

# The Canadian Community Health Survey as a Potential Recruitment Vehicle for the Canadian Longitudinal Study on Aging\*

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## RÉSUMÉ

Le but de l'Étude longitudinale canadienne sur le vieillissement (ÉLCV) est de recruter 50 000 participants âgés de 45 à 85 ans et de les suivre pendant 20 ans. Les processus d'échantillonnage et de recrutement pour une étude de cette envergure représentent d'importants défis. Statistique Canada a été approché pour collaborer avec l'ÉLCV dans le but de déterminer si l'Enquête sur la santé dans les collectivités canadiennes (ESCC) pourrait être utilisée comme véhicule de recrutement pour l'ÉLCV. Dans cette étude pilote réalisée en 2004, il a été déterminé que 63,8 pour cent et 75,8 pour cent des répondants accepteraient de partager leurs coordonnées et leurs réponses à l'ESCC avec l'ÉLCV, respectivement. Les réticences les plus souvent rapportées étaient reliées à la confidentialité, le manque d'intérêt et le niveau d'engagement demandé. Cette étude pilote a permis d'identifier quelques défis liés à l'utilisation de l'ESCC comme véhicule de recrutement pour l'ÉLCV.

## ABSTRACT

The goal of the Canadian Longitudinal Study on Aging (CLSA) is to recruit 50,000 participants aged 45 to 85 years of age and follow them for at least 20 years. The sampling and recruitment processes for a study of this scope and magnitude present important challenges. Statistics Canada was approached to collaborate with the CLSA with the goal of determining whether the Canadian Community Health Survey (CCHS) could be used as a recruitment vehicle for the CLSA. In this pilot study conducted in 2004, it was determined that 63.8 per cent and 75.8 per cent of the respondents agreed to share their contact information and their survey responses with the CLSA, respectively. The most commonly reported concerns were confidentiality/privacy issues, lack of interest, and commitment issues. This pilot study identified some challenges to the use of the CCHS as a recruitment vehicle for the CLSA.

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## Introduction

The Canadian Longitudinal Study on Aging (CLSA), a component of the Canadian Lifelong Health Initiative (CLHI), was conceived as a study of adult development and aging. The CLSA is a population-based study that will recruit and follow 50,000 individuals aged 45 to 85 years of age for at least 2 decades. Within this cohort study, two levels of data collection will be carried out. Questionnaire-based information will be collected on all 50,000 participants. In addition, 30,000 of the 50,000 will undergo in-depth data collection consisting of physical assessments and biological samples, including blood and urine. For the complete cohort, questionnaire information will be collected by computer-assisted telephone interviews, while for the in-depth assessment, participant presence at a local site equipped to conduct such data collection is required.

The large sample size, the need to provide national data on aspects of health and aging (particularly in relation to health and social policy), as well as in-depth data collection on a sub-cohort (including clinical examinations and biological testing in an academic center), present particular challenges to the sampling and recruitment processes for the CLSA. In Canada, there are a number of possible strategies – including provincial health registries, telephone directory listings, and random digit dialing – for identification of potential participants. These have all been considered as sampling frames for the CLSA. However, none ensures that all Canadians in the targeted age range have an equal chance of being listed in this sampling frame. In addition, the sampling design required to incorporate both a nationally representative sample alongside a sample that must be collected from around academic centers for the in-depth data collection will require sophisticated statistical methodology.

Recognizing the complexity of the challenges faced in the design of the CLSA, the CLSA investigators approached Statistics Canada, a government agency mandated to collect and publish statistical information on social, financial, and other activities of the Canadian population, to collaborate on the sampling strategy. Statistics Canada, in collaboration with the Canadian Institute for Health Information and Health

Canada, created the Canadian Community Health Survey (CCHS) to respond to some issues with the health information system raised by the National Task Force on Health Information. Following full consideration of the options available, the CCHS Cycle 4.2 (on Healthy Aging) was identified as a survey instrument that could potentially be used to generate a sampling frame for the CLSA. The CCHS includes individuals aged 12 years and over living in all provinces and territories across Canada, and uses computer-assisted personal and telephone interviews to collect data on health determinants, health status, and health system utilization. Prior to each wave (or cycle) of the CCHS, Statistics Canada conducts pilot work to evaluate the instruments and procedures to be used. This mechanism was used to examine some of the issues pertinent to the use of the CCHS as a recruitment vehicle for the CLSA.

The CLSA collaborated with Statistics Canada and in 2004 contracted them (a) to determine the willingness of the CCHS pilot study participants to share their contact information and/or survey responses with the CLSA, and (b) to investigate potential participant concerns regarding their willingness to share this information.

## Methods

The feasibility study took place in two phases. The first phase, “qualitative testing”, was designed to obtain qualitative feedback from participants on their overall impressions and reactions to the questionnaires, to identify specific issues of concern, and to evaluate their understanding and willingness vis-à-vis CLSA contact and sharing questions. Qualitative data were collected by Statistics Canada in April 2004 in Montreal, Ottawa, and Toronto with both English- and French-speaking CCHS participants aged 40 to 84. A total of 35 participants were recruited for this phase. Face-to-face interviews were conducted at the participant’s residence during which participants were asked about their general impression regarding the pilot questionnaire and their willingness to release their contact information and their survey responses to the CLSA. The interviews lasted 60 to 75 minutes. During the interview, both the interviewers and CCHS observers took notes.

**Table 1: Qualitative testing: Characteristics of respondents**

Language	French (10 participants)				English (25 participants)			
	Male		Female		Male		Female	
<b>Sex</b>								
<b>Age Group</b>	40–59	60–84	40–59	60–84	40–59	60–84	40–59	60–84
<b>Total</b>	0	3	3	4	3	2	9	11

**Table 2: Final response rate by regional office**

Regional Office	Response Rate (%)
Halifax/Atlantic	72.1
Montreal	78.9
Vancouver	71.4
<b>Combined Regional</b>	<b>74.1</b>

The goals of the second phase of the feasibility study were to collect data to estimate the agreement rates to share participant contact information and/or survey responses with the CLSA and to identify respondents' and interviewers' primary concerns regarding the CLSA (see Appendix 1). In this "field testing" phase, targeted sampling was used to ensure an appropriate number of participants aged 40 years and over. A total of 318 participants in Vancouver, Montreal, and Halifax participated in this phase between June and August 2004. The interview package, which included an example of a CLSA consent form and information brochure, was modified to address the concerns (information sheet too long/too much information, and respondents did not have a clear understanding of what they were actually agreeing to do) raised in the qualitative phase. Prior to conducting the survey, the 43 Statistics Canada interviewers underwent a 2-day training session that included materials developed by the CLSA research team. All interviews were computer-assisted personal interviews. As part of the CCHS pilot, there were also questions asked about participants' agreement to share their responses with government agencies, health ministries, and the Institut de la Statistique du Québec. Only those individuals who agreed to share with these agencies were subsequently asked the CLSA module questions (i.e., sharing contact information and CCHS responses with the CLSA, and identifying their concerns regarding the CLSA).

## Results

### Qualitative Testing

For the qualitative test, 25 Anglophones and 10 Francophones aged 40 to 84 were recruited. The

characteristics of the participants are presented in Table 1.

The general impression vis-à-vis the pilot questionnaire was very positive. Most of the respondents were receptive to the questionnaire, found the interview easy to complete, and understood the terms used in the questionnaire. Some participants, however, mentioned that they felt that the questionnaire was too long to complete. One of the major observations recorded by the interviewers and the CCHS observers was that respondents would have liked to expand on their answers regarding their health. Because health care is an important issue in Canada, participants felt that it was important to participate in this survey. Overall, participants felt positive about the survey.

As noted, only participants who agreed to share their data with health ministries were asked the CLSA sharing questions. The majority of the respondents asked for more-detailed explanations about the study to understand it better before making a decision. When more information was provided by the interviewers, the respondents were more willing to consent to share. Nevertheless, despite the effort from interviewers to give additional information, several participants did not give their consent to share their information with the CLSA. One of the major concerns was related to the fact that participants did not recognize the CLHI and as a consequence were unsure if they could trust the CLHI with access to personal information.

Only half of the participants read the consent form, partially or totally, and even fewer actually looked through the additional information (i.e., pamphlet) that was provided. The information read out loud by the interviewers helped many participants make their decision. Additional comments were made by the participants regarding the respondent material. Many mentioned that the information sheet was too long and/or contained too much information. Others found it difficult to read the information at the same time that the interviewers were reading the introduction to them. Finally, some participants suggested that the information

**Table 3: Characteristics of all respondents of the field test**

	Regional Office							
	Atlantic		Quebec		British Columbia		Combined Regional	
	Male	Female	Male	Female	Male	Female	Male	Female
40–54	22	22	24	21	24	26	70	69
55–64	14	8	18	20	17	10	49	38
65–74	9	7	8	9	11	6	28	22
75 +	3	9	4	7	6	13	13	29
<b>Total</b>	<b>48</b>	<b>46</b>	<b>54</b>	<b>57</b>	<b>58</b>	<b>55</b>	<b>160</b>	<b>158</b>

**Table 4: Percentage of eligible respondents who agreed to share contact information, survey data, and sign consent form by sex (n)**

Agree to ...	Sex		
	% Male (n)	% Female (n)	% Total (n)
Share Contact Info	64.7 (97)	62.8 (93)	63.8 (190)
Share Survey Data	75.3 (113)	76.4 (113)	75.8 (226)
Sign Consent	71.3 (107)	71.6 (106)	71.5 (213)

sheets should be left behind with them so they could read them over before making their choice on their own time instead of being “rushed” by the interviewers to give an answer.

Based on what they observed during the test, interviewers recommended that the consent request should be revised because many participants did not clearly understand to what they were agreeing. The information sheet with the introduction read by the interviewer was the best strategy to increase informed consent agreement. An option to read the consent form at a later time and return the response in a self-addressed prepaid envelope could help to minimize further losses. Finally, the interviewers should be prepared and have a list of “questions and answers” to provide responses to those who request additional information.

### Field Collection

As a result of the suggestions and concerns expressed in the qualitative test, adjustments were made before conducting the second phase of the study where consent to share contact information and survey data with the CLSA was addressed. For this phase, a new sample of 592 persons aged 12 years of age and over was selected. The overall response rate for the CCHS was 74.1 per cent, and regional response rates are presented in Table 2. Of this sample, 318 respondents were 40 years and over (see Table 3 for respondent characteristics). From these 318 participants, 94 per cent agreed to share their survey data with the health ministries and the Institut de la Statistique du Québec. Thus, there were 298 eligible respondents aged 40 years and over who were asked about sharing contact information, sharing survey data, and signing the

consent form (for sharing contact information and survey data) for the CLSA.

### Agreement Percentages

Participants were more likely to agree to share their survey data with the CLSA (almost 76%) than their contact information (almost 64%). A total of 71 per cent of participants signed the consent form before the end of the feasibility study. Although there was little variation in agreement percentages between women and men (Table 4), differences were noted by age group (Table 5) and region (Table 6). The highest agreement rate was found in the 55–64 age group, followed by the 40–54 and 75 and over age groups. Those in the 65–74 age group were the least likely to agree to share. With respect to geographic region, Montreal was the region where the respondents were most likely to agree to share data and contact information, and to sign the consent form. The lowest agreement percentages were noted in Vancouver.

### Signed consent according to types of agreement to share

To further characterize the profile of the respondents who agreed to sign the consent form, participants were examined according to the three types of sharing agreement: (a) sharing contact information only, (b) sharing survey information only, and (c) sharing both contact and survey information. Of the 213 respondents who agreed to sign the consent form, more than 85 per cent also agreed to share both their contact and survey information with the CLSA (Table 7).

### Signed consent received after the collection period

Although there was no protocol to convert the people who refused to share information with the CLSA, 15 respondents who initially refused to share their contact information and 3 respondents who initially refused to share both contact and survey information subsequently changed their minds and returned a signed consent form (Table 7). Thus, including these 18 respondents who changed their mind after the data collection period, the percentage of respondents who signed the consent form increased from 71 to 77 per cent.

**Table 5: Percentage of eligible respondents who agreed to share contact information, survey data, and sign consent form by age (n)**

Agree to ...	Age Group				% Total (n)
	% 40–54 (n)	% 55–64 (n)	% 65–74 (n)	% 75 + (n)	
Share Contact Info	63.9 (85)	76.8 (63)	46.7 (21)	55.3 (21)	63.8 (190)
Share Survey Data	73.7 (98)	86.6 (71)	64.4 (29)	73.7 (28)	75.8 (226)
Sign Consent	74.4 (99)	84.2 (69)	48.9 (22)	60.5 (23)	71.5 (213)

**Table 6: Percentage of eligible respondents who agreed to share contact information, survey data, and sign consent form by geographic region (n)**

Agree to ...	Regional Office			
	% Halifax/ Atlantic (n)	% Montreal (n)	% Vancouver (n)	% Total (n)
Share Contact Info	69.7 (62)	78.1 (82)	44.2 (46)	63.8 (190)
Share Survey Data	74.2 (66)	90.5 (95)	62.5 (65)	75.8 (226)
Sign Consent	73.0 (65)	84.8 (89)	56.7 (59)	71.5 (213)

### *Respondents' and interviewers' concerns with CLSA/CLHI*

The respondents who agreed to sign the consent form were also asked about their concerns regarding the CLSA-CLHI initiative (Table 8), and 58 per cent of the respondents expressed concerns and/or asked questions about this initiative. The three most commonly reported concerns were (a) confidentiality/privacy issues (16%), (b) lack of interest (7%), and (c) commitment issues (7%). Among those who expressed concerns, "confidentiality/privacy issues" were identified as the most important (43%). Interviewers were also asked to report which concerns and questions they found difficult to explain to respondents. Confidentiality/privacy issues were the most-cited concerns expressed by the interviewers (9%).

## Discussion

Overall agreement rates to share contact information and survey responses with the CLSA and to sign the consent form were lower than expected considering that only the respondents who agreed to share their CCHS survey data with health ministries and the Institut de la Statistique du Québec were selected. Although these findings raise concerns about the utilization of the CCHS as a survey instrument to generate a sampling frame for the CLSA, the CCHS remains a potentially viable option for several reasons. First, the agreement rate to sign the consent form estimated during the feasibility study did not reflect what was actually collected because 18 respondents changed their

mind and signed the consent form after the end of the study. Thus, more than 77 per cent of the respondents, instead of 71 per cent as initially reported, agreed to sign the consent form. This suggests that a protocol to convert the people who refused to share information with the CLSA may significantly increase the agreement rates. Second, the feasibility study was conducted in the summer of 2004 before CLSA informational materials such as brochures, the official website, and the toll-free phone number were available. Thus, providing detailed CLSA information through these several strategies may also help to increase the agreement rates since at the time of the study CLSA was unknown to respondents. Given that agreement rates differed by age group, utilization of different recruiting approaches should be developed to target specific audiences. One of the respondents' main concerns was related to confidentiality/privacy. To address this issue, sufficient information about the CLSA should be provided to ensure that any uncertainties concerning confidentiality/privacy will be clarified.

As with any study, the feasibility study had its limitations. The first phase of this study was qualitative, thus the results were not representative of all survey participants and cannot be generalized to the Canadian population. Although the results should not be viewed in statistical terms, they do provide essential information about respondents' impressions, reactions, issues, and concerns. In the second phase of the feasibility study, participants aged 40 years and over were targeted, and because the study was presented to potential participants as a test and not a true study, this may also have influenced the results. Finally, the feasibility study did not include a follow-up to determine the success rate of actually contacting the CCHS respondents who agreed to be contacted by the CLSA. These limitations may have resulted in either an over- or an under-estimation of the proportion of those approached that would agree to share their contact information and/or survey data.

The findings of this feasibility study raised concerns as to whether low agreement rates were due to the feasibility study's design and content or whether they reflected a limitation of the CCHS as a sampling vehicle for the CLSA. Thus, it was concluded that a second

**Table 7: Percentage of eligible respondents who agreed to sign consent form by types of agreement (n)**

Type of agreement	% Before the end of the collection period (n)	% After the end of the collection period (n)
Share Contact Info Only	2.4 (5)	0
Share Survey Info Only	12.2 (26)	88.3 (15)
Share Both Contact and Survey Info	85.4 (182)	16.7 (3)
<b>Total</b>	<b>100 (213)</b>	<b>100 (18)</b>

**Table 8: Reported concerns vis-à-vis the CLSA/CLHI (n)**

Type of Issues	Issues as reported by ...		
	% Respondents Mark All (n)	% Respondents Single Most Important (n)	% Interviewers Mark All (n)
Confidentiality/Privacy Issues	16.4 (49)	42.6 (43)	8.7 (26)
Compensation Issues	0 (1)	1.0 (1)	0 (1)
Commitment Issues	6.7 (20)	11.9 (12)	3.7 (11)
Lack of Interest	7.1 (21)	15.8 (16)	N/A
Lack of Information on CLSA	3.0 (9)	3.0 (3)	2.4 (7)
Lack of Information on CLHI	3.4 (10)	4.0 (4)	1.7 (5)
Providing Additional Information on Share and Consent	N/A	N/A	1 (2)
No Concerns/ No Difficulty	41.6 (121)	N/A	58.6 (174)

study should be undertaken to measure the willingness of the CCHS respondents to share their survey responses and their contact information. Although the objectives are very similar to those from the feasibility study, the methodology will be modified. First, all CCHS respondents, including those who refused to share their data with the provincial ministries of health, will be asked about their willingness to share information with the CLSA. The CLSA information package, including brochure, website, and toll-free phone number, will be improved, and the interviewers will also be better informed about the CLSA. To address respondents' concerns related to confidentiality/privacy, there will be clarification about the organization with which the data will be shared. The identification of an optimal sampling frame for the CLSA is an important task, and it is crucial to determine if the CCHS is the best option.

## APPENDIX 1: Consent to share with Canadian Lifelong Health Initiative

### A. Questions for the respondents – Consent to share

Statistics Canada has been asked by the Canadian Lifelong Health Initiative to seek your permission to obtain your contact information, including your name, address, and telephone number.

As you will read from the consent form, Statistics Canada would also like your permission to share the information collected in this survey with the Canadian Lifelong Health Initiative.

Please read this form completely before deciding if you wish to consent (*the written Consent Form for review was given to respondents*).

#### All information will be kept confidential.

1. Did the respondent say they want to fill out the form later and then mail it to us?
2. Did the respondent agree to share their contact information?

3. Did the respondent agree to share their survey responses?
4. Did the respondent agree to sign the written Consent Form?
5. What were the concerns or questions raised in regards to the Canadian Longitudinal Study on Aging (CLSA) or the Canadian Lifelong Health Initiative (CLHI)? Mark all that apply.

- a) Confidentiality/Privacy Issues
- b) Compensation Issue (reimbursement for travel, for time spent)
- c) Commitment Issue (time required)
- d) Lack of interest
- e) Lack of information on CLSA project including type of questions asked, frequency, type of medical information
- f) Lack of information on CLHI
- g) Other – Specify
- h) No concerns/questions raised – Refuse – Don't know

6. What was the single most important concern or question raised in regards to the Canadian Longitudinal Study on Aging (CLSA) or the Canadian Lifelong Health Initiative (CLHI)?

- a) Confidentiality/Privacy Issues
- b) Compensation Issue (reimbursement for travel, for time spent)
- c) Commitment Issue (time required)
- d) Lack of interest
- e) Lack of information on CLSA project including type of questions asked, frequency, type of medical information
- f) Lack of information on CLHI
- g) Other – Specify – Refuse – Don't know

Your written consent can be mailed back to us, either as completed or rejected. Please send it using this envelope within the next 10 days; we will call you to remind you.

### B. Questions for the interviewers

1. Which concerns or questions raised in regards to the Canadian Longitudinal Study on Aging (CLSA) or the Canadian Longitudinal Health Initiative (CLHI) did you find difficult explaining?

Mark all that apply

- a) Confidentiality/Privacy Issues
- b) Compensation Issue (reimbursement for travel, for time spent)
- c) Commitment Issue (time required)
- d) Lack of interest
- e) Lack of information on CLSA project including type of questions asked, frequency, type of medical information
- f) Lack of information on CLHI
- g) Other – Specify
- h) No concerns/questions raised – Refuse – Don't know