White Paper

Renewed Interest in Clinical Research Helps Change the Conversation about Trial Participation

New survey shows participant interest in clinical research at an all-time high, but it could dissipate if the biopharma industry doesn't act.

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Introduction

Over the last year consumers have monitored the development of vaccines and treatments created to address the COVID-19 pandemic, which could point to a rising interest in trial participation. Living through and monitoring the development of vaccines engaged consumers with the research process, which could be a bonus for future recruiting efforts.

Survey respondents across all age groups and demographics now say they are extremely or very interested in participating in clinical trials.

40%
VERY INTERESTED

A new global survey of 6,410 participants conducted by IQVIA found that roughly 40% of patients across all age groups and demographics now say they are extremely or very interested in participating in clinical trials. Patient openness to clinical research represents an exciting opportunity for the biopharma industry to engage with patient communities and accelerate research. But as an industry, we must act now to prove participation in trials will be worth the effort.

“The pandemic raised awareness about clinical research and the benefits that it brings to the entire community,” says Mark Brown, Vice President, Global Patient and Site Solutions, IQVIA. “It has created a unique opportunity for life sciences organizations to change the conversation about trial participation.”

The survey, which included 6,410 people across the United States (US) and Europe (EU), measured overall perception of clinical research one year into the COVID-19 pandemic. The data captures consumers’ attitudes about clinical trial participation, the motivators, and barriers they face, and how their opinions have evolved since the pandemic began.

“Seeing friends and family participate in trials, and the impact the vaccine is having worldwide made clinical research more accessible,” says Brown.

The data show consumers are open to all types of clinical trials – not just those focused on COVID-19 vaccines – and that different populations have unique concerns and motivations. If sponsors can address those issues in their outreach and trial design, they can more effectively translate their interest into action.

Key findings

- **The majority of respondents say they are open to participating in clinical research.** Roughly 70% of US respondents and 80% of EU respondents say they are somewhat interested in trial participation, and more than 23% are extremely interested. Those with the highest level of interest skew urban, have participated in clinical research in the past, and are more likely to suffer from conditions being studied.
- **New faith in pharma**. Among those who are very/extremely interested in trial participation, almost half of US respondents and a third of EU respondents say their trust in clinical research has increased since the start of the pandemic. Awareness of COVID-19-related clinic trials, positive vaccine perceptions, and news coverage of vaccine and treatment development are the top influencers of that trust.
- **Everyone expects flexibility and minimal disruption as a condition of participation**. Fully 68% want access to telehealth, in-home care, and use of their physician/local labs when possible – but 74% report being unaware that these decentralized clinical trial (DCT) features were even an option.
- **In the US, more than one-third of Black/African Americans surveyed said they have improved trust in clinical research now due to COVID-19**. This group showed the most significant shift in thinking.
- **COVID-19 had a more significant impact on the desire to participate in trials among Black / African Americans and Hispanics / Latinos in the US**. Roughly one-in-four say they are “much more interested” in being a part of trials compared to about 15% of white respondents.
- **Patients worry more about the health risks than a time commitment.** When asked what prevents them from participating in a trial, fears about their health and safety (62%) far outweighed concerns about time (37%), logistics (18%), and negative press about research (8%).

All these data points should be exciting for the biopharma industry. The pandemic’s profound impact on consumer perception of clinical research could transform their recruiting strategies, timelines, and budget – if we can figure out how to convert this interest to drive long-term results.

MEDIA'S ROLE IN PATIENT ENGAGEMENT

The experience of living through COVID-19 and watching pharma companies collaborate with industry, government, and community to develop vaccines in record time changed the way consumers think about clinical trials.

The global health crisis caused consumers to engage with clinical research as a media event. The global value proposition tied to the speed and success of vaccine trials spurred organic interest in the research. Consumers were bombarded with news reports, articles, and first-hand accounts about COVID-19 trials written in language that made these stories accessible and consumer-friendly.

Experiencing the evolution of COVID-19 vaccines as a media event transformed the way many consumers think about trials. According to survey results, almost half of adults globally say they are now "more interested" in participating in clinical research, according to survey results.

Their interest is primarily driven by awareness of clinical trials related to the pandemic, and positive vaccine perceptions in both the US and Western Europe. For about 20% of US adults, health experiences during the pandemic – either their own or friends/family – also influenced interest; while in Western Europe, 25-30% of adults say the news and their own health experiences were vital influencers.

The experience caused them to think about trial participation as a good choice and a compelling care option. In both the US and EU, the top motivators included the desire to help others and advancing science.

However, the clinical research community cannot can't afford to continue along the same path as before the pandemic.

> ***"As an industry, we have to respond to their interests by creating more engaging trial experiences that lower the burden of participation through optimized trial designs. When sponsors design trials with the goal of mitigating the burden of participation, it results in more patient-centric experiences, which will ultimately help accelerate recruiting and improve retention."***
>
> *— David Cameron, Head of Novel Trial Design Solutions, IQVIA and co-developer of the Patient Friction Coefficient* (PFC)*

*The Patient Friction Coefficient (PFC) is a data-informed protocol assessment that characterizes and quantifies potential patient burden.

"The COVID pandemic has made me conclude that everyone needs to help any way they can," wrote one survey respondent (US, Female, 35-44, White, Hispanic). "If I can help someone by participating in a study I would definitely do [it]."

RETHINK PATIENT ENGAGEMENT

While the media made consumers broadly aware of clinical research during the pandemic; the vaccine developers amplified that interest by engaging participants directly. Instead of relying on healthcare professionals (HCPs) as the primary conduit for recruiting to trials, they used direct-to-patient (DTP) advertising, one-click sign up opportunities, and targeted outreach customized to the unique interests and concerns of different communities.

These DTP outreach efforts brought research to the masses. Sponsors advertised vaccine trial opportunities on social media, through the news, and community outreach events, adapting ads for targeted demographics.

When patients interacted with these campaigns, sponsors leveraged user-centric platforms to instantly direct consumers to pre-screening questionnaires. If they met inclusion criteria, they were invited to sign-up via online platforms to complete the necessary paperwork, find a site, and set up their first appointments, from wherever they are.

The speed, ease of use, and consumer-driven experience helped accelerate recruiting while reducing attrition to the recruiting funnel.

The ease of use and control had a powerful impact on public perception of research and the pharma companies supporting it. More than one-third of US and nearly half of EU respondents cited awareness of clinical research related to COVID and as the leading influencer (see charts) of their interest in clinical research. And roughly half of the respondents who are most interested in participating in a trial say their trust in clinical research has grown since COVID-19.

ALTRUISM, REPRESENTATION DRIVE INTEREST

When asked why they were now interested in clinical research, those with high interest couldn't pinpoint one specific driver. The majority cited a combination of their desire to help others (63%), and to advance science (63%), and interest in "earning extra money" (53%).

INFLUENCE VARIES ACROSS DEMOGRAPHICS

Awareness of research during the pandemic drove interest in research across all demographics; however, different populations varied in what other factors influenced them.

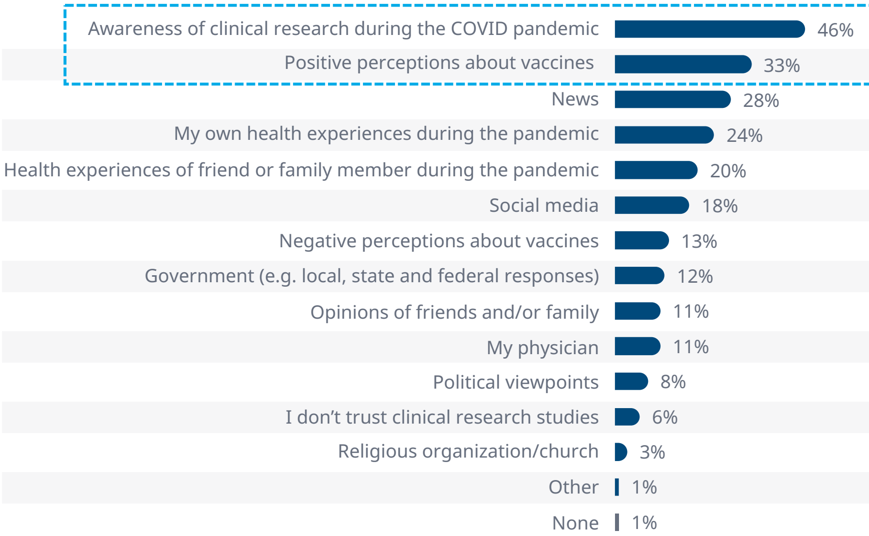
- In the US, Black / African Americans were twice as likely to cite religious organizations as a top influencer than the overall population (10% vs. 4%); and Black / African American women were more likely to cite their own health experiences (37% vs. 24% overall).
- US males 35-54 were more likely to cite opinions of friends and family as an influence than other groups (24% vs. 14% overall).
- Young adults (18-24) were almost twice as likely to reference their political viewpoints as an influencer (17% vs. 9% overall).
- In the EU, high-income earners were more likely than any other group to say the health experiences of friends and family affected their options (39% vs. 23% overall).

Forty percent of those with high interest also cited the desire for “people like me” to be represented in clinical research. Black / African American respondents (33% overall) in the US were more likely to choose this reason than any other demographic (compared to 21% from their white US counterparts). This underscores the importance of improving demographic representation in clinical trials as both a public and regulatory expectation.

“People want to see proof that the pharmaceutical industry values diversity and inclusion in research,” says Pankaj Patel, Head of Diversity and Inclusion for R&D, IQVIA. “Sponsors who communicate commitment to diversity, equity and inclusion in recruiting may be better able to engage diverse communities in their research efforts.”

Likewise, when aided, awareness of clinical research during the pandemic and postive vaccine perceptions are influential

Influences on interest in clinical research since COVID-19

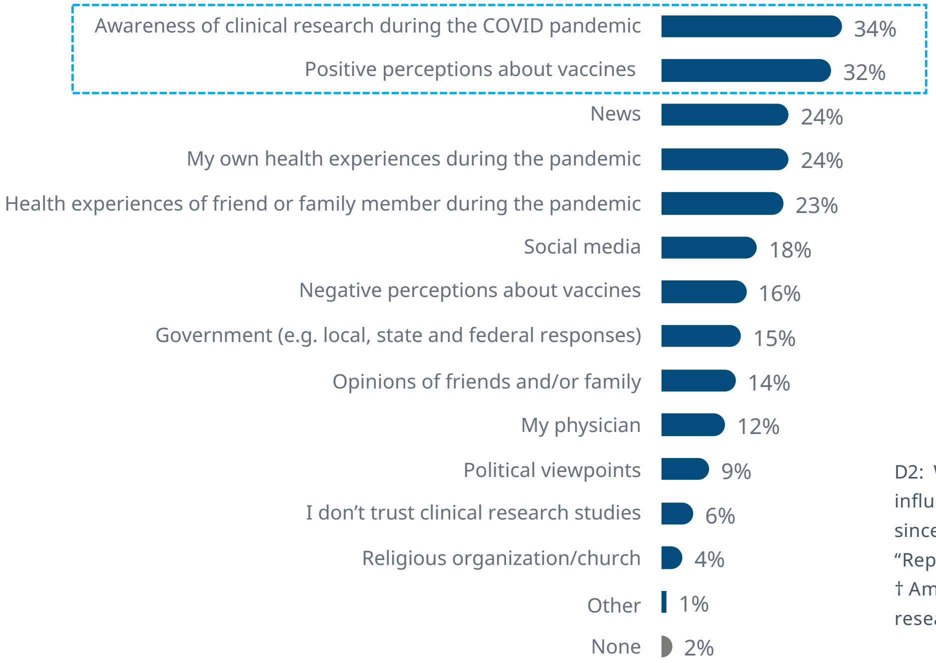


		Country				
		UK	FR	DE	IT	SP
		A	B	C	D	E
Awareness of clinical research during the COVID pandemic	46%	51%^{BC}	33%	44%^{B}	53%^{BC}	52%^{BC}
Positive perceptions about vaccines	33%	44%^{BCDE}	23%	36%^{BD}	29%^{B}	35%^{BD}
News	28%	28%	29%	26%	30%	26%
My own health experiences during the pandemic	24%	25%	22%	26%^{D}	21%	27%^{BD}
Health experiences of friend or family member during the pandemic	20%	22%^{BC}	13%	17%	20%^{B}	25%^{BCD}
Social media	18%	15%	22%^{ACE}	15%	20%^{ACE}	16%
Negative perceptions about vaccines	13%	12%	12%	11%	16%^{ABC}	14%
Government (e.g. local, state and federal responses)	12%	13%^{DE}	13%^{DE}	13%^{DE}	9%	9%
Opinions of friends and/or family	11%	8%	14%^{ACE}	10%	12%^{A}	10%
My physician	11%	9%	12%	10%	11%	12%
Political viewpoints	8%	5%	9%^{A}	11%^{ADE}	7%	6%
I don’t trust clinical research studies	6%	3%	7%^{A}	8%^{AD}	4%	6%^{A}
Religious organization/church	3%	3%	3%	4%	4%	3%
Other	1%	0%	1%	1%	1%	1%
None	1%	1%	2%	2%	1%	1%

D2: Which of the following have had any influence on your interest in clinical research since COVID?
Total EU n=3,365; UK n=665, FR n=662, DE n=579, IT n=714, SP n=745
† Among those whose interest in clinical research studies has changed due to COVID-19
AB = Significant difference at 95% confidence interval

When aided, awareness of clinical research during the pandemic and positive vaccine perceptions are top influencers

Influences on interest in clinical research since COVID-19



D2: Which of the following have had any influence on your interest in clinical research since COVID?
"Rep" Sample n=638
† Among those whose interest in clinical research studies has changed due to COVID-19

CONVERGENCE OF CLINICAL CARE AND CLINICAL RESEARCH

The survey found that less than 10% of respondents globally said they would participate in a trial to access care and novel treatments, even though this is considered a leading benefit of trial participation. This could indicate that physicians are not routinely talking about clinical research as a care option, and that patients are unaware of the advantages of participating in clinical research.

This presents an opportunity to change the conversation about clinical research. The data shows that sponsors cannot rely on physicians alone to educate patients about the value of clinical research as a care option. So they need to be more proactive in their direct-to-patient outreach.

Patients who participate in trials could gain access to some of the most innovative treatments under the close supervision of treatment specialists. When sponsors highlight these benefits in their advertising, patient profiles, recruiting campaigns, marketing materials, and community outreach, it can help discover that trial participation is a way to take greater control over their healthcare journey. While this messaging will require careful presentation of potential risks and benefits, it will help sponsors refocus the message to patients that clinical research offers an opportunity to patients that could provide real value to their lives.

> ***"Clinical research can provide qualifying patients with alternative treatment paths that could improve their outcomes and give them access to leading researchers in their disease. Patients must know these options exist so they can make the most informed decisions about their care."***
>
> *— Pankaj Patel, Head of Diversity and Inclusion for R&D, IQVIA*

WHAT'S NEXT?

The key now is figuring out how to target 'high interest' patients in recruiting efforts and maintain the population's burgeoning interest in trial participation for the long term.

"We cannot rely on the enduring impact of the pandemic to hold patient interest," says Cyndi Verst, President, Design & Delivery Innovation at IQVIA. "We have to fuel their continued interest through direct-to-patient outreach, education, and engagement with the patient community."

WHO'S INTERESTED?

The survey found that 64% of US consumers and 77% of EU consumers show interest in trial participation. The numbers are even higher for trials studying non-life-threatening conditions (79% and 87%) representing a huge swath of the population most likely to convert to participation in the future. However, interest rates vary based on demographics, location, and research/healthcare experience. Sponsors can use these trends to target their recruiting strategies and inform site selection for future trials.

- EU respondents are more likely to say they are very trusting of clinical research than US respondents (61% vs. 72%).
- People who live in cities are more likely to be interested in trial participation than rural dwellers.
- Respondents who have participated in clinical research in the past and/or who suffer from relevant conditions are more likely to be interested in future trial participation.
- In the US, 40% of respondents said they were interested in participating in a global pandemic-related study.
- Higher-income earners in both the US and EU are more interested in trial participation, whereas those in the lowest income bracket and/or retired are least interested.

Sponsors and sites can analyze real-world data (electronic medical records, claims data, etc.) as part of their recruiting efforts to identify patients who fit high-interest profiles – (urban addresses, prior trial experience, and relevant conditions) and to shape outreach strategies based on demographic preferences.

They can also use these analytics tools to monitor recruiting progress across different participant demographics to adapt recruiting strategies on the fly. During the pandemic, some sponsors used real-time analytics in vaccine trials to monitor demographics in their recruiting funnels. They could adapt ads and shift outreach resources helping them accelerate results and exceed diversity goals in trial populations.

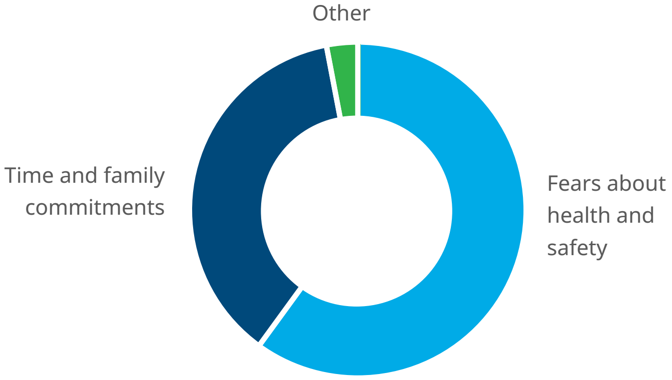
Once identified, the survey shows that email continues to be the preferred method of contact between sites and patients (US 53%, EU 59%), far outweighing every other contact option. Text (12%) and snail mail (11%) were more desirable than phone calls, which were cited as the least preferred outreach option among every demographic.

>50% of patients are comfortable using digital forms of communication, like email and mesaging

BARRIERS TO OVERCOME

Consumers may be more interested in clinical research than ever before, but their participation isn't guaranteed. Those with high interest require reassurance and education about what the experience involves as a condition of their participation. To start, sponsors must address safety concerns.

Obstacles preventing participation within clinical trials



WHY THEY SAY NO

Among those not interested in clinical research, fears about being a test subject were their chief concern. Participants are also **more likely to cite health and safety risks as a barrier**, suggesting fear and lack of trust still play a role in the negative perception of clinical research.

"I'm too healthy to take an unnecessary risk with unproven, untested, drugs," wrote one respondent (US, Male, 35-44, Bi-racial/Multi-racial). "I value my own life and healthy body too much to get involved in an unproven method."

Black / African Americans are more likely to cite the trust of the research team as a barrier to participation than other demographics. Those over 55 in all demographics are more distrustful than those 35-54.

For sponsors who want (or need) to attract these populations, addressing concerns about health risks in patient outreach and discussing safety strategies in initial conversations may help ease their concerns.

HYBRID OPTIONS ARE NOW THE NORM

The survey shows that participants don't want to travel long distances – just 26% will travel more than 20 miles to a trial site. They have limited tolerance for any trial that will be overly disruptive to their daily lives.

68% expect a trial to include flexible options, including telehealth, in-home care, and use of their physician/ local labs when possible. Yet 74% were unaware that these technologies are a part of clinical research today. It is a surprising knowledge gap that sponsors need to address.

The use of telehealth and electronic consent platforms, wearables, online patient portals, and other DCT elements soared during the pandemic, freeing patients to engage in trials with minimal site visits. This trend dramatically reduced the burden and time commitment commonly associated with trial participation, making it easier for patients to weave the trial into their daily lives.

"Even in non-pandemic times, I'd always rather be able to stay home and not have to drive to an office and find parking and sit in a waiting room," concluded one US respondent (Female, 35-44, White, Non-Hispanic).

Technology-enabled DCT models were a huge success during the pandemic, and these options are expected to become a permanent part of clinical research. That's good news for sponsors as the benefits of DCTs can make the decision to participate easier for busy patients.

However, it only adds value if patients are aware of these options. To avoid losing participants due to misperceptions about the time commitment, sponsors have to promote their DCT models and communicate the trial experience at every touchpoint in the recruiting process.

68%

of patients expect **flexibility and remote options**, like telehealth and in-home care, when it comes to participating in trials

TREAT PATIENTS AS FUTURE CHAMPIONS

In the survey, patients who had participated in past trials (14% of the survey population) reported an overall positive experience, and 63% would encourage others to follow their path. However, they were largely unimpressed with the follow-up they received post-trial.

70% of US and 73% of EU respondents felt that it was essential to receive a summary of the study results once the trial was over, yet only 36% and 38% received one. About 60% also said they wanted the opportunity to share their perspective on the research, but only about one-third were given that chance.

These past trial participants represent a vital grassroots community who could participate in future trials and encourage their peers to do the same. But if sponsors want their continued support, they need to treat them as valued stakeholders and provide them with the data they seek (where appropriate), and opportunities to share their ideas and feedback on the study experience.

“Their insights can help to create more engaging future trials and ensure past study participants remain committed advocates in the research community,” says Brown.

MAKE THE MOST OF THIS MOMENT IN TIME

The survey shows the pandemic was a point of disruption for clinical trials. Consumers have never been more interested in trials or informed how they work than they are today, which could have a substantial long-term impact on trial recruiting. But it won’t last forever.

Biopharma companies engaging in and delivering clinical trials must respond to this trend by ramping up engagement efforts, communicate with patients about the safety and impact of their research, and use DCT elements to reduce burdens associated. This combination of communication and adaptation will help solidify interest and support newfound faith in the clinical research industry.

About the survey

Clinical Research Perceptions, Global Summary, June 2021
This IQVIA patient survey was conducted in the spring of 2021 with the intent to capture participant viewpoints on factors regarding participation, motivation and barriers of clinical research trials. In total, 6,410 participants from the United States, United Kingdom and Western Europe (France, Italy, Spain) were surveyed.

Meet the contributing experts

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