What Do Clinical Trial Participants Want?

Patient Preferences For Clinical Trial Information

How do you search for information about clinical trials?

43% of patients use a ‘general internet search’

How interested would you be in registering your contact information so you can be informed when a clinical trial becomes available that is appropriate for you?

92% are ‘somewhat’ to ‘very’ interested

If you found a clinical trial appropriate for you (or the person you care for), would you contact the clinical trial location directly?

Patients say:
- Yes: 72%
- No: 28%

Would you discuss clinical trial participation with any of your doctors or healthcare professionals before contacting a clinical trial location directly?

Survey participants say:
- Yes: 56%
- No: 23%
- Not sure: 21%

If you (or the person you care for) decided to participate in a clinical trial, what information would you want before the clinical trial begins?

Patient respondents:
- ‘want their own information (test or lab results)’ 81%
- ‘want to know ‘the activities to expect during their next visit’ 71%

If you (or the person you care for) were to participate in a clinical trial, what information would you want during the clinical trial?

What is important for you to have or know before seriously considering clinical trial participation?

The Top Four desired pieces of information include:
- ‘Knowing the potential risks and benefits of the study’ 81%
- ‘Knowing the number and length of visits to the clinical trial location that would be required’ 67%
- ‘Knowing the medical tests required and/or other activities involved with each visit to the clinical trial location’ 67%
- ‘Knowing that my health and treatment record will be shared with me after my participation in the trial (e.g. my personal results)’ 66%

What would you like to discuss with your doctors or healthcare professionals prior to contacting a clinical trial location directly?

Top discussion points with HCPs:
- 65% risk associated with participation in the clinical trial
- 62% how participation in the clinical trial may benefit their overall health

If you found a clinical trial appropriate for you (or the person you care for), would you contact the clinical trial location directly?

72% Yes
28% No

If you (or the person you care for) decided to participate in a clinical trial, what information would you want before the clinical trial begins?

76% ‘who to contact/contact information of the medical center’

67% ‘what to do in case of an emergency’

If you (or the person you care for) were to participate in a clinical trial, what information would you want after the clinical trial ends?

83% ‘lab/test results’

80% ‘general results of the clinical trial’

71% ‘the name of the drug when approved’

68% ‘whether they received the study drug or placebo’

62% ‘whether the drug will be approved in their country’

Find out more about TransCelerate’s proposals to meet patient preferences for clinical trial information:

Improving Investigative Site Contact Options on Clinical Trial Registries: Making it Easier for Patients to Find Clinical Trials: http://bit.ly/2hLUq3S


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