

Insights Into Patient Attitudes to Clinical Trials **During the COVID-19 Crisis**

A Study and Survey Results



Introduction

Those seeking clinical trials have been traditionally thought of as patients whose treatment failed their expectations for symptom relief. Treatments in development, however, don't have to be a last resort when all else fails and patients have gone through all available options.

Innovation should be accessible to everyone who can benefit from it. This is the reason why the work of <u>FindMeCure</u> and <u>FindMeCure Foundation</u> has been focused on patient advocacy and raising awareness about clinical research among patient communities. Our experience also points out to the fact that when patients become aware of clinical trials as a possibility for them, they are very willing to participate even with the current limitations of traditional clinical trials.



85 %

Patients are unaware of clinical trials at the time of diagnosis.

75%

Of them would have been willing to participate if they knew it was an option, according to the NI¹.

Despite patients' willingness to make weekly protocol visits a part of their schedule, the current health crisis caused by Covid-19 highlighted alternative options for patient engagement. Travelling long distances to get to the trial site as well as the logistics associated with it (taking a leave from work, finding a babysitter and sometimes even accommodation in another city where the site is located) prevent many patients from enrolling or staying enrolled in clinical trials.

¹ https://www.nih.gov/health-information/nih-clinical-research-trials-you/need-awareness-clinical-research

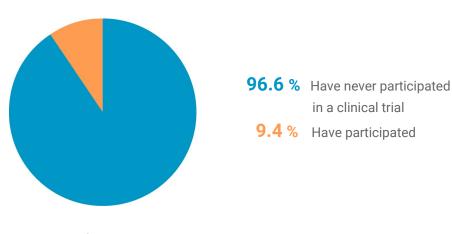
While completely virtual trials are not always an option, leveraging technology to simplify the patient experience and limit the amount of time spent travelling or in a hospital setting can significantly improve recruitment and retention rates.

That being said, in this study we explore patient attitudes to clinical trials particularly as it relates to the current coronavirus pandemic. The views expressed by our respondents do not reflect those of patients worldwide but rather the attitude of people seeking trials in the USA and the UK. It's important to also take into consideration the national epidemiological situation as well as the specific regulations in a given country.

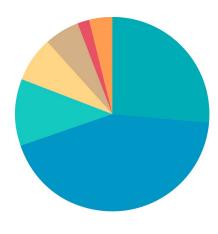
Public attitudes to the pandemic as well as to the measures taken by the government can also impact patients' level of anxiety when it comes to the risk of becoming infected, particularly in a hospital setting.

Methods & Survey Sample

We reached out to the patients who searched for clinical trials through our platform FindMeCure in the last two weeks of April. We wanted to know how they feel about volunteering for a clinical trial in times of pandemic. 54 respondents answered our survey. The majority live in English speaking countries - the USA and the UK.



^{*} Patients from the UK & USA



*Patients from the UK & USA

26.4 % are healthy volunteers

The rest are battling a serious condition:

43.4% live with a chronic condition

11.3% have a life-threatening disease

7.5% suffer from mental illness

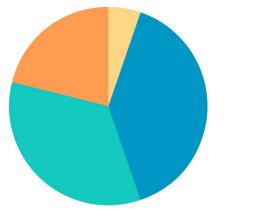
5.7% have a rare disease

1.9% live with a disability

3.8% chose the option 'other

The majority of patients are on 1st line treatment

Very few, 5.3%, are on 3d line treatment. 39.5% are not on any treatment and the second major group 34.2% are on 1st line treatment. 21.1% are trying an additional, 2nd line treatment at the moment of searching for a trial.



5.3 % are on 3d line treatment

39.5% are not on any treatment

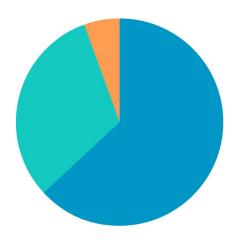
34.2% are on 1st line treatment

21.1% are on 2nd line treatment

*Patients from the UK & USA

Majority of patients seeking trials not satisfied with current treatment

Predictably, the majority of respondents are not satisfied with their current treatment (63.2%), yet 31.6% of people seeking trials report they actually are satisfied with their treatment. (5.3% - chose the option 'other')



*Patients from the UK & USA

63.2 %

Are not satisfied with their current treatment

31.6%

Report they are satisfied with their treatment

5.3%

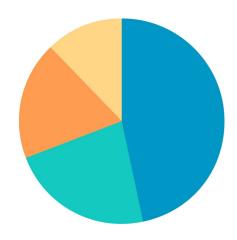
Chose the option "other"



They want to contribute to medicine

The number one reason for participating in a clinical trial - 43.4% want to contribute to medical progress. 20.8% report their treatment doesn't work or has stopped working, 17% cannot afford treatment and 11.3% are looking for a clinical trial hoping for treatment with fewer side effects than their current one.

What is your reason to look for a clinical trial?



*Patients from the UK & USA

43.4 % Want to contribute to medicine

20.8 % Report treatment doesn't work or stopped working

17.0 % Cannot afford treatment

11.3 % Hope for a treatment with fewer side effects



Previous clinical trial experience

The majority (90.6%) have never participated in a clinical trial. Those who have (9.4%) describe their experience as 'beneficial', 'good' as it taught them useful skills, 'great'.

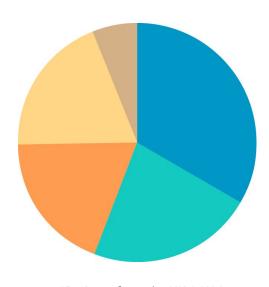


Participating in a clinical trial was very helpful and beneficial to understanding my 'conditions', their ramifications on my lifestyle, and the impact on my extended family who also have asthma.

Many patients belong to risk groups

Most of the respondents belong to various risk groups when it comes to Covid-19. 26.4% are over the age of 60; 22.6% have a long-term medical condition; 22.6% have a weakened immune system. Still, 39.6% don't fall into any risk group - a likely overlap between the healthy volunteers.

Are you in any of the higher risk groups?



*Patients from the UK & USA

39.6 %

No, I am not

26.4%

60 years of age and over

22.6%

I have a long-term medical condition - for example, heart disease, lung disease, diabetes, cancer or high blood pressure

22.6%

I have a weak immune system (immunosuppressed)

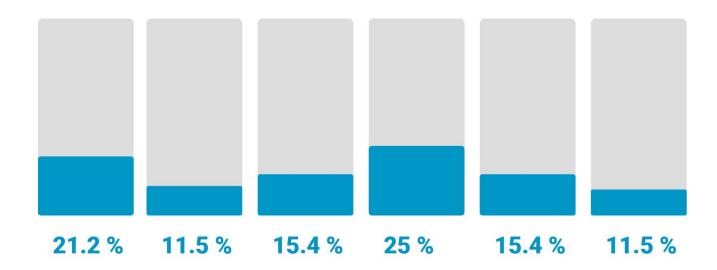
7.5 %

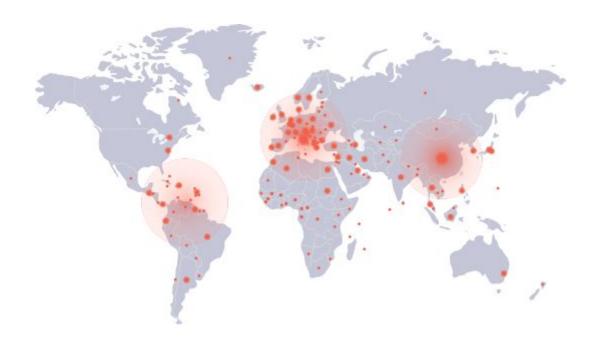
Other

Moderate level of fear of becoming infected

No trend is noticeable in regards to their fear of becoming infected, however, as their responses belong all across the spectrum. Still, a quarter report their fear is 3 out of 5. Few are very afraid of becoming infected with Covid-19 - 11.5% report a 5 out of 5 level of fear relative to the novel virus.

How afraid are you of becoming infected with coronavirus?

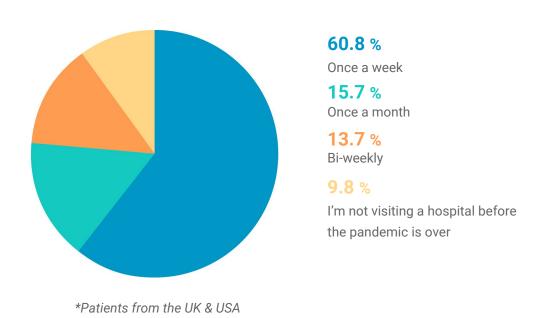




Willing to visit a hospital as part of a clinical trial

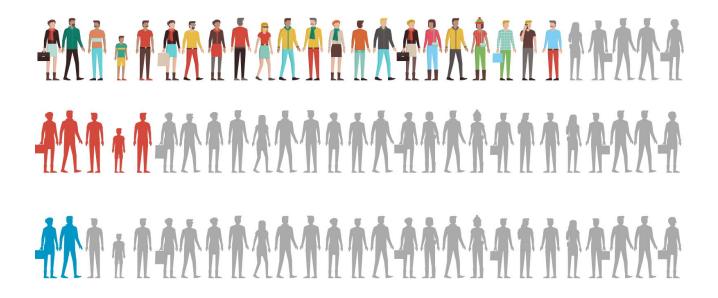
The majority of respondents - 60.8% - are willing to visit a hospital as part of a clinical trial once a week. 15.7% prefer a monthly visit, 13.7% would rather visit a hospital bi-weekly and a small but still significant minority (9.8%) say they're not visiting a hospital before the pandemic is over.

How often would you be willing to visit a doctor in a hospital as part of a clinical trial?



Motivated even if they have to wait

When asked how willing they are to wait for their chosen trial to resume, **80.8% report** they're very motivated to participate even if they have to wait. A significant number, however, need urgent treatment - **15.4%**. A very small percentage are not sure if they will still be interested after a waiting period - **3.8%** of all respondents.



The most common questions patients asked us during quarantine

- Am I immunocompromised if I don't take immunosuppressants for my autoimmune disease?
- What is my risk of becoming infected (I have myasthenia gravis/another autoimmune disease)?
- How can I join a coronavirus study?
- I think I had the coronavirus, is there a study for antibodies? Can I contribute to research in any way?

Healthy volunteers have their stories too

In March, as research was slowing down and study coordinators often responded to applications with uncertainty, we received the following email from a healthy volunteer:

Afternoon,

Thank you for your email

Do you have any idea when medical trials might start up again? Or any coronavirus medical trials that might be starting up soon?

My partner has a blood and bone cancer so is having to self isolate for 3 months. This is hard as I am having to stay apart from her, so if i can do anything to help then this self isolation can only be of benefit.

Kindest regards, Michael

What does this mean for clinical trials?

Aware patients are motivated patients. The more well informed they are about clinical research and the easier it is for them to search and apply for a trial - the more likely they are to seek trials not as a last resort but as an improvement on their current treatment. This is what years of experience in patient recruitment have confirmed time and time again.

In terms of how patients respond to the Covid-19 pandemic, this observation rings true as well. Better informed patients make better decisions for their health and feel empowered to search for alternative options earlier on.

Not only do our respondents report being highly motivated to participate in clinical trials but they also report high levels of altruistic motivation to do so. This can be tied to findings from other patient surveys that show sudden illness, especially chronic, can make patients seek meaning through contribution to a bigger cause.

Insights Into Patient Attitudes to Clinical Trials During the COVID-19 Crisis

Patients' willingness to wait for their chosen trial to resume is also reflected in their communication with us when, having applied for a trial through our search platform FindMeCure.

they receive a response from the coordinator that the trial has been Suspended. Commonly, patients remain interested and express a desire to eventually be contacted again when recruitment resumes.

These attitudes lead us to believe that our previous assumptions about patients being anxious to visit sites even after quarantine is over were at least partially incorrect. Although at the beginning of the pandemic, patients living with chronic illness showed high levels of anxiety, this slowly turned into a downwards trend as the situation progressed.











Whether the subsiding fear of becoming infected is due to the phenomenon of 'disaster fatigue' (becoming tired of bad news and subsequently caring less about the 'disaster') or due to a feeling of confidence in the way governments respond to the crisis is worth examining. Nevertheless, both the results of our survey and our own observations and data on patient behaviour on our website FindMeCure point out to lower levels of anxiety compared to the beginning of the pandemic.

Outside the realm of speculations, the real challenge to patient recruitment (and retention) is not a lack of motivated patients. And in light of the current crisis, it's not patient anxiety either.

This is why TrialHub was created as an all-in-one feasibility platform for clinical trials. A successful patient recruitment and retention strategy begins as early as the planning stage of a study. To make innovative treatments accessible to more patients and to accelerate timelines, TrialHub helps feasibility teams play out different scenarios and take into account multiple factors.



About FindMeCure and TrialHub

The Bridge Between Patients and Clinical Trials

FindMeCure is a TA-agnostic platform allowing patients and caregivers to volunteer for clinical trials and engage with sites. This allows sponsors to provide excellent support to volunteers for their clinical trial while boosting patient recruitment. So far 620,000 patients have searched for clinical trials through the FindMeCure infrastructure.

We understand the industry's **need for fast, accurate and condition-specific data,** therefore we created **TrialHub**

TrialHub provides real-time Intelligence on country feasibility and patient recruitment:

- over 335 000 clinical trials analysed for competition, enrollment, and country capacity
- database of more than 1 million investigators in 70 countries
- country-specific patient pathway mapping
- direct-to-patient channels assessment

For more information:

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