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High quality indicators are required to guide policy and services addressing gender and sexual health equity throughout Canada

The Canadian Sexual Health Survey

Proposed Methodology

The Canadian Sexual Health Survey Team
University of British Columbia

CART-GRAC
Contraception and Abortion Research Team
Groupe de recherche sur l'avortement et la contraception

CSHS
Canadian Sexual Health Survey

Contraception & Abortion Research Team (CART-GRAC)
http://www.cart-grac.ubc.ca/
320-5950 University Boulevard, Dept Family Practice, UBC. Vancouver, BC V6T 1Z3
604.761.7767 f: 1.866.656.5544 wendy.norman@ubc.ca cart.grac@ubc.ca

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The Canadian Sexual Health Survey team

Wendy V. Norman, MD, MHSc, Associate Professor and PHAC-CIHR Chair, Family Planning Applied Public Health Research, University of British Columbia (**UBC**)

Sheila Dunn, MD, MSc, Associate Professor and Clinician Investigator, Department of Family and Community Medicine and Dalla Lana School of Public Health, **University of Toronto**

Mark Gilbert, MD, MHSc, Medical Director, Clinical Prevention Services, BC Centre for Disease Control, and Associate Professor, SPPH, **UBC**

Lori A. Brotto, PhD, Professor, and Canada Research Chair (CRC, Tier 1) in Women's Sexual Health, and Executive Director, Women's Health Research Institute (WHRI), Dept of Obstetrics & Gynecology, **UBC**

Gina Ogilvie, MD, DrPH, Professor and CRC Tier 1 in Global Control of HPV related diseases and prevention, School of Population and Public Health (SPPH), **UBC**

Donald B. Langille, Professor, Community Health & Epidemiology (Post Retirement Appointment), **Dalhousie University**

Edith Guilbert, MD, MSc, Professeur de Clinique, Département d'obstétrique, de gynécologie et de reproduction, **Université Laval**, and Médecin-conseil, Family Planning, Institut national de santé publique du Québec (**INSPQ**)

Melissa Brooks, MD, Assistant Professor, Dept of Obstetrics & Gynecology, **Dalhousie University**

Janusz Kaczoroswki, PhD (Medical Sociology), Professeur titulaire, and titulaire de la Chaire Sadok Besrour en médecine familiale et de la Chaire GlaxoSmithKline (GSK)-IRSC en gestion optimale des maladies chroniques, Département de médecine de famille et médecine d'urgence, Faculté de médecine, **l'Université de Montréal**

Audrey Binette, MD, obstétricien-gynécologue – Centre hospitalier, **Universitaire de Sherbrooke**

Marie-Soleil Wagner, MD, MSc, Professeur agrégée de clinique, Département d'obstétrique-gynécologie, **Université de Montréal**, and Médecin spécialiste conseil en santé publique, **INSPQ**

Stephanie Begun, PhD, MSW, Assistant Professor, Factor-Inwentash Faculty of Social Work, **U of Toronto**

Saied Samiedaluie, PhD, Assistant Professor, School of Business, **University of Alberta**

Bryan Stirling, PhD, Professor (Health Economics), SPPH, **UBC**

Kim McGrail, PhD, Professor, School of Population and Public Health, and Director, Population Data BC and Canada's SPOR National Data Platform, **UBC**

Patricia Rosselet, MD, PhD, Research Associate, Department of Family Practice, **UBC**

Laura Schummers, PhD (epidemiology), Postdoctoral Fellow, Department of Family Practice, **UBC**

Regina Renner, MD, MPH, Clinical Associate Professor, Dept of Obstetrics & Gynecology, **UBC**

Jean A Shoveller, PhD, Professor, SPPH, **UBC** and co-director, **Centre for Gender & Sexual Health Equity**, Providence Health, Vancouver, BC.

Members of The **Contraception and Abortion Research Team - Groupe de recherche sur l'avortement et la contraception (CART-GRAC).** CART-GRAC is a UBC based national, interdisciplinary, cross-sectoral collaboration performing research to support health services and policies to ensure equitable access to high-quality family planning knowledge, methods and services throughout Canada.

Executive Summary

In Canada, there is currently little population data available to support understanding key indicators of sexual and reproductive health. Accurate data on prevalence of sexually transmitted infections, gender-based and intimate partner violence, gender inequities, reproductive coercion, contraception use and type of method, pregnancy intention, sexual behaviour, and the associated social determinants of health are lacking. These indicators are essential to decision makers to assess the need for services, evaluate the impact and equity of health policies and programs and examine trends over time.

Several countries, including the UK and the USA, conduct robust iterative door-to-door surveys to collect indicators on sexual health. Data from these studies have informed health policy and helped decision makers support optimal sexual and reproductive health and health equity.

Our team developed a pilot instrument and fielded in 2015 in the province of British Columbia. We measured several indicators not collected in Canada, with a focus on sexual health behaviour, pregnancy intention, prevalence of contraceptive use, and correlation with pregnancy outcomes and social determinants of health among a representative sample of females aged 14-49 years. The survey achieved a high response rate of 75.3%. Nearly 90% of respondents currently wished to avoid pregnancy. Among women who had been pregnant in the last 5 years, 40% of pregnancies had been unintended. Most unintended pregnancies (56.8%) resulted in birth. A minority of females at risk of unintended pregnancy were using a highly effective method of contraception.

We have built upon the successful BC pilot survey using valid and widely used scores to present the Canadian Sexual Health Survey (CSHS) instrument with these features:

- For use among a sample of 15,000 males and females age 14 to 69
- We collect a broad range of sexual and reproductive health indicators and gender equity determinants including rates for: sexually transmitted infection (sub-sample for urine/dried blood spot testing); intimate partner violence, reproductive coercion; attitudes and perceptions; pregnancy intention; sexual behaviours; contraception use and gender identity.
- Collection of personal health number to facilitate linkage with census and health administrative data (via Canada's new SPOR National Data Platform) to offer a more comprehensive evaluation of population health risks and determinants

We propose a rigorous methodology using an international gold standard evidence-based approach (Computer-Assisted Personal interviews (CAPI) with Audio-Computer-Assisted Self Interviews (ACASI) to reliably and effectively capture accurate sensitive and stigmatized behaviour data). By undertaking a national survey using validated and robust questions from high impact iterative national sexual and reproductive health surveys such as the UK's NATSAL and the USA's NSFG, fielded using high quality methodology, Canada will be able to obtain quality indicators to guide policy and service allocation, to allow comparisons to similar countries, and to best support equitable achievement of gender equity and sexual and reproductive health among Canadians.

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Introduction

The Canadian Sexual Health Survey aims to provide population representative data on multiple indicators for which there is currently no information being collected for Canada. Although the Canadian Community Health Survey collects information on condom use, age at first intercourse and number of partners, there is, for instance, no information on other known risk factors indicators (intimate partner violence, reproductive coercion, contraception use), on service coverage indicators (access to sexual health clinics, satisfaction with contraception), and on health system indicators (obstetric and gynecologic admissions owing to abortion). These gaps have been highlighted by Canadian government agencies as well as from the literature, which all underline the need for quantitative data (1-15). For instance, we are currently unable to assess population-level data on testing patterns to evaluate the impact of STIs testing strategies, and understand the true rates of both reportable and non-reportable STIs. Both the USA and the UK, among other countries, have been collecting nation-wide sexual health surveys since 1973 and 1990 respectively, with new rounds of surveys every few years. These surveys provide data on sexual behaviour trends, contraceptive use, and pregnancy intentions, as well as other indicators that have extensively been used to inform decision and to help policy-makers develop appropriate policies. By undertaking a national survey, measuring similar indicators, it will be possible to obtain high quality data on sexual health and compare Canada to other high-income countries.

Methodology of the 2015 BC Sexual Health Survey – B.C. pilot

The 2015 B.C. sexual health survey (B.C. pilot) functioned as a pilot for the proposed national sexual health survey. It collected responses from a representative sample of 1671 females, aged 14 to 49 years, living in British Columbia. The questionnaire consisted of 102 questions divided into 12 categories: Introduction and Consent; Sex, Gender and Orientation; Sexual Behaviours; Sexual History; Sterilization and Fecundity; Pregnancy History and Outcomes; Contraception History; Partners; Access and Information; Sexually Transmitted Infections; Pregnancy Intentions; Demographics. The questions included in the B.C. pilot were generated using questions from existing validated survey instruments, with slight modifications to fit the Canadian context. The survey underwent extensive remodeling with expert review, cognitive testing, piloting, and several rounds of revisions. It was translated into Punjabi and Chinese using translation and back-translation and focus testing methods. The validity and reliability of questions were then evaluated after the fielding of the B.C. pilot.

Sampling strategy

The primary sampling units were Local Health Authorities (LHA). Four or five LHAs were randomly selected from each Regional Health Authority, for a total of 21 LHAs in our sample, out of the 89 LHAs for the Province. In large population centers and most cities, postal code areas provided the smaller unit of sampling. In areas of very low density, sampling within the LHA was based instead on Dissemination areas, a Statistics Canada metric which represents the smallest standard geographic area for which all census data are disseminated. A random sample of postal codes was generated for each LHA, from the

master sample of postal codes assigned to each of the 21 LHAs. From each primary sampling unit, 75 surveys were randomly collected from households, with a maximum of one survey per household.

We oversampled females under 30 years old, those living in rural areas (by collecting 75 surveys per LHA, no matter its population size), and those from lower income households.

The survey was collected by door-to-door interviews, starting with a consent process, then a computer assisted personal interview (CAPI), followed by an audio-computer assisted self-interview (ACASI) for the more sensitive questions. The average time to complete one survey was 8.2 hours of surveyor work, and 22 minutes on average for a participant to complete the survey.

We conducted the B.C. pilot successfully in every community selected for our sample. We collected data on sexual health behaviour and experience from a representative sample of reproductive aged females, using rigorous and reproducible sampling and methodology. Our research team achieved a survey cooperation rate of 75.3% across the province among eligible participants found at home, including over 80% outside of the largest urban areas.

We tested the validity and reliability of the survey using criterion validity, test-retest (by interviewing 48 participants twice at 2 different time points) and consistency evaluation on the data collected from the 1671 participants. High levels of validity and reliability were achieved, reaching 85% for the test-retest and 89% for the consistency testing. The criterion validity could not be compared to an existing Canadian sexual health survey, as none exist, but several questions were compared to the sexual behaviour questions from the Canadian Community Health Survey with similar proportions reported.

Proposed methodology for the Canadian Sexual Health Survey

We propose a nationally representative sexual health CAPI/ACASI survey of 15,000 participants including both females and males aged 14 to 69 years. This methodology is comparable to both the UK's National Survey of Sexual Attitudes and Lifestyles (NATSAL) and the USA's National Survey of Family Growth (NSFG) which each target a similar sample size. By expanding the age group and collecting data on participants aged 50 to 69, we aim to capture not only sexual behaviours in this age group, but also Sexually Transmitted Infections (STIs) prevalence, which has been shown in samples of other countries to be quite high and on the rise in this age group (16), as well as allowing for analyses analysing changes over time or generations on rates for reported first episode sexual and reproductive experiences.

The survey will be accompanied by collection of urine and dried blood spot samples to test for up to 6 common STIs. Biological sampling allows for objective measurements, which are not prone to reporting bias and can improve the validity of the self-reporting.

Justification for the proposed CAPI/ACASI Methodology

Computer-assisted personal interviews (CAPI), combined with Audio-computer assisted self-interviews (ACASI), are considered the best collection methods when faced with sensitive data such as sexual

health behaviours and outcomes (17-18). They are the methods chosen by both the USA and the UK governments to collect data on sexual health, through the NSFG and the NATSAL respectively.

Although there is now a trend to move to online, web-based interview due to cost- and time-savings, we argue that an online survey would not be optimal for the proposed instrument, for the following reasons:

1. **Selection bias**: for a national survey, it is critical to obtain data from a representative sample of the population. It not only requires a probability sampling to be certain that the selected population is random, but also necessitates that there be no selection bias due to non-responses of participants. Both conditions are not met with the online surveys: it is difficult to obtain a probability sampling as there is no central registry of internet users, whereas postal addresses are available through the Address Register obtained from the Census. Online data collection is most convenient when targeting a specific population, or convenience samples, but more difficult to use when attempting to gather data from a representative sample of the population. (19,20).
2. **Demographics between internet users and non-users are known to differ** (19,21). Web surveys do not offer the same coverage that can be obtained with in-person interviews, and internet coverage is not equally distributed in the population. In addition, email requests may be treated as spam, and ignored by recipients, further decreasing the representability of the sample (22). Finally, with an online survey, it is not possible to verify that the selected participant is the one taking the survey, rather than someone else in the household. This is a particularly strong caveat when dealing with sensitive topics such as sexual health, with questions on intimate partner violence or reproductive coercion. Without the interviewer present, the partner could be answering instead of the selected participant or could be controlling what the selected participant is reporting.
3. **Response bias**: Although collection methods with an interviewer may elicit response bias, such as social desirability bias or interviewer bias, other types of response bias are also present in online surveys (for instance, acquiescence bias or recall bias) (23). However, with the in-person surveys, biases can be limited with assurances of confidentiality and anonymity, and the participant may provide more honest answers when discussing with a trained interviewer, as good rapport is being built (24). Moreover, the combination of in-person and self-reporting reduce the probability of response bias, since the questions that tend to elicit social desirability are being asked in the self-reported section (17). In online surveys, it has been shown that there is less commitment to the survey when there is no interviewer present, leading to sacrificing or to less effort with recall (25).

4. **Response rates**: compared to other collection methods which only use self-administered questionnaires (telephone, postal, online), in-person surveys achieve the highest response rates, lower nonresponse rates to specific items (17) and allow for more complex questions, longer interviews, and concomitant biologic sampling, therefore resulting in more data, of better quality (17,21-23). Due to the sensitivity of the topics covered by the CSHS, a skilled interviewer

can provide the appropriate setting to allow the potential participant to feel at ease and agree to participate.

5. **Concomitant Biologic Sampling**: The prevalence of STI's in Canada is currently not known. The collection of urine among a representative sub-sample in the proposed survey would provide for accurate national prevalence estimates, and could be undertaken during a CAPI/ACASI administration, more reliably than during internet based surveying.

In order to minimize the above-mentioned limitations, we argue that both CAPI and ACASI are necessary to ensure that the best data is collected, as each method is useful in its own way.

CAPI: as mentioned previously, in-person interviews achieve the highest response rates, as the interviewer creates good rapport with the participant, can explain difficult terms and help with recall or inconsistencies issues (26, See box 3.4.1). Furthermore, we intend to include a calendar to collect data on contraception use, pregnancies and vaginal intercourse over the last 18 months that will be used for modelling purposes, which needs to be collected in person through CAPI. A similar method is used in NSFG and was used in the B.C. pilot to develop a cost-effectiveness modelling study to better understand the costs associated with unintended pregnancy compared with contraceptive subsidy costs.

ACASI: this collection method has the main advantage that it reduces the probability of response biases that may have occurred in the CAPI part. As this section is self-reported, the participant may be more honest in their answer; it provides a great platform for sensitive questions, with respondents more likely to report stigmatised behaviours and fewer missing data due to nonresponse (17,18). In addition, since the interviewer is still present, they will be available to provide clarifications. Combining both methods also provides the means for data triangulation, with internal consistency checks, by asking the same question in both sections, which will be even strengthened with biological sampling.

In summary, given the methodological limitations of web-based surveys and the gains in validity and response rates using the in-person interviews, we propose this survey be administered using the gold standard methodology for sexual and reproductive health surveys, and which was the method of the B.C. pilot, which proved highly successful. In its next round, NATSAL will keep the CAPI/ACASI format, as the advantages of this method far outweigh its limitations (mostly cost related). Last but not least, using the same collection methods as both the NSFG and NATSAL, from which questions have been extensively used to develop the CSHS, will allow for greater consistency between the surveys to enable between nation comparisons.

Proposed CSHS Instrument overview

We augmented the B.C. pilot to develop the Canadian Sexual Health Survey instrument. The Canadian Sexual Health Survey will gather comprehensive information on sexual health indicators in Canada in order to meet the needs of Canadian government and Canadian reporting to international organisations. In addition to the survey items on unintended pregnancy, use of contraception, and pregnancy history and outcomes captured in the B.C. pilot, the national survey will also collect representative data on sexual violence, including intimate partner violence, reproductive coercion, female genital cutting, adverse childhood experiences and sexually transmitted infections. These will be the first measures of the true prevalence of these issues in Canada. Each of these indicators report on issues that have negative short- and long-term impact on sexual health, health equity and population health.

There will be approximately 180 questions for female participants and approximately 140 questions for male participants (depending on their personal histories). The 14 to 69 age bracket was determined by the cognitive ability of respondents to respond to the survey (younger participants would have required a simplified version) and the upper limit was decided after discussing with experts from the NATSAL surveys (NATSAL-3 surveyed females and males up to the age of 74, but the investigators reported no added value of targeting people aged 70 to 74).

We are prepared to lead testing for feasibility and acceptability of the survey, or to support Statistics Canada to do so. We would begin by undertaking cognitive testing of the instrument in focus groups, followed by a pilot testing of the survey with samples of eligible participants. This testing will measure the interpretation and acceptability of the questions, as well as the flow and length of the survey. The survey will be available in both French and English.

The proposed structure of the CSHS instrument is the following:

CAPI

1. Consent
2. Date of Birth
3. Smoking and Alcohol Behaviours
4. Learning About Sex
5. Sex, Gender and Orientation
6. Sexual History (intro)
7. Contraception History
8. Pregnancy History (intro)

ACASI

9. Sexual Behaviours, History and Partners

10. Sexual Violence
11. Reproductive Coercion
12. Pregnancy History and Outcomes
13. Pregnancy Intentions (unplanned pregnancies)
14. Attitudes and Perceptions
15. Sexually Transmitted Infections and HPV vaccinations
16. Substance Use
17. Female Genital Cutting
18. Adverse Childhood Experiences
19. Infertility and Sub-fertility

CAPI

20. Access and Information
21. Demographics
22. Consent to share personal health number

Sampling

Framework

We propose to sample 15,000 females and males aged 14 to 69, with a ratio of 2 females for 1 male, divided into 5-year age bands, except from the 14 year old group. The sample size should be representative of the Canadian population in both age groups and sex, and representative within all ten provinces.

Our sampling frame aims to be compliant with existing sample frames that have been used in other Statistics Canada surveys, such as the Canadian Health Measure Survey (27) or the Canadian Community Health Survey (28), as both have used door-to-door in-person interviews. We are available to work with the Government to find the right sampling strategy for the proposed survey.

We propose a representative sample from all Provinces or Regions, with or without the Territories. We suggest previous specifications from Statistics Canada surveys, such as excluding: persons living on reserves and other Aboriginal settlements in the Provinces, full-time members of the Canadian Armed Forces, the institutionalized population, and households in extremely remote areas with very low population density, and those living in the Territories. In order to include vulnerable populations, we suggest to survey non-household structures such as community centres/safe locations/homeless shelters in Census Metropolitan Areas. The sampling strategy could be a multi-stage, clustered and stratified probability design.

We propose to use census data to obtain listing from sampled households. The number of persons selected per household would depend on the composition of the household. Among the full sample respondents, several subsamples could be selected, with oversampling of specific populations groups, for example among females $\leq$35 years old, as they are at highest risk for unintended pregnancy.

We propose a strategy for dried blood spot and dried urine dip sampling, emulating that used for NATSAL in the UK, in order to reduce costs associated with on-site lab testing. In regards to differences to the CHMS, we suggest to collect urine samples at the time of interview and in a representative portion of the population. The interviewer would then mail or drop off the urine samples to the lab on the day of interview, rather than to send participants to a central clinic or use a mobile clinic.

Responding to this survey would be voluntary. Specific consent would be obtained before collecting a urine sample. As the final question for the survey, specific consent for data linkage with census data and personal health numbers is collected. Data will be collected directly from survey respondents.

We suggest to comply with the existing administration used by Statistics Canada, regarding the introduction letter, selection of household and options for scheduling an interview.

Sub-sample for STI testing

A sub-sample of the survey's respondents will be used for urine samples (as urine or via a dried blotting paper sample) to test for Chlamydia, gonorrhoea (and potentially HPV and m. genitalium, but collecting and interpreting this data may be of less relevance and may be considered controversial). Additionally, our discussions with the PHAC National Reference Laboratory indicate the potential to collect Dried Blood Samples (DBS) to allow testing for HIV, Hepatitis B, Hepatitis C, and Syphilis.

We propose to randomly select for biologic samples from a specific sexually active subgroup among consenting 18 to 69 year olds.

Proposed Administration

Introduction letter

A letter explaining the rationale for the study and how the household was selected will be delivered to each selected household a few days prior to the door-to-door interview. To improve survey collection time, we propose that this letter include the invitation to the survey, pre-select the appropriate household member, as done in Statistics Canada invitation letters for web surveys, and allow the respondent to schedule the interview.

Selection of Household and Respondent

The selection of households and respondents would be made using the selection frame previously used in other door-to-door Statistics Canada surveys. We propose to split the fieldwork into a number of different "waves" to allow for adjustments to the number of collection sites selected, and age group subsamples.

CAPI

The survey will begin with a computer-assisted personal interview section, in order to build rapport and to collect in the most efficient way indicators that were judged to be acceptable in terms of sensitivity, with participants responding verbally to a trained interviewer. This will allow collection of information in a calendar (month-by-month reporting on a range of sexual behaviours over the prior 18 months), which will be filled by the female participants, to be used for modelling behaviours and behaviour changes related to contraception, vaginal intercourse and the relation to pregnancy.

The survey will also end using CAPI as it will allow to ask more general questions (on access and demographics) and to wrap up the interview.

ACASI

To accommodate ideal responses on questions of high sensitivity being asked in this survey, it is necessary to include most sections into the ACASI category. The respondent will be able to read or listen to a recording of the question and answer the question directly by using the computer/tablet provided, thus ensuring complete privacy when replying to the questions. The interviewer will be available to answer any question the participant may have while replying to the survey.

Personal Health Number collection for linked data analyses

Linking surveys to census data and health administrative data (using each participant's personal health number) would markedly expand the impact of this survey. Canada is in a unique position to provide nationally representative data on the relationship between sexual health indicators, gender identity, social determinants of health and health equity and health outcomes, due to the rich population-level linked health administrative data available in some Canadian provinces. This linkage would enable a comprehensive evaluation of the relationships between the survey-collected sexual health indicators and prior or subsequent health system encounters or health outcomes, enabling decision-makers to understand the population burden of health associated with these indicators. In combination with a

cross-sectional survey, linkage with census data and personal health number provides a longitudinal dimension, offering information on participants' health history and future.

To provide some examples of how this linkage could be used to understand the health burden associated with sexual health indicators, this linkage would enable governments or researchers to answer questions such as:

- What is the association between intimate partner violence and hospital admission rates or adverse pregnancy and birth outcomes among Canadians?
- What is the relationship between pregnancy intention and pregnancy and birth outcomes?

Multi source data collection allows for information triangulation, which will improve the reliability and precision of the data obtained from individuals (29), provide background data to contextualise some indicators and their relationships to other indicators collected elsewhere. The combination of data source can help promote inter-sectorial exchanges between the public health agencies and clinical organizations and provide a more complete representation of the population. This gain in insight offers a better characterisation of the complexity of the issues and of the dynamic relationships. It can also better estimate coverage issues in access to care and unmet needs as well as better plan for future population needs (30).

It is therefore not only useful for research purposes to link data, but it is also a public responsibility to make sure that the best data is collected and used in the best possible way, reducing unnecessary duplication of data gathering, thereby reducing costs, and ensuring that the data is not disconnected from the whole system (31).

We suggest ideally a plan to link CSHS data to administrative data from the Discharge Abstract Database (DAD), health practitioner payment or shadow-payment codes, pharmaceutical dispensing data where available, vital statistics related to births and deaths, consolidation or registry files, and/or data only available in some provinces, such as the perinatal registry. Both cross-sectional and longitudinal linkages could be utilized, in order to determine concurrent and antecedents factors associated with adverse outcomes or health inequalities.

According to Statistics Canada (32), the 5 conditions that must be satisfied in order to link with administrative data are:

1) Information obtained from microdata linkage is used to produce statistical information that facilitates the better understanding of the Canadian society, economy and environment, and subsequent benefits are clearly in the public interest
2) Confidentiality of information relating to individual persons, businesses or organizations (public or private, including public institutions and non-government organizations (NGOs)) used in microdata linkages is strictly maintained and the results of the microdata linkage will not be used for purposes that can be detrimental to the persons, businesses or organizations whose information is involved
3) Outputs of the microdata linkage will be released only in accordance with the confidentiality provisions of the *Statistics Act* and with any applicable requirements of the *Privacy Act*;

4) The microdata linkage offers demonstrable cost or respondent burden savings over other alternatives, or is the only feasible option to meet the project objectives;
5) The microdata linkage is judged not to jeopardize the future conduct of Statistics Canada's programs.

The proposed data linkage aims to satisfy all 5 criteria and linkage keys and direct identifiers will be retained in accordance to the Directive on the Management of Statistical Microdata files(32).

Consent for linking data will be requested from each participant at the end of the survey, and the confidentiality of the personal information will be explained.

Management of Biologicals Collection

We propose to collect DBS (Dried Blood Spot) and urine samples. The urine collection could be in the same way as was done during NATSAL-3 (33). The method consists of using the "firstburst® urine collection device"(Maddison UK), or a similar urine collection device, which will be given to the participant by the surveyor. The specimen is collected on site and then packaged by the interviewer and posted to the lab by mail on the same day, thus avoiding the cost and geographic limitation of having a laboratory near the household. The PHAC National Reference laboratory is also working to validate a means of collecting urine through the dipping of blotting paper in the urine sample, and mailing the dried blotting sample.

The following steps would be taken:

- Explain the purpose and procedure of the DBS and urine test to all eligible participants at the end of the interview
- Provide a leaflet explaining the purpose and procedure, the confidentiality of the results
- Obtain written consent on the biologicals testing before collecting the sample. Only those who consent will be tested. Notify that the results of the test will not be provided (see rationale). If results need to be provided, the alternative approach would be to create a temporary website where participants can access their results, through a personal code and password, as done in the Québec PIXEL study (34). Or if the tests are sent to Provincial lab centres, the participant could obtain anonymous results, as done in B.C. with the testing service "getcheckedonline" (https://getcheckedonline.com/Pages/HowGetCheckWorks.aspx).
- Obtain written consent for storing urine for potential future measurements on prevalence of past or current infection with other (unspecified) pathogens
- Collect up to 5ml of urine in a sterile plastic container
- Specimen is packaged by interviewer and posted on the same day by the interviewer. (No urine collection is to take place on a day preceding a bank holiday to avoid delays)
- We would recommend offering a gift or money voucher to increase response rates.

Rationale for not providing the results of the STI to the participants (35):

- Free tests are available elsewhere

- Quality of the test is not optimal (higher level of false negative and false positive) compared to clinical testing
- Does not provide results for all STIs (people may falsely think they are STI free)
- Too costly and time consuming to find every person and follow up

Impact

The measurement of key variables related to sexually transmitted infections, sexual violence and reproductive coercion, pregnancy, contraception, determinants of health, behaviours, at a national scale, will allow for a better understanding of the sexual health and health equity, particularly gender equity, of Canadians. The CSHS instrument will provide representative data on the factors that contribute to unplanned pregnancy, unmet contraception needs, STIs and adverse behaviours, by using validated indicators.

Iterations of this survey bear the potential to provide information on trends, changing prevalence and emerging behaviours, and to measure the relation of policy changes to overall health equity and sexual health.

The indicators determined will illuminate the multistage pathways that may lead to STI, sexual violence or abortion by looking at a range of associated determinants at the individual, regional and population level. These multistage pathways are also linked with socioeconomic determinants, which may differ between regions, sub-populations and countries, and may be articulated in the CSHS data.

This nationally administered instrument will provide comparative data with international data from similar surveys, in order to assess how Canada fares in relation to other high-income countries. Both the NSFG and the NATSAL have successfully been measuring current data on sexual health for decades, as well as changing trends, providing key information for policy development, programme planning and health services management.

Data from this study will be useful to inform policy, system and program decisions to support Canadians to equitably achieve their sexual and reproductive health goals.

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Contraception & Abortion Research Team (CART-GRAC)
http://www.cart-grac.ubc.ca/
320-5950 University Boulevard, Dept Family Practice, UBC. Vancouver, BC V6T 1Z3
604.761.7767 f: 1.866.656.5544 wendy.norman@ubc.ca cart.grac@ubc.ca

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