

CHORDOMA FOUNDATION

Making Chordoma Clinical Trials Work for Patients

Patient and caregiver insights for successful clinical trials

Table of Contents

Introduction **3**

Key Findings **4**

Detailed Findings **5**

Hope and hesitation: Motivations and barriers that shape trial decisions 6

Clear communication can close the information gaps 12

Doctors are trusted but underused trial guides 16

Patients weigh trials against off-label options 17

Patients want trial participation to feel coordinated, responsive, and supportive 20

Implications **22**

For trial sponsors and designers 23

For trial teams 24

For clinicians caring for people with chordoma 24

A Call to Action **25**

Appendix **26**

Objectives and methodology 26

Introduction

Chordoma research is entering a period of unprecedented opportunity. Years of work by patients, researchers, clinicians, and partners have produced more promising treatment strategies than ever before, with several new therapies now moving toward clinical trials.

But opportunity will only lead to better treatments if trials can successfully enroll, retain, and support participants through completion. For chordoma, this is especially challenging: the eligible population for any study is small and globally dispersed, and many patients are managing effects of the disease or prior treatment that make travel and frequent study visits difficult. Design decisions that might modestly affect enrollment in a common cancer trial can determine whether a chordoma trial is completed at all.

To understand what's needed to make trial participation possible, we partnered with Edge Research to conduct listening sessions with patients and caregivers, survey more than 350 people across 39 countries, and complete in-depth follow-up interviews.

The pages that follow describe what patients and caregivers told us about their motivations and hesitations, the information they need, the role their doctors play, how they weigh trials alongside off-label treatment, and what good care looks like throughout the trial experience. These findings are translated into practical considerations for sponsors and trial designers, study teams, and clinicians caring for people with chordoma, with the goal of ensuring that future trials are not only scientifically rigorous, but also aligned with the realities of patients' lives.

These findings do not ask the field to choose between scientific rigor and patient-centered care. **For chordoma, thoughtful, patient-informed design is essential to conducting rigorous research that can be completed.**



Shannon Lozinsky
Director of Patient Services
Chordoma Foundation



Josh Sommer
Executive Director
Chordoma Foundation

Key Findings

1 Willingness to join clinical trials is strong when they are designed around patients' realities

Across the chordoma community, 53% of patients are open to participating in clinical trials, and 74% of caregivers would encourage a loved one to participate—but they want trials to be understandable, feasible, and built around their needs. Hesitation reflects thoughtful decision-making, not resistance to research. This hesitation is highly addressable if trials are designed to reduce burden, communicate expectations clearly, and demonstrate genuine support of trial participants.

2 Information gaps impact trial participation

Patients and caregivers often lack clear, accessible information about how trials work—from eligibility to logistics to costs—and confusion can persist even during participation. Among patients familiar with trials, only 15% say they understood the information they received "very well." Simple, timely, plain-language communication is one of the most powerful levers to increase patient interest in trials.

3 Trial design shapes trust and willingness to enroll

Decisions about placebo vs. active control, safety monitoring, and side effects directly shape willingness to enroll: 59% of patients and caregivers say they would be very likely to join a trial with an active control, compared to just 12% if the trial used a placebo. Propensity to participate increases when trials clearly demonstrate fairness, transparency, and a strong margin of safety.

4 Physicians are critical, but underutilized gateways to trials

Patients deeply trust their doctors for guidance on clinical trials: 69% of patients say they trust their doctor to answer trial questions, yet only 24% have received information from a physician. When physicians raise and discuss trials—even early or hypothetically—patients are far more likely to consider participation.

5 Patients are actively weighing trials against off-label options

Clinical trials are sometimes evaluated alongside off-label treatments. When comparing the two, patients weigh factors such as access to treatment, cost, travel requirements, continuity of care, physician recommendations, side effect management, monitoring, and logistical support. Trials become more attractive when they offer clear advantages in these areas, including earlier access to treatment, strong oversight and support, continuity with a patient's existing healthcare team, and reduced participation burden.

6 Patients consider the experience of a trial as well as its outcome

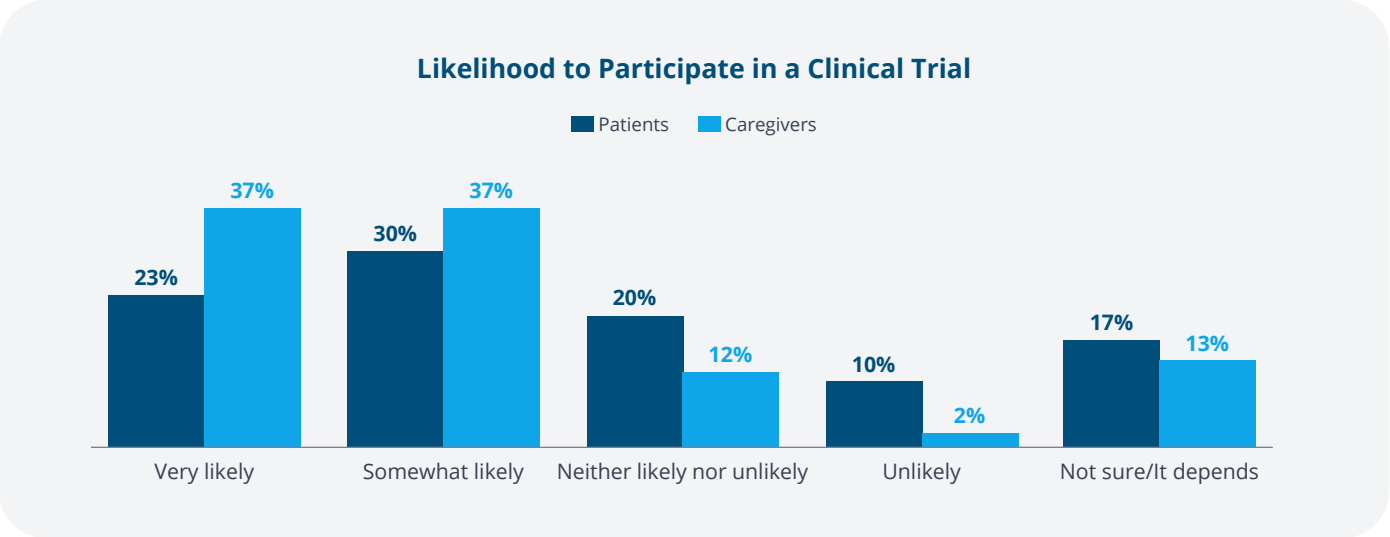
Patients judge trials not only by medical results, but by whether they feel cared for, supported, and treated as individuals: 67% say comprehensive care is a must-have when considering trial participation. Across the journey—from considering a trial to participating and beyond—patients and caregivers are looking for guidance, coordination, emotional support, and connection. Many feel they must navigate complex decisions largely on their own. Patients need help understanding options, support around managing logistics, and reassurance that they are not alone in the process. For trials to succeed, they need to deliver both scientific rigor and a human-centered experience of care.

Detailed Findings



HOPE AND HESITATION: MOTIVATIONS AND BARRIERS THAT SHAPE TRIAL DECISIONS

Chordoma patients and caregivers are receptive to clinical trials: just over half (53%) of patients report being open to participating in a trial, and three-quarters (74%) of caregivers are likely to encourage their loved one to participate. Openness to participation depends on clarity, feasibility, and trust.



Trials are simultaneously viewed as hopeful and intimidating; but hesitation reflects careful deliberation, not resistance.



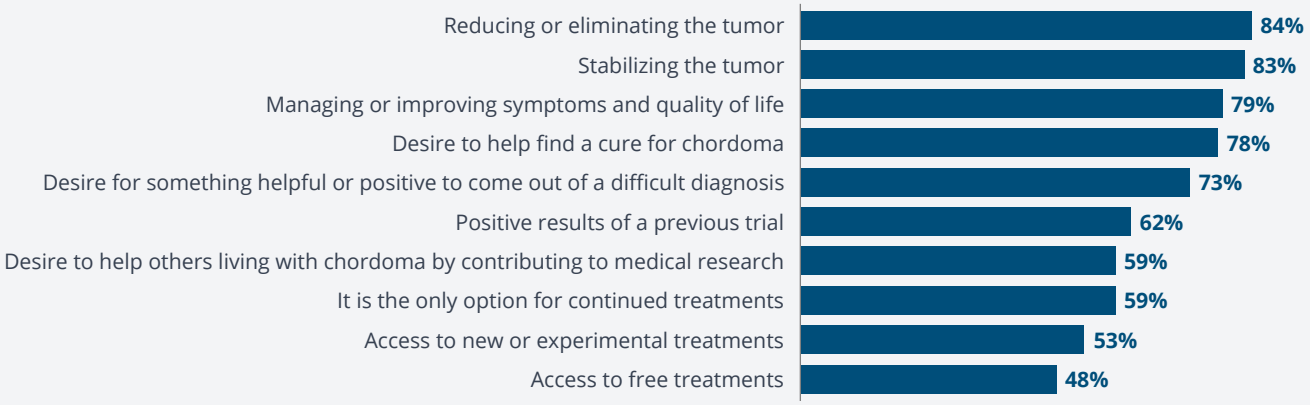
> ***My preconceived notion was that clinical trials are a last resort… Now I believe in them as the future—a necessary and thriving component of our medical healthcare right now."***
>
> – Trial participant with metastatic disease

MOTIVATIONS TO PARTICIPATION

When patients and caregivers think about the benefits of participating in a clinical trial, top motivations include improvements in their disease status (i.e., tumor stabilization or shrinkage), improved quality of life, and overall progress toward cures. Patients are just as motivated to participate by the possibility of stabilizing their tumor as they are by reducing or eliminating a tumor. Three-quarters of patients are driven by both the desire to help themselves and the broader chordoma community. These higher order aspirations are key messages to consider when designing and conducting successful trials and show how motivated the chordoma community is in finding cures and better treatments for all.

How important are each of the following factors in making the decision to participate in a clinical trial for chordoma?

Among patients only | % Very Important



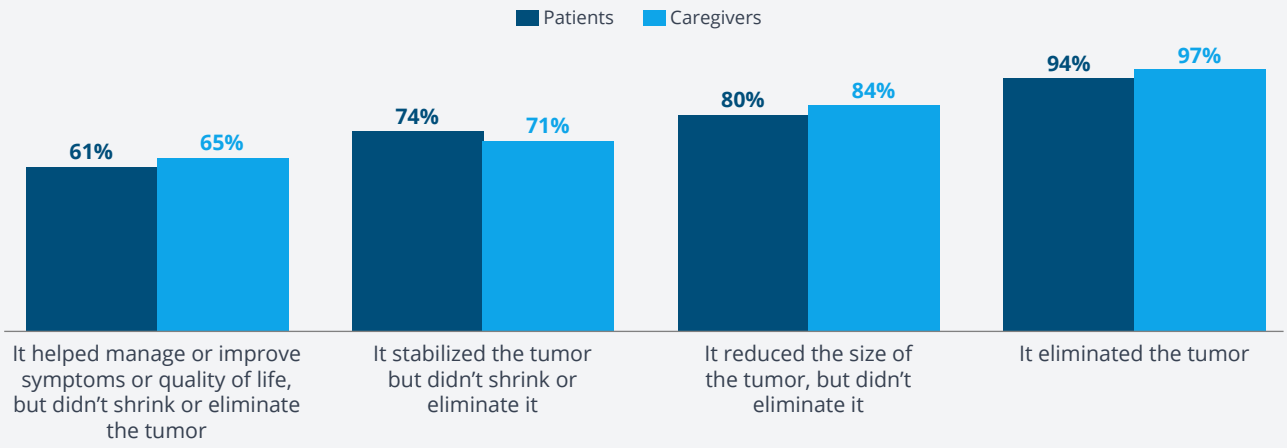
Secondary motivations include contributing to medical research, access to new or experimental treatments, and receiving free treatment.

A clear message from the study is that for this community, quality of life is just as important as disease outcomes. While at least three-quarters of patients would participate in a clinical trial if the new treatments stabilized, reduced, or eliminated their tumor (74%, 80%, and 94% respectively), 61% would participate if their symptoms were alleviated and their quality of life improved, even if there was no tumor regression.

> ***"Quality of life is a huge issue for me, more than the quantity of life. If something improved the quality of my life, I would be super happy about it, regardless of tumor progression."***
>
> – Chordoma patient

There are several potential outcomes of a clinical trial that is testing new treatments. Would you participate/your loved one participate/have participated in a trial if ...

% Yes



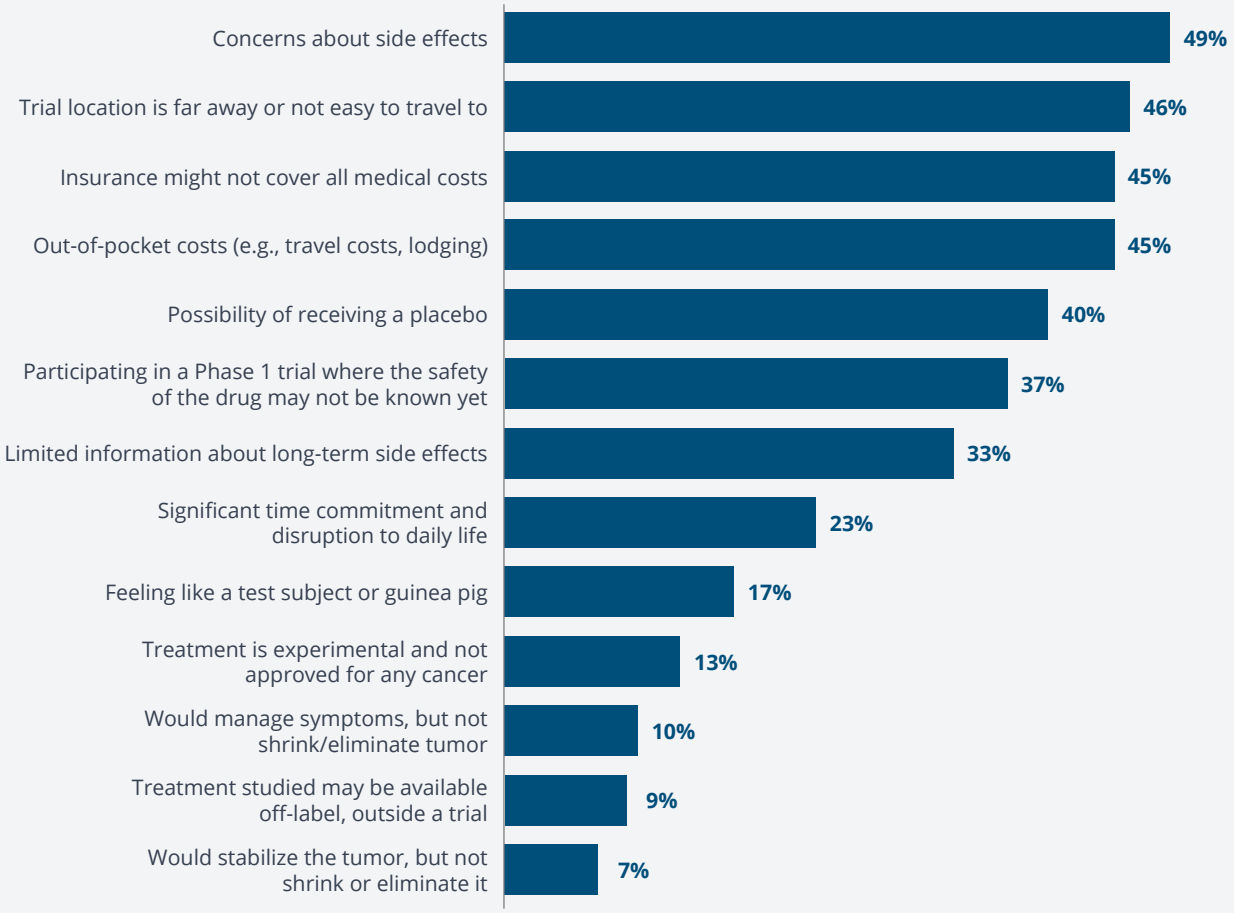
BARRIERS TO PARTICIPATION

Hesitancy about clinical trials exists, but many of the concerns can be addressed with information and clear communication about the trial. Patients report the most common reasons they would decide not to participate in a trial are:

- Safety (side effects, long-term risks, early-phase uncertainty)
- Feasibility (travel distance, time disruption)
- Financial (coverage, costs)
- Fairness/benefit (placebo, fear of wasting time)

Which of the following would make you decide NOT to participate in a clinical trial? Select all that apply

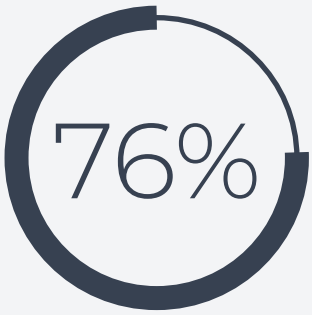
Among patients only



TRAVEL CHALLENGES

Trial location is an important consideration for chordoma patients and caregivers. Nearly half of patients (46%) say if the trial is far away or not easy to travel to, they would choose not to join. Among those who have participated in a trial, three-quarters (76%) spent over an hour in transit, one way, to their trial site, mainly by car. This is where participants and their loved ones were least satisfied in their trial journey—only 35% say they were "very satisfied" with the travel logistics or costs related to their participation.

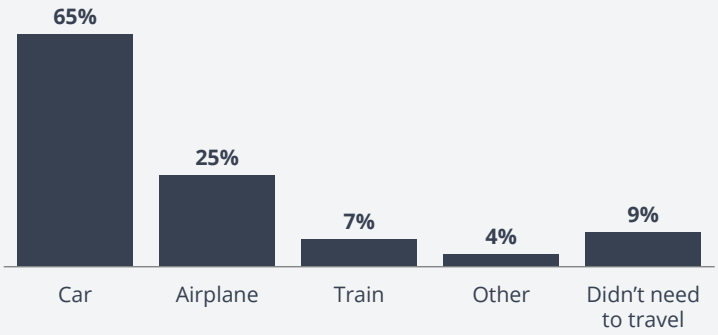
> ***Traveling and rest days take one week of three of what's left of my life.*** *I wish treatment could be available in more locations—just being able to do part of it closer to home would make a huge difference."*
>
> – Trial participant with metastatic disease



of patients and caregivers with trial experience spend over an hour in transit, one way, to the site

Typical Mode of Transport to Clinical Trial Site

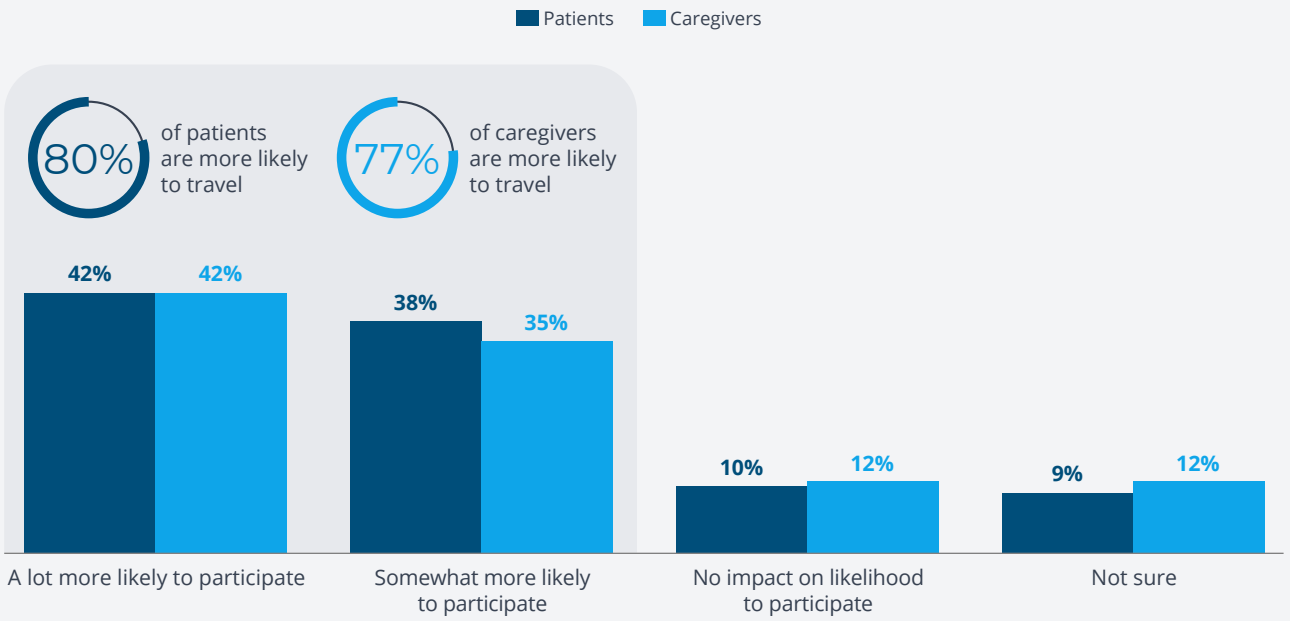
Among patients and caregivers with trial experience



Given the burden of travel, the Chordoma Foundation launched the Clinical Trial Assistance Program in 2022, providing financial support for transportation, lodging, gas, parking, and meals to patients enrolled in an eligible clinical trial. Only a quarter of patients (21%) and caregivers (27%) are aware of this program. Increasing awareness of this support is important, because 80% of patients reported being more likely to travel for a trial knowing about this stipend.

> *The financial burden and the time burden that the Chordoma Foundation is helping with is really forward-thinking on their part. It makes it doable financially but also mentally. I'm not depleting our savings to do this...* ***I think my doctor was kind of poking me and saying, you should reach out to [Chordoma Foundation]."***
>
> – Trial participant with metastatic disease

What impact would the Chordoma Foundation's Clinical Trial Assistance Program, or another program like it, have on your/your loved one's likelihood to travel to participate in a clinical trial?



PLACEBO VS. ACTIVE CONTROL

The possibility of receiving a placebo is another major deterrent for trial participation. Forty percent of patients say this would stop them from participating. That number increases among patients whose tumors are metastatic or advanced (53%) and among caregivers (54%). Concern about placebos is highest among those with trial experience (65%).

Possibility of receiving a placebo would stop me from participating/encouraging my loved one to participate in a clinical trial



of metastatic/ advanced patients

of caregivers

of patients and caregivers with trial experience

> *I'd be pretty surprised if they did [a placebo] at this [stage of disease]...* ***In my eyes, that's a really bad thing to give someone at this level, with this sort of cancer, that would really offend me.*** *Because you're wasting time, and time's valuable."*
>
> – Trial participant with advanced disease

Given this hesitation, the study sought to understand if patients' willingness to participate in a clinical trial changes when an **active control** is used instead. To ensure survey takers understood this option, the following explanation was used:

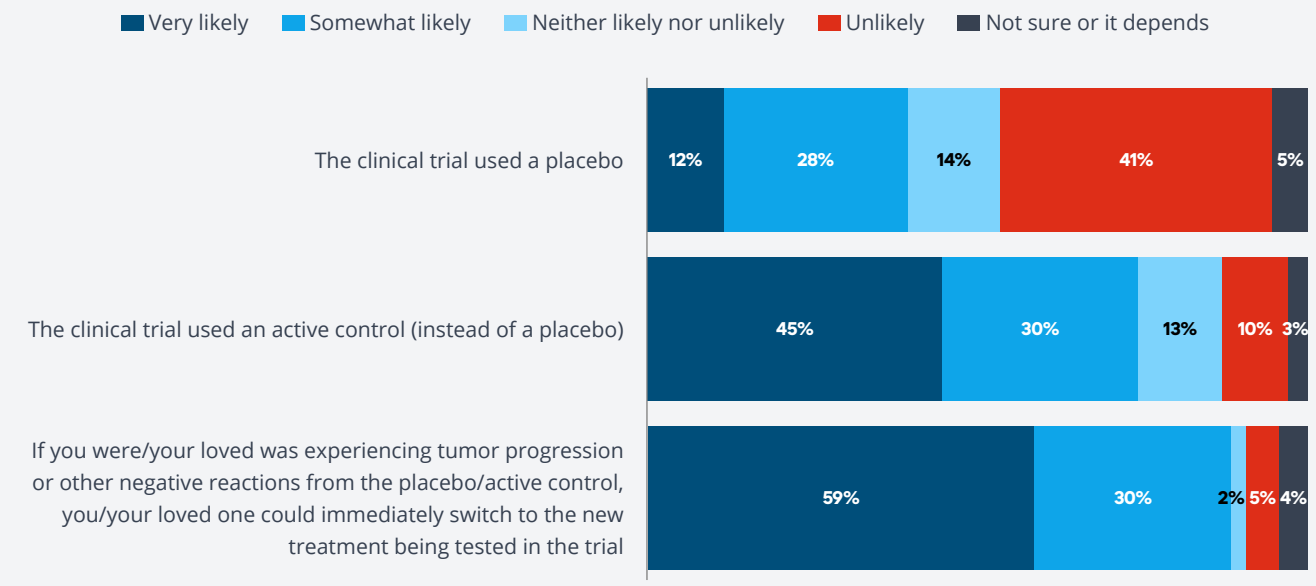
SURVEY DESCRIPTION OF PLACEBO VS. ACTIVE CONTROL:

"In clinical trials, researchers compare a new treatment being tested in the trial to something else. Sometimes they use a placebo—a 'pretend' treatment that looks real but has no active ingredients. Other times they use an active control—a treatment that is already proven to work. Participants are randomly assigned to receive either the new treatment or the placebo/active control."

Just 12% of patients and caregivers say they would be "very likely" to participate or encourage their loved one to join a trial with a placebo. The same audience is four times more inclined to join (45%) when a trial uses an active control. Interest jumps to 59% when patients are told they can switch to the new treatment if their tumor progressed or they experienced adverse reactions on the placebo/active control.

How likely would you be to participate/encourage your loved one to participate in a clinical trial if...

Among patients and caregivers



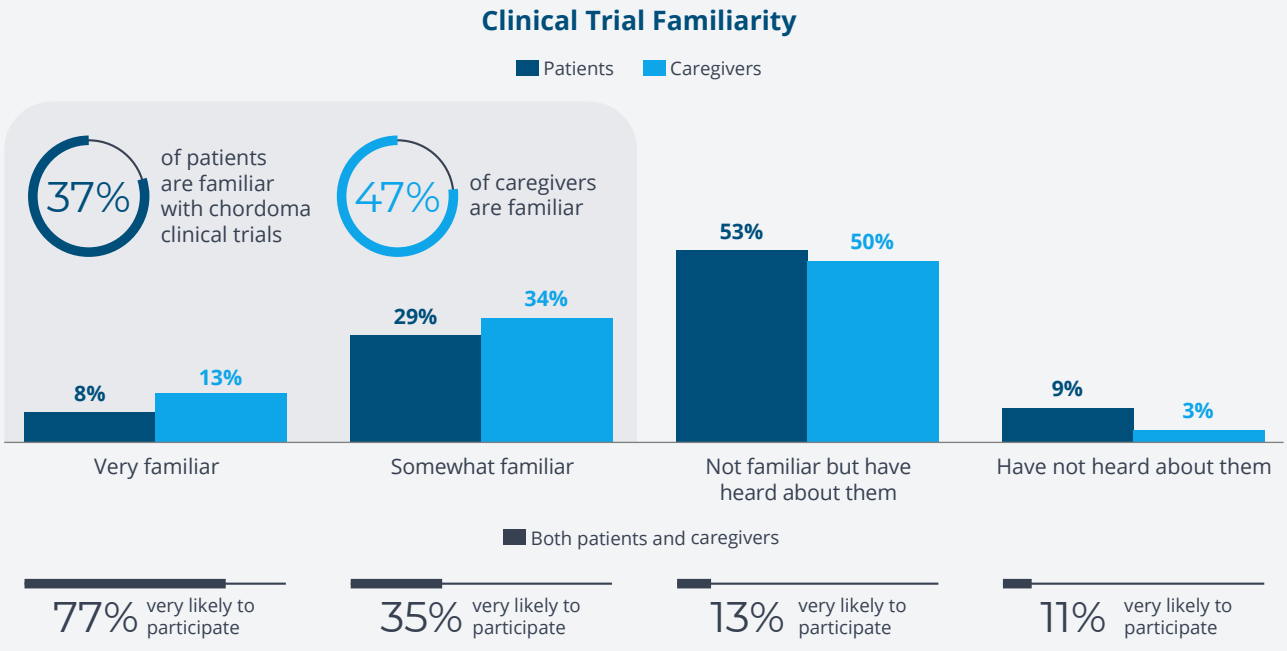
Trial design and communication can help alleviate uncertainty and questions about clinical trials. Over a third (37%) say one of the things that makes them most likely to participate is if they have a better understanding of possible side effects, risks, and personal benefits, as well as knowing they will be allowed to discontinue the treatment if they experience any negative health effects.

Which of the following would make you most likely to participate in a clinical trial for chordoma? Select up to three (3). Top choices:	Patients only
Understanding the possible side effects and risks of participation	**37%**
Knowing that you will be closely monitored and removed from the study immediately if there are any negative health effects	**35%**
Understanding the possible benefits of participation	**33%**

> *I think understanding the risk/benefit in terms of side effects and the role of the placebo would be deciding factors. In addition, travel and healthcare navigation would also be a part of the decision-making process. Ultimately, recommendation from the patient's chordoma expert would be the deciding factor."*
>
> – Caregiver with no prior trial experience

CLEAR COMMUNICATION CAN CLOSE THE INFORMATION GAPS

Most patients and caregivers are unfamiliar with clinical trial options for chordoma; less than half say they are very or somewhat familiar. Yet the more aware patients are about trials, the more likely they are to participate. Education is imperative to close this knowledge/participation gap.



Even among patients who are familiar with or have heard about chordoma trials, just 15% say they understood the information they received "very well". While caregivers are more likely to understand trial information, only a quarter felt this way.

COMMUNICATION DURING TRIAL OUTREACH

Chordoma patients could use more information in many areas, particularly with the more practical and logistical aspects of a clinical trial. Among those familiar with clinical trials, less than half understand the different phases, eligibility requirements, finances/costs involved with participating, and where they can go if they need financial assistance.

How well do you feel you understand the following aspects of clinical trials? *Among those who are familiar/heard about clinical trials*	**Patients** *Understand very/ somewhat well*	**Caregivers** *Understand very/ somewhat well*
Informed consent process	**56%**	**61%**
Potential benefits	**53%**	**70%**
Potential risks	**44%**	**55%**
Trial phases	**44%**	**48%**
Eligibility criteria	**43%**	**53%**
Logistics of participation	**40%**	**48%**
Financial assistance available	**32%**	**47%**
Costs related to trial participation	**30%**	**45%**

Three-quarters (72%) of patients say clear and simple communication about trial goals, risks, and benefits is a must-have.

When *considering* a trial, patients and caregivers say the following are most important:

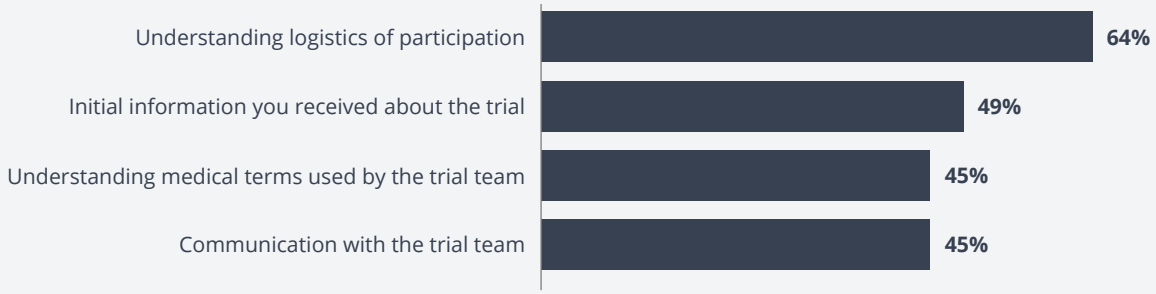
- Clear explanations of possible risks, side effects, and potential benefits (95% very important)
- Step-by-step walk-through of what will happen in the trial (86%) and clear explanations on how clinical trials work (77%)
- Communication directly between patients and healthcare teams to gather information on eligibility (82%)
- Communication directly between patients and clinical trial teams to coordinate screenings and enrollment (79%)
- Help understanding costs, insurance coverage, and financial assistance (73%)
- Ongoing availability for check-ins as the patient thinks through the decision (65%)

COMMUNICATION DURING THE TRIAL

Uncertainty can continue even during trial participation. Among clinical trial participants, a majority say they were very satisfied with their understanding of the overarching logistics of their participation. But drilling down into specifics shows that less than half were very satisfied with the initial information they received and their communications with the trial team. In fact, 45% were unsure of the phase of the trial in which they participated.

Very Satisfied with Aspect of Clinical Trial Participation

Among patients and caregivers with trial experience



Two-thirds of patients (65%) agree that regular communication, along with the ability to ask questions of the trial team, is a must-have. Balancing these interactions between personal and digital channels is important. Just as many want in-person meetings and phone calls as those who want emails, text messages, and online portal posts.

How would you prefer to communicate with staff during the trial?	Patients	Caregivers
In-person meetings	**63%**	**69%**
Emails	**63%**	**73%**
Phone calls	**62%**	**69%**
Online portal	**49%**	**56%**
Text messages	**42%**	**52%**
Total Personal (in-person, phone calls)	**80%**	**81%**
Total Digital (emails, text, online portal)	**84%**	**94%**

One clinical trial participant described how his trial team was effectively communicating—making him feel seen and supported:

> *"They're checking in all the time. Like, 'How are you feeling? What do you need? Have you tried this? What's helpful? What's not? How are you sleeping? How are your bowels? Do you have fever, rashes?'* ***I love that they're checking in. I can honestly even text them or correspond with them at any time.*** *And the researchers themselves knowing more details about the drugs and how they work is great for my brain. I want to know, what are we trying to do here? What's the goal? How is it working?... There's a portal that they use, MyChart, and that's the main way [I get this information]."*
>
> – Trial participant with metastatic disease

When *participating* in a trial, patients and caregivers say the following are very important:

- Clear guidance on who to contact if there are concerns, including after hours (81%)
- Clear communication if anything about the trial changes (81%)
- A single point of contact who can answer questions (even case-specific) (77%)
- Clear explanations of what will happen as the trial goes on (77%)
- Directly sharing what has been learned from the trial (71%)
- Regular updates about the progress of the trial (67%)

The solution is not just patient education, but also communicating the information in a way that makes sense to the patient, at the right time.



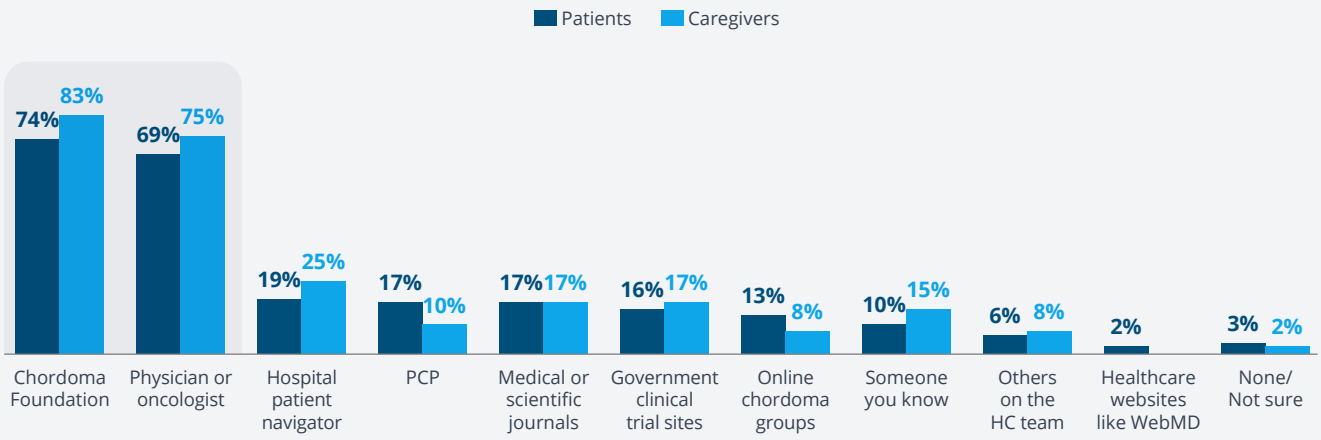
> *Knowing what is normal and understanding that each person will probably respond differently to the trial [was important... so was] trying to understand how to best support my husband and [communicating] with the same person [who] is going to provide consistent responses and someone who understands how my husband reacts to the clinical trial and not having to bring someone back up to speed each time."*
>
> – Caregiver with no prior trial experience

DOCTORS ARE TRUSTED BUT UNDERUSED TRIAL GUIDES

For most chordoma patients, drug therapy clinical trials are not an immediate treatment consideration. Because surgery and radiation remain the main treatments for primary disease and many local recurrences, discussions about drug therapies and clinical trials often occur later in the disease course. Introducing clinical trials earlier in the disease journey (even if they aren't options for a new diagnosis) can give patients and caregivers time to learn, ask questions, and build familiarity with the concept, so they are better prepared to make informed decisions if trials become an option in the future.

Against this backdrop, physicians are trusted, but underutilized, trial educators and guides. When it comes to who patients and caregivers want to hear from about clinical trial participation, physicians/oncologists and the Chordoma Foundation are by far the most trusted messengers. Almost 70% (69%) of patients and three-quarters (75%) of caregivers say they trust their doctors to answer their clinical trial questions. However, few discuss clinical trials with their healthcare providers. Less than half (44%) of metastatic patients say they have talked with their providers about trials. This drops to just a quarter (28% of patients, 23% of caregivers) among those without trial experience.

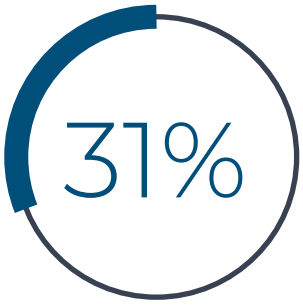
Which of the following sources do you trust MOST to answer your questions about participating in a clinical trial? Select up to 3.



Because many patients have a 'doctor knows best' mindset, they look to their healthcare team for cues about when new options should be considered. While trials may not be immediately relevant for many patients, the absence of any discussion can leave patients unaware of how trials fit into the chordoma care continuum or when they may become an option in the future.

> *Because my doctors have not brought any to my attention, I have not gone and sought out any on my own.* ***If there's one that seems particularly appropriate for me, I would hope that they would mention it… I do trust my medical team to mention things*** *that are appropriate treatments for me."*
>
> – Non-trial participant with advanced disease

Where have you received information about clinical trials for chordoma? *Asked of those familiar/ heard about clinical trials*	Patients	Caregivers	Patients and caregivers with clinical trial experience
Chordoma Foundation	**81%**	**85%**	**73%**
The treating physician or oncologist	**24%**	**26%**	**66%**



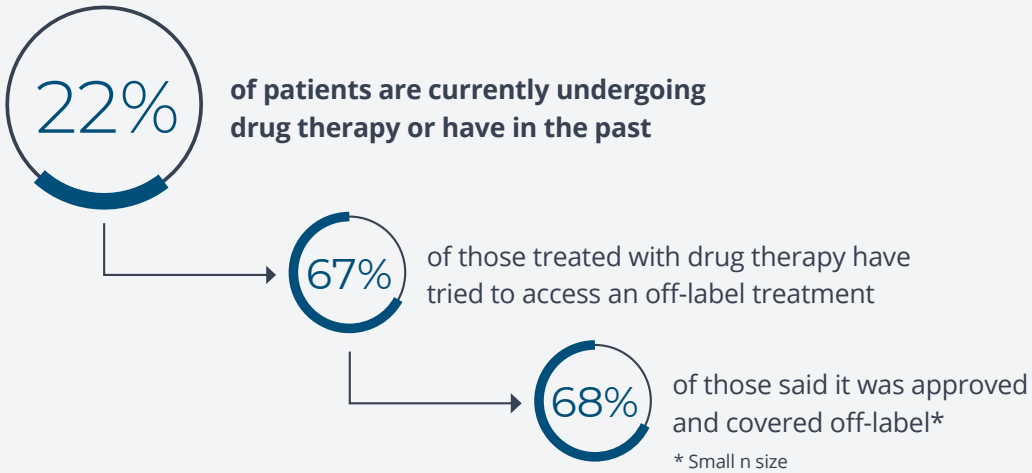
of patients say a recommendation from their doctor or healthcare team would make them most likely to participate in a trial

At the same time, physicians are not currently a primary channel through which patients learn about trials, even among those with trial knowledge. While over 80% mention the Chordoma Foundation as a place they have received trial information, just a quarter (24% of patients, 26% of caregivers) say they've received trial information from their physicians. A recommendation from their doctor or healthcare team is one of the top motivators to participate in a clinical trial.

Physicians and oncologists can serve not just as referral sources, but as early educators. Introducing the concept of clinical trials before they are needed helps patients understand how trials work, when they may become relevant, and where they can turn for information and support. As a result, if a patient eventually reaches a stage where a trial is appropriate, the idea feels familiar rather than overwhelming.

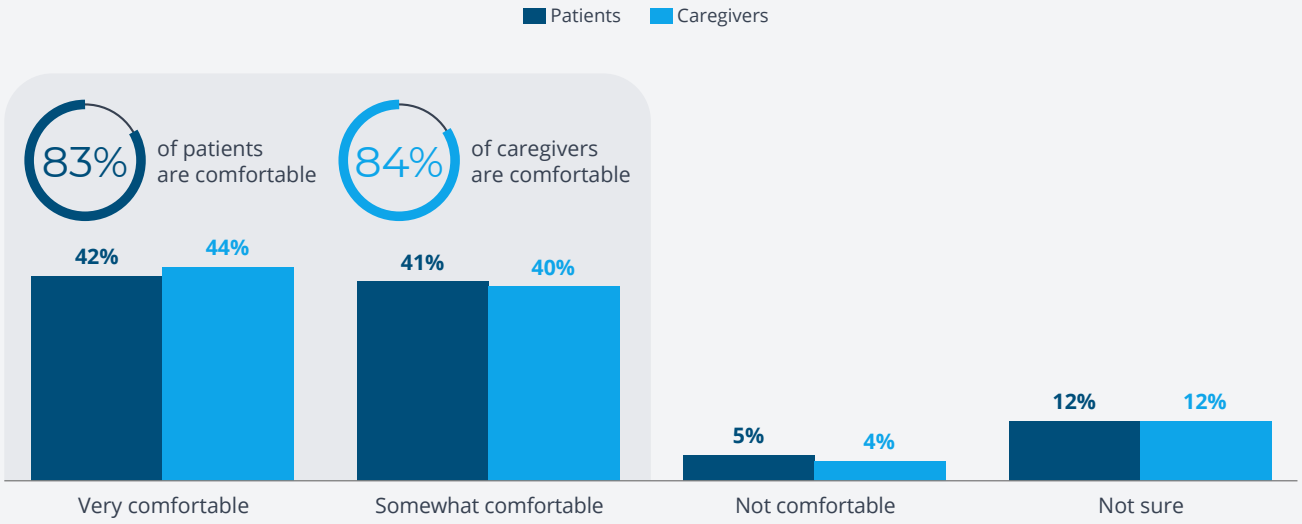
PATIENTS WEIGH TRIALS AGAINST OFF-LABEL OPTIONS

The study also explored how chordoma patients make decisions between off-label treatments and clinical trial participation. In this survey, 22% of patients reported current or previous drug therapy, and among those, two-thirds (67%) tried to access an off-label treatment.

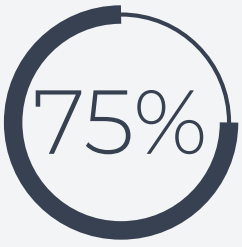


Given there are no drug therapies approved for chordoma, it is no surprise that most (83% of patients and 84% of caregivers) are comfortable with the idea of using off-label treatments for chordoma if they have the support of their physician. Off-label drugs become attractive compared to clinical trial participation when it is the same treatment being tested, is covered by insurance (either fully or partially), and/or eases the burden of trial participation. Three-quarters (75%) of those with trial experiences said they are likely to choose off-label vs. a trial in that scenario.

How comfortable are you with the idea using off-label treatments for chordoma if supported by your/your loved one's doctor?



If the treatment being studied in the clinical trial had been available off-label, and was fully or partially covered by insurance or the health system, how likely would you be to choose that option instead of participating in trial?



of patients and caregivers with trial experience are "likely"

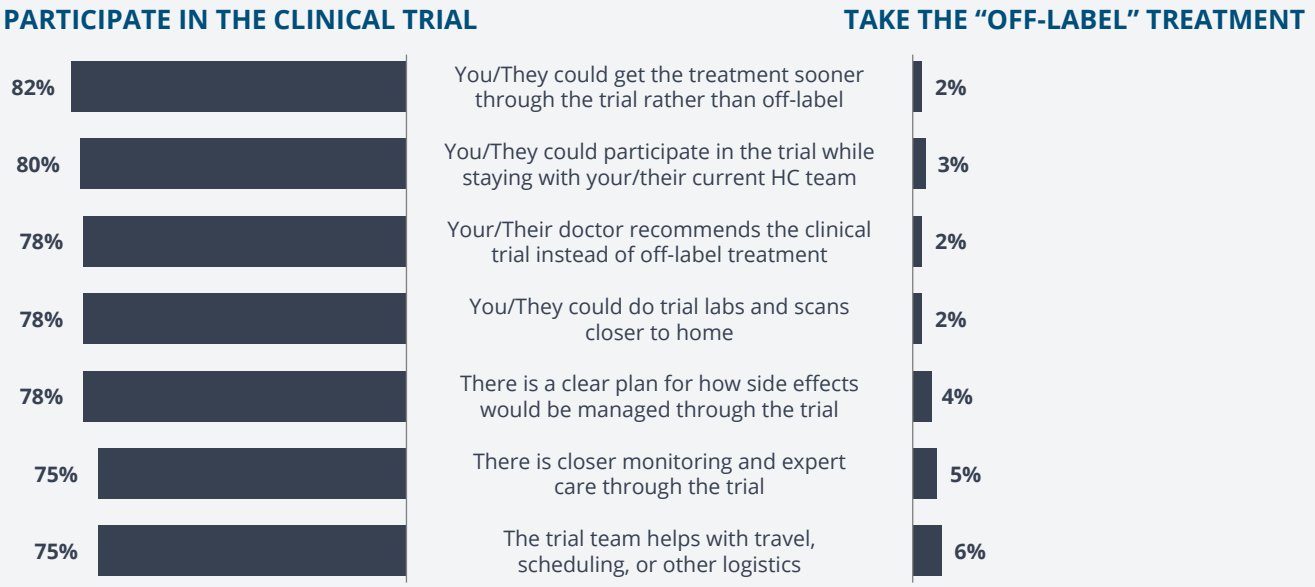
> *It'd be easier. You know, the trial comes with all the constraints of a trial. You have to fill out the forms. You've got to show up here. I can only do it here [in another state], on their schedule, right? I think off-label sounds easier."*
>
> – Trial participant with metastatic disease

However, trial participation is strongly preferred over off-label treatments when certain enabling conditions are present:

- The treatment is available sooner through the trial (82% prefer vs. "off-label") or at a lower cost (72%)
- They could remain under the care of their current healthcare team while participating in the trial (80%)
- Their doctor recommends the clinical trial instead of the off-label treatment (78%)
- Trial labs and scans can be done closer to home (78%)
- There is a clear plan for how side effects will be managed (78%)
- There will be close monitoring throughout the trial (75%)
- The trial team will help with travel, scheduling, and other logistics (75%)

Imagine a scenario in which the treatment being studied in a chordoma clinical trial was also available "off-label" and at least partially paid for by your/your loved one's insurance or health system. If each of the following happened, what would you/your loved one be more likely to do?

Among patients and caregivers



For chordoma patients and caregivers, participating in a clinical trial is often a trade-off decision. What does the trial ask patients to give up—time, travel, continuity of care, predictability—and what do they get back? When the benefits of trial participation are unclear, off-label treatment becomes more attractive. When the trial offers clear clinical value and reduces burden on the patient, patients tend to prefer the trial.

PATIENTS WANT TRIAL PARTICIPATION TO FEEL COORDINATED, RESPONSIVE, AND SUPPORTIVE

Chordoma patients and caregivers want clinical trial participation to include more comprehensive care of the whole person, rather than feeling like they are a number in a research study. Proactive communication and responsiveness are important, and human support plays a critical role in shaping trust, satisfaction, and willingness to participate.

EXPECTATIONS FOR COMPREHENSIVE CARE

Two-thirds (67%) of patients say the "highest standard of care" is a must-have if they are considering participation. In qualitative interviews, patients describe this as care that includes:

- Treating patients with dignity—like humans, not numbers or test subjects
- Having extensive knowledge of chordoma
- Proactively communicating with patients
- Closely monitoring patients' health and responding to concerns
- Ensuring that the clinic environment is clean and comfortable

> *Emergency contact telephone number available… in case of problems arising whilst at home and/or between appointments. Support available for caregivers to discuss worries/anxieties as general practitioner contact [is] limited or not available quickly if needed."*
>
> – Caregiver with no prior trial experience



TRIAL EXPERIENCES FALL SHORT ON QUALITY OF LIFE FACTORS

As patients are looking for treatments to improve their quality of life, clinical trial participants are not completely satisfied with their experiences. Just a third of trial participants (36%) were very satisfied with the impact their trial had on their health and quality of life. Additionally, only 42% were very satisfied with how their side effects were managed while participating in the trial.

But it's not just their physical health that trial teams should be focused on—emotional and mental health is just as important. Less than half (45%) were very satisfied with the emotional or psychological support they received from the trial team.

Very Satisfied with Aspect of Clinical Trial Participation

Among patients and caregivers with trial experience



While only a quarter (27%) of patients consider emotional and psychological support as a clinical trial must-have, another 55% say it would be nice to have. Four-in-10 (43%) trial participants also want regular check-ins about how they are feeling emotionally, and a third (34%) say it's important to offer emotional support and reassurance during stressful points in the trial.

Very Important to Have Types of Support During/After a Trial

Among patients and caregivers



Implications

WHAT THESE FINDINGS MEAN FOR THOSE WHO ARE DESIGNING AND CONDUCTING CHORDOMA CLINICAL TRIALS



The findings in this study can translate directly into decisions about protocol design, communication, and care that are largely within the control of the people who plan, run, and support chordoma trials. Because the stakes of each choice are higher in chordoma than in more common cancers, these implications deserve consideration at every stage: as protocols, budgets, and site plans take shape; in the day-to-day conduct of a study; and in conversations between doctors and patients about trials.

Below are recommendations for putting these findings into practice. Not every recommendation will be feasible in every trial; scientific requirements, funding, timelines, and site capabilities will sometimes limit what is possible. **The goal is not perfection but intention: the more of these recommendations a trial incorporates from the outset, the more likely it is to enroll fully, retain participants, and generate the evidence the chordoma community urgently needs.**

FOR TRIAL SPONSORS AND DESIGNERS

1. **Write feasibility into the protocol.** Nearly half of patients would decline a trial that is far away or hard to travel to, and travel logistics were the least satisfying part of participants' trial experience. Wherever scientifically possible, allow labs, imaging, and follow-up visits to happen close to home or by telehealth; keep required visits to a minimum; and consolidate screening, treatment, and testing into as few trips as possible.
2. **Choose active-control or crossover designs over placebo whenever possible.** Patients and caregivers are more likely to join a trial with an active control or if they can switch to the experimental treatment if their tumor progresses or they experience adverse reactions. If a placebo is scientifically necessary, explain the rationale, safeguards, and monitoring plan in plain language in patient-facing materials.
3. **Measure what matters to patients, not just tumors.** Patients are as motivated by tumor stabilization as by shrinkage, and nearly two-thirds would join a trial if the treatment alleviated symptoms and improved quality of life even without tumor regression. Where appropriate, include quality-of-life and symptom endpoints alongside tumor response, and anchor recruitment messaging in the outcomes patients say they value: meaningful tumor control, better daily life, and progress toward cures for the whole community.
4. **Build in practical supports a rare disease trial can realistically offer.** Funding patient travel is out of reach for most chordoma trial budgets, but a protocol can build in flexibility that costs little, when possible: visit windows generous enough to accommodate long-distance travel, scheduling that adapts to patients' lives, labs and scans coordinated close to home, and site staff empowered to help with appointments and logistics. The majority of patients say help with travel, scheduling, and other logistics would tip their preference toward a trial over an off-label treatment.
5. **Treat patient-facing information as a core trial deliverable.** Few patients who received trial information understood it "very well," and understanding is weakest where worry runs highest: in relation to costs and financial assistance. Budget for plain-language materials that walk patients step-by-step through how the trial works, its risks and benefits, logistics, expenses, and who to contact, with versions for people considering the trial and for those already enrolled.
6. **Build comprehensive care into the design where possible.** Most patients want patient-centered care that closely monitors their health and supports them as people, not test subjects. Specify side-effect management plans, structured emotional check-ins, clear monitoring and withdrawal provisions, and consistent standards for communication and staff training across sites.

FOR TRIAL TEAMS

1. **Communicate clearly at every stage, through various channels.** Patients want a single point of contact, after-hours contact information for critical needs, and to be kept up to date on trial progress. Ask each patient how they prefer to hear from you, revisit key information throughout participation, share what the trial is learning, and make sure they know how to reach key trial team members.
2. **Schedule around the patient's travel reality.** Most trial participants traveled more than an hour each way to their site. Consolidate clinic visits, imaging, and tests into as few trips as possible; try to avoid rescheduling appointment times that families have built travel plans around; help patients access local labs when possible; and refer patients to the Chordoma Foundation Clinical Trial Assistance Program for financial support. The majority of patients say they would be more likely to travel for a trial knowing that support exists, yet few are aware of it.
3. **Make side-effect care excellent, not adequate.** Less than half of participants were "very satisfied" with how their side effects were managed, yet a better quality of life is a leading reason patients enroll. Help patients understand what to expect, make sure they know exactly how and who to report side effects to as soon as they appear, check on symptoms proactively rather than waiting to be asked, and respond quickly when problems arise.
4. **Keep the experience human.** Patients define a successful trial in part by whether they feel cared for and treated as individuals. Regular check-ins on how patients are feeling, not just how their labs look, and including caregivers in communication can make a big difference.

FOR CLINICIANS CARING FOR PEOPLE WITH CHORDOMA

1. **Raise clinical trials proactively, even when they aren't yet an option.** Patients trust their doctors more than almost any other source of trial guidance, but fewer than half of metastatic patients have discussed trials with their care providers, and patients may read silence as a signal that trials are irrelevant to them. Introducing trials early, even hypothetically, gives patients time to learn, ask questions, and be ready to decide if a trial becomes appropriate.
2. **Help patients truly understand how trials work.** Only about a quarter of patients have ever received trial information from their physician, and knowledge gaps persist around trial phases, eligibility, safety monitoring, and what happens if a treatment isn't working. A brief, plain-language explanation from a trusted clinician addresses the knowledge gaps patients and caregivers describe most often.
3. **Talk through the trial-versus-off-label decision openly.** For many patients, both options may be feasible and worth considering. Discuss the trade-offs, including access, cost, monitoring, side-effect management, and continuity of care, and share your clinical perspective. When you believe a trial is the best option, say so clearly: most patients want and value their physician's recommendation when making this decision.
4. **Connect patients with the Chordoma Foundation.** Patients name the Foundation as their leading source of clinical trial information. Referring patients to our Patient Navigators gives them expert help identifying trial options and navigating screening and enrollment, and our Clinical Trial Assistance Program can help offset travel costs—support most patients do not know exists.

A Call to Action

Promising chordoma treatments can only become a reality if clinical trials can successfully enroll and retain patients. The findings in this report provide a clear mandate: we must work together to make trials easier to understand, more realistic to participate in, and more responsive to the needs of chordoma patients and their caregivers.

We invite sponsors, investigators, trial teams, and clinicians to partner with us to turn these insights into action—beginning with the trials being planned today.

Patient input should be sought early, reflected in substantive design decisions, and revisited throughout the life of a trial. Progress should be measured not only by whether a trial opens, but by whether patients remain engaged and feel meaningfully supported throughout the process: finding trials for which they are eligible; receiving trustworthy information about what participation involves; avoiding excessive administrative, logistical, or financial burdens; and feeling they are receiving the highest level of care.

The Chordoma Foundation is committed to helping researchers and trial sponsors act on these insights. Through our Clinical Trial Support Program, we provide funding, partnership, and patient-centered input to help design and advance trials that are scientifically strong, feasible to participate in, and aligned with the needs of the chordoma community.

We are equally committed to supporting patients and caregivers as they consider and navigate trial participation. Our Patient Navigators help patients learn about trials, identify studies they may be eligible for, and understand the screening and enrollment process, while our Clinical Trial Assistance Program provides direct financial support to patients to help reduce practical barriers to participation.

The path to better treatments depends on all of us. We are deeply grateful to the patients and caregivers whose experiences, insights, and participation make progress possible, and to the research community whose commitment and collaboration turn those insights into stronger studies and, ultimately, better care. Together, we can build clinical trials that generate the evidence needed to move the field forward while truly serving the people at the heart of this work.

Appendix

OBJECTIVES AND METHODOLOGY

The Chordoma Foundation commissioned Edge Research, an independent research firm with extensive expertise working with patient organizations, to conduct a study to better understand the attitudes, values, concerns, and preferences of chordoma patients and caregivers when it comes to clinical trials.

TOPICS IN THE SURVEY INCLUDED:

- Awareness and understanding of clinical trials and participation in chordoma research
- Attitudes and concerns about trials
- Access to clinical trials
- Motivations and barriers to clinical trial participation
- Trial design to encourage participation and overcome barriers
- Messaging and communication channels

The survey was designed and deployed using a multi-modal, iterative methodology:

- The process began with two 60-minute listening sessions with small groups of chordoma patients and caregivers, exploring key topics to get their input and hearing the language they use to talk about trials to aid in survey design.
- A survey was distributed through the Chordoma Foundation's network of individuals living with or caring for someone with chordoma. The survey was fielded from May 14 to July 9, 2025, and more than 350 individuals completed it, including 286 adult patients and 68 caregivers. Of the total respondents, 14% of patients (n=39) and 31% of caregivers (n=21) had previously participated or were currently participating in at least one clinical trial. Due to small base sizes, patients and caregivers are combined for a readable trial participant sample. The survey was offered in English, Spanish, Dutch, and Italian. People from 39 countries took the survey.
- To further understand the survey findings, Edge conducted eight follow-up in-depth interviews between July 29 and August 19, 2025 to explore key topics in more detail. Interviews were conducted via video call among both clinical trial participants and non-participants.
- Following the 2025 research, the Chordoma Foundation had follow-up questions about clinical trial support and decision-making factors. In February 2026, Edge deployed a short survey to respondents who opted in to additional research. That survey yielded 107 partial and complete responses.



CHORDOMA
FOUNDATION

chordomafoundation.org

The Chordoma Foundation is recognized by the IRS as a 501(c)(3) non-profit organization, and donations are tax-deductible to the full extent allowed by law. EIN 20-8423943.