

## Important Statement Regarding Informed Consent

- A. The HPRC has adopted the position that all human participants (e.g., interviewees, research subjects, community members, etc) have the right to be informed of:
- the nature of the research (hypotheses, goals and objectives, etc.);
  - the research methodology to be used (e.g., medical procedures, questionnaires, participant observation, etc.);
  - any risks or benefits;
  - their right not to participate, not to answer any questions, and/or to terminate participation at anytime without prejudice (e.g., without academic penalty, withdrawal of remuneration, etc.)
  - their right to anonymity and confidentiality;
  - any other issues of which the participants should be aware that are relevant to specific protocols and research projects.
- B. The HPRC recognizes that the manner the researcher uses to obtain the informed consent varies according to the nature of the research, status of the participants, and culturally-specific norms. Although the HPRC requires that the principles of informed consent (outlined in A. above) be met, it is very flexible in how this consent is obtained. The HPRC will accept any of the three methods outlined below:
1. **Informed consent form:** The traditional informed consent form is the standard for research involving human participants. This would detail the principles outlined in A. above, and require the participants' signatures.
  2. **Letter:** Where the traditional informed consent form is not appropriate (e.g., interviews with artists or government officials, mass mailed questionnaires, etc.), the researcher may wish to seek permission through a letter inviting them to participate. This letter must nonetheless incorporate the principles of informed consent outlined in A. above.
  3. **Verbal statement:** In some instances, where written communication is not feasible (children, illiterate adults, certain communities), researchers can relay the principles outlined in A. above verbally.

Although it is impossible to come up with *one* generic model that will suffice for every research endeavour, a sample of all three types of informed consent statements are attached for your reference. (These are “real-life” examples previously reviewed and approved by the committee, and used with permission of the researchers, having expunged identifying information.)

- C. The HPRC recognizes that researchers completing this protocol may not be at the stage of their research where they are able to provide this information. Nonetheless, the HPRC requires that a “best effort” draft be attached to this protocol. **PROTOCOLS THAT DO NOT ATTACH THIS INFORMATION WILL BE RETURNED TO THE RESEARCHER.**

## Sample 1: Informed Consent Form

I am a graduate student at York University. I am working on a project where I need to create a data bank of voices for analysis. I am therefore asking if you would agree to participate in my research by engaging in three different speaking tasks which I will be recording.

The speaking tasks will be:

reading a word list

reading two paragraphs

answering an open ended question

It goes without saying that you do not have to participate at all, or you can terminate your participation at any time during the course of the recording. In addition, once the recording is finished, you have the right to ask me to erase the recording.

At this point, I cannot reveal the purpose of the study. You will, however, be given this information at the conclusion of the taping. At that point, you will again have the option of asking me to erase the recording.

I can tell you that your voice may be selected to be played for other researchers for their opinions, or may be selected to be played in a public forum (e.g. classroom, conference presentation, etc.). I can assure you that I will never identify you as the speaker, or play any part of the tape that would reveal your identity.

In return for your efforts, I am offering you a \$10 gift certificate to HMV Music upon completion of all the speaking tasks.

If you have any questions or concerns, please feel free to contact York University's Human Participants Review ('Ethics') Sub-Committee at 416-736-5055 ([research@yorku.ca](mailto:research@yorku.ca)).

## Sample 2: Letter of Informed Consent

Dear XXXXX

*On many occasions, we survivors of the Nazi concentration camps have come to notice how little use words are in describing our experiences. Their “poor reception” derives from the fact that we not live in a civilisation of the image, registered, multiplied, televised, and that the public, particularly the young, is ever less likely to benefit from written information....In all of our accounts, verbal or written, one finds expressions such as “indescribable”, “inexpressible”, words are not enough....”, “one would need a language for...”. This was, in fact, our daily thought [in the camps]; language is for the description of daily experience, but here it is another world, here one would need a language “of this other world,” a language born here.*

Primo Levi\*

\*Originally printed in the catalogue *Rivistando I Lager* for the exhibition of photographs at the Galleris San Fedele, Milan, 1986

We are preparing a research project that proposes to look at the way in which post-war artwork (including architecture, installation art, painting, sculpture and film) about the Holocaust is used to shape collective memory and history. The events of WWII have forced a rethinking of traditional aesthetic conventions to dramatise the ‘indescribable’, ‘where words are not enough’ (Primo Levi). Because historical realities such as Auschwitz are outside the realm of everyday experience, artists have struggled to find a language to describe and retell these events. This project aims to examine how are referring to the War and its aftermath explores the language of representation. While historians and philosophers have raised some of the issues regarding the difficulties of representation, there is little available from an aesthetics and cultural sphere. There has been enormous hesitation to approach retelling these histories through are because of sensitivities regarding “authentic” representation of the facts and the emotional trauma surrounding the Holocaust. Can art adequately recreate or evoke the “reality” of the event, and, if so, what language renders this utterance possible? At the same time there has been an increasing urgency to document and retell personal narratives given the passing of time, the ageing survivor population and the emergence of a post-war generation anxious to preserve historical memory.

A number of artists and filmmakers have produced work addressing such profoundly disturbing events which challenge traditional models of representation. Our research project will examine selected case studies which are exemplary in the way they address testimony, experience and memory about the Holocaust within forms of discourse which must be stretched, challenged, or redefined to accommodate them. As our objectives are both commemorative and didactic, we wish to reach a wide public audience and we have therefore developed the following phases of the project to be carried out over three years:

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A book entitled **Culture, Memory & Resistance: Representation and the Holocaust** (with colour and black-and-white illustrations) will include the following themes:

1. *Designing memorial sites and the relation of architecture to memory*
2. *Documenting memory*
  - a. *Art by survivors: personal testimonies*
  - b. *Art by families of survivors (“second generation”)*
  - c. *National expressions of historical memory in art*
3. *Questions of accountability and social responsibility: the impact of the war on contemporary society and culture.*

In addition, we plan to mount a series of events to include film screenings, panel discussions and small-scale exhibitions.

Your work as an artist/filmmaker interests enormously for this project. We would like to invite you to partake in this project with us by participating in an interview with you (to be held in your city or preferred location). Our approach combines interviews with descriptive and interpretative archival research. These interviews and visits will be conducted for inclusion in the above mentioned book. The intention is to investigate artists' personal archives, collect photographic documentation and visit their studios over a period of a few days per interviewee.

Our interview strategy will include some of the following questions: How do these works investigate strategies of storytelling to retell events that challenge traditional narrative representational forms? How does the art contribute to the way in which the Holocaust and Jewish identity is being shaped and remembered? What are the aesthetic choices made that affect one's perception and comprehension of history? Does a fictional dramatisation impose limits on historical veracity? How is historical memory shaped by art? In what ways do these works demand an engagement with the sacred activity of commemoration?

We want to critically formulate these discussions with artists such as yourself, and in so doing, foreground the search for an aesthetic language to address what Primo Levi regards as the “indescribable”, where “words are not enough.” As we are committed to accessibility, we will be using everyday language for a lay public using a wide body of artistic production for the exhibition, the book and the speakers series. We will record interviews on tape recorders and videotape. Without compromising intellectual rigour, this project promises to serve as an educational tool with wide accessibility so that cultural production normally restricted to a small academic audience can be appreciated and experienced on a broad scale.

The book will include historical and theoretical ideas to ground the reader (offered in a clear, comprehensible style) and will be accompanied by interviews with artists and filmmakers. Illustrations will comprise an important percentage of the book as it aids in clarity and accessibility and invites a wider readership.

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After agreeing to meet with us, and should you choose, after our interview, not to participate or have your name included in our project, we require a written letter from you requesting to be dropped from inclusion in our book and project. Your participation is an active ingredient to the success of this project and we look forward to your contribution. Should you have any questions, please let us hear from you. There will be contribution. Should you have any questions, please let us hear from you. There will be no remuneration for your involvement. If the book is published as projected, we will ensure copyright privileges for you and respect all credits for photographic inclusion.

**Yours sincerely,  
XXXXX**

## Sample 3: Verbal Informed Consent

Hello, my name is XXXXX.

I am a student at York University. I have been working in the Native student's office there, and have for many years had an interest in Native issues. I am working with Professor on this survey that is designed to keep track of the thoughts and feelings of people at during the next couple of years as new development is taking place. I am very happy to have this opportunity to hear directly from people in your community, in order to more deeply understand the kinds of challenges and opportunities you face.

Your answers will be kept confidential. An overall summary of the opinions gathered will be distributed but no individual opinions will be identified in that summary. The overall summary may help inform development here at XXXXX, both in knowing what to continue doing because it is working well, and where and how changes might need to be made. So please be as honest and open as possible.

As you can see, your name is not written anywhere on this answer sheet, and these sheets will be stored in a locked container at York University. Anytime I ask a question that you would prefer not to answer, I invite you to say so, and we will simply continue to the next question. In addition, I will respect your wishes if at any time you decide you prefer not to answer the survey at all.

I would like to ask you 15 questions about your experiences in this community. I'll first ask you to tell me the extent to which you agree with each statement:

**Not at all-----a little-----somewhat-----very much**

And then I would like to hear anything further you would like to add.

Once I have talked with as many people as possible, I will prepare a summary of the options, and make sure you receive a copy. We will also be making recommendations to XXXXXX, The Committee, and the council, based on an understanding of community opinion, but again, no one but myself and Professor XXXXXXXX will have no access to the individual responses.

Other than providing a summary of the results, are there other ways in which you feel that this research could be helpful to you or the community?

Would you like to proceed with the interview?

Would you mind if I also interview your son/daughter (ages 10-16)?