



**badgut.org**  
Gastrointestinal Society  
Canadian Society of Intestinal Research

# Clinical Trials SURVEY RESULTS

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March 2023 // **Gastrointestinal Society**

## Background

Clinical trials are a vital step in the development of new treatments, and they contribute to a well-balanced, effective healthcare. Without clinical trials, we would never be able to adequately test new treatments, including medicines, supplements, devices, dietary modifications, behavioural and psychological therapies, various procedures, and more. No testing means no new medications could be released, so our ability to treat diseases would remain stagnant.

In a clinical trial, researchers take a treatment that has already been analyzed in other ways (e.g., lab testing, animal testing), and test it on volunteers to determine if it is safe and effective. These volunteers typically need to be diagnosed with a particular condition that the treatment is likely to help, and sometimes they also need to fit other demographic categories (e.g., age, sex, disease subtype, etc.). Many clinical trials separate volunteers into groups to test the effectiveness of the treatment against an inactive treatment (placebo), or treatments that patients currently take for comparison purposes. This means that some individuals will receive the treatment under study, some might stay on their existing medication, while others might receive a placebo. It is common for the participant and the researcher to not know during the trial which group the person is assigned to (double blind). Clinical trial design can take different approaches to determine how a medication is used best, which are complex.

We were interested to learn how the average person feels about clinical trials. This includes what questions people had about participating in clinical trials, what factors made them consider participating or not participating, their general feelings on the topic, and more.

## Methods

We hosted a survey on our websites and social media, in English and French, from October 2022 to January 2023, asking adults who live in Canada what their opinions are on clinical trials. This survey was shared by our colleagues in other patient groups so we could cover a wide range of therapeutic areas. In total, 1,093 respondents answered some questions, while 815 completed the survey.

## Results

### Demographics

Most respondents were female (83%) and aged 55-64 (29%), 65-74 (40%), or 75-84 years (17%). Ontario (43%), British Columbia (19%), and Alberta (11%) were the most represented provinces, with all other provinces and

territories, except Nunavut, comprising the remaining 27%.

We were interested in two streams of experience: individuals who had participated in one or more clinical trial and individuals who had not participated in a clinical trial. In our survey, 18% of respondents had participated in a trial and the remaining 82% had not.

### Never Participated in a Trial

Of the respondents who had not participated in a trial, 8% indicated that they attempted to join a clinical trial but did not qualify. There are many reasons why an individual could be disqualified from a clinical trial, including demographics, having other diseases, having disease that is too severe or not severe enough, etc.

While these individuals had never participated in a clinical trial, many were interested in the idea. In fact, 34% said they would participate in a clinical trial and 58% said that they might. Only 8% indicated that they would not participate in a clinical trial.

We asked participants which factors would make them more likely to participate in a clinical trial and which would make them wary. Respondents were most interested in clinical trials:

- to receive the latest medical care (46%)
- that were nearby (39%)
- that provided adequate support (36%)
- to gain access to specialists (32%)
- to help advance science (29%)

The factors that made respondents hesitant to participate in trials include potential side effects and risks (66%), location (65%), and not enough information (56%). Consistent with a previous question, 8% of respondents would not participate in a clinical trial for any reason.

### Participated in One or More Trials

Of the 18% of respondents who had participated in a clinical trial, 68% had participated in 1 trial, 28% participated in 2-5 trials, and 4% participated in 6 or more. In addition, not everyone completed the clinical trial they participated in, with 7% dropping out before the trial was finished. Reasons for dropping out included side effects or concerns about side effects, feeling unwell, and the trial being in an inconvenient location.

58% initially heard about the clinical trial from a healthcare provider, 26% from social media, and 13% from print media. Respondents generally got most of their information about the clinical trial from their primary source, with only 20% consulting other sources of

information, mostly the internet, to learn more.

Overall, respondents seemed to feel quite positive about their experiences, as 72% said they would participate in another trial, 27% said they might, and only one respondent would not participate in another clinical trial. In addition, 48% feel more knowledgeable about their disease after participating in a trial, with another 22% indicating that they might be more knowledgeable. However, 42% do not believe that the clinical trial improved their access to medical care, compared with 29% who said it did improve their access to care and 28% who indicated that it might have.

They had a variety of reasons for choosing to participate in trials, the most common being to advance medical science (58%), because it was in a convenient location (58%), and to receive the latest medical care (27%).

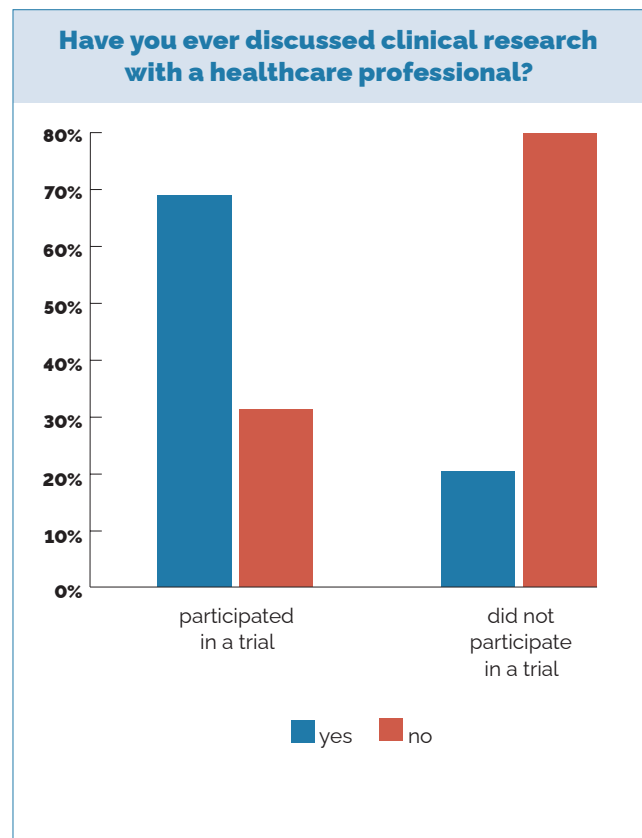
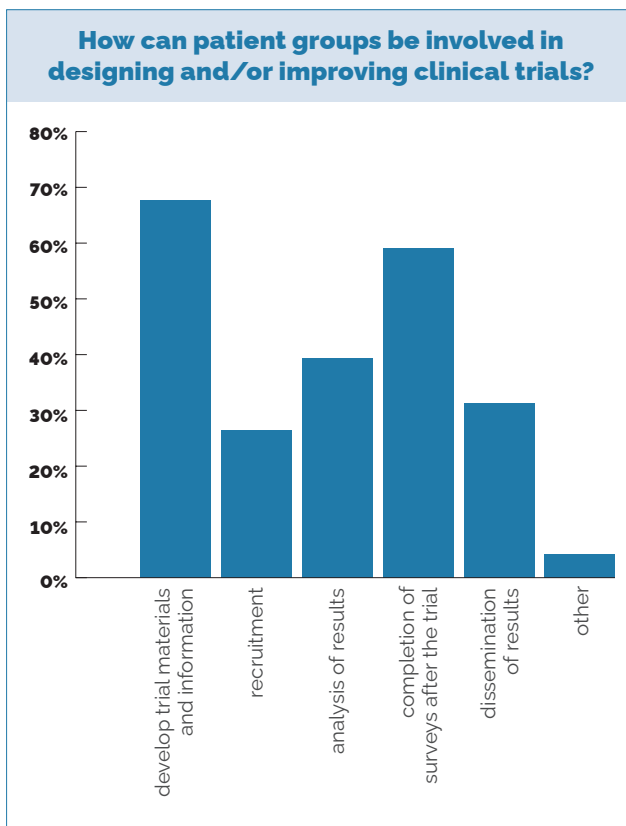
### Understanding Clinical Trials

Predictably, those who had participated in a trial were more familiar with how clinical trials work, with 34% being very familiar and 56% being somewhat familiar, compared with 8% who were very familiar and 44% who were

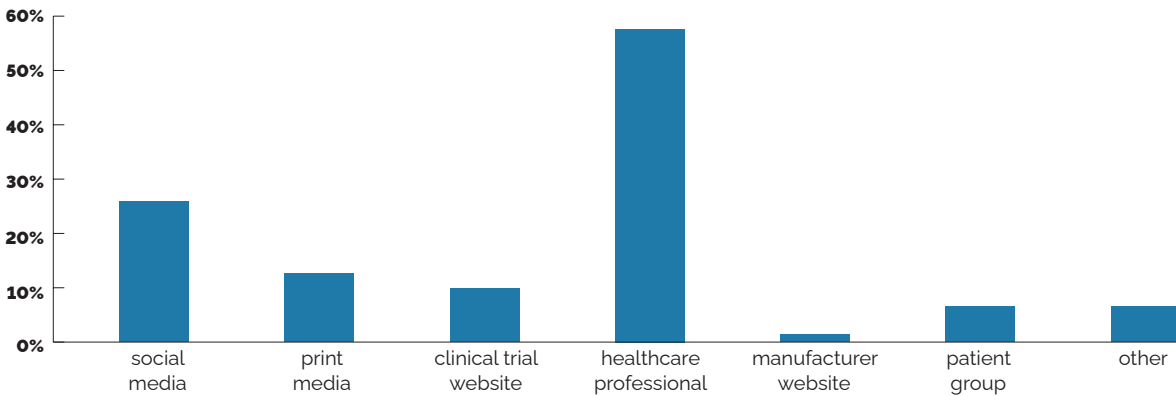
somewhat familiar in the group who hadn't participated in a trial. In addition, only 9% of those who had participated in a trial were not very familiar and 1% were not at all familiar with how clinical trials work, compared to 31% and 17% respectively in the other group.

Previous trial participants were also more likely to have discussed clinical research with a healthcare professional (69% vs 20%). However, many respondents from both groups (57% of trial participants and 47% of the others) thought that their healthcare providers should bring up clinical trials as an option at the beginning of treatment, when mentioning other available treatments. A further 24% of those who had been in a trial, and 33% of those who had not, thought their physician should introduce the idea as an alternative to surgery if initial treatments were ineffective.

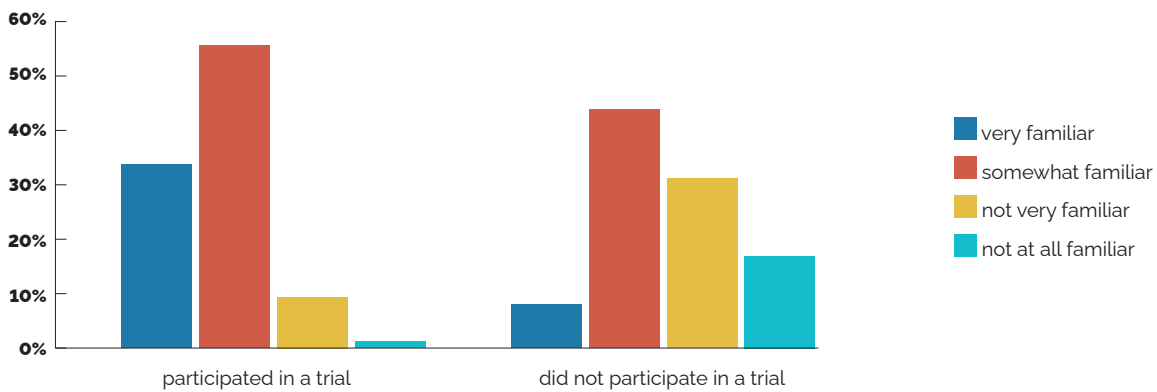
When it came to how they would like to receive information about clinical trials, 45% chose online/digital materials, 42% chose online/digital as well as print, and only 13% wanted just print materials. Participants also wanted to know the results once a trial is over, with 90% of respondents being very interested and 7% moderately interested in having access to this data.



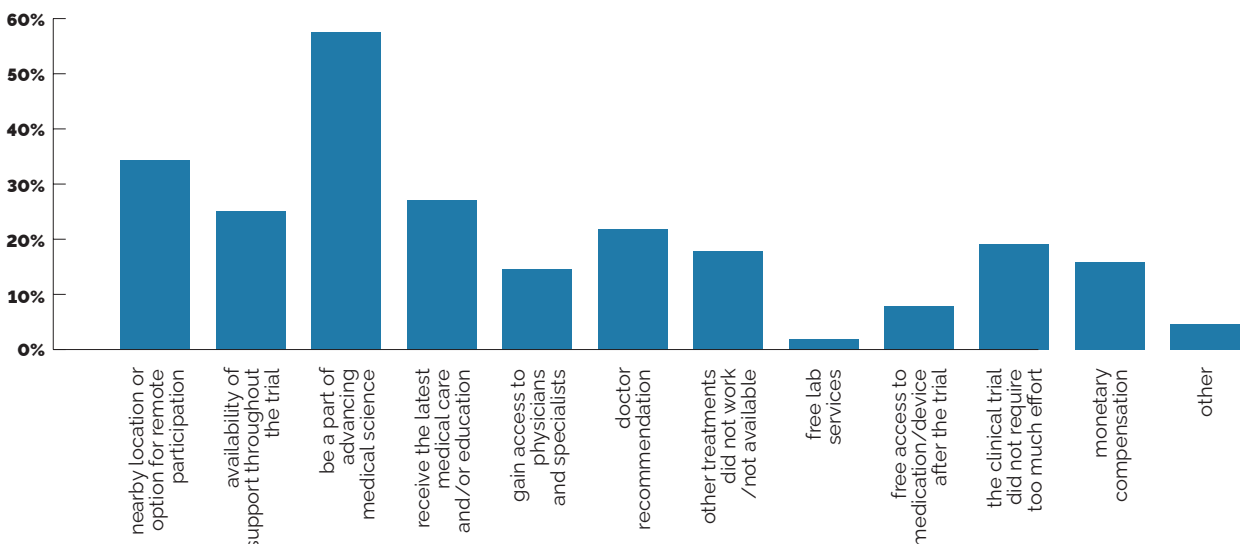
How did you hear about the clinical trial(s)?



How familiar are you with how clinical trials work?



Which of these factors influenced your decision to participate in a clinical trial? (CHOOSE UP TO 3)



An important area for consideration is which resources and information participants think is important for clinical trials to provide. This list shows the respondents' preferences from most to least votes:

- explanation of clinical study and research, risks and benefits, and number of visits required (90%)
- follow up and care after the trial (71%)
- ability to use local labs for testing and visiting nurses if trial sites are far from home (68%)
- reimbursements for out-of-pocket medical expenses associated with participation (65%)
- professionalism and availability of clinical trial staff (64%)
- ability to use virtual appointments when applicable (63%)
- privacy and confidentiality (61%)
- ability to take the new treatment after the trial, even if I received a placebo (58%)
- availability of home visits, ambulance, and transportation services if I feel too sick during the trial (48%)
- monetary compensation (25%)

### Patient Group Involvement in the Trial

We also wanted to know how we can better serve the community, so we asked how patient groups should be involved with designing and/or improving clinical trials. 68% of respondents thought patient groups could develop trial materials and information so that they are easier to understand, 59% thought patient groups could complete surveys after the trial, 39% thought they could analyse

results, 31% disseminate results, and 26% thought patient groups could be involved with recruiting participants.

### Conclusions

Most respondents feel positively about clinical trials and the potential for new, more effective treatment options that they bring. Both those who had participated in a trial and those who had not considered location an important factor, so making clinical trials accessible to patients living outside of major city centres could bring many more interested participants. There is also opportunity for healthcare professionals to speak with their patients about clinical trials more often, as some patients would prefer having the option to participate in them earlier on in their diagnosis.

### Please Note

We have rounded percentages to the nearest whole number.

Thank you to Dr. Jesse Siffledeen, gastroenterologist, Edmonton, and Dr. James Gray, gastroenterologist, Vancouver, for their guidance on this survey. We received an educational grant from Bristol Myers Squibb to conduct this survey. Survey participants had the option to enter a draw for one of three \$100 Amazon gift cards.

The Gastrointestinal Society does not intend that this report replace the knowledge or diagnosis of your physician or healthcare team, and we recommend seeking advice from a medical professional whenever a health problem arises.

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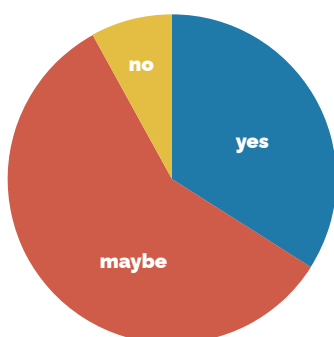
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### If you haven't already, are you interested in participating in a clinical trial ?





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