

Hello Helen, here are our answers. We hope they provide you with the information you need.

**1 - Where consent is required in Stats Can voluntary surveys how is this defined?**  
**2 - Does Statistics Canada consider "passive consent" (that is a lack of refusal without an active written or verbal consent to participate) considered an acceptable form of consent ?**

"Here is a brief overview that I hope answers your first two questions.

For all Statistics Canada surveys, there is certain key information that must be communicated to respondents. This is accomplished through various means (introductory letter, pamphlets, as part of the questionnaire/interview, the StatsCan web site, etc.). The information in question includes:

- \* the purpose of the survey included expected uses of the information,
- \* that the survey is conducted under the authority of the Statistics Act and that the information respondents provide will remain confidentiality unless permission to disclose it is given or is permitted under the Act,
- \* whether their participation is mandatory or voluntary
- \* whether there is an agreement with other organizations (such as another federal or provincial government department) for the sharing of the survey information and the identification of the data-sharing partners, and finally
- \* if there are plans to use the information for research involving record linkage (data-matching)

For telephone or personal interviews, a brief summary of this information is read to the respondent before the survey starts, so a respondent clearly knows whether the survey is voluntary or not. In the case of the NLSCY respondents are also sent a letter and a brochure explaining this information. Therefore by not indicating that they do not wish to participate, their consent is assumed and the interview starts. However, at any time during the interview the respondent can refuse to answer specific questions and/or terminate the interview, though that generally is a rare occurrence.

In the case of data-sharing, because participants of household surveys have the right to refuse to share their information, a specific question is asked at the end of the interview (requiring simply a yes/no response). Because respondent will know what information they provided during the interview and with whom it will be shared, they can make an informed decision or whether they want to share their information or not. Only the information of those who answer "yes" will be shared. If the respondent answers "no" or the question is not answered, their data are not shared.

In the case of record linkage, brief details of the record linkage plans are provided and the respondent is asked a yes/no question for permission to the link the data. Similar to data-sharing, a "yes" response is considered as consent while a "no" response or lack of a response means that their information will be excluded from the planned record linkage."

**3- In the case of involving young children, would "consent" be considered to be obtained by sending a letter to parents through the school via the children, when the letter does not ask parents to return a signed consent form granting permission for their child to be included in a research project or data collection project or data linkage project?**

"In surveys that involve children, Statistics Canada considers the age of consent to be 15 years in order to decide to participate in a survey, or to agree to

sharing and having their information linked. In the case the NLSCY involving children under the age of 15 the interview is conducted in the child's home and the information about the surveys (as discussed above) would have been sent to the parent (or person most knowledgeable). There is not a specific consent form that parents have to sign to authorize their child's participation in the survey.

There have been other surveys that have been conducted in school, notably the Program for International Student Assessment, but the target audience for the survey were children 15 years or older. However in the case of this survey, information was sent to parents on the survey and if a parent did not want their child to participate, it was respected."

**5 - In the National Longitudinal Survey of Children and Youth are parents aware of their own and their children's participation?**

"Parents or guardians are aware of their participation when they are contacted by an interviewer assigned to their case. They are provided all the information outlined in the response to questions 1 and 2. If the parents or guardians do not refuse to participate then they will be interviewed over the phone and/or in person. The parent/guardian interview consists of questions about themselves and the child that was selected to participate by Statistics Canada. Parent/guardian participation is only required if the selected child is between 0 to 17 years of age, except for youth aged 16 or 17 years old who are living independently (the parents would not then be interviewed). The Person Most Knowledgeable (PMK) answers the Child component questions. The PMK is usually the child's mother, but it could also be the father, a step-parent or an adoptive parent who is living in the same dwelling. Only the PMK or his/her spouse is permitted to answer the questions in this component."

"There is a youth component to the interview as well. It is for selected children aged 16 and above. The youth is the only person permitted to answer the questions in this component, whether he/she is living in the family home or not. Since the child is over 15 years of age, no parental consent is required. The child would have the right to refuse to answer, or refuse to answer any question in this part of the questionnaire."

Self-complete paper questionnaires were provided to 10 to 17 year olds. Interviewers are to ask for verbal consent from the PMK to give the questionnaire to the child. If the PMK is not legally responsible for the child, the interviewer must then contact the child's parent or legal guardian to ask permission for the child to complete the questionnaire. The interviewer provides a questionnaire to the child and encourages him/her to complete it in a private setting with the interviewer present in the household. If it is not possible to arrange for the child to be home to complete the questionnaire with the interviewer in the household, the interviewer is to try to complete the questionnaire with the child over the telephone. Upon completion, the questionnaire is sealed in an envelope to ensure confidentiality. The PMK was informed of the confidentiality of the questionnaire before giving permission for the child to complete it.

Direct measures are also administered to children at various ages. Some of the direct measures are activities done with an interviewer (Who Am I, Number Knowledge and the Peabody Picture Vocabulary Test), and some of them were on paper and given to the child for the child to write the answers (there was a mathematics test for children in grades 2 to 10 and a cognitive measure test for 16 and 17 year olds). After 1998-99, the direct measures done with children older than 5 years olds have been done in the child's home. Before this, these direct measures were administered in the child's school. Interviewers are instructed to obtain verbal

consent from the parents to administer the assessments. Please refer to the answer provided at question 7 for consent from parents when direct measures done in child's school.

For children aged 0 to under 4 years of age, there is no participation required by the children."

**7 - In the NLSCY teachers were involved in answering questions about their students. Were parents aware of the teachers involvement? Was parental consent to this aspect of the NLSCY obtained?**

"Data from teachers was not collected after cycle 5 (2002-2003).

When information was collected from teachers and/or principals or children completed assessments at school, the parents provided written consent for Statistics Canada to request this information from their child's school. Statistics Canada did not inform the parents whether or not their child's teacher completed the questionnaire or if the child completed the assessment."

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