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## Learning the Unique and Peculiar Challenges of Direct Health Measures Surveys: The Canadian Experience

Mark S. Tremblay<sup>1</sup>

### Abstract

The Canadian Health Measures Survey (CHMS) represents Statistics Canada's first health survey employing a comprehensive battery of direct physical measurements of health. The CHMS will be collecting directly measured health data on a representative sample of 5000 Canadians aged 6-79 in 2007-09. After a comprehensive in-home health interview, respondents report to a mobile examination centre where direct health measures are performed. Measures include fitness tests, anthropometry, objective physical activity monitoring, spirometry, blood pressure measurements, oral health measures and blood and urine sampling. Blood and urine are analyzed for measures of chronic disease, infectious disease, nutritional indicators and environmental biomarkers. This survey has many unique and peculiar challenges rarely experienced by most Statistics Canada surveys; some of these challenges are described in this paper. The data collected through the CHMS is unique and represents a valuable health surveillance and research resource for Canada.

KEY WORDS: CHMS; Health measurement; Physical measures; Biospecimen; Biorepository; Fitness measures

### 1. Introduction

Most Canadian health monitoring and surveillance information is based on self- or proxy-reported information, or health care administrative records. In either case, these data may be incomplete or inaccurate. Self- or proxy-reported data are limited by the precision of the collection instrument; interpretations of the data collection query; recall ability; reporting bias; and knowledge of the existence of health characteristics or conditions (Tremblay, 2004). The use of health care administrative records or physician files has the inherent limitation of representing only those who access such services and almost certainly do not provide a population-representative sample.

Connor Gorber et al. (2007) provide an example of the systematic reporting error associated with self-reported health indicators. Their systematic review reports a consistent pattern of over-reporting height and under-reporting weight, relative to directly measured results, which results in a significant distortion of population prevalence of overweight or obesity measured by body mass index (weight in kilograms divided by height in meters<sup>2</sup>).

An objective of the Health Information Roadmap Initiative (Canadian Institute for Health Information, 2000; IBM Business Consulting Services, 2003) was to address health information and surveillance data gaps through the creation of a national direct health measures survey – the Canadian Health Measures Survey (CHMS). The objectives of the CHMS are to:

- Estimate the numbers of individuals in Canada with selected health conditions, characteristics and exposures
- Estimate the distribution and distributional patterns of selected diseases, risk factors and protective characteristics
- Assess the validity of prevalence estimates based on self- and proxy-reported information
- Monitor trends to the extent possible with available historical direct measures data
- Ascertain relationships among risk factors, protective practices and health status
- Explore emerging public health issues and new measurement technologies

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<sup>1</sup>Mark S. Tremblay, Physical Health Measures Division, Statistics Canada, Room 0005, Main Building, Tunney's Pasture, Ottawa, Ontario, Canada, K1A 0T6 (mark.tremblay@statcan.ca)

- Establish a national biorepository for the storage and future analysis of biospecimens (plasma, serum, whole blood, purified DNA, urine) from consenting participants of the CHMS
- Provide a data collection platform and infrastructure for ongoing physical measures surveys and possible add-on studies

The development and implementation of a comprehensive national direct health measures survey represented a significant deviation from existing practice and experience within Statistics Canada and raised several unique and peculiar challenges for the CHMS and Statistics Canada. Extensive consultations with various expert groups were central to overcoming many of the challenges. The external consultation structure for the CHMS is discussed by Day et al. (2007) and includes ongoing consultations with Health Canada, the Public Health Agency of Canada, the National Center for Health Statistics in the U.S. (National Health and Nutrition Examination Survey - NHANES), an Expert Advisory Committee, Laboratory Advisory Committee, Physician Advisory Committee, Quality Assurance and Quality Control Advisory Committee, Health Canada Research Ethics Board, Office of the Privacy Commissioner of Canada, health research and surveillance stakeholder groups, and samples of Canadians through focus group meetings. A complete pre-test of the survey was completed in Calgary in 2004 to further inform the survey procedures (Tremblay et al., 2007). These external consultations and experiences in combination with internal expertise led to the establishment of the CHMS data collection parameters, structure and functions.

## **2. Survey Design and Measures**

The CHMS represents Statistics Canada's first health survey employing a comprehensive battery of direct physical measurements of health. The CHMS will collect directly measured health data on a representative sample of 5000 Canadians aged 6-79 in 2007-09. Details of the sampling methodology are provided by Giroux (2007). After a comprehensive in-home health interview, respondents report to a mobile examination centre (MEC; 2 x 53 foot trailers joined by a pedestrian pedway – see Figure 1) where direct measures of various health indicators are collected. The MEC is set-up for approximately 6 weeks in each of the 15 selected sites across Canada. Approximately 350 respondents are measured per site by 30 field and interview staff that travel around the country with the MEC. Direct measures include fitness tests, anthropometry, objective physical activity monitoring, spirometry, blood pressure measurements, oral health measures and blood and urine sampling. Blood and urine are analyzed for measures of chronic disease, infectious disease, nutritional indicators and environmental biomarkers. Blood and urine samples are also taken to be stored in the CHMS biorepository located at the National Microbiology Laboratory in Winnipeg. Further details on the survey background, measures, logistical and operational parameters are provided elsewhere (Bryan et al., 2007; Tremblay and Wolfson, 2007).

The CHMS is a voluntary survey and direct health measures are only collected on those who provide written, informed consent and who have no contraindications to any of the procedures based on a comprehensive pre-testing screening protocol. The in-home health interview takes approximately one hour while the clinic visit takes an average of 2.5 hours. Details on the ethical, legal, privacy and social issues related to the survey are provided by Day et al. (2007).

The CHMS provides enormous, and in some cases unprecedented, analytical potential: 46 questionnaire modules containing 722 questions; approximately 50 physical measures; over 100 direct physical activity measures; over 120 biospecimen analytes; about a dozen environment Canada weather and pollution indicators; potential prospective linkages to health records, vital statistics and mortality databases; and future biorepository sample analyses. Regardless of this appealing array of analytical potential, the survey encountered major ethical, privacy, legal, logistical, organizational and management challenges when developing and implementing the survey. Samples of the unique and peculiar challenges associated with the CHMS are discussed below.

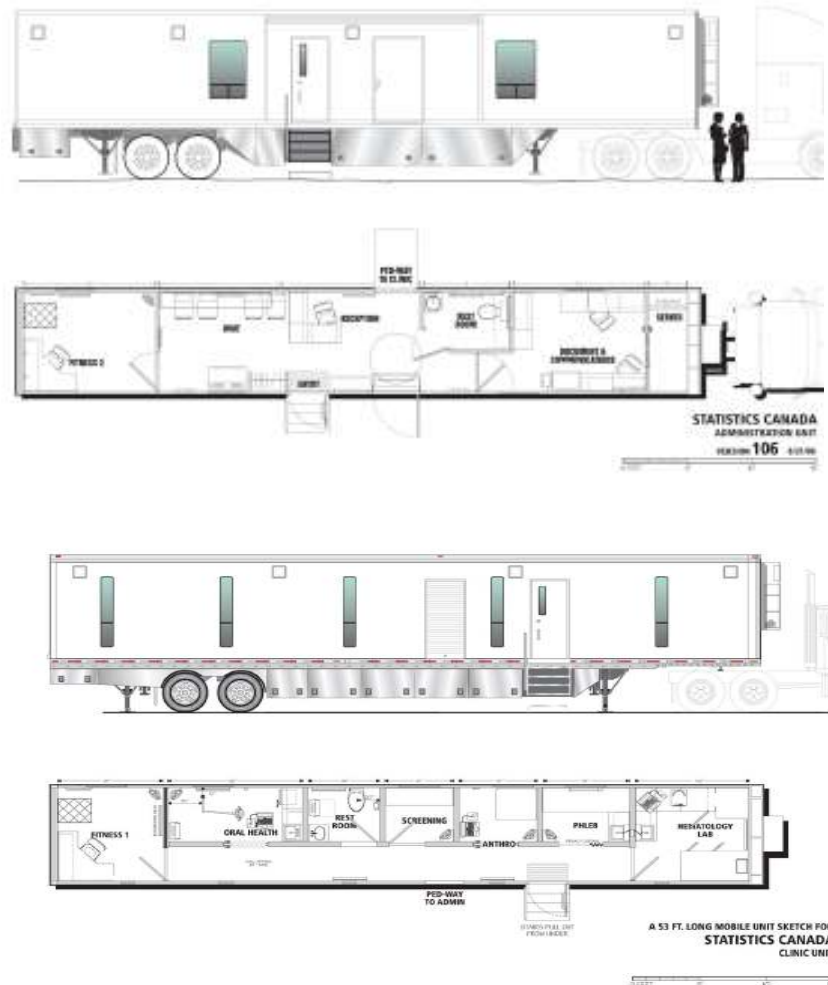


Figure 1. Schematic of the CHMS mobile examination centre (administration trailer – top; clinic trailer – bottom).

### 3. Unique and Peculiar Challenges

#### 3.1 Staffing Peculiarities

There are many staffing peculiarities associated with the CHMS. First, the staff needed to work in the MEC require special qualifications not common to Statistics Canada employees (e.g. medical lab technologist, phlebotomist, kinesiologist, dentist, medical advisor). This reality necessitated administering several external staffing competitions. External staffing actions for the CHMS required the classification of new positions (even new staffing categories), the preparation of job descriptions, work descriptions, written exams (and answers and scoring), oral interview questions (and answers and scoring), establishing interview boards and administering the interviews; all in both official languages. Without existing staff with background in these content areas, the staffing competitions were a challenge.

Some health professional staff are licensed provincially (medical lab technologist, dentist, physician) yet the CHMS collects data in five provinces (New Brunswick, Quebec, Ontario, Alberta, British Columbia). Obtaining provincial licenses for all staff, in each province, can be difficult, time-consuming and costly. Through discussions with Statistics Canada legal counsel, the Health Canada Research Ethics Board and provincial health ministries, it was determined that CHMS staff performing health surveillance activities inside the MEC and within their professional scope of practice is acceptable provided that they hold a current provincial license in Canada.

It was determined that one measurement and interview team of employees dedicated to working only on the CHMS would produce the best quality data and response rates. This practice is atypical for Statistics Canada Survey Operations Division and requires the CHMS field staff to live “on the road” continuously for two years, while relocating approximately every six weeks. This nomadic lifestyle requires substantial support for car rentals, phone and email contact, personal mail delivery, health care, living arrangements, personal emergencies, recreation, etc. This arrangement means the staff are on permanent travel so Treasury Board guidelines apply for travel expenses, requiring significant administrative support to process travel expense claims and incidental expenses incurred by the staff.

Other peculiar staffing issues include the very close (tight) working conditions within the MEC; unusual working hours (early, late, weekends, holidays); and the very close working relationships between interviewing staff (administered by Survey Operations Division) and the measurement staff (administered by the Physical Health Measures Division).

### **3.2 Climate Challenges**

The CHMS relied very heavily on the experiences of the National Health and Nutrition Examination Survey (NHANES) in the U.S. (Centers for Disease Control, 2007) to inform many operational procedures. The NHANES survey cycles through the U.S. annually in a pattern that avoids being in the northern states during the winter months. Consequently, they had very little experience to share with respect to challenges related to harsh climates. Climate conditions (cold, snow, freezing rain, heat, temperature fluctuation, light/dark fluctuations, etc.) impose many operational and logistical challenges including snow removal, heat and air conditioning of the MEC (stable temperature required for testing conditions), freezing pipes, ice build-up, slippery stairs, mud, etc. Procedures ensuring accessible, safe, secure, standardized and clean conditions for the MEC and its surrounding area needed to be established and implemented, including business continuity plans for severe weather, power outages, electronic communication interruptions and road closures (Bryan et al., 2007; CHMS Business Continuity Plan, 2007).

### **3.3 Mobile Examination Centre Requirements and Constraints**

At each of the 15 data collection sites the MEC (pair of 53 foot trailers) requires a large space to manoeuvre them into position to be levelled and for the pedway to be aligned and installed. The trailers require an area 60 feet x 50 feet once parked. They require electrical, water, sewer and telecommunications connections to be installed in a secure and reliable fashion. There needs to be good lighting, ready access, parking, public transit near-by, snow removal services (seasonal), biohazardous waste disposal services, cleaning services, garbage removal, address for shipments, regular courier pick-up for biospecimen shipping and a recognized location for emergency services (if required). Advance arrangements staff work to stay a site ahead of the data collection team to ensure these and other services are in place and functioning.

### **3.4 Data Flow Complexities and Tracking Systems**

A typical Statistics Canada telephone or personal in-home interview requires secure, encrypted data flow from head office to the interviewer for their cases, and from the interviewer to head office to transmit the results. These procedures and the associated electronic communications architecture are well established. The information flow is normally from the respondent to Statistics Canada, rarely does Statistics Canada provide the confidential reported information back to the respondent. The unique nature of the CHMS required secure and confidential procedures, processes and communications architecture to be created to:

- obtain some information from the personal interview, via head office, to the MEC
- get direct measures results and clinic questionnaire results back to head office for linkage with personal interview data
- give immediate feedback (report) to the respondent based on the results of physical measures tests (e.g. blood pressure, spirometry, anthropometry, fitness)

- send and track biospecimens with barcode identifiers to three reference laboratories (Ottawa, Winnipeg, Quebec City)
- retrieve results from reference laboratories in Statistics Canada head office for linkage with other respondent-specific data
- send biorepository samples to National Microbiology Laboratory in Winnipeg for secure, confidential, de-identified storage
- send surplus biospecimens from Ottawa and Quebec City labs to National Microbiology Laboratory for storage
- retrieve the accelerometers (used for objective physical activity monitoring) from each respondent one week after their clinic visit
- send laboratory findings report to respondents after all lab results have been received
- ensure destruction of confidential specimens and results in reference laboratories upon completion and verification of all confidential results

### **3.5 Physical Measures and Invasive Sampling**

A variety of unique and peculiar challenges are associated with collecting direct physical measures of health on a random sample of Canadians aged 6-79 years. In cramped conditions measurement staff need to have valid, reliable measurement protocols and associated equipment ready and available for the battery of physical measures included in the CHMS. The level of invasiveness of these measures, including the collection of biospecimens (blood and urine), far exceeds that of other Statistics Canada health surveys. This requires that training and measurement procedures be in place to ensure a safe, sensitive, respectful, private, professional environment and testing protocol. Systems and protocols were required for physical (e.g. blind, deaf, mobility limitations), linguistic (neither English nor French speaking) and cognitive limitations. The extensive menu of operations manuals prepared for the measurement staff is summarized by Bryan et al. (2007).

### **3.6 Potential for Adverse Events**

Careful screening and safety procedures are in place to minimize the risk of an adverse event or injury occurring as a result of the CHMS testing procedures. Universal precautions, standard operating procedures, approved clinical practises, vigilant observations by measurement staff and careful application of quality assurance and safety procedures are also employed to ensure the safety of respondents and staff. Nevertheless, there remains the possibility of an adverse event or accident. These may include (for example) a cardiac incident while performing the cardiovascular fitness test, hematoma or phlebitis from the venipuncture, vasovagal response from blood sample, infection from the oral health exam or a pulled muscle from the flexibility test. It is also possible that a serious health condition (e.g. oral cancer) is identified during the clinic measurements. Procedures to deal with these were required and include ensuring all staff are trained in cardiopulmonary resuscitation, first aid and emergency procedures; 911 response is in place; and that staff training included simulated emergency situations.

### **3.7 Respondent Burden and Reimbursement**

The CHMS not only requires approximately an hour of respondents time for the personal health interview, but also requires them to travel to the MEC (could be up to 100 km away) to participate in the clinic portion of the survey, which takes on average an additional 2.5 hours (plus travel time). In addition, to the time and travel, the CHMS, with respondent consent, requires significant physical exertion and some discomfort. For half of the sample (morning participants) they are required to attend the clinic having fasted for the previous 12 hours. This level of burden far exceeds what is associated with a typical Statistics Canada survey. Not only is the CHMS burdensome but it also requires some expenses to be incurred by the respondent. This required a reimbursement process to be instituted to compensate respondents for real expenses they incurred as a result of their participation (e.g. mileage, parking, meal for those fasted).

### 3.8 Reporting to Respondents and Reportable Diseases

A number of infectious diseases, if identified during clinical practice, are required to be reported to regional and provincial public health authorities. This requirement is supported by provincial law and is in place to protect the greater public good. The CHMS analyses blood samples for hepatitis B and C in a manner that makes the findings reportable by law. This provincial law is in conflict with the legal requirements of the Statistics Act to preserve the confidentiality of respondent's data. Legally the Statistics Act supersedes the provincial public health reporting requirement. Nevertheless, the CHMS was able to respect both laws by asking respondents permission to share their hepatitis B and C results with public health authorities, if positive results were observed. If respondents did not consent to this disclosure, the hepatitis tests were not performed. Procedures were also put in place to have an infectious disease counsellor contact respondents with positive hepatitis B or C results by telephone before the laboratory results were sent by mail or courier.

### 3.9 Biospecimen Transport

A tracking system needed to be built to monitor the transportation, reception and location of the biospecimens at all times. The biospecimens, though unidentifiable to anyone other than a few at Statistics Canada (they are identified by a random barcode label only), represent confidential data collected under the Statistics Act. The careful tracking of these samples is required to ensure they do not get misplaced, but also to ensure the integrity of the biospecimens for the intended analyses. The biospecimens are required to be shipped under certain conditions (usually frozen) requiring the regular acquisition and handling of dry ice. These procedures required special training for all staff that prepares the biospecimens for transport, as well as the development and documentation of related procedures.

### 3.10 Biorepository Development, Access and Function

The development of the CHMS biorepository required, and continues to require, very careful implementation and oversight. A nationally representative sample of biospecimens represents an important public health and research resource. This resource must preserve the privacy and confidentiality of respondents; recognize it is a finite resource; and approve only projects that are consistent with and respect the original consent provided by the respondent. An overview of the process for approving the use of biospecimens stored in the CHMS biorepository is provided in Figure 2 below. In addition to this rigorous process, which is managed and controlled by Statistics Canada, an arms-length committee will be established to provide independent oversight ensuring that the use of the stored samples remains consistent with the original intent. The Health Canada Research Ethics Board, the Office of the Privacy Commissioner of Canada and Statistics Canada Policy Committee, agreed upon this process.

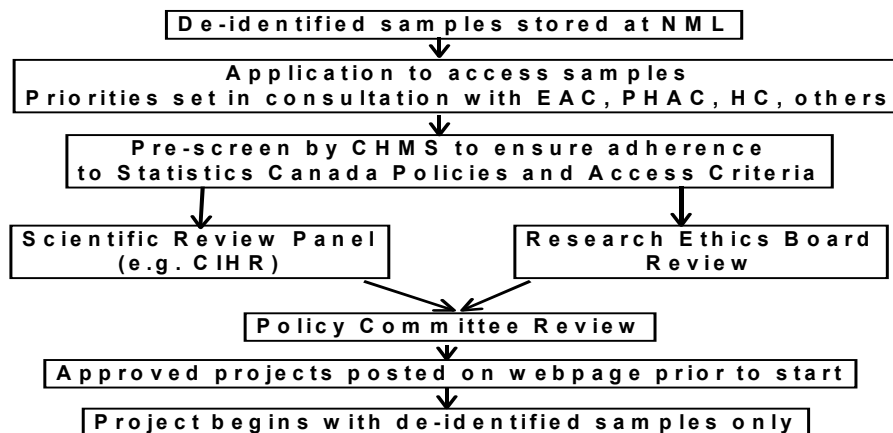


Figure 2. Overview of process for access to samples in the CHMS biorepository. NML = National Microbiology Laboratory; EAC = CHMS Expert Advisory Committee; PHAC = Public Health Agency of Canada; HC = Health Canada; CIHR = Canadian Institutes of Health Research.

### **3.11 Communications**

Statistics Canada typically employs a passive approach to media exposure during the data collection phase of a survey. The extensive experience of the NHANES suggests that proactive local media exposure immediately prior to data collection helps improve response rates and provides public reassurance of the legitimacy of the survey. Accordingly, the CHMS developed a communications plan that includes a local “launch” of the CHMS in each collection site in an effort to get on local news programs and in local newspapers. The interviewers when responding to legitimacy concerns expressed by potential respondents can subsequently use this coverage.

It is also a significant communications challenge to ensure that the final laboratory results get to respondents in a manner that adheres to the strict confidentiality requirements of the Statistics Act. Many procedures have been implemented to provide assurances that the respondent, and only the respondent, receives their results.

### **3.12 Ethical, Privacy, Legal, Social Issues**

Many of the unique and peculiar challenges of the CHMS listed above raise ethical, privacy, legal and social issues new to Statistics Canada. Collectively, these challenges required, for the first time, a complete Statistics Canada survey to be reviewed by an external research ethics board. This process was very constructive and valuable to the survey development. Similarly constructive, and instructive, were regular meetings with the Office of the Privacy Commissioner of Canada. Bioethics, privacy and social issues particularly related to population genetic and genomic research are dynamic and evolving. Identifying the acceptable and appropriate balance among biospecimen collection and utilization, data maximization, public acceptability and ethical/privacy oversight will be an ongoing challenge to the CHMS. The CHMS has accepted this challenge and is playing a lead role in Canada and internationally in studying, advancing and monitoring policies, procedures and practices related to these areas.

## **4. Conclusions**

The CHMS provides: a unique, nationally representative dataset; stored biospecimen samples (serum, plasma, whole blood, DNA, urine) for future research; experience and expertise in direct health measurement surveillance; training opportunities; a secure infrastructure for a national biorepository; comprehensive measurement scope; and opportunity for continuity and expansion (additional content, sample size and / or geography). The CHMS has been endorsed by the Canadian Medical Association, Canadian Dental Association, Canadian Red Cross, Dietitians of Canada, Heart and Stroke Foundation of Canada, Canadian Lung Association, Canadian Hypertension Society and has the support of the Canadian Public Health Association and the College of Family Physicians of Canada.

This survey has many unique and peculiar challenges rarely experienced by most Statistics Canada surveys. These include: a new level of respondent burden (travel, time, expense, physical exertion, pain); data transfer complexity (interviewer-clinic-lab-Statistics Canada-respondent report); privacy and ethical considerations (age range for testing, consent, data confidentiality, participant anonymity, storing biospecimens for future analysis, collecting DNA samples); communications (reporting to respondents, reportable diseases, media, public); and the potential for adverse events (phlebitis, cardiac event during fitness testing) or adverse findings (previously undiagnosed infectious disease, oral cancer). Though the challenges are many, the data collected through the CHMS are unique and provide a valuable health surveillance and research resource for Canada.

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