Action/Participatory/Practitioner Research: Special Considerations in Ethical Reviews

Receipt of “ethics approval” signifies that the study to be undertaken involves procedures that are consistent with the current ethical standards of research practice. The Tri-Council Policy Statement on “Ethical Conduct for Research Involving Humans”, developed by the three major research councils of Canada in 1998, provides guidelines for this review process.

One major concern in evaluating the ethics of human (behavioural) research is safeguarding and protecting the rights of participants in the research. This becomes particularly important in participatory, action or practitioner research when:

- Researchers are investigating their own practice or communities are investigating issues of concern to them.
- Dual relationships exist between researcher and participant, especially when people in positions of power or status undertake research in addition to their already established roles and responsibilities and that research will potentially involve individuals of lesser power or status such as students, employees, inmates and/or clients.
- Information and results obtained regarding “practice” is made public through research presentations, publications, etc.

In submitting a request for the ethical review of this type of research to the UBC Office of Research, it is important for investigator(s) to address two critical issues.

- The first issue concerns the nature of the relationships between researcher and participant, which may affect the degree to which participants are able to consent freely to involvement. The right of voluntary participation may be jeopardized in cases where dual relationships exist (e.g., the researcher is also the participant’s employer or teacher), and/or where a power differential exists between researcher and participant. Article 2.2 of the Tri-Council Policy Statement is relevant here:

  Article 2.2: Free and informed consent must be voluntarily given, without manipulation, undue influence or coercion. [Selected excerpts]

  The element of voluntariness has important implications. Consent must be freely given and may be withdrawn at any time. Undue influence may take the form of inducement, deprivation or the exercise of control, or authority over prospective subjects.

  Voluntariness is especially relevant in research involving restricted or dependent subjects, and is absent if consent is secured by the order of authorities or as a result of coercion or manipulation. The influence of power relationships on voluntary choice should be judged according to the particular context of the prospective subjects. For example, the voluntariness of prisoners, members of organizations with authoritarian structures (such as the military, police, some religious groups or street gangs), or of employees or students may be restricted because of their institutional context implies undue pressure. Care should be exercised in developing relationships between researchers and authorities, so as not to compromise either the free and informed consent or the privacy and confidentiality of the subjects.
Research Ethics Boards should also pay particular attention to the elements of trust and dependency, for example within doctor/patient or professor/student relationships, as these can constitute undue influence on the patient to participate in research projects, especially those involving residents in long-term care facilities or psychiatric institutions.

Researchers should avoid being put in a position of becoming informants for authorities or leaders of organizations. The offer of benefits in some contexts may amount to undue inducement, and thus negate the voluntary aspect of the consent of subjects who may perceive such offers as a way to gain favour or improve their situation.

Given the unique researcher-participant relationship that exists in action/participatory/practitioner research, it is especially important to explain how the possibility of participant coercion will be avoided. This is often dealt with in terms of proposed recruitment procedures and strategies for obtaining informed consent. An example illustrates how this might be accomplished. Assume that you want to conduct a school-based, practitioner research project in which a teacher uses his/her own site or classroom to investigate his/her method of teaching or practice.

- How will you, as researcher, assure parents that students are truly free to participate or not?
- How will you assure students that their participation is entirely voluntary?
- How can you assure parents that students who refuse to participate or who do not receive parent permission will not be penalized in any way?

Some considerations for the consent form:

- Assure parents and students in consent forms that they have the right to refuse or withdraw their child’s participation in the research without consequence or penalty of any kind.
- Add a sentence in the permission letter to parents that indicates that the researcher is aware that parents may feel pressure to agree to their child’s participation because the researcher is also the child’s teacher and assure them that this is not the case.
- Inform parents that if they do have concerns about their child’s rights or treatment in connection with the research project, they can contact the Director of the UBC Office of Research Services at 822-8598.
- In some cases, it may be useful to explain how there is no disadvantage in not participating (e.g., all students will be taught the lesson). This may be especially important when research is conducted with an intact population with an ongoing relationship between researcher and participants (e.g., teacher, employer). The researcher must anticipate the impact of the experience on those who are not participating as well as those who are participating.

- A second, but equally important, issue is maintaining the anonymity and respecting the privacy of participants. Although individuals may agree to participate in research, they nevertheless have a right to privacy. Especially in cases where the research is being conducted within an intact, public group, it becomes important to recognize that participants’ identity must be protected, as individuals and as a group.

As a researcher, it is important that you explain both the extent to which and the means by which confidentiality and anonymity will be maintained. Although research ethics boards recognize that there are exceptional situations in which confidentiality can be violated justifiably (e.g., mandatory reporting of child abuse or intent to murder), the principle of free and informed consent requires that participants be informed of the limits and extent of confidentiality that can be assured.

According to the Tri-Policy Statement (page 3.2), “as a general rule, the best protection of the confidentiality of the personal information and records will be achieved through anonymity.” If complete anonymity cannot be assured, it becomes important to explain how and to what degree confidentiality will
be achieved across various phases of the project - in your research procedures, in your handling, storing and coding of confidential data, in terms of who has access to the data, and in how the information obtained in the study will be disseminated. For example,

- How will individuals and their responses (e.g., in discussions, interviews, surveys, videos, etc.) be protected in terms of anonymity?
- How will these data be stored?
- Who has access to results and data collected? Are the participants aware of this access?
- Once the study is complete, how will the confidentiality of the participants be protected when the findings are disseminated? How will the identity of the group, school, community, etc. be protected? Does it need to be protected?

Action, participatory and practitioner research may present unique difficulties for efforts to maintain full anonymity and confidentiality, given the dual and ongoing relationships that may exist between researcher and participant. It is therefore critical that these issues be addressed directly in the ethical review process. Although there is general consensus regarding the rights of participants to privacy, and the duty of the researcher to maintain confidentiality, these are not absolute, and there is recognition of justifiable exceptions. It is the job of the researcher to think through, explain and justify the ethical approach taken in maintaining confidentiality so that the Research Ethics Board can appropriately judge the adequacy of the proposed procedures.

Some suggestions:

- Specify in consent form just how the data will be used and stored, who will have access to the data, and how participant anonymity will be protected.
- Specify, in advance, how confidentiality and identity of the group can be preserved when results of the project are disseminated.
- In cases where research participants are considered co-researchers working in collaboration with the principal investigators and want to be identified and receive credit for their efforts, investigators would need to verify permission of participants to waive confidentiality and anonymity rights.