

Survey about information on ClinicalTrials.gov

The National Library of Medicine (NLM) is working with Health Literacy Media (HLM), a Missouri-based nonprofit organization, to improve the information about clinical trials on the ClinicalTrials.gov website.

We're asking you to complete this survey to share your thoughts and opinions about what information related to clinical trials would be most helpful to you. This survey will take about 15 minutes to complete.

Please answer honestly – there are no right or wrong answers.

You are not required to answer any question. All of your responses will be kept private and won't be linked to you. HLM will analyze all data collected and report only overall, group findings.

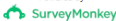
Please share this link to this survey to others who you think may be interested in helping improve ClinicalTrials.gov:
<https://www.surveymonkey.com/r/RRY5DQ2>

Thank you!

OMB Control Number: 0925-0648
Expiration date: 06/31/2021

Public reporting burden for this collection of information is estimated to average 18 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a current valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to NIH Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0648). Do not return the completed form to this address.

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Survey page 2

Clinical Trials

First, we'll ask you a few general questions about clinical trials.

1. Please tell us how strongly you disagree or agree with the following statement: I know what a clinical trial is.

- Strongly disagree
- Disagree
- Agree
- Strongly agree

2. In your own words, please describe a clinical trial?

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Clinical Trials

3. For this survey, we define a clinical trial as: A type of study in which a researcher gives people a medical product or treatment based on a research plan to learn more about ways to treat or detect health problems. Researchers may design clinical trials to compare a new medical product or treatment to an existing one or nothing at all.

Have you ever participated in a clinical trial as a researcher or a participant? (Please select all that apply)

- Yes, as a participant
- Yes, as a researcher
- No
- I don't know

4. Please tell us how strongly you disagree or agree with the following statement: I have used the results of clinical trials to make health decisions for myself or someone else, such as a family member or friend.

- Strongly disagree
- Disagree
- Agree
- Strongly agree

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Now, we'll ask you a few questions about information and sources of information about clinical trials.

5. If you wanted to learn more about clinical trials, who would you want to get information from and where would you look for it? (Select all that apply)

- Doctor
- Medical researcher
- Nurse or other health care professional
- Public health department
- Library
- Family member
- Friend
- Google or other search engine
- Facebook
- Twitter
- LinkedIn

Are there any other sources of information, such as specific websites? If so, please provide the names or web links below.

6. Below is a list of the parts of a summary of a clinical trial. Please indicate how important learning about each part is to you based on what you'd want to know about a clinical trial.

	Not important	Somewhat important	Important	Very important
Who leads a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who funds a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What happens during a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who can take part in a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where a clinical trial takes place	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to learn more about a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Now, please tell us how important each of the following aspects of the categories from the previous question are to you.

7. When you consider who leads and funds a clinical trial, how important are each of the following to you?

	Not important	Somewhat important	Important	Very important
The main sponsor or funder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any other funders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Partners involved in the clinical trial (e.g. medical, research, or logistical support partners)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who provides information about the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. When you consider what happens during a clinical trial, how important are each of the following to you?

	Not important	Somewhat important	Important	Very important
The treatment or medical product being studied (also called interventions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A brief general description of the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Design of the clinical trial (the methodology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The groups of participants in the clinical trial that researchers will compare (also called arms)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What the researchers will measure about participants' health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What happens if participants report any health problems during the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The results of the clinical trial after it has ended	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. When you consider who can take part in a clinical trial and where it takes place, how important are each of the following to you?

	Not important	Somewhat important	Important	Very important
Who can and can't join a clinical trial (also called eligibility or inclusion and exclusion criteria)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where the clinical trial takes place (locations)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about who monitors a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about how participants are protected	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. When you consider how to learn more about a clinical trial, how important are each of the following to you?

	Not important	Somewhat important	Important	Very important
How to contact someone for more information about participating in the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where people could send complaints about the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where people could send questions about the clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to get complete reports about a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to get easy-to-read summary reports about a clinical trial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>


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Clinical Trials

11. Below are frequently asked questions about **how researchers design clinical trials**. Please indicate how important learning about each topic is to you based on what you'd want to know about a clinical trial.

	Not important	Somewhat important	Important	Very Important
What is a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How do researchers design clinical trials?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Why are clinical trials done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How do new drugs get approved?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What does a randomized clinical trial mean?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Why do researchers use randomized clinical trials?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who carries out clinical trials?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where do clinical trials take place?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How long do clinical trials last?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How are clinical trials different from health care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Clinical Trials

12. Below are frequently asked questions about **taking part in clinical trials**. Please indicate how important learning about each topic is to you based on what you'd want to know about a clinical trial.

	Not important	Somewhat important	Important	Very Important
What will I be asked to do if I join a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How are people who join clinical trials protected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What things should I think about when choosing to join a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What does it cost to be in a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Will participants be paid or compensated for participating in a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I take part in a clinical trial, how do researchers decide what product or treatment I'll get?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Why should I take part in a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How do I find out the results of clinical trials?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What is informed consent and why is it done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What happens if someone wants to stop after joining a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How is my privacy protected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What happens if something goes wrong during a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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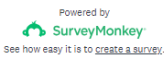
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Clinical Trials

13. Below are frequently asked questions about **finding a clinical trial to join**. Please answer each question carefully. Please indicate how important learning about each topic is to you based on what you'd want to know about a clinical trial.

	Not important	Somewhat important	Important	Very important
Who can join a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How do I join a clinical trial?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How can I find clinical trials that I can join?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does my doctor know about clinical trials for me?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Clinical Trials

14. What other questions related to clinical trials are important to you?

15. What format would you like to get information about clinical trials to answer the previous questions? (Select all that apply).

- Video
- Written text
- Graphics and visuals
- Audio

Other (please explain)


Next

Now, we'll ask you a few questions about the website, ClinicalTrials.gov.

* 16. Have you ever heard of ClinicalTrials.gov?

- Yes
- No
- Don't know

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Skip Logic: Survey page 11a (if "yes" answer to Q16)



* 17. How often do you visit ClinicalTrials.gov?

- Never
- Less than once a month
- At least once a month
- At least weekly
- Every day

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Skip Logic: Survey page 11b (if "no" or "Don't know" answer to Q16)

ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world. The U.S. National Library of Medicine created ClinicalTrials.gov to provide patients, family members, and members of the public current information about clinical research studies.



17. If you decided to visit ClinicalTrials.gov, what tasks would you be most interested in? (Select all that apply)

- Search the database of clinical trials to learn what scientists discovered
- Search the database of clinical trials to find a trial for me or a family member to join as a participant
- Submit a study to be listed in the database
- Use the database of clinical trials to research a specific topic
- Learn more about clinical trials in general

Other (please specify)

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Skip Logic: Survey page 12a (if "yes" answer to Q16 and visited to Q17)



18. How often do you visit these parts of ClinicalTrials.gov?

	Never	Less than once a month	At least once a month	At least weekly	Every day
The studies listed on the website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General information about studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The pages on how to submit a study to the website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The collection of resources, such as selected publications by ClinicalTrials.gov staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information about the website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



19. Which of these devices do you prefer to use to visit ClinicalTrials.gov?

	Never	Sometimes	Often	Always
Mobile phone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tablet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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* 20. What tasks are you most likely to do on ClinicalTrials.gov? (Select all that apply)

- Search the database of clinical trials to learn what researchers discovered
- Search the database of clinical trials to find a trial for me or someone else to join as a participant
- Submit a study to be listed in the database
- Use the database of clinical trials to research a specific topic
- Learn more about clinical trials in general

Other (please specify)

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Please tell us a little bit about yourself. This will help us analyze the survey. Please remember we will never share individual or identifying information.

19. How often do you search the internet for health information?

- Never
- Rarely
- Sometimes
- Often

20. How comfortable are you at navigating the internet for health information?

- Very comfortable
- Comfortable
- Somewhat comfortable
- Not comfortable

21. With so much information about health on the internet, how do you decide what is good information?

22. How often do you engage in the following tasks?

	Never	Sometimes	Often	Always
Find and look for health information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand information about your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evaluate how health information relates to your life (for example, determine if and how information is relevant to your life)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicate about your health to others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Act on information about your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ask questions of your health care professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Would you say that in general your health is...?

- Excellent
- Very good
- Good
- Fair
- Poor

24. Please tell us your age (in years)

25. Gender:

- Male
- Female
- Other

26. Please tell us your highest level of education.

- Completed grade school
- Completed high school
- Associates degree
- Bachelors degree
- Masters degree
- Ph.D., M.D., D.O., J.D., etc.

27. Which of these best describes your ethnicity (choose one)?

- Hispanic or Latino
- Not Hispanic or Non-Latino

28. Which of these best describes your race (choose one or more)?

- American Indian or Alaska Native
- Asian
- Black of African American
- Native Hawaiian or other Pacific Islander
- White

29. What languages do you speak at home: (Select all that apply)

- English
- Spanish
- Arabic
- Chinese
- French
- German
- Haitian Creole
- Hindi
- Korean
- Russian
- Tagalog
- Vietnamese

Other (please specify)

30. What is your current employment status?

- Full time
- Part time
- Retired
- Unemployed


* 31. Do you have more than one job:


- Yes
- No

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Skip Logic: Survey page 15 (if “yes” answer to Q30)

Clinical Trials

 → 31. Please tell us how many jobs you have

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32. Do you work in a health or medical related field?

Yes

No

33. What is your household income:

Less than \$15,000


\$15,000-\$30,000

\$30,000-\$50,000

\$50,000-\$100,000

More than \$100,000

Prefer not to say


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Clinical Trials

Thank you for taking this survey!

We'll use your contribution to help improve educational information about clinical trials on the website
ClinicalTrials.gov.

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