is required in pedagogical contexts; for example:

- Thesis and dissertation projects, as well as other individual student projects should require individual review;

- Ethics review is required only if publication is to occur;

- Student pedagogical exercises/research should always be minimal risk –eliminating much of the need for REB oversight; and,

- That need for approval should depend on level of risk.

Although some responses distinguished between undergraduate and graduate student activities, most did not. However, the importance of distinguishing between a pedagogical exercise (i.e., not requiring review) and student "research" (i.e., requiring review) was made.

## 1.13 Scholarly Review

Respondents commented on the nature of scholarly review as part of the ethics review process, noting the following general themes:

- Several mentions of fear of "mission creep" of REBs; others felt that the current process works well;

- Some respondents favour scholarly review for all proposals; others only favour review for those that are possibly above minimal risk;

- Some respondents were uneasy with idea of the REB assessing scholarly merit as many REBs do not have the necessary qualitative research expertise.

"We are not qualified to provide expert peer review in all of the areas whose research we review for ethics, reviewing for ethics has nothing to do with reviewing for scholarly/scientific merit, and setting up still another set of committees to which researchers have to submit their plans will not only take enormous amounts of time and effort (for both the researchers and the committee members), but may even further alienate an already pretty resentful research community from the ethics process.… I, for one, would much prefer to have the research community think of the REB as being on their side in helping them to avoid lapses of judgment or attention to the welfare of their subjects, rather than viewing us as an enemy dedicated to delaying and frustrating them."

## 1.14 For Future Discussion

Respondents also mentioned areas that they thought were not adequately addressed or were missing from this discussion on qualitative research.

- Several submissions commented on what was perceived as a bias in what qualitative research techniques were focused on. It was felt, particularly, that qualitative research methods from the health sciences were not represented.

- The lack of discussion about the sometimes exploratory nature of some qualitative research was also mentioned; and while the desire by the SSHWC to avoid the pitfall of having all qualitative research consigned to being "exploratory", as has often occurred in the past was understood, it was suggested "that the breadth of the goals of qualitative researchers could be respected without appearing to deny that some qualitative researchers understand their work to be exploratory."

- Other areas of concern included insufficient attention paid to the issues surrounding research on or with particular groups, such as children and youth, the physically or mentally challenged, or public figures.

- A couple of submissions brought up the particular case of marketing research and another defining the line between journalism and research, and yet another the lack of guidance in the TCPS for covert research.

- Finally, the lack of guidance for qualitative research in an international setting was also mentioned.

## 1.15 Total number of respondents for each question in the *Qualitative Research in the Context of the TCPS* document

*Qualitative Research in the Context of the TCPS*, **main document**

| Questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Total number of answers* | 96 | 68 | 57 | 48 | 38 | 58 | 48 | 48 | 52 | 50 | 45 | 49 | 40 | 45 | 43 |

*Qualitative Research in the Context of the TCPS*, **Appendix A**

| Questions | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| *Total number of answers* | 26 | 26 | 26 | 25 | 24 | 25 |

Total number of submissions:  97.