



FindMeCure

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FOUNDATION

TrialHub

# The patient journey of **people actively looking for clinical trials**

Study and survey results



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# Introduction

Patient-centricity is now at the heart of many pharmaceutical companies' philosophies and a key pillar they are eager to implement within their strategy. The patient's voice is no longer something that the industry only talks about but is already becoming a part of clinical trials planning and execution.

Looking at a chronic disease through the eyes of a patient is one of the most insightful ways of determining the patient's most pressing challenges and needs and how to best implement them within the drug development process. Because the patient journey is always unique and might be different than what doctors initially think it is. In the patient's mind it may often start well before an episode of care, and continue on far after their discharge.

At [FindMeCure](#) we have always been close to people living with chronic illnesses thanks to our global clinical trial portal and the awareness work which [FindMeCure Foundation](#) has been doing together with Patient Advocacy Groups worldwide. Our experience revealed how many hurdles the drug development process hides which prevents patients from being able to access a relevant clinical trial. At the same time, this delays clinical trial timelines and the possibility of new treatments to become available much sooner.

In this study, we have mapped the **experience of people with chronic and life-threatening conditions that are actively looking for new treatment options in research**. It is vital to understand and identify the barriers, drivers, challenges, opportunities, emotions, attitudes, behaviours and influences along the patient pathway so below we present an overview of some of the interesting findings we have extracted.

## Methods & Survey Sample

We reached out to the patients who searched for clinical trials through our platform FindMeCure between January and February 2020. We wanted to know what made them look for treatments in development and what their experience with the condition has been since the first symptoms appeared.

174 respondents answered our survey. They represented countries such as the USA, UK, Canada, Australia and countries from Europe, such as Hungary, Bulgaria, Romania and others.



**Sample size:** 174 respondents



**Period:** January 2020 - February 2020



<b>Countries</b>	USA	<b>68.39 %</b>
	UK	<b>11.49 %</b>
	Other	<b>20.12 %</b> ( Canada, Australia, Europe)

## Types of diseases:



33.5 %	Chronic condition
27.1 %	Life-threatening disease
14.1 %	Healthy volunteers
10.6 %	Mental illness
5.3 %	Rare disease
4.1 %	Disability
5.3 %	Other

## Findings

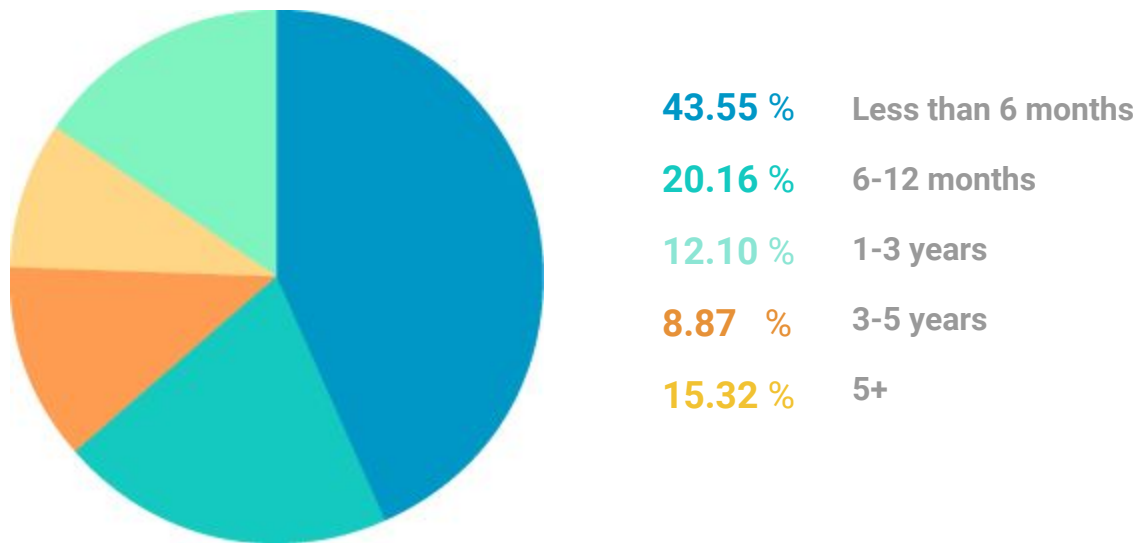
- **From symptoms to diagnosis**

Getting diagnosed seems to be one of the biggest obstacles for many people out there. When it comes to rare diseases, for instance, the length of time from symptom onset to an accurate diagnosis is around 5-7 years depending on the country where patients live.

Predictably, for the majority of patients that completed our survey, it took less than six months, with a big number of them diagnosed within weeks. We should attribute this result to the wide variety of technologies and tools that have been involved in the diagnostic process in recent years and the better knowledge doctors have gained on many indications. Still, for **36.29%** of our respondents, the journey to diagnosis took

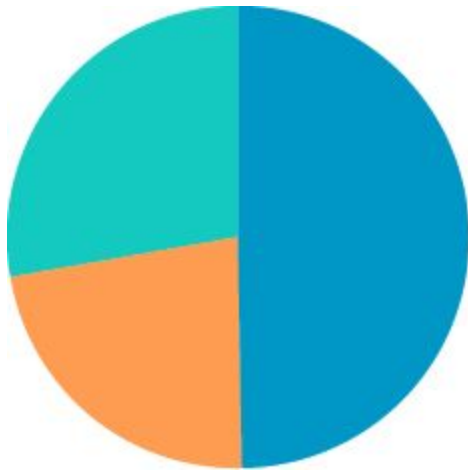
years, **15.32%** of them had to lose more than 5 years visiting multiple doctors and doing lots of tests and procedures to finally have a diagnosis.

### Length of time between symptoms to correct diagnosis



**48.9%** of patients had to visit only one doctor to understand their health condition. The majority of respondents shared that it was their Primary Care Physician who either identified immediately what's wrong by prescribing the right tests and procedures or directly referred them to the right specialist after hearing about the symptoms. Still, **27.6%** reported they needed to visit multiple specialists until their illness got diagnosed which caused further implications on their health, social life and mental well-being.

## Different types of doctors visited to get a diagnosis



**48.9 %** 1 doctor  
**23.6 %** 2 doctors  
**27.6 %** 3 or more



*"It took long. I had to visit Primary Care Physician, neurologist, cardiologist, pain management specialist, Arachnoiditis Intractable Pain Specialist, endocrinologist, rheumatologist, dermatologist, Genetic specialist, anesthesiologist, dysautonomia specialist"*

*"Urgent Care Doctor -2 times, Primary care Doctor - 2 times, Ear Nose and Throat Doctor, Allergy, Dermatologist. I don't even remember the number of times I had to seek advice"*



## ● Treatment pathway

**46.7%** of the respondents report they have tried different treatment options within the standard of care in their respective country but still do not get the expected outcomes.

**40.7%** of people are still on their primary therapy as prescribed by their doctor but some of them report doctors are unwilling to change their medications even though patients continue to face the downfalls of their condition.

### Current therapy



**40.7 %** First-line (the first (primary) treatment)

**35.9 %** Second-line

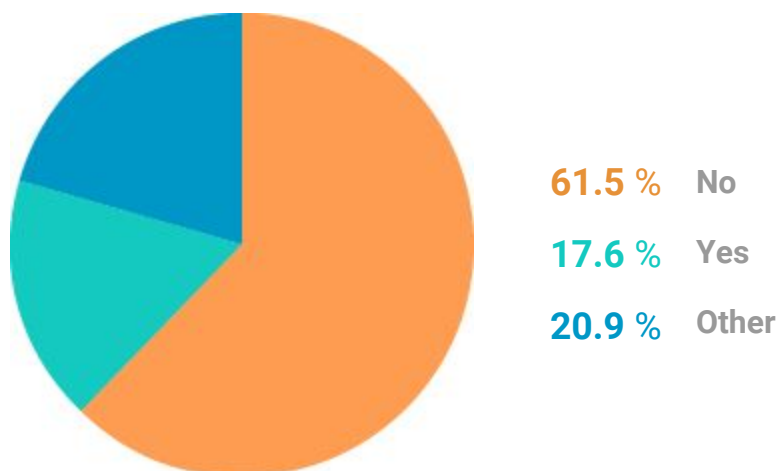
**10.8 %** Third line

**8.2 %** Not taking any therapy at the moment

**4.4 %** Other



## Satisfied with current treatment



The majority of people (**61.5%**) are not satisfied with their current treatment and this explains their motivation to look for an investigational therapy in clinical trials. **20.9%** of them could not relate to any of the answers (Yes//No) due to various reasons, such as:

*"Yes but I'm curious about new treatment methods"*





*“Not always, the treatment effects are not consistent to ensure a better quality of life”*

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*“Semi satisfied but I would like to better understand my condition”*

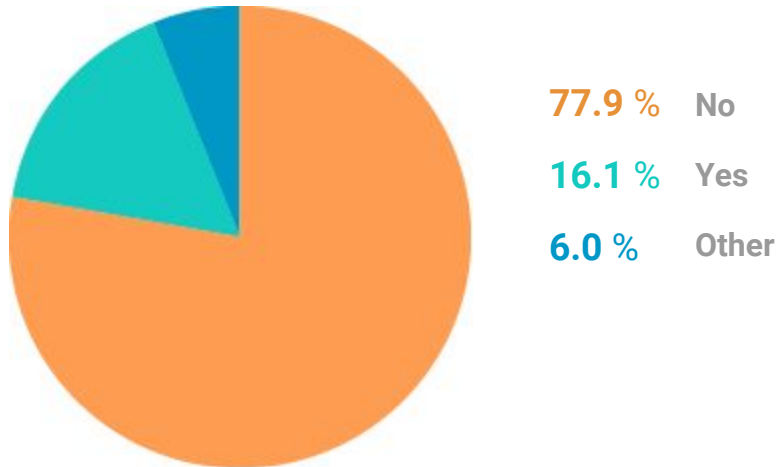


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## ● Clinical trials

As we expected, most of the respondents had not been referred and advised by their doctor to look for a clinical trial option. **77.9%** say they have not even discussed this step during their hospital visits. Only **16.1%** report they have been made aware by their doctor that such a treatment option exists. It is interesting to mention that those who were informed, were actually told that there were no trials in their country or **the doctor was not aware of any trials outside of their facility.**

## Have you discussed clinical trials with your doctor?



This proves that more clinical trial awareness is needed not only among patients and their families, but also among doctors which are usually overwhelmed and do not have the time to dedicate to additional clinical trial search and support for the patient. These are critical touchpoints of the patient journey where all parties require attention.

Another interesting finding worth sharing is related to the **inability for people to receive more information once contacting a particular research team and expressing interest for a certain trial**. This is where clinical trial sponsors (either academia or industry) should put more consideration too.

Our work at FindMeCure helped us gain insights on the most common hurdles in the patient recruitment process preventing motivated patients from even getting to learn more about a certain trial. These include but are not limited to:

- ***Inefficient Call Centre Services*** that make it difficult for patients to talk to a real person instead of voice messages or losing precious time in back and forth communication from people in different departments not getting to speak with the right person in charge.
- ***Automatic email responses to patient requests*** - a common pick by bigger sponsors because automation is the best fit when dealing with the large volume of requests. However, this approach prevents people from being able to ask their questions and doesn't add any value to their ask.
- ***Investigator/Study team not reachable*** or ***contacts not up to date***
- ***Refusal to provide information with no doctor's referral*** and many more.

**This matters because in order to move closer to fully-enrolled on-schedule trials stakeholders need to remove existing barriers to patient recruitment.**

**Understanding and empathizing with the patient journey also means extending consideration towards the anxious patients who - having just made a leap into the unknown - would benefit from human contact on the other side.**

*"My doctor says there are no trials he knows of in Canada for my age group"*



*"I've tried to contact a research center about a new trial, but have not received a reply. I left a message by phone but no one came back."*

*"I've tried to search for trials on my own, I haven't informed my doctor. It's hard to find information that you understand"*



**35.6% of patients realize the value of patient participation** in research and are willing to contribute to it which is admirable. Still, other patients have another motivation for looking for a trial option. **20.9% of them are not satisfied with their current treatment** so their only option is to look for investigational therapies. According to our observations so far, this is very much valid for people living with autoimmune or inflammatory diseases, such as Ulcerative Colitis and Crohn's disease where many available treatments stop working over time. When it comes to the rest of respondents, **17.6% don't have any alternatives** as there is no treatment available and **13.5% can't afford to pay for a treatment** so they hope they can find their saviour in clinical trials. **7.6% of patients report that the treatments they have taken showed many side effects** which threatens their quality of life.

### Reason to look for a clinical trial



- 35.6 %** I want to contribute to medicine
- 20.9 %** My treatment doesn't work/stopped working
- 17.6 %** No available treatments
- 13.5 %** I can't afford to pay for a treatment
- 7.6 %** Side effects of my current treatment
- 4.8 %** Other



*"Doctors never talk about new treatments.  
I want to get rid of this disease too"*

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*"My current treatment is not really effective and my  
quality of life and family are being affected by my  
condition"*



*"It's like a guessing game, no one really knows how to  
treat it and stop it. We need a cure! Also, it can be  
expensive when you are trying anything to help."*

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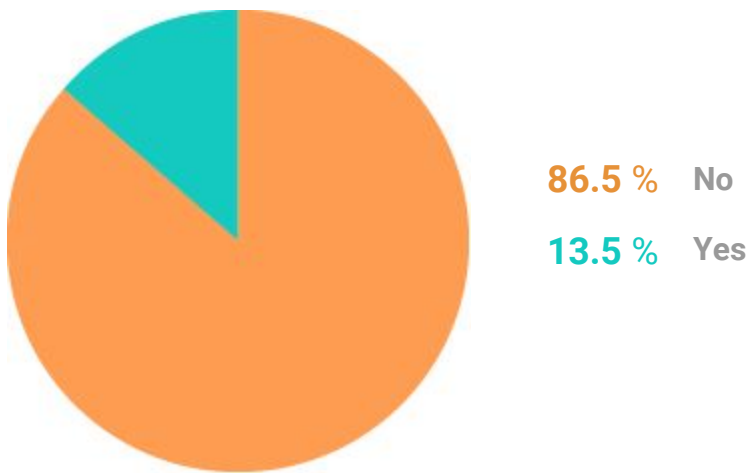
*“Need to find a cure for this disorder”*



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The clinical trial experience of respondents corresponds to the general statistics of people aware of clinical trials so this is no surprise at all and it is something we are actively working to address through clinical trial awareness and support.

### **Past clinical trial experience**





From that **13.5%** who have been part of a clinical trial, the majority report their participation was beneficial. What is more interesting to share though is what people shared further with us regarding their overall experience and what should improve:

*"My child participated. I found it to be very beneficial to science, the doctors involved and to my child, the patient."*

*"Screening should improve"*

*"I took part but I am not sure of the outcome. No one shared anything with me"*

*"Positive experience, some tasks could have been done at home"*

*"Good. Dates of future trials, length and frequency of visits should be included on websites where trials are advertised"*

*"The treatment was effective for me, minimizing symptoms greatly and sometimes having them almost completely managed. The trial was discontinued before my open label time was completed."*



## The value of the **patient journey for the future of drug development**

The industry has a unique opportunity now to leverage knowledge and experience that was overlooked for decades. Patient engagement does not merely relate to the phases of patient recruitment or market authorization and post-approval where we know patient input and advocacy is much needed and requested. It is crucial quite before that - when gap analysis, unmet needs and patient-relevant value and outcomes are being explored and defined.

From *the first symptoms* through *misdiagnosis* and *receiving the right diagnosis* to *trying different treatment options* and *living with the disease* - these are just some of the critical moments that need to be considered and taken into account when developing new therapies. Also, it is important to examine the patient-doctor relationship, as well as patient-to-patient interactions and the interactions patients have with patient support organisations in order to gain a holistic picture of what the patient feels, experiences, thinks and how he or she behaves as a result.

Healthcare organizations must now update their priorities in order to remain competitive in the marketplace. And the only way to differentiate and create impact is to interact, listen and apply relevant feedback by those who are supposed to buy and take the medication at the end of the chain - the people living with chronic illnesses.

How a patient (prospective research subject) navigates through the healthcare system and the touch points where they might learn about and encounter opportunities to get involved in a given clinical trial is the key to precision when it comes to planning patient recruitment efforts. Without this information, study teams and sites are not able to systematically identify the most strategic sources of patients and the best tactics to ensure these sources are aware of the study opportunity. This results in inefficient recruitment campaigns, wasted time and effort, and, ultimately, very poor returns on the recruitment enhancement investments.

It is crucial to also understand that a patient journey is a global representation. How a patient experiences a chronic condition or disease is similar across the world. However, what differs from country to country is how the condition and the patient are managed under different healthcare systems and the impact cultural factors have on patients. Recruitment strategies should be adapted to reflect the nuances and differences across regional and country-specific healthcare systems.

A key part of making clinical trials work efficiently is realizing that although good science is important, it also has to be feasible, convenient and culturally acceptable for those taking part in them. This is where knowing the patient pathway makes the biggest difference for patient recruitment and efficient clinical trial conduct.

Build your feasibility, site selection and recruitment strategies on the basis of in-depth country-specific understanding which

FindMeCure's [TrialHub intelligence platform](#) can offer you.

All with the patient in mind.



## About Us

### **Bringing Clinical Trials Closer to Patients**

**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.

**FindMeCure Foundation** is a not-for-profit organisation devoted to improving the understanding of patient organizations, support groups and their members worldwide about clinical research. Its aim is to support patients to be up-to-date with the ongoing research studies and help them to be fully prepared and knowledgeable about the drug development process. One of its main focuses is to foster patient engagement in research and to sustain patients' key role in the drug development process.

**TrialHub** provides real-time Intelligence on country feasibility, site selection and patient recruitment:

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

For more information:

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