Received: 26 August 2020 | Accepted: 20 April 2021

DOI: 10.1002/pds.5255

ORIGINAL ARTICLE

WILEY

Chronic pain patients' willingness to share personal identifiers on the web for the linkage of medico-administrative claims and patient-reported data: The chronic pain treatment cohort

Anaïs Lacasse[1] | Véronique Gagnon[1] | Hermine Lore Nguena Nguefack[1] | Mélissa Gosselin[1] | M. Gabrielle Pagé[2,3] | Lucie Blais[4] | Line Guénette[5,6]

[1]Département des sciences de la santé, Université du Québec en Abitibi-Témiscamingue (UQAT), Rouyn-Noranda, Canada

[2]Centre de recherche du Centre hospitalier de l'Université de Montréal (CRCHUM), Montréal, Québec, Canada

[3]Département d'anesthésiologie et de médecine de la douleur, Faculté de médecine, Université de Montréal, Montréal, Québec, Canada

[4]Faculté de pharmacie, Université de Montréal, Montréal, Canada

[5]Faculté de pharmacie, Université Laval, Québec, Québec, Canada

[6]Centre de recherche du CHU de Québec – Université Laval, Québec, Québec, Canada

Correspondence
Anaïs Lacasse, Département des sciences de la santé, Université du Québec en Abitibi-Témiscamingue, 445, boul. de l'Université, Rouyn-Noranda, QC J9X 5E4, Canada.
Email: lacassea@uqat.ca

Funding information
Quebec Network on Drug Research, a thematic network of the Fonds de recherche du Québec - Santé (FRQS)

Abstract

Purpose: The linkage between patient-reported data and medico-administrative claims is of great interest for epidemiologic research. The goal of this study was to assess the willingness of people living with chronic pain to share personal identifiers on the web for the linkage of medico-administrative and patient-reported data.

Methods: This methodological investigation was achieved in the context of the implementation of the chronic pain treatment (COPE) cohort. A web-based recruitment initiative targeting adults living with chronic pain was conducted in the province of Quebec (Canada).

Results: A total of 1935 participants completed the questionnaire (mean age: 49.86 ± 13.27; females: 83.69%), 921 (47.60%) of which agreed to data linkage and shared their personal identifiers (name, date of birth, health insurance number online). The most common reasons for refusal were: (1) concerns regarding data security/privacy (25.71%) and (2) the belief that the requested data were too personal/intrusive (13.52%). Some participants did not understand the relevance of data linkage (11.81%). Participants from the COPE cohort and those from the subsample who agreed to data linkage were comparable to other random samples of chronic pain individuals in terms of age and pain characteristics.

Conclusions: Although approximately half of the participants refused data linkage, our approach allowed for the implementation of a data platform that contains a diverse and substantial sample. This investigation has also led to the formulation of recommendations for web-based data linkage, including placing items designed to assess willingness to share personal identifiers at the end of the questionnaire, adding explanatory videos, and using a mixed-mode questionnaire.

Preliminary results of this study were presented at the 2019 annual meeting of the Quebec Network on Drug Research (RQRM) held in Orford (Quebec, Canada), November 13–14, 2019. Proceedings were not published in a scientific journal.

KEYWORDS
acceptability, administrative databases, chronic pain, claims, COPE cohort, linkage, methodological recommendations, patient-reported data, personal identifiers, web, willingness

1 | INTRODUCTION

Medico-administrative databases are the preferred data source for the study of the real-world utilization of drugs and healthcare resources. Such databases contain precise data on a very large number of individuals over long periods of time.[1-4] For example, prescription claims in Canada hold data pertaining to individuals covered by provincial public drug insurance plans. In the province of Quebec, approximately 3.7 million individuals are covered by a public drug plan (46.3% of the population).[5] Claims can also be used for those covered by private insurance[6] (59.4% of Canadians[7]). As for hospitalizations and physician services, all Canadians are covered (universal insurance),[8] which makes medico-administrative data of great interest for epidemiologic and/or pharmacoepidemiologic studies. While they are not designed for research purposes, claims offer several advantages. For instance, they include no recall bias and offer high efficiency.[1-4] However, several key variables are often unavailable through these claims (e.g., illness severity, functional impact, over-the-counter drugs, gender roles, smoking, and body mass index). It is therefore beneficial—sometimes crucial—to link patient-reported data with medico-administrative databases.[9-11] Linkage is also valuable when medico-administrative data alone make it difficult to identify/characterize patients suffering from specific conditions, notably chronic pain.[12]

Data linkage raises many societal concerns, including informed consent and confidentiality.[10,13,14] For the linkage of medico-administrative and patient-reported data, it is possible to adopt prospective recruitment strategies and make direct requests for consent.[15] When participants accept to share their personal identifiers (i.e., health insurance number, date of birth, name) to enable data linkage, researchers can request claims from data holders. However, the acceptability of sharing such identifiers varies. In a previous study, the medical directors of Quebec pain clinics wrote and mailed a letter to patients listed in the Quebec Pain Registry, asking them to share their health insurance number in order to link their clinical and medico-administrative data.[16] The return and acceptance rate was 44.3%. In the context of the Canadian Community Health Survey, 72.1%–74.4% of Quebec residents shared their health insurance number for linkage purposes during phone or in-person interviews[17,18] (the rate in other provinces is 66.5%–85.3%[19,20]). When individuals were asked in person to provide personal identifiers for the reMed registry (sample of Quebec residents covered by a private drug insurance), 83% accepted.[6] Several factors could possibly explain the variability of the acceptance rate, including the characteristics of the populations, the inability to reach certain participants due to changes in contact information, pre-existing relationships (e.g., through a clinic), the level of awareness of the initiative (e.g., government survey), and/or the recruitment method.

Key Points

- This study aimed to fill a research gap and evaluate the willingness of sharing personal identifiers for the linkage of medico-administrative and patient-reported data collected on the web.
- Although about half of the participants did not consent, our web-based approach allowed for the implementation of a data linkage platform that is composed of a substantial and diversified sample of participants from the target population.
- Concrete recommendations for data linkage using the web are provided (e.g., place items designed to assess willingness to share personal identifiers at the end of the questionnaire, add explanatory videos, using a mixed-mode questionnaire).

As digital data theft is evermore present, the acceptability of sharing personal identifiers for data linkage purposes through web-based recruitment is questionable. While web-based studies offer many benefits (e.g., rapid recruitment of large samples at low costs, no geographic barriers, reduction of data entry errors[21-23]), they are expected to limit the development of trust-based relationships. Thus, the goal of this study was to explore the willingness of people living with chronic pain to share personal identifiers on the web for the linkage of medico-administrative and patient-reported data.

2 | METHODS

2.1 | Study setting and population

This methodological study was conducted in the context of the implementation of the chronic pain treatment (COPE) cohort. The COPE cohort is a web-based prospective study intended to gain a better insight into the real-world utilization of pharmacological and non-pharmacological treatments among people living with chronic pain in the province of Quebec (Canada). Eligibility requirements for participants were as follows: (1) to report persistent or recurrent pain for more than 3 months (as defined by the International Association for the Study of Pain[24]), (2) to be at least 18 years of age, (3) to reside in the province of Quebec, and (4) to be able to complete a web-based questionnaire in French (the residents of this east-central Canadian province are predominantly French-speaking: 85.5% report French as

their first language, and 94.4% are able to speak French[25]). This study was approved by the research ethics committee of the *Université du Québec en Abitibi-Témiscamingue* and conforms to the Tri-Council Policy Statement.

2.2 | Web-based recruitment

The online survey software SurveyMonkey® was used to publish the study questionnaire and collect data. Building on the success of previous online studies,[26,27] a web-based dissemination strategy was implemented to reach a community sample of people living with chronic pain. All the advertisements included a hyperlink to the web-based questionnaire. When individuals clicked on this link, they were brought to the study's landing page where sufficient information was provided to ensure free and informed consent.

The web-based dissemination strategy included: (1) invitations advertised by chronic pain patient associations/advocacy groups via newsletters, social media pages, and/or websites (i.e., Quebec Chronic Pain Association, Arthritis Society), (2) invitations shared among various Facebook® support groups related to chronic pain, (3) email invitations and social media posts (Facebook®, Instagram®, Twitter®, LinkedIn®) shared by key colleagues and friends with various socioeconomic statuses (snowballing technique), and (4) email invitations and social media posts shared by research networks (i.e., Quebec Network on Drug Research, Quebec Pain Research Network, Quebec Network of Junior Pain Investigators). The study's launch was announced in a press release issued by the principal investigator's institution. The press release attracted significant media attention and the study was covered in numerous broadcasts and text interviews published online. Paid advertisements were not used. The online questionnaire was available for 18 weeks (June 11 to October 15, 2019) and two waves of advertisements were carried out: one in June, when the study was launched, and one in early September.

2.3 | Measures

The goal of the COPE cohort is to collect a common set of patient-reported measures useful for research on the treatment for chronic pain. Table 1 shows a detailed description of the variables and the validated measurement scales included in the COPE cohort web-based questionnaire. The choice of items was inspired by: (1) core outcome domains and measures recommended by the Initiative on Methods, Measurement and Pain Assessment in Clinical Trials,[28,29] (2) items of the Canadian minimum dataset for chronic low back pain research,[30] and (3) variables assessed in the Quebec Pain Registry.[31] In addition to the variables prioritized by the research team (the balance between validity and parsimony was assessed thoroughly), all indicators identified for a minimum dataset by the Canadian Registry Working Group of the Strategy for Patient-Oriented Research (SPOR) Chronic Pain Network (CPN)[32] were included in the questionnaire: pain location, circumstances surrounding its onset, duration, frequency, intensity, neuropathic component, interference, physical function, anxiety and depressive symptoms, age, sex, gender, and employment status. Participants were also asked: (1) how they heard about the study, (2) to provide their email address to receive a summary of the study results, and (3) if they accepted to be contacted for future studies conducted by the research team. The questionnaire was divided into seven sections (see Table 1), and the most important questions were presented at the beginning (pain characteristics). The bottom of each section (page of the web-based questionnaire) featured a completion progress bar.

Before the launch of the study, the questionnaire was revised by a linguist and pretested to assess its accessibility for individuals with varying levels of literacy. The subjects of the pretest were three men and two women, with and without high school diplomas, most suffering from chronic pain. Also, the questionnaire was tested on various platforms (computer, tablet, mobile phone). Participants could skip some items during the completion of the questionnaire for ethical reasons and as there is evidence that forced answering can increase dropout rates and decreases the quality of the answers.[33,34]

2.4 | Willingness to share personal identifiers for data linkage

Section 4 of the web-based questionnaire was designed to assess the willingness of participants to share personal identifiers for the linkage of their responses with medico-administrative databases (Table 1). While the landing page of the study contained information designed to ensure free and informed consent regarding participation, ethical aspects related to data linkage were only brought up in the middle section (Section 4) of the questionnaire. In fact, announcing at the outset that the study involved sharing personal identifiers, such as one's health insurance number, could have led to a selection bias. Participants more sensitive to issues of confidentiality and trust related to data linkage could have been less inclined to start the questionnaire, thus leading to an overestimation of acceptability among study participants. In addition, guidelines suggest to insert sensitive or objectionable questions only 5–10 min into the questionnaire.[34]

2.5 | Data cleaning

In our study, participants were defined as individuals meeting the eligibility requirements and having completed most items included in the first section of the web-based questionnaire (pain location, onset, duration, frequency, pain intensity at its worst, pain intensity on average, catastrophizing). The data cleaning process included the assessment of multiple participations by cross-referencing nominative information included in the database, such as IP address (recorded by default by the SurveyMonkey® collector), email address, name, date of birth, and health insurance number. In cases of multiple participations, a standardized two-fold rule was applied: (1) the most complete

TABLE 1 Description of variables and validated measurement scales included in the COPE cohort web-based questionnaire

Variables	Measurement	Sections of the questionnaire
Chronic pain characteristics and interference[a]		
Location	Semi closed-ended question[b]	1
Circumstances surrounding onset	Semi closed-ended question[b]	1
Duration	Open-ended question about the number of days, months or years since the onset of pain (allowing the assessment of chronic pain presence)[b]	1
Frequency	Closed-ended question[b]	1
Intensity	11-point (i.e., 0–10) numerical rating scales[c]—On average in the past 7 days/At its worst in the past 7 days[b]	1
Tendency to pain catastrophizing	Closed-ended question: Agreement with the statement "I feel that my pain is terrible and it's never going to get any better"[d]	1
Neuropathic component	Neuropathic pain questionnaire (DN4)—Interview part[60] (a score > 3/7 indicates a likely presence of a neuropathic component to the patient's pain; when some items were filled [yes = 1 point], items not filled in were considered as 0 points[61])[b]	2
Interference	Brief Pain Inventory (BPI)—Interference scale[62,b,c]	3
Pain treatment and healthcare		
Section of the questionnaire designed to obtain consent for data linkage	Free and informed consent form specific to data linkage (yes/no, reasons of refusal) Space to provide personal identifiers if linkage with public medical/drug insurance claims (health insurance number, first name, last name, date of birth) Private drug insurance information if applicable	4
Pharmacological pain treatments	Closed-ended questions about current use of prescribed pain medications (yes/no) and over-the-counter pain medications (yes/no) Will be complemented by prescription claims	5
Adverse effects of pharmacological pain treatments[a]	Standardized checklist of adverse effects related to pain treatment evaluated in terms of presence and intensity (mild, moderate, severe)[e]	5
Non-pharmacological pain treatments	Closed-ended question about current use of non-pharmacological pain treatments (yes/no) Semi closed-ended question about the type of treatments that are used. Listed treatments were inspired by the work of the Canadian Agency for Drugs and Technologies in Health[63] and the Quebec Pain Registry[31]	5
Percentage of relief provided by pain treatments	Numeric scale ranging from 0% (no relief) to 100% (complete relief) adapted from the Brief Pain Inventory (BPI).[62] The BPI version only covered the past 24 h so it was adapted to cover general relief provided by current use of pain treatments.	5
Most effective treatment	Open-ended question	5
Access to a trusted healthcare professional for pain management	Closed-ended question with the following examples: physician, nurse, pharmacist, physiotherapist, psychologist	5
Sociodemographic profile		
Age,[b] sex,[b] race/ethnicity, country of birth, employment,[b] involvement in litigation related to a disability benefit claim, education level, region of residence	Open-ended, closed-ended and semi closed-ended questions	6
Gender[b]	Gender roles scale: Bem Sex-Role Inventory (BSRI)[64]—18-item French version[65]	6
Health profile		
Health-related quality of life[a]		7

(Continues)

TABLE 1 (Continued)

Variables	Measurement	Sections of the questionnaire
	Three items of the SF-12v2 Health Survey (SF-12v2)[66] allowing the norm-based scoring of 2 of the 8 SF-12v2 subscales, that is, Physical Functioning (PF)[b] and General Health (GH)	
Polypharmacy	Closed-ended question about the number of medications currently used (including prescribed, over-the-counter, pain-related and other diseases-related medications)	7
Emotional functioning[a]	Anxiety and depressive symptoms measured by the Patient Health Questionnaire—4 items (PHQ-4)[67,b]	7
Smoking, alcohol, and drugs	Closed-ended questions[d]	7
Cannabis use	Closed-ended questions about past year use of cannabis for pain management (yes/no), management of other health problems (yes/no), recreational purposes (yes/no)	7
Obesity	Open-ended question about weight and height[d]	7

[a]Core outcome domains recommended by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT).[28]
[b]Included in the minimum dataset suggested by the Canadian Registry Working Group of the Strategy for Patient-Oriented Research (SPOR) Chronic Pain Network (CPN).[32]
[c]Validated scales recommended by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT).[29]
[d]Items from the Canadian Minimum dataset for chronic low back pain research.[30]
[e]Items from the Quebec Pain Registry.[31]

entry was kept, (2) when both entries were complete, the first entry in terms of calendar date was kept.

2.6 | Statistical analysis

Descriptive statistics were calculated to summarize the characteristics of the study population and those of the subsample of participants who accepted or refused to share their personal identifiers for data linkage. These characteristics were compared to the profiles of Canadian and European representative samples of individuals living with chronic pain (random samples from previous national surveys[35-40]) in order to explore the representativeness of the COPE cohort. The proportion of missing values for the first item or measurement scale of each section of the questionnaire was calculated, and then depicted using a line chart comparing trends of the whole sample to those of participants having agreed to data linkage.

Descriptive statistics were used to describe data linkage acceptability and the reasons for refusal. To achieve this, the reasons collected using an open-ended question (verbatim) were reviewed line by line to develop a coding system. Coding was then performed by one coder and verified by another (consensus was reached for any non-concordance). During the recruitment process, an unexpected financial data breach, made public on June 20, 2019, was widely publicized in the national press. This breach affected approximately 2.7 million Canadians and 173 000 businesses.[41] A chi-squared test was used to compare the proportion of participants who agreed to data linkage before and after this scandal.

A multivariable logistic regression model was used to identify the sociodemographic and clinical characteristics of participants associated with the willingness to share personal identifiers for data linkage (dependent variable). A broad set of potential associated factors to be included in the model was determined a priori based on the hypothesis that socioeconomic and health statuses have the potential to affect trust toward medical research.[42] For all variables included in the multivariable model, variance inflation factors (VIFs) were below <2.5 (VIF < 5 or 10 are often suggested for detecting multicollinearity[43]). The results are presented as adjusted odds ratios (aOR) along with their respective 95% confidence intervals (95%CI). Since a quantitative interpretation of OR can be misleading when the outcome is not rare and when effect sizes are modest to strong, the OR were interpreted qualitatively[44] (i.e., presence of a statistically significant association and its direction rather than its magnitude). All statistical analyses were performed using SPSS Statistics for Windows® version 26 (IBM Corp., Armonk, NY, USA)) and SAS® version 9.4 (SAS Institute, Cary, NC, USA).

3 | RESULTS

A total of 2637 individuals reached the survey platform, from which were removed 197 multiple participations identified according to email addresses, names, dates of birth, and health insurance numbers, 381 individuals who did not complete most items included in the first section of the questionnaire, 76 multiple participations identified according to IP addresses, and 48 individuals not eligible in terms of age, presence of chronic pain or province of residence. Thus, 1935 eligible participants from the 17 administrative regions of the province of Quebec completed the web-based questionnaire between June and October 2019. These individuals made up the COPE cohort. The

characteristics of the study population are summarized in Table 2 (first two columns). Participants were aged between 18 and 88 years old and 83.69% were women. Only 36.15% of participants reported being employed (full- or part-time). On average, participants had been suffering from pain for 12.84 years (52.78% reporting pain for at least 10 years). Most reported using prescription drugs (79.61%) or over-the-counter drugs (66.92%) to ease their pain, and the most common pain location was the back (61.45% of participants). Most participants were recruited through emails sent by patient associations/advocacy groups (48.21%) or Facebook (38.84%; including patient association pages, pain support groups and snowball technique).

Among the 1446 participants who answered the section of the questionnaire designed to assess the willingness to share personal identifiers for linkage purposes (name, date of birth, health insurance number), 921 agreed to data linkage (Figure 1). This yielded a 63.69% acceptability rate (921/1446) among completers (listwise deletion of missing data). However, the acceptability rate among the entire COPE cohort was 47.60% (921/1935). The difference in the number of participants recruited before ($n = 830$) and after the massive digital data theft ($n = 1105$) was substantial, and the proportion of participants who agreed to data linkage before and after was 51.33% and 44.80%, respectively (p-value: 0.0622).

Figure 2 illustrates the proportion of missing values for the first item or measurement scale of each section of the web-based questionnaire. In the whole sample ($n = 1935$), a substantial increase in missing data can be observed when participants reached the section of the questionnaire designed to assess willingness to share personal identifiers for linkage purposes (Section 4). Among participants who agreed to data linkage ($n = 921$), the proportion of missing data was below 6% throughout the questionnaire (Figure 2). Within this subsample, increased missing data were observed after the sixth section of the questionnaire (after 82 items). The mean completion time among those who completed the entire questionnaire was 22 min.

The characteristics of the subsample of participants who agreed to data linkage are summarized in Table 2 (third and fourth columns). The most common reasons for data linkage refusal (Figure 3) were: (1) concerns regarding data security and privacy (25.71%) and (2) the belief that the requested data were too personal/intrusive (13.52%). Some participants did not understand the relevance of data linkage (11.81%), and some participants using few medications reported that they did not want to share their information because they felt it was not relevant.

Table 3 shows the results of the multivariable logistic regression model used to identify the clinical and sociodemographic characteristics associated with the willingness to share personal identifiers for data linkage. The analysis revealed that, independently of other characteristics included in the model, three variables were associated with an increased likelihood of sharing personal identifiers for data linkage purposes: (1) non-cancerous disease as the circumstance surrounding the onset of pain (aOR: 1.506, 95%CI: 1.022–2.218), (2) a greater number of medications currently used (including prescribed, over-the-counter, pain-related and other diseases-related medications; aOR: 1.067, 95%CI: 1.016–1.121), and (3) agreeing to be contacted for future studies conducted by the research team (aOR: 9.988, 95%CI: 6.357–15.693). Sociodemographic characteristics, including age, sex, gender roles, and education, were not associated with the likelihood of agreeing to data linkage.

Through our findings, we were able to put forward concrete methodological recommendations for future studies aiming to achieve data linkage using web-based recruitment methods. These recommendations are presented in Table 4.

4 | DISCUSSION

This study aimed to evaluate the willingness of participants to share personal identifiers for the linkage of medico-administrative and patient-reported data collected online. Although approximately half of the study's participants did not consent to data linkage, our approach allowed for the implementation of a data linkage platform that is composed of a substantial and diversified sample of participants from the target population. Furthermore, despite there being a non-statistically significant downward trend in terms of the acceptability of sharing personal identifiers for linkage purposes following a highly publicized major digital data theft, it can be said that acceptability appeared stable before and after the event. The circumstances surrounding the onset of pain and the use of multiple medications were associated with the likelihood of sharing personal identifiers.

4.1 | Reaching a representative sample via the Internet

The recruitment strategy used in this study was efficient in reaching a large sample of participants ($n = 1935$) within a short period of time (4 months). We were able to reach individuals from all regions of the province of Quebec (including a number of remote and rarely studied regions). Furthermore, our sample was quite representative of people living with chronic pain. Participants of the COPE cohort and the subsample agreeing to data linkage were comparable to other large random samples of chronic pain individuals in terms of age, employment status (most were not working), level of education (most had a post-secondary education), pain duration, pain intensity, and most common pain locations[35-40]). However, participants were different in terms of sex and pain medication usage. The oversampling of women could possibly be explained by survey recruitment methods and the mode of administration (Table 1). In fact, within the general population, more women than men use Facebook®[45] or work in an online environment.[46] Given the upward trends in prescription drug use over the past decades[47-49] and considering that more women than men use drugs,[50] it is unclear whether the differences in the usage of pain medication can be explained by: (1) the specific time when the random sample surveys were conducted (those reporting on medication use were published between 2002 and 2007), (2) the greater proportion of women in our sample, or (3) an oversampling of drug users. This possible sampling bias may affect the external validity of certain

TABLE 2 Characteristics of the study population and the subsample of participants who accepted to share their personal identifiers for data linkage in parallel to the profile of other representative samples of individuals living with chronic pain

Characteristics	COPE cohort	Subsample of participants who accepted data linkage	Subsample of participants who refused data linkage	Boulanger et al.[35] Canada	Moulin et al.[36]—Prevalence survey Canada	Moulin et al.[36]—Impact survey Canada	Schopflocher et al.[37] Canada	Toth et al.[38] Province of Alberta, Canada	Bouhassira et al.[39] France	Breivik et al.[40] 15 European countries + Israel
n	1935	921	525	~263 (25% of the 1055 sample)	585	340	NR	423	7522	4839
Mode of administration	Web	Web	Web	Telephone (random digit dialing)	Telephone (random digit dialing)	Telephone (random digit dialing)	Telephone (random digit dialing)	Telephone (random digit dialing)	Face-to-face, mail, telephone (random sampling)	Telephone (random digit dialing)
Definition of CP	Pain that persists or recurs for longer than 3 months (ICD-11 definition)[68]	Pain that persists or recurs for longer than 3 months (ICD-11 definition)[68]	Pain that persists or recurs for longer than 3 months (ICD-11 definition)[68]	Continuous or intermittent pain for ≥6 months	Continuous or intermittent pain for ≥6 months	Continuous or intermittent pain for ≥6 months + prescription analgesic use	Pain for ≥6 months + had experienced pain in the last month + several times a week + ≥5 pain intensity on a 0–10 scale	Daily or nearly daily pain for ≥3 months	Daily pain for ≥3 months	Pain for ≥6 months + had experienced pain in the last month + ≥2 times per week + ≥5 pain intensity on a 0–10 scale
Prevalence of CP	NA (all participants had CP)	NA (all participants had CP)	NA (all participants had CP)	25%	29%	NA (all participants had CP)	18.9%	35%	31.7%	19%
Mean age (years)	49.86 (95%CI: 49.17–50.56)	50.37 (95%CI: 49.50–51.23)	48.81 (95%CI: 47.63–49.99)	NR	47.7 (95%CI: 47.0–48.4)	NR	NR	46.6–48.4	NR	49.9 (SD: 17.4)
Age categories (years)	18–34: 13.36% 35–54: 48.21% ≥55: 38.43%	18–34: 12.31% 35–54: 48.79% ≥55: 38.90%	18–34: 15.27% 35–54: 47.70% ≥55: 37.03%	NR	NR	18–34: 6.2% 35–54: 44.7% ≥55: 49.1%	NR	NR	NR	18–30: 16% 31–50: 39% ≥51: 46%
Females	83.69%	82.15%	86.35%	NR	55%	65.3%	NR	56.5%	NR	56%
Employed	36.15%	34.19%	39.80%	NR	NR	38% (excluding self-employment)	NR	66.9%	NR	44%
Post-secondary education	79.19%	78.49%	80.82%	NR	NR	NR	NR	67.6%	NR	NR
Pain duration (years)	Mean: 12.84 (95%CI: 12.33–13.36) Median: 10	Mean: 12.93 (95%CI: 12.17–13.70) Median: 10	Mean: 12.75 (95%CI: 11.78–13.72) Median: 10	Mean: 9.8	NR	Mean: 10.7 (95% CI: 9.7–11.9)	NR	NR	NR	Median: 7

TABLE 2 (Continued)

Characteristics	COPE cohort	Subsample of participants who accepted data linkage	Subsample of participants who refused data linkage	Boulanger et al.[35] Canada	Moulin et al.[36]—Prevalence survey Canada	Moulin et al.[36]—Impact survey Canada	Schopflocher et al.[37] Canada	Toth et al.[38] Province of Alberta, Canada	Bouhassira et al.[39] France	Breivik et al.[40] 15 European countries + Israel
Pain duration categories (years)	≥10 years: 52.78% 5–9 years: 21.59% 1–4 years: 22.37% <1 year: 3.27%	≥10 years: 51.30% 5–9 years: 22.72% 1–4 years: 23.04% <1 year: 2.93%	≥10 years: 53.92% 5–9 years: 21.99% 1–4 years: 21.03% <1 year: 3.06%	≥10 years: 12% 5–9 years: 15% 1–4 years: 42% <1 year: 31%	NR	NR	≥10 years: 46.7% 5–9 years: 19.6% 1–4 years: 30.0% <1 year: 3.7%	NR	NR	≥10 years: 46% 5–9 years: 20% 1–4 years: 30% <1 year: 4%
Pain intensity (mean score on a 0–10 scale)	5.44 (95%CI: 5.36–5.53)	5.49 (95%CI: 5.36–5.62)	5.31 (95%CI: 5.14–5.47)	6.9	NR	6.3 (95%CI: 6.2–6.4)	NR	NR	4.5 ± 2.1	NR
Mild (1–4 unless stated otherwise)	31.33%	30.07%	34.55%	12%[a]		20.3%	NA since intensity ≥5 was an inclusion criteria		33.9% (NRS 1–3)	NA since intensity ≥5 was an inclusion criteria
Moderate (5–7 unless stated otherwise)	53.42%	54.63%	51.44%	37%[a]		47.9%	68.1%		46.5% (NRS 4–6)	66%
Severe (8–10 unless stated otherwise)	15.25%	15.31%	14.01%	51%[a]		31.7%	31.9%		16.1% (NRS 7–10)	34%
Taking prescription drugs for pain management	79.61%	83.86%	72.50%	49%	Only reported across age groups: 18–34: 5% 35–54: 12% ≥55: 19%	NA since it was an inclusion criteria	NR	NR	NR	52%
Taking over-the-counter drugs for pain management	66.92%	64.22%	71.76%	NR	NR	30%	NR	NR	NR	47%
Most common pain locations[b]	1. Back (61.45%) 2. Neck (44.13%)	1. Back (61.89%) 2. Neck (44.08%)	1. Back (62.67%) 2. Neck (45.33%)	1. Back[a] 2. Knees[a] 3. Neck[a] 4. Head[a]	NR	1. Back 2. Legs 3. Head 4. Neck	1. Back 2. Knees 3. Legs 4. Shoulders	NR	NR	1. Back 2. Knees 3. Head 4. Legs

(Continues)

TABLE 2 (Continued)

Characteristics	COPE cohort	Subsample of participants who accepted data linkage	Subsample of participants who refused data linkage	Boulanger et al.[35] Canada	Moulin et al.[36]— Prevalence survey Canada	Moulin et al.[36]— Impact survey Canada	Schopflocher et al.[37] Canada	Toth et al.[38] Province of Alberta, Canada	Bouhassira et al.[39] France	Breivik et al.[40] 15 European countries + Israel
	3. Shoulder (43.57%) 4. Hips (37.05%) 5. Legs (36.74%)	3. Shoulder (43.32%) 4. Legs (39.74%) 5. Hips (38.87%)	3. Shoulder (43.43%) 4. Legs (36.00%) 5. Hips (35.05%)	5. Hips[a]		5. NR	5. Neck			5. Joints (unspecified)

Abbreviations: CI, confidence interval; CP, chronic pain; ICD, International Classification of Diseases; NA, not applicable; NR, not reported in this article; SD, standard deviation.

[a]According to clinicians.

[b]Categories are not mutually exclusive.

prevalence measures, but the diversity of our sample (substantial number of males and nonusers of medication) still allows for statistical association testing between different exposures and outcomes of interest using the COPE cohort.

4.2 | Willingness to share personal identifiers for data linkage

The acceptance rate (47.60%) was lower than previously achieved in person or by telephone in Quebec (72.1%–83%[6,17,18]) or other Canadian provinces (93%–96.5%[51,52]). This was expected as web-based recruitment probably limits the development of trust-based relationships. In general, there is a high level of trust toward medical research in the community (85.3% show favorable attitudes[42]; 74.8% would be willing to share unidentified electronic medical records for research purposes[53]). However, the sharing of personal identifiers in this study involved not only trust in researchers, but also trust in internet security. According to a survey conducted among a random sample of adults in 2019, 69% of Canadians are concerned about identify theft.[54] Surprisingly, the proportion of participants who agreed to data linkage before and after the massive digital data theft was similar. This shows that achieving data linkage through the web is a sound strategy, even in an era where digital data theft scandals are more and more common.

Some participants who were nonusers of drugs or healthcare resources perceived that medico-administrative data was not relevant in their case. It came as no surprise that those using more medications were more likely to agree to data linkage. In addition, it may be possible that the more medications a participant used, the more they perceived that they could benefit from sharing existing data. As trust in researchers, but also in the initiative (e.g., professional approach, graphic design, credibility of institutions) are most likely linked to participants' willingness to provide consent, it was expected that data linkage acceptance would go hand in hand with openness toward being contacted for future studies at the end of the questionnaire. As for the circumstances surrounding the onset of pain, more studies are needed to better understand why participants reporting diseases such as arthritis, lupus, or diabetes (as opposed to other circumstances such as injury, surgery, stressful events, or no specific cause) were more likely to agree to data linkage. One hypothesis that would require further investigation is that the unexpected onset of chronic pain may compromise the belief in world justice.[55] That said, perceived injustice is a factor known to affect one's level of trust in medical research.[42]

Published data are scarce regarding the determinants of the acceptability to share personal identifiers—such as the health insurance number—online. In fact, these determinants have never been assessed in chronic pain patients. A parallel can, however, be drawn with other studies involving factors associated with trust toward medical research in general[42] or willingness to share unidentified electronic medical records for research purposes.[53,56] While previous research identifies age,[42,56] race/ethnicity,[42,53] education,[42,53] self-

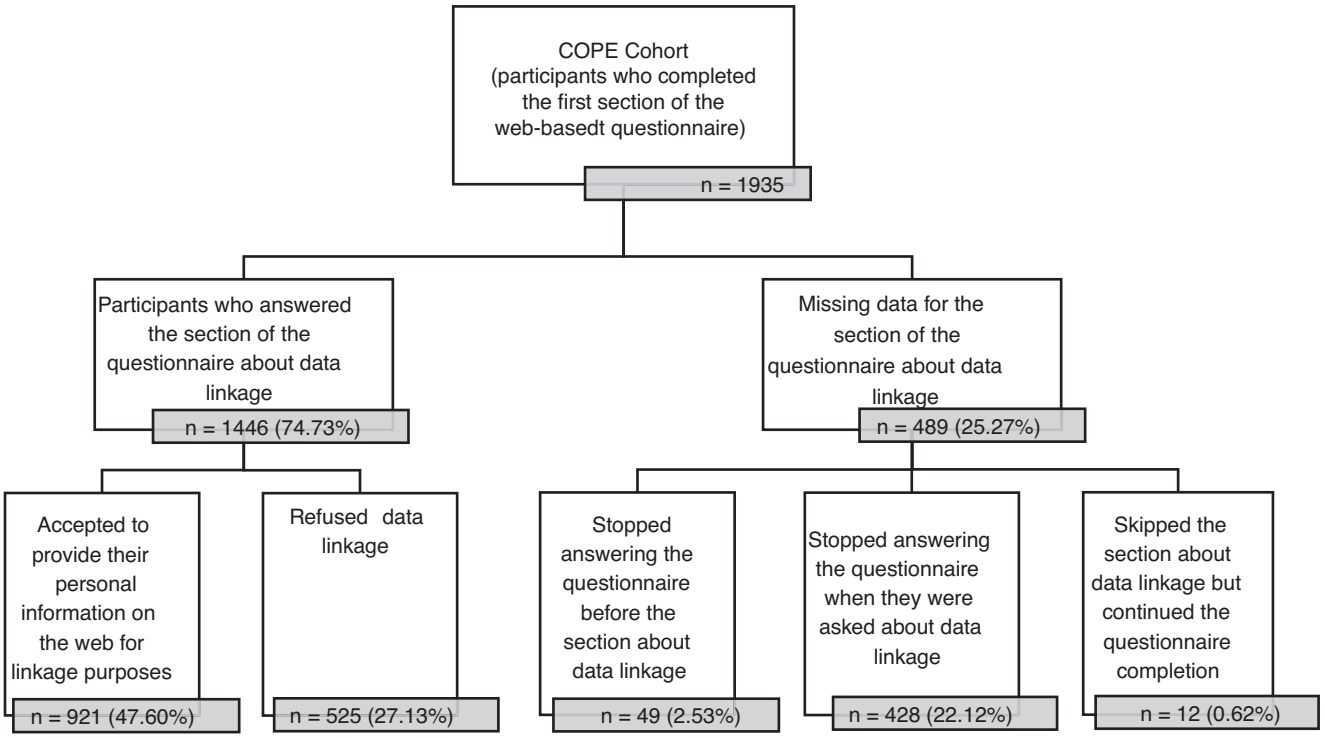

FIGURE 1 Participants' willingness to share personal identifiers on the web for the linkage of medico-administrative and patient-reported data about their treatments

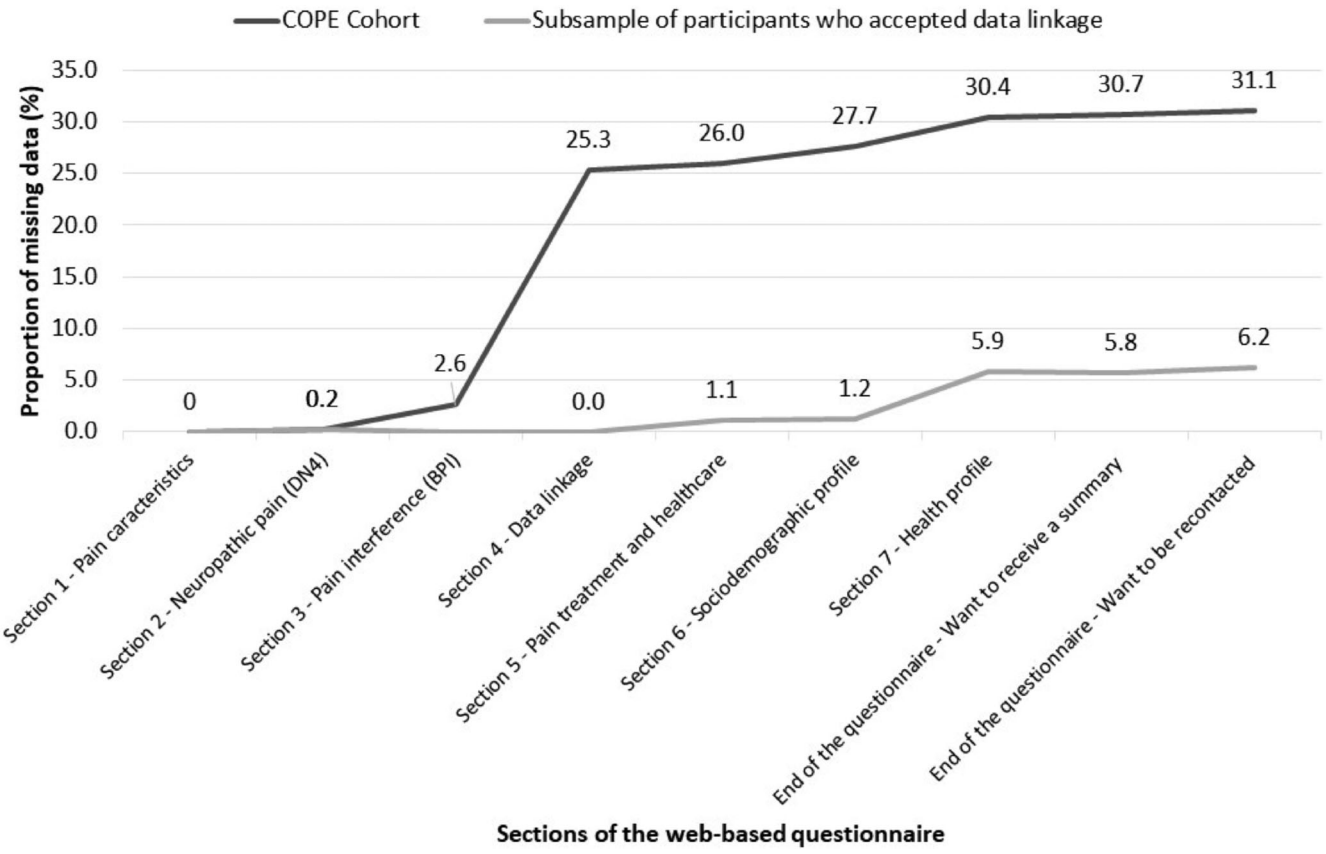

FIGURE 2 Proportion of missing data across sections of the web-based questionnaire. DN4, Neuropathic pain questionnaire; BPI, Brief Pain Inventory

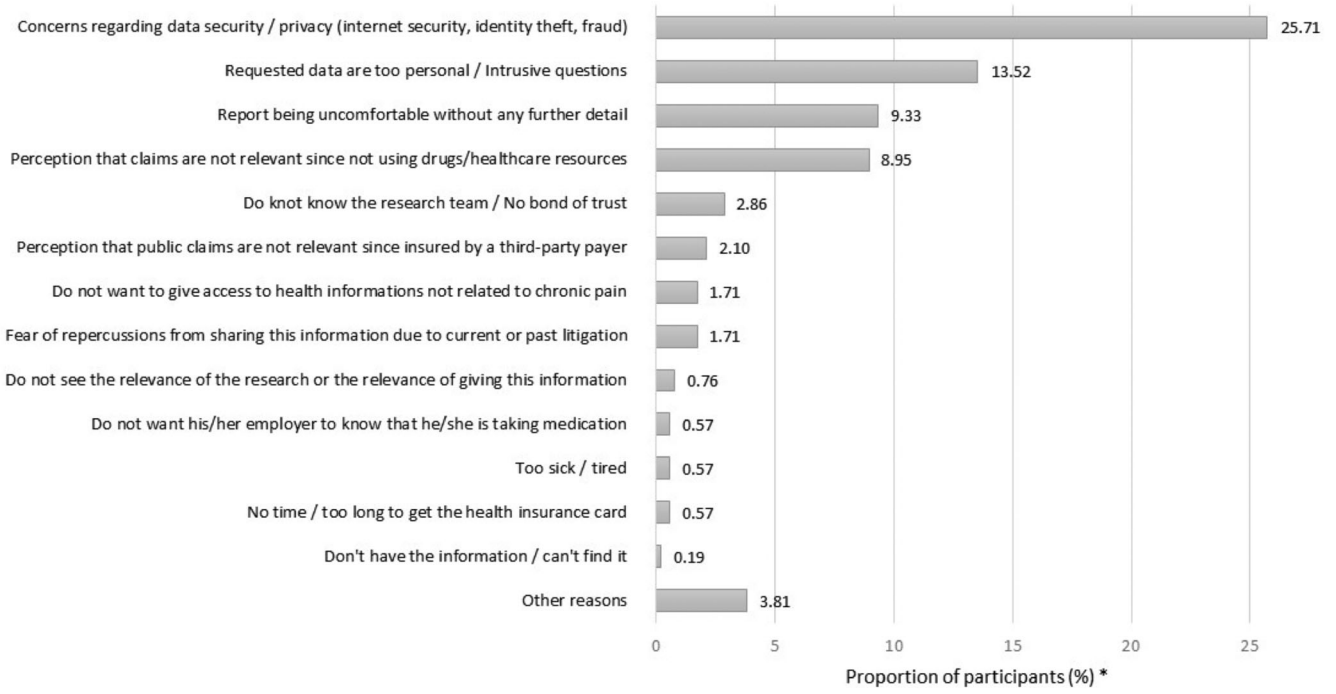

FIGURE 3 Reasons behind data linkage refusals. *Categories are not mutually exclusive since participants could list various reasons. One hundred sixty-five of the 525 participants who refused data linkage did not provide any specific reason

perceived health,[56] or disability[42] as such factors, these were not associated with the willingness to share personal identifiers for data linkage in this study. These dissimilarities could possibly be attributable to differences in terms of the nature of consent, the study topic or the population.

4.3 | Methodological recommendations

Our data reflect a certain misunderstanding regarding the relevance of data linkage, including the perception that public claims are not relevant when someone is not using drugs/healthcare resources or when someone is insured by a private or third-party payer. Some participants also believed their claims would be used to validate their responses (as if we doubted the accuracy of their response). Despite the use of an explanatory text that was pretested and deemed acceptable by the ethics committee in terms of informed consent, it seems further clarification is required regarding the purpose and usefulness of medico-administrative data. A potential solution would be to provide an explanatory video "Why is this data useful?" This would also help establish a human contact—an issue raised by some participants (verbatim example: "I do not know you"). Also, a second video "How are we going to keep your data confidential?" could also address some of the participants' fears and concerns that their medical information would be shared with their employer or with litigation parties. Video-enhanced web-based surveys are, in fact, an option to assist participants. Such features should, however, be optional (clickable) as not all participants are equipped in terms of computer capabilities, audiovisual plug-ins, and internet connection.[34] With hindsight, the section of the questionnaire designed to assess the willingness of participants to share personal identifiers for linkage purposes should have gone through cognitive testing.[57]

Another means of increasing the participation rate and decreasing missing values for the various study variables could be to use a mixed-mode questionnaire, allowing participants to do it over the phone, by mail or email, for instance.[34] In fact, this option was brought up by some participants when they were asked for their health insurance number (verbatim examples: "Please contact me by email, I will sign your document and return it by mail" or "I need to be able to see and talk with someone before I can give this personal information."). Also, a substantial increase in missing data was observed in the section of the questionnaire designed to assess willingness to share personal identifiers. Thus, this section should be placed at the end of the questionnaire, and the questionnaire should be shorter than the one used in this study. Accordingly, we should aim for a shorter completion time. Finally, the web-based advertisement campaign should include strategies targeting men.

4.4 | Strengths and limitations

This study has several strengths, including its unexpected timing alongside a massive digital data theft scandal. When identifying the characteristics associated with the willingness of the participants to share personal identifiers, the possibility of a type II error was minimal due to the substantial sample size (the 10–20 events per variable included in the regression model rule[58] was respected; 921 participants agreed to data linkage, and 34 variables/dummy variables were

TABLE 3 Multivariable logistic regression model used to identify participants' sociodemographic and clinical characteristics associated with the acceptability to share personal identifiers for data linkage

Participants characteristics *Sociodemographic profile*	Adjusted OR	95% confidence interval	*p*-value
Age (years)	0.988	0.972–1.004	0.1424
Sex (women vs. other[a])	0.828	0.503–1.364	0.4591
Gender roles—According to the BSRI (vs. undifferentiated)			
Feminine	0.891	0.547–1.452	0.6423
Masculine	0.887	0.535–1.472	0.6429
Androgynous	1.232	0.775–1.959	0.3780
Prescription drug coverage (vs. public insurance)			
Private insurance	0.769	0.516–1.146	0.1967
Do not know	0.509	0.154–1.682	0.2681
Country of birth (Canada vs. other)	0.353	0.077–1.612	0.1790
Aboriginal (yes vs. no)	0.635	0.185–2.171	0.4685
Employed full- or part-time (yes vs. no)	0.743	0.495–1.116	0.1521
Disabled (yes vs. no)	1.385	0.805–2.383	0.2391
Post-secondary education (yes vs. no)	1.000	0.628–1.591	0.9989
Residing in a remote region (vs. nonremote regions)[b]	1.198	0.785–1.829	0.4027
Chronic pain characteristics and interference			
Generalized pain (yes vs. no)	1.302	0.871–1.947	0.1981
Multisite pain (yes vs. no)	0.715	0.403–1.270	0.2528
Circumstances surrounding pain onset reported being related to a non-cancerous disease (yes vs. no)[c]	1.506	1.022–2.218	**0.0385**
Frequency (continuous vs. intermittent)	1.260	0.725–2.191	0.4129
Duration—years	0.995	0.980–1.010	0.5153
Pain intensity on average in the past 7 days—0–10 NRS	0.973	0.866–1.092	0.6378
Tendency to pain catastrophizing (yes vs. no)	0.990	0.655–1.498	0.9633
Neuropathic component—According to the DN4 (yes vs. no)	1.214	0.836–1.762	0.3094
Interference—BPI score	0.995	0.883–1.122	0.9347
Pain treatment and healthcare			
Using prescription drugs for pain management (yes vs. no)	1.229	0.754–2.004	0.4076
Using over-the-counter drugs for pain management (yes vs. no)	0.766	0.526–1.114	0.1632
Using non-pharmacological treatments for pain management (yes vs. no)	0.671	0.401–1.121	0.1273
Using cannabis for pain management (yes vs. no)	1.195	0.800–1.784	0.3839
Pain relief provided by treatments—0%–100%	0.995	0.986–1.004	0.2697
Access to a trusted healthcare professional for pain management (yes vs. no)	1.011	0.647–1.579	0.9628
Health profile			
Perceived general Health (GH)—0–100 SF-12 score	1.012	0.995–1.029	0.1651
Number of medications currently used (including prescribed, over-the-counter, pain-related and other diseases-related medications)	1.067	1.016–1.121	**0.0092**
Physical Functioning (PF)—0–100 SF-12 score	1.022	1.000–1.045	0.0549
Agree to be contacted for future studies conducted by the research team (yes vs. no)	9.988	6.357–15.693	**<0.0001**
Time of questionnaire completion (after vs. before the massive digital data theft)	0.851	0.600–1.205	0.3628

Abbreviations: BPI, Brief Pain Inventory; BSRI, Bem Sex-Role Inventory; DN4, neuropathic pain questionnaire; NRS, numerical rating scale.

[a]Remote resource regions as defined by Revenu Quebec (i.e., the provincial revenue agency): Bas-Saint-Laurent, Saguenay—Lac-Saint-Jean, Abitibi-Témiscamingue, Côte-Nord, Nord-du-Québec, Gaspésie—Îles-de-la-Madeleine. Nonremote regions are near a major urban center.

[b]In opposition to other circumstances such as injury, surgery, stressful event, or no precise cause. This classification was chosen according to the distribution of data (contingency table).

[c]Men and participants who self-identified themselves as unknown or unspecified sex were regrouped as the latter included only four individuals. Bold = statistically significant associations

TABLE 4 Methodological recommendations for future studies aiming at the achievement of data linkage through a web-based recruitment

Section of the questionnaire designed to assess the willingness of participants to share personal identifiers for linkage purposes
Place such a section at the end of the survey
Add a clickable explanatory video "Why is this data useful?"
Add a clickable explanatory video "How are we going to keep your data confidential?"
Investigate whether the section fulfills its intended purpose using cognitive testing
Use a mixed-mode questionnaire (participants can choose the option to do it over the phone, by mail or email)
General recommendations
Use a short questionnaire (<82 items)
Plan a sex-specific web-based advertisement campaign

included in the model). The success of this web-based recruitment and data collection initiative is directly related to the technological capabilities of the target population.[34] With 94% of Canadians having home internet access and 71% of seniors reporting internet use in 2018,[59] it is not surprising that we were able to reach chronic pain participants of 18–88 years of age. Even though this study was conducted in a single province, the COPE cohort and its subsamples are representative of the target population based on comparisons with other large random samples of chronic pain individuals in terms of pain characteristics, age, employment status, and level of education. However, the over-representation of women and drug users is a limitation of the dataset.

In conclusion, this study demonstrates the feasibility of recruiting a large and diversified sample of chronic pain patients who are willing to share their personal identifiers for linkage with medico-administrative databases through a web-based questionnaire. Our observations and recommendations can help plan future studies and improve worldwide web-based recruitment initiatives conducted among chronic pain individuals and other types of populations.

ACKNOWLEDGMENTS

We would like to thank all organizations who helped with the advertisement of our study. We thank Ms. Emily-Jayn Rubec and Geneviève Lavigne who provided linguistic revision services. We would also like to thank Mr. Mamadou Diallo who helped with data cleaning. This study was supported by the Quebec Network on Drug Research, a thematic network of the Fonds de recherche du Québec – Santé (FRQS). MGP and AL are, respectively, Junior 1 and Junior 2 research scholars from the FRQS. VG was supported by master's degree scholarships from the FRQS, the Canadian Institutes of Health Research (CIHR), the Quebec Pain Research Network (travel award), and the Fondation de l'Université du Québec en Abitibi-Témiscamingue (FUQAT). The Chronic Pain Epidemiology Laboratory led by AL is funded by the FUQAT, in partnership with local businesses: the Pharmacie Jean-Coutu de Rouyn-Noranda (community pharmacy) and Glencore Fonderie Horne (copper smelter). LB received research grants from AstraZeneca, TEVA and Genentech, as well as consultation fees from AstraZeneca, TEVA and Genentech for projects unrelated to this study.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ETHICS STATEMENT

This study was approved by the research ethics committee of the Université du Québec en Abitibi-Témiscamingue and conforms to the Tri-Council Policy Statement (TCPS).

AUTHOR CONTRIBUTIONS

AL, MGP, LB, and LG conceptualized the project. VG made substantial contributions to the design of the questionnaire and acquisition of data. Cleaning, analysis, and interpretation of data were conducted by AL with the help of VG, HLNN, and MG. LB is more specifically involved in the linkage of self-reported data with the reMed private prescription claims registry. AL drafted the manuscript and all authors revised it critically, gave final approval of the final version, and agreed to act as guarantors of the work.

ORCID

Anaïs Lacasse https://orcid.org/0000-0002-3992-5145
Line Guénette https://orcid.org/0000-0001-9769-7550

REFERENCES

1. Bellows BK, Kuo KL, Biltaji E, et al. Real-world evidence in pain research: a review of data sources. *J Pain Palliat Care Pharmacother*. 2014;28(3):294-304.
2. Lix LM, Walker R, Quan H, Nesdole R, Yang J, Chen G. Features of physician services databases in Canada. *Chronic Dis Inj Can*. 2012;32(4):186-193.
3. Strom BL, Kimmel SE, Hennessy S. *Pharmacoepidemiology*. 5th ed. Sussex: Wiley-Blackwell; 2012.
4. Tamblyn R, Lavoie G, Petrella L, Monette J. The use of prescription claims databases in pharmacoepidemiological research: the accuracy and comprehensiveness of the prescription claims database in Quebec. *J Clin Epidemiol*. 1995;48(8):999-1009.
5. Régie de l'assurance maladie du Québec. Rapport annuel de gestion 2018–2019; 2019. http://www.ramq.gouv.qc.ca/SiteCollectionDocuments/citoyens/fr/rapports/rappann1718.pdf. Accessed March 3, 2020.
6. Assayag J, Forget A, Kettani FZ, Beauchesne MF, Moisan J, Blais L. The impact of the type of insurance plan on adherence and persistence with antidepressants: a matched cohort study. *Can J Psychiatry*. 2013;58(4):233-239.
7. Bolatova T, Law MR. Income-related disparities in private prescription drug coverage in Canada. *CMAJ Open*. 2019;7(4):E618-E623.
8. Health Canada. Canada's Health Care System; 2012. http://www.hc-sc.gc.ca/hcs-sss/pubs/system-regime/2011-hcs-sss/index-eng.php. Accessed March 26, 2015.
9. Doiron D, Raina P, Fortier I. Linking Canadian population health data: maximizing the potential of cohort and administrative data. *Can J Public Health*. 2013;104(3):e258-e261.
10. Harron K, Dibben C, Boyd J, et al. Challenges in administrative data linkage for research. *Big Data Soc*. 2017;4(2):2053951717745678.
11. Pratt NL, Mack CD, Meyer AM, et al. Data linkage in pharmacoepidemiology: a call for rigorous evaluation and reporting. *Pharmacoepidemiol Drug Saf*. 2020;29(1):9-17.

12. Lacasse A, Cauvier Charest E, Dault R, et al. Validity of algorithms for identification of individuals suffering from chronic noncancer pain in administrative databases: a systematic review. *Pain Med*. 2020;21(9):1825-1839. https://doi.org/10.1093/pm/pnaa004.
13. Xafis V. The acceptability of conducting data linkage research without obtaining consent: lay people's views and justifications. *BMC Med Ethics*. 2015;16(1):79.
14. Brown AP, Ferrante AM, Randall SM, Boyd JH, Semmens JB. Ensuring privacy when integrating patient-based datasets: new methods and developments in record linkage. *Front Public Health*. 2017;5:34.
15. Sakshaug JW, Couper MP, Ofstedal MB, Weir DR. Linking survey and administrative records: mechanisms of consent. *Sociol Methods Res*. 2012;41(4):535-569.
16. Lacasse A, Ware MA, Dorais M, Lanctot H, Choiniere M. Is the Quebec provincial administrative database a valid source for research on chronic non-cancer pain? *Pharmacoepidemiol Drug Saf*. 2015;24(9):980-990.
17. Institut de la statistique du Québec. *Trajectoires de soins des patients ayant des conditions propices aux soins ambulatoires de l'Unité de soutien à la recherche axée sur le patient (SRAP). Rapport d'appariement—Phase 1*. Québec; 2018.
18. Institut de la statistique du Québec. *Trajectoires de soins des patients ayant des conditions propices aux soins ambulatoires de l'Unité de soutien à la recherche axée sur le patient (SRAP). Rapport d'appariement—Phase 2*. Québec; 2019.
19. Rotermann M. Evaluation of the coverage of linked Canadian community health survey and hospital inpatient records. *Health Rep*. 2009;20(1):45-51.
20. Sanmartin C, Decady Y, Trudeau R, et al. Linking the Canadian community health survey and the Canadian mortality database: an enhanced data source for the study of mortality. *Health Rep*. 2016;27(12):10-18.
21. Eysenbach G, Wyatt J. Using the internet for surveys and health research. *J Med Internet Res*. 2002;4(2):E13.
22. Wyatt JC. When to use web-based surveys. *J Am Med Inform Assoc*. 2000;7(4):426-429.
23. Heiervang E, Goodman R. Advantages and limitations of web-based surveys: evidence from a child mental health survey. *Soc Psychiatry Psychiatr Epidemiol*. 2011;46(1):69-76.
24. Treede RD, Rief W, Barke A, et al. Chronic pain as a symptom or a disease: the IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11). *Pain*. 2019;160(1):19-27.
25. Statistique Canada. *Census in Brief: French and the Francophonie in Canada*. Ottawa: Statistique Canada; 2011.
26. Benyamina Douma N, Cote C, Lacasse A. Quebec serve and protect low Back pain study: a web-based cross-sectional investigation of prevalence and functional impact among police officers. *Spine*. 2017;42(19):1485-1493.
27. Lacasse A, Choiniere M, Connelly J-A. Knowledge, beliefs, and attitudes of the Quebec population toward chronic pain: where are we now? *Can J Pain*. 2017;1(1):151-160.
28. Turk DC, Dworkin RH, Allen RR, et al. Core outcome domains for chronic pain clinical trials: IMMPACT recommendations. *Pain*. 2003;106(3):337-345.
29. Dworkin RH, Turk DC, Farrar JT, et al. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. *Pain*. 2005;113(1–2):9-19.
30. Lacasse A, Roy JS, Parent AJ, et al. The Canadian minimum dataset for chronic low back pain research: a cross-cultural adaptation of the National Institutes of Health Task Force Research Standards. *CMAJ Open*. 2017;5(1):E237-E248.
31. Choiniere M, Ware MA, Page MG, et al. Development and implementation of a registry of patients attending multidisciplinary pain treatment clinics: the Quebec pain registry. *Pain Res Manag*. 2017;2017:8123812.
32. CPN. *Chronic Pain Network Annual Report 2016/2017*. Hamilton, ON; 2017.
33. Decieux JP, Mergener A, Sischka P, Neufang K. Implementation of the forced answering option within online surveys: do higher item response rates come at the expense of participation and answer quality? *Psihologija*. 2015;48:311-326.
34. Dillman DA, Smyth JD, Christian LM. *Internet, Phone, Mail and Mixed-Mode Surveys: The Tailored Design Method*. 4th ed. Hoboken, NJ: Wiley; 2014.
35. Boulanger A, Clark AJ, Squire P, Cui E, Horbay GL. Chronic pain in Canada: have we improved our management of chronic noncancer pain? *Pain Res Manag*. 2007;12(1):39-47.
36. Moulin DE, Clark AJ, Speechley M, Morley-Forster PK. Chronic pain in Canada—prevalence, treatment, impact and the role of opioid analgesia. *Pain Res Manag*. 2002;7(4):179-184.
37. Schopflocher D, Taenzer P, Jovey R. The prevalence of chronic pain in Canada. *Pain Res Manag*. 2011;16(6):445-450.
38. Toth C, Lander J, Wiebe S. The prevalence and impact of chronic pain with neuropathic pain symptoms in the general population. *Pain Med*. 2009;10(5):918-929.
39. Bouhassira D, Lanteri-Minet M, Attal N, Laurent B, Touboul C. Prevalence of chronic pain with neuropathic characteristics in the general population. *Pain*. 2008;136(3):380-387.
40. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *EurJ Pain*. 2006;10(4):287-333.
41. Jonathan Montpetit Personal data of 2.7 million people leaked from Desjardins. *CBC News*. 2019.
42. Smirnoff M, Wilets I, Ragin DF, et al. A paradigm for understanding trust and mistrust in medical research: the community VOICES study. *AJOB Empir Bioeth*. 2018;9(1):39-47.
43. Vatcheva KP, Lee M, McCormick JB, Rahbar MH. Multicollinearity in regression analyses conducted in epidemiologic studies. *Epidemiology (Sunnyvale)*. 2016;6(2):227.
44. Davies HT, Crombie IK, Tavakoli M. When can odds ratios mislead? *BMJ*. 1998;316(7136):989-991.
45. CEFRIO. L'usage des médias sociaux au Québec. *Enquête NETendances*. 2018;9(5):1–18. https://transformation-numerique.ulaval.ca/wp-content/uploads/2020/09/netendances-2018-usage-medias-sociaux.pdf.
46. Marshall K. Utilisation de l'ordinateur au travail. *L'emploi et le Revenu en Perspective - L'édition en Ligne*. 2001;2(5). https://www150.statcan.gc.ca/n1/pub/75-001-x/00501/5724-fra.html.
47. Zhang F, Mamtani R, Scott FI, Goldberg DS, Haynes K, Lewis JD. Increasing use of prescription drugs in the United Kingdom. *Pharmacoepidemiol Drug Saf*. 2016;25(6):628-636.
48. Kantor ED, Rehm CD, Haas JS, Chan AT, Giovannucci EL. Trends in prescription drug use among adults in the United States from 1999-2012. *JAMA*. 2015;314(17):1818-1831.
49. Mojtabai R, Olfson M. National trends in psychotropic medication polypharmacy in office-based psychiatry. *Arch Gen Psychiatry*. 2010;67(1):26-36.
50. Loikas D, Wettermark B, von Euler M, Bergman U, Schenck-Gustafsson K. Differences in drug utilisation between men and women: a cross-sectional analysis of all dispensed drugs in Sweden. *BMJ Open*. 2013;3(5):e002378.
51. Hay AE, Leung YW, Pater JL, et al. Linkage of clinical trial and administrative data: a survey of cancer patient preferences. *Curr Oncol*. 2017;24(3):161-167.
52. Rhodes AE, Fung K. Self-reported use of mental health services versus administrative records: care to recall? *Int J Methods Psychiatr Res*. 2004;13(3):165-175.
53. Kim KK, Sankar P, Wilson MD, Haynes SC. Factors affecting willingness to share electronic health data among California consumers. *BMC Med Ethics*. 2017;18(1):25.
54. CPA. *CPA Canada 2019 Annual Fraud Study*. Toronto, ON: Chartered Professional Accounts of Canada (CPA); 2019.

55. Bissell DA, Ziadni MS, Sturgeon JA. Perceived injustice in chronic pain: an examination through the lens of predictive processing. *Pain Manag*. 2018;8(2):129-138.
56. Weitzman ER, Kaci L, Mandl KD. Sharing medical data for health research: the early personal health record experience. *J Med Internet Res*. 2010;12(2):e14.
57. Willis GB, Artino AR Jr. What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys. *J Grad Med Educ*. 2013;5(3):353-356.
58. Vittinghoff E, McCulloch CE. Relaxing the rule of ten events per variable in logistic and cox regression. *Am J Epidemiol*. 2007;165(6):710-718.
59. Statistics Canada. *Canadian Internet Use Survey*. Ottawa: Statistics Canada; 2019.
60. Bouhassira D, Attal N, Alchaar H, et al. Comparison of pain syndromes associated with nervous or somatic lesions and development of a new neuropathic pain diagnostic questionnaire (DN4). *Pain*. 2005;114(1–2):29-36.
61. Timmerman H, Steegers MAH, Huygen F, et al. Investigating the validity of the DN4 in a consecutive population of patients with chronic pain. *PLoS One*. 2017;12(11):e0187961.
62. Cleeland CS. *The Brief Pain Inventory User Guide*. Houston, TX: The University of Texas MD Anderson Cancer Center; 2009.
63. CADTH. *Access to and Availability of Non-Pharmacological Treatments for Chronic Non-Cancer Pain in Canada: An Environmental Scan*. Ottawa: Canadian Agency for Drugs and Technologies in Health (CADTH); 2018.
64. Bem SL. The measurement of psychological androgyny. *J Consult Clin Psychol*. 1974;42(2):155-162.
65. Fontayne P, Sarrazin P, Famose J-P. The Bem sex-role inventory: validation of a short version for French teenagers. *Eur Rev Appl Psychol/Rev Eur Psychol Appl*. 2000;50(4):405-416.
66. Maruish ME. *User's Manual for the SF-12v2 Health Survey*. 3rd ed. Lincoln, RI: QualityMetric Incorporated; 2012.
67. Kroenke K, Spitzer RL, Williams JB, Lowe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics*. 2009;50(6):613-621.
68. Treede RD, Rief W, Barke A, et al. A classification of chronic pain for ICD-11. *Pain*. 2015;156(6):1003-1007.

How to cite this article: Lacasse A, Gagnon V, Nguena Ngueфack HL, et al. Chronic pain patients' willingness to share personal identifiers on the web for the linkage of medico-administrative claims and patient-reported data: The chronic pain treatment cohort. *Pharmacoepidemiol Drug Saf*. 2021;30:1012–1026. https://doi.org/10.1002/pds.5255