Appendix 1. Detailed Methods for Ipsos Survey

Clinical Trials Ontario (CTO) and the British Columbia Clinical Research Infrastructure Network (BCCRIN) developed the survey and contracted with Ipsos Canada to administer the survey. The survey was administered electronically. Target sample size was 1600 panelists—800 in British Columbia and 800 in Ontario. The results were de-identified by Ipsos and provided to the research team to be analyzed.

Sampling frame

Ipsos used a panel of online survey participants drawn from registered users of the i-Say online survey rewards community. https://i-say.com/ Users registered with the i-Say panel did so externally to this research study. Users of this website have agreed to the terms and conditions set out in the i-Say privacy policy, available at: https://www.i-say.com/Footerlinks/PrivacyPolicy/tabid/282/language/en-CA/Default.aspx

Ipsos carries out recruitment of its panelists through a combination of:

- Various wide net methods (e.g., email campaigns, affiliate networks, banner ads, text ads, search engine, co-registration, offline-to-online, specialized websites)
- Referrals from past or present panel members
- The Ipsos iSay website
- Customized incentives and materials for recruiting special targets such as mothers of babies, age group 55+, etc.

Moreover, Ipsos continuously tests new recruitment sources and methods (specialized websites, social networks, etc.).

Sampling of panelists was carried out via a proprietary sampling application that allows Ipsos to construct complex samples based on the target and screening requirements. The software selects potential respondents that balance according to the targets (i.e., selected to be representative of the general population).

The simulation of a representative sample involves a proprietary process using the following elements:

- Name
- Gender
- Birth year
- State/Province/Region
- Zip/Postal code
- Email
- Education level
- Employment status
- Occupation
- Sector of activity
- Annual Household income
- Household size
- Internet usage
- Age and gender of other household members

The software uses an interactive selection algorithm that balances one variable at a time in order of priority, as follows:

- The first step is to extract all active and available panelists that meet the screening criteria (e.g., demographic, geographic)
- The sample pool is randomly sorted
- The algorithm then examines the first (primary) variable and selects the number of panelists who satisfy each target. (Sometimes, there may not be enough available sample to fill all cells and since some variables are more important than others, lower priority variables may not balance precisely.)
- Finally, the sample may be distributed and balanced among more than one cell so that different treatments or surveys may be fielded in equal balanced groups or cells.

Inclusion Criteria:

- Must reside in Ontario or British Columbia
- 18 years of age or older

Exclusion Criteria:

- Ipsos clients, competitors and employees
- People who work in advertising or market research
- Panelists with email domains from “5 minute mail” providers (websites that generate email addresses that are available only for a few minutes or only for a limited number of messages received).
- Panelists who have received more than three survey invitations in any single week in North America

Survey Administration

The sample was deployed in batches. This was controlled by the email application used in the management of the panel mail-outs. The mail-out tool allowed automatic mailing at a predefined time/day and by batches.

Quotas were set based on age, region (and sub regions within the respective provinces) and gender based proportionately on census data for the two provinces. Some flex may have been granted in an effort to obtain the total number of desired completes. In which case, weighting may have been applied to ensure the data reflects the general population of the two provinces.

During the quotas' open period only, should a respondent click the link and the quota was full, they instantaneously were redirected to another Ipsos survey. So, for example, a 65 year old female in BC would be instantaneously sent to another survey if the quota for this age, region and gender was closed. Ipsos does not count these redirects as part of the sample approached, as they are counted in the subsequent study. The respondent in the above example would not have made it at all to the study introduction, only the screening questions which are the triggers to continue or redirect.
Each potential participant received an email inviting them to complete the survey. Potential participants have the option to participate and complete the survey or decline.

Compensation

All panelists receive incentives to participate in Ipsos surveys. Ipsos uses a point system to incentivize panelists, along with sweepstakes draws. Points systems are recognized as being the best in class in online market research, as they are seen as a neutral system which does not skew the participation of specific groups of people. From time to time, Ipsos strengthens the incentive policy by adding prize draws or other incentives.

Incentive points are allocated depending on the questionnaire length. Panelists who don’t qualify for a survey (i.e., are screened out after the screening questions) receive a small number of points for their willingness to participate. Accumulated points can be redeemed on the dedicated panelists’ website for a variety of rewards.

Consent and Opt-In to be a Survey Panelist

There was no written consent incorporated into this particular study. Potential participants received an email with a link to the survey. Each potential participant could choose to complete the survey or deny/ignore the survey request. The survey also contained the following consent information:

‘Taking part in this survey is entirely up to you. You have the right to refuse to participate in this survey. If you decide to take part, you may choose to pull out of the survey at any time without giving a reason and without any negative impact on your participation in other surveys. This survey is completely anonymous, and no information that identifies you, such as your name or email address, will be linked with any study records.’

Users who register to the i-Say panel do so externally to this research study. This registration process uses a “double opt-in” process for all panelists. Individuals wishing to join the Ipsos i-Say panel first complete the online recruitment survey, and accept the terms and conditions of membership. The panelists are informed that Ipsos agrees to keep all personal information regarding its panelists confidential (their habits, preferences, personal addresses, etc.), and that this information is used only for Ipsos research. Likewise, panelists are requested to adhere to rules regarding the confidentiality of Ipsos surveys. Agreement to these terms and conditions provides the first “opt-in” to panel membership.

Once the recruitment questionnaire is completed, panelists receive an e-mail and are required to click on a link to confirm they would like to participate in panel membership. This constitutes the second “opt-in.”

Upon completion of the recruitment questionnaire, a subsequent series of short profiling questionnaires are made available to panelists so that we may gather additional information like: pet ownership, car ownership, internet usage, household equipment, etc. This information is for Ipsos use only and is not included in the data collection for this study under review.

Finally, i-Say panelists are emailed a welcome note that indicates their information has been received and they will be receiving their first survey in a few days. The panelists are also informed of their website username and password, and at the same time provided with information about the dedicated hotline where they can send any queries.

Individuals can view the Ipsos Privacy Policy at the time of panel registration. As well, the introduction to our standard survey invitation includes a link to the policy, and reminds panelists that we hold all information provided to us in the strictest of confidence.

Data cleaning

Speeders – i.e. respondents who complete a survey much more quickly than would be expected – are filtered out/terminated before the data set is compiled and are not counted as a complete. Respondents fitting this description are cleaned out during the data collection phase and not the data processing phase.

In a similar fashion, before a respondent reaches the end of the survey, Ipsos cleans out straightliners. Straightliners are those who choose only one response throughout the survey. Normally the two (speeders and straightliners) are one in the same.

The data processing team scans for outliers, the coding team scans for profanity and offensive and non-related content (e.g. talking about peanut butter if the survey is about medical topics). The coding team does allow for blank statements (if the program allows) or gobbledygook such as “asdf” and such if the programming does not provide for a “Prefer not to say” or “Don’t know/Unsure” option.

Data analysis

The research team conducted descriptive statistics of the survey findings and basic cross-tabulations by province, respondent sex, age group, and similar demographics.

Ipsos calculated the confidence intervals for each province interviewed (i.e. n=800 for each of British Columbia and Ontario). The precision of Ipsos online surveys is measured using a Bayesian credibility interval. In this case, the survey was accurate to within $\pm 4.0$ percentage points, 19 times out of 20, had the entire population of British Columbia and Ontario been polled.

Weighting was applied and its impact was zero on the majority of results and at most results shifted by 1% (including <1% rounded up). For illustrative purposes only: if “55% of respondents are aware” unweighted, the result may have changed to either 54% or 56% due to weighting.

Appendix 2. Public Survey re: Perceptions of Clinical Trials

Study Purpose

The purpose of this survey is to better understand the attitudes of the public regarding clinical trials.
Clinical trials are a type of research designed to answer questions about how well medicines or other treatments work by looking at their effects in people. They usually compare a new treatment with either the “tried-and-true” treatment or with a placebo, which doesn’t have any medicine or active ingredients. Clinical trials test many types of treatments such as drugs, devices (e.g. a pacemaker) or lifestyle practices (e.g. diet or exercise).

We want to learn what people see to be the benefits and risks of participating in a clinical trial and their willingness to participate in a clinical trial. We also wish to learn what are the characteristics of people who would and would not be interested in participating in a clinical trial.

Consent Information

Taking part in this survey is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to stop answering the survey at any time without giving a reason and without any negative impact on your participation in other surveys. This survey is completely anonymous, and no information that identifies you, such as your name or email address, will be linked with any other study records.

Questions

1. Have you or someone close to you, ever been invited to participate in a clinical trial? (Someone close means spouse, parent, child, or close friend or relative.)
   - No
   - Yes (check as many as apply)
     - I have [If checked, provide question at end inviting respondent to participate in the Clinical Trial Participation Survey.]
     - Someone close to me has
   - Unsure
   - Prefer not to answer

2. Overall, how would you rate your general knowledge of clinical trials?
   - Very informed
   - Somewhat informed
   - Not very informed
   - Not at all informed

3. a) Overall, would you say your views about clinical trials are:
   - Very positive
   - Somewhat positive
   - Neither positive or negative
   - Somewhat negative
   - Very negative

   b) Please explain your answer. [free response]

4. In your opinion, how safe are clinical trials?
   - Very safe
   - Somewhat safe
   - Not very safe
   - Not at all safe

5. Which of the following do you consider to be the risks of participating in a clinical trial?
   - Possibility of side effects
   - Possibility of receiving a placebo or inactive drug (sugar pill)
   - Possible disclosure of my private medical information
   - Possible risks to my overall health.
   - Other – (specify)
   - None – I do not believe there are risks.

6. Which of the following do you consider to be the benefits of clinical trials to society:
   - May help advance science
   - May improve our health care system
   - May help or save improve the lives of patients
   - Other: (specify)
   - None - I do not believe there are any benefits.

7. Which of the following do you consider to be the personal benefits of participating in a clinical trial?
   - May help improve my disease/condition
   - May provide money for participation
   - May provide free medication
   - May provide free medical procedures and care
   - May provide more time and attention with medical experts
   - May help my family understand an inherited disease/condition
   - May provide the satisfaction of helping others
   - Other: (specify)
   - None - I do not believe there are any benefits

8. Please review the following statements about clinical trials and respond according to your views.

| Statement | SA | A | N | D | SD |
|-----------|----|---|---|---|----|
| People who participate in clinical trials: |
| • ... have access to the best doctors |
| • ... get the best and latest treatments that they would not get if they did not join the clinical trial. |
| • ... are treated like experimental test subjects, not people. |
| • ... learn more about their health condition |
| • ... make an important contribution to science |
| • ... are taking a gamble with their health |
| • ... receive more time and attention from doctors and their staff. |
9. If given the opportunity, how willing would you be to participate in a clinical trial?
- [ ] very willing
- [ ] somewhat willing
- [ ] not very willing
- [ ] not at all willing
- [ ] I am not sure

10. How important are each of the following factors in making your decision whether or not to participate in a clinical trial. Please rate your response on a scale of 1 to 5, where 1 is “not at all important” and 5 is “very important”

| Statement | 1 | 2 | 3 | 4 | 5 |
|-----------|---|---|---|---|---|
| If I had a terminal illness | | | | | |
| If I thought a study treatment might cure me | | | | | |
| If I knew that I would receive an active drug and not an inactive substance or sugar pill (placebo) | | | | | |
| If I received money for participating | | | | | |
| My doctor’s opinion about the trial | | | | | |
| If the treatment were free of charge to me | | | | | |
| If I thought the treatment would help me | | | | | |
| If I had a chronic illness | | | | | |
| If there were no other medical options available to me | | | | | |
| The side effects associated with the treatment | | | | | |
| If I thought the treatment would help someone else in the future | | | | | |
| If I knew someone else who had a good experience participating in a clinical trial | | | | | |
| The opinion of my family or close friends | | | | | |
| Opinions posted on an online social network or disease forum | | | | | |
| The time commitment | | | | | |
| How far I had to travel | | | | | |
| If child care was available | | | | | |

11. If you were thinking about participating in a clinical trial where would you turn for information? Choose as many as you feel appropriate.
- [ ] My family doctor
- [ ] My specialist doctor
- [ ] Other healthcare professional, e.g. nurse, physiotherapist etc.
- [ ] Friends and family
- [ ] Disease networks or charitable organizations
- [ ] Patient advocacy group
- [ ] Media, e.g. newspaper, radio, television
- [ ] The internet
- [ ] Social media. Click all that apply
  - [ ] Facebook
  - [ ] Twitter
  - [ ] YouTube
  - [ ] MySpace
  - [ ] Flickr
  - [ ] Message boards and other forums
  - [ ] Others (specify)
  - [ ] Nowhere
  - [ ] Not sure
  - [ ] Other, please specify.

12. Demographics

We would like to ask a few questions about you, so we can see how people’s answers may differ by things like age, sex, education, etc.

a) How old are you?
- [ ] 18 to 24 years old
- [ ] 25 to 34 years old
- [ ] 35 to 49 years old
- [ ] 50 to 64 years old
- [ ] 65 to 74 years old
- [ ] 75 years or older

b) What is your gender or gender identity:
- [ ] Prefer not to answer
- [ ] Male
- [ ] Female
- [ ] Other _______________

c) What is the highest level of education you have completed?
- [ ] Did not complete high school
- [ ] High school diploma
- [ ] Some university or community college (College Classique, CEGEP), trade, technical school
- [ ] College Diploma or University degree
- [ ] Graduate degree
- [ ] graduate school or professional degree (Law, Medicine, Dentistry)
- [ ] Post Graduate degree
- [ ] other ____________________
d) Which best describes your current work or main activity?
   □ working at a full-time job
   □ working at a part time job
   □ self-employed
   □ looking for work, in between jobs
   □ on maternity / paternity leave
   □ on long-term disability
   □ homemaking/caregiving
   □ going to school
   □ retired

e) We are interested in learning if people’s views are different in different parts of the country. Would you be willing to share with us the first three digits of your postal code? That will give us enough information about where you live without identifying you.

f) How would you describe your health?
   □ Excellent
   □ Good
   □ Fair
   □ Poor
   □ Very poor

g) Do you currently have any chronic health conditions?
   □ No
   □ Yes
      □ one
      □ two
      □ three or more

h) Have you ever had a life-threatening illness?
   □ No
   □ Yes

What best describes your ethnic background?
   □ Prefer not to answer
   □ White / Caucasian
   □ Asian
   □ South Asian
   □ Black
   □ Arab / West Asian
   □ First Nations / Aboriginal
   □ Filipino
   □ Latin American

What is your household income?
   □ Prefer not to answer
   □ < $15,000
   □ $15,000 to $29,999
   □ $30,000 to $49,000
   □ $50,000 to $74,999
   □ $75,000 to $100,000
   □ >$100,000

Thank you for taking the time to do this survey. The information you have provided will be used to help organizations like the BC Clinical Research Infrastructure Network (BCCRIN) and Clinical Trials Ontario (CTO) to develop materials and programs for patients and the public to better describe clinical trials and how they might become involved in research. The results of the survey will be published on their websites and presented at meetings. You will not be identified in any way. Any comments you have made in the survey are anonymous.

For more information on BCCRIN please visit www.bccrin.ca. For more information on CTO please visit www.ctontario.ca