GO CART Patient Sub themes

Most Relevant Domains

The most relevant domains were identified based on the criteria outlined by Atkins et al. (2017). Relevant domains were chosen based on the frequency with which beliefs and themes appeared in each domain, the presence of conflicting beliefs, and perceived relevance to the target behaviour.

Key domains for the patient interviews were knowledge, social influence, beliefs about consequences, goals, environmental context and resources, and intention. Memory, skills and behaviour regulation also point to potential strategies for improving patient experiences with clinical trial participation.

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Knowledge

$N=13$

Trials

Participants were asked what they knew about clinical trials. Responses demonstrated a range of knowledge with some knowing about some aspects of clinical trials ($n=10$) and others stating they knew very little ($n=4$). Most participants ($n=10$) indicated knowing that clinical trials were often designed to control for extraneous factors and minimize bias. Seven knew clinical trials were used to test the efficacy of new treatments. Seven specifically knew about placebos and comparison groups, two knew about randomization, two knew trials adhered to specific inclusion and exclusion criteria, and one participant mentioned blinding and reliability. Only one participant knew about the different phases of clinical trials.

R: Well my with clinical trials from what I understand somebody has a therapy whether it’s a drug or whatever and they’ve gone beyond the laboratory portion and now they’re at the stage where they want to actually see how patients respond to that therapy. So often in a clinical trial you will either—I think they often try to do them as a double-blind if they can. In which case you either get the treatment or you get some other treatments and you don’t know what it is and the person giving it to you doesn’t really know and so that way they can decide whether or not the new therapy is working without any bias.

Participant #8

R1: Specifically step by step like it’s no. I know it’s the process they’ve gone through to, to improve and better the whole.

Participant #3

CAR-T Cell Therapy

When asked about their familiarity with CAR-T cell therapy, participants similarly indicated a range of knowledge. Some ($n=8$) indicated having heard about CAR-T cells from doctors, national organizations (e.g., LLSC) and the news while others reported never having heard of them before they were interviewed ($n=5$). Descriptions of CAR-T cells were often brief and tentative. However, three were aware that T-cells were modified to target cancer cells and another three were aware of some of the side effects and efficacy findings.

R: Yeah I’ve heard about them. From what I understand they basically are trying to target your own immune system to, to get at the cancer cells. So, they, they take the, the I believe it is the T-cells from the immune system and then they, they put unless I’m getting this mixed up with something else, I thought they put a virus into it.

Participant #8

And then the, the success rate has been quite high in terms of achieving remission in patients. And they’re continuing to monitor people for how long that remission is lasting, but of course, the flip side is that there’s no reliable off switch yet and sometimes people end up dying so yeah.
Participant #1

Regardless of how much participants already knew about CAR-T cells, most (n = 12) expressed a desire to know more. The most sought-after information concerned treatment safety and side effects, including how side effects might be managed (n = 11). Participants also wanted to know more about treatment efficacy (n = 10) including remission rates, how it compared to other treatment options, and the outcomes other patients have experienced. Ten participants indicated they wanted to know more about the logistics and experience of the therapy (e.g., frequency of appointments, pain and discomfort), six wanted to know more about the long-term effects, and one suggested he would like to know more about global research on CAR-T cells.

You know and possible side effects and what any side effects like you were saying and what if there’s any back-up plan to, you know, like you say reversing those side effects. Or I know there’s no guarantee about anything but just if there was, you know, a plan implemented to mitigate, you know, most or whatever could be, could be done to reverse the, the side effects or, or treat the side effects. Yeah, you know, appropriately or if possibly and, and to know, know the, know all, all the risks, you know, of doing the trial.

Participant #7

R: I guess I would want them to sort of have a fairly good sense as to whether or not overall it was gonna be beneficial for me long-term or, you know, especially in comparison with, you know, what other treatment modalities are available to me.

Participant #8

R: I think that would depend on like how what would be the, what would be the logistics? Is it now I’m, I’m supposing that it would be done at or around the hospital but in other words is there something which could be done at hospital, at home? Is it all hospital? Depending on, on the nature of the, of the tests and trials and so forth is it once/week or once every 3 weeks, you know, those, those kinds of things. So, it would be important to know what the, what the logistics would be to say, you know, can I, can I manage this?

Participant #13

Trial Information Delivery

In addition to wanting more information about CAR-T cell therapy, participants also indicated several preferences for how to receive trial information. Some indicated wanting online information (n = 4) and others suggested written was advisable because they could take their time absorbing the information (n = 6). However, most were concerned about ensuring that information was accessible (n = 7) and that it was sufficient for them to feel well-informed (n = 7). Some participants indicated wanting detailed information and others stated they preferred “not too much” or that striking a balance was key.

R: I think paper and online both, but I think making the, the information as like I don’t know striking a balance between being very detailed and still being like using accessible language. And I don’t know I’m a very big fan of info graphics and stats and percentages...
but obviously there wouldn’t be that many that much of that because that’s the whole point of doing the clinical trial to get that information. But yeah, yeah

*Participant #5*

R: Who’s making the decisions and where, where are we in the whole test? So I know this is gonna be the third time I’ve said this but I’m an equal partner in it. I don’t need to see all the data because I wouldn’t understand it but in terms of decision making I would need to be talked to and I need to be respected and kept informed.

*Participant #2*

This suggests that the informed consent process is highly individualized, and that care should be taken to ensure each trial participant feels they have been well-informed.

**Social Influence**

*N = 13*

**Influential Stakeholders**

Participants identified six distinct influential stakeholders with varying degrees of influence on their decision making – specialists (hematologists and oncologists), hospitals and the healthcare system, friends and family, research staff, other healthcare providers, and past CAR-T cell therapy participants.

**Hematologists and Oncologists**

Every participant indicated that hematologists and oncologists influenced their decision to participate in a CAR-T clinical trial and many suggested they would actively seek out their physician’s input about whether they should participate in a CAR-T trial or not. When asked who they would want to get study information from, nine participants indicated they preferred receiving trial information from their hematologist. Half (*n = 7*) of the participants also shared that they trusted their hematology teams, describing them as confident and knowledgeable, and expressed confidence, faith, and a willingness to follow their advice.

R: I’m open to the idea of it but I would need to consult with what I like to call my team, [laugh] you know, with doctors [name retracted, name retracted] and all of them. I would, I would be so relying upon their advice and their views on the impact on me.

*Participant #2*

R: My hematologist yeah Dr. [name] I mean they’re like the group of seven, you know, they’re all a whole bunch of painters, you know, and they all sit together and, and discuss which I’m so fortunate. So yeah from, from the team from the haematology team that would be beneficial if it came from [hospital], yeah.

*Participant #4*

R: And like I know the haematology team here is really great and really communicative with each other and plugged into the, you know, the global picture and state of affairs for
research and everything. So, I would definitely be seeking their opinion on sort of where things are at and, and should I or shouldn’t I participate?

Participant #1

R: Yeah I would, I would definitely look to my physician like, you know, oncologists, right, whether it’s, you know, whether I should be with the, the state of, you know, my wellbeing opposed, you know, compared with my cancer and, and, and what I’ve been through. Like, you know, there may be some concerns they have with doing it too late, but I’m not an oncologist or a doctor.

Participant #7

A few participants (n = 3) further suggested that they would only want information from specialists and that residents and other health care providers would not suffice.

R: I know but also you ask a resident like a question and they’re like I’ll just be right back I have to ask the doctor. So, when like it’s something that serious you want to talk to a doctor about it not somebody who has to go and consult and then bring you back an answer. You just want to talk directly to the primary source who has the information.

Participant #11

Finally, three participants indicated that they would likely do what their doctor advised.

R1: Oh so pretty much all of my involvement through my diagnosis is just needing to follow directions of my doctors and the suggestions or approval from my wife. [laugh] So I’m, I’m indifferent to what happens it’s just if the right people are telling me what to do then I’m, I’m happy to do it.

Participant #10

R: If my own haematologist felt that it was a worthwhile thing to try I’d probably, I’d probably consider it.

Participant #8

Healthcare System

Participants were similarly confident in the health care and advice they received from hospitals. When asked whether they could count on the health care system during difficult times, most (n = 11) confirmed that they could. Many spoke positively about their experiences and shared that they were impressed with the care and attention they received from both doctors and nurses while in treatment. Some mentioned specific hospitals as trustworthy sources of information that inspired confidence.

R1: Because I when I talk to anybody my friends or anybody I always mention how I don’t want to hear anybody complain about the [province] healthcare system because I’ve been, the care has been phenomenal for me.

Participant #10
R: I think, you know, for my best experience I can recall I’m pretty sure 100% because I was very impressed with the, the health system with during my, my treatment and my cancer. They were, you know, I think we can rely on them 100%. I don’t have any problem at all.

Participant #12

R: I, I think so like what I did a stem cell transplant in [city] and you know what it was yeah it was a very excellent facility there in the [hospital], and I would recommend it to anybody, you know, who is burdened with, you know, making the decision of going through with it or not. I felt very, you know, I entrusted in them and I do.

Participant #7

R1: I think the fact that I had a high opinion of the whole the hospital system here and the fact that the research is wanted to be done and people recognize the necessity for it. That it’s, it’s those individuals that are starting this process that make you want to be involved with it.

Participant #3

Friends and Family

Friends and family were also an important source of advice and counsel. Participants (n = 10) described wanting to hear the opinions of their family and friends, involving them in the decision-making process, and how their support networks helped them sort through the available information to arrive at a well-informed decision.

R: I, I would definitely bring my family members into account. Their, their opinions would be strong and strongly involved.

Participant #8

R: But because I had my family here they, they understood. They looked into the stuff and they and they all decided that yes while they had emotions about it they needed to use their intellect and not be guided by their emotions. So, there were times when things were coming up and there was a choice to be made and they explained it to me like you might not want to do this, but you got to do this. And then I just listened to them. And so, I would need that if I were part of the trial I would need that on a regular basis [laugh]

Participant #2

Two participants also described prioritizing the points of view of friends with medical expertise. While they valued the input of hematologists, researchers, and family, they indicated that hearing from their friends with medical backgrounds would be important to them. In fact, one participant, unlike the rest of the interview participants, indicated that their clinician friends would provide the most influential advice.

R: Hmm good question. I think my medical doctor friends would be probably the most influential and because I, they, they would inform me in what I would how I would inform my husband too because he’s not kind of medically oriented and in how he thinks
and his interests and things. So, he would be relying heavily on me to explain sort of the risks and possible benefits and all that stuff. So, yeah I think it would be my medical doctor friends.

Participant #1

This emphasizes the importance of having trusted medical experts provide their input on whether participating in a clinical trial is advisable. While there are some exceptions, hematologists and oncologists were identified as the most important trusted medical experts.

Research Staff

Some participants (n = 7) also indicated they would want to hear from research staff who can provide important study details. However, hearing from research staff was often thought of as secondary to hearing from specialists. Those that indicated that they would want information from the research team also mentioned wanting information from physicians, particularly principal investigators. Some indicated they would consider the clinical research team’s input when deciding to participate.

I: would you like to hear this from your, your actual haematologist, a family doctor, a research team member?

R: I think I’d be pretty comfortable with all of the above. I would definitely be discussing it with my haematologist… So, but yeah in terms of entry into a study I think anyone working on the study is who can answer a few questions and is knowledgeable about it would be good. It doesn’t matter what their title is. [laugh]

Participant #1

I: Is whose opinion would be the most important when you would be considering whether to participate or not?

R: I think the, the, you know, the doctors, the researchers all of them would be very important. … my main source would be the researchers and, you know, and the medical team who will do the research.

Participant #12

Two participants mentioned they would want the research team to present information in a positive way and one participant indicated they would rather receive information from a hematologist because research staff may encourage participation whereas hematologists were thought to be impartial.

R: No because like yeah I’d want all the information from the research team that’s very important but I’d also want somebody who’s not like I’m not saying you guys are biased but like you guys obviously want me to participate in this study. But a haematologist will be like these are the risks but if you do this it’s almost guaranteed to make you better, you know. Like or like, you know, the risks are 50-50 either way so...

Participant #11

Trustworthy Healthcare Providers
A few participants \((n = 5)\) indicated that they valued hearing from trustworthy healthcare providers. Three specifically said they would want to hear their family doctor’s opinion because they had known them for decades and trusted their input. Another three suggested that any trusted health care provider would be important to hear from.

R: I would say in choosing, you know, we are fortunate we’ve had a doctor here, family doctor for over 20 years and he is just the nicest, kindest and we went to him around Christmas time too just to sort of bring him in and say look I may need some help, may need a home visit. And he was just perfect to have that discussion. So, if there was a sort of a trusted member either of the, you know, somebody who’s had a longer-term relationship with a physician. I realize that’s tougher these days but because a physician is somebody who, you know, we do or, or a nurse or like I say sort of a trusted, trusted individual

\textit{Participant #13}

R: Hmm I think like it would be like actually my nurses who have been with me physically through kind of the worst parts of it. Because they’ve seen other people like me who have had better experience or worse experiences and they I feel like they’re almost the boots on the ground when it comes to seeing symptoms manifest themselves. And the doctors do as well but, you know, they’re in a different way. Like I feel like my nurses have seen the raw, the rawness of, of treatment and yeah and I guess my family as well and my doctors my haematologist.

\textit{Participant #5}

\textbf{Other CAR-T Trial Participants}

Two participants also mentioned wanting to hear from other trial participants regarding their experiences.

And if other patients, other patients that’s participating or participated before could give us some feedback this would be better. It would be probably remove some fears.

\textit{Participant #12}

However, one participant indicated she would not trust other patient’s opinions.

As far as other patients are concerned there’s so much bad knowledge out there far too many people listen to the wrong sources of information or look at, you know, like all the junk that’s out on the Internet. All the anti science like the anti vaccers and the holistic people and, you know, homeopathy and everything. There’s so much junk out there that the average patient is unfortunately not sophisticated enough from a scientific or medical standpoint that I wouldn’t put a lot of effort, or put a lot of emphasis on other, other patients’ opinions.

\textit{Participant #8}

\textbf{Diverse Perspectives}
Four interview participants indicated they would want to hear information and opinions from a variety of sources including hematologists, research staff, other healthcare providers, family, and friends to help guide decision making.

Yeah I think it’s always good to get a diverse set of opinions. And at the end of the day treatment is treatment and you can’t expect, you know, something radically different from person to person, but the way things are framed it can sometimes be helpful to hear it in a different way from another person.

Participant #5

Social Support

Current Sources of Support

In addition to the care and support received from healthcare professionals, participants indicated they valued the support they received from their caregivers, family and friends (n = 8). Caregivers, friends and family were described as playing key roles. Caregivers were often tasked with keeping track of appointments and scheduling, attending appointments, providing care and social support, relaying medical information to patients, and playing an active role in treatment decision making. Other friends and family helped gather information and offered to drive patients to their appointments. One caregiver described having her own support network to help with household chores while she dedicated her time and energy to her daughter’s cancer treatment and recovery.

Six participants mentioned instances of relying on friends and family for various types of support.

because my wife and daughter are so important to me, I’ve been fortunate that I’ve had mostly, I’m gonna say, mostly good days. And, and when I haven’t they’ve been there for me.

Participant #13

R: Yeah we’re like I have to come month on month off Monday to Friday every day. I’m on a month off right now, but what [Patient's partner] did was this is gonna make me cry again we have lots of good friends who said we’ll drive [Patient].

Participant #2

Five specifically mentioned relying on caregivers to gather information and help with decision making.

Yeah it’s kind of a bit frightening but it’s like okay we’re, we made a decision together and we’re good with that decision together.

Participant #13

Two participants indicated that they also found that patient and caregiver support groups were helpful.
R: And I think, you know, from my experience some other cancers don’t get the same kind of specialization. I don’t know why that is. Maybe it’s because it’s more common or I don’t know maybe the history here in the hospital but, you know, we’ve, we’ve attended this patients’ group and, you know, for people who have gone through leukemia which is associated with a hospital here. So I think we’ve been lucky but if we didn’t have those things, you know, if we were in another country, you know, we were on holidays and we were in another country for—we’ve have to do a lot of research first to make sure we’d have the support available to us.

Participant #2

**Desired Social Supports**

A number of participants (n = 8) shared that they not only valued social support but wished to improve access to social support through health care institutions. There were some participants (n = 5) who mentioned difficulties in accessing specialists for non-emergency matters, wanting to receive care from one responsible physician rather than a team or residents, feeling as though they were not being given enough detailed information, and suspecting that physicians who are involved in research do not always have the patient’s best interest in mind.

The question I would be asking myself is, what’s the balance of whoever’s directing this test that they are striking between paying attention to the test itself and my own survival or well being. I would be wondering who which I mean you could do both but if I were in the test I’d be far more concerned about my own well being ...

Participant #2

Specifically, five mentioned that it was important to have a health advocate who could speak on behalf of patients and ensure they received necessary information and attention. One participant indicated that an advocate would be important for presenting clinical trial options. Another suggested that advocates were useful for accessing specialists who may be difficult to contact. A few discussed how they had to advocate for themselves.

When things are less than life and death, no our system is a little too backlogged. Various specialists are hard to get into unless you have somebody really fighting for you. You have to be your own advocate in some cases but you almost have to have a little way in a little backdoor or know somebody in some cases as well. Or you have to be willing to stand your ground and make a fuss with certain people and, and it’s kind of sad that way.

Participant #8

Others (n = 2) suggested they received great care and support during treatment but lamented the lack of support post treatment. Participants also mentioned the importance of improving access to social workers and resources (n = 2) as well as psychological services and counselling (n = 2). One participant indicated they would appreciate a patient and caregiver online forum as a way to manage concerns during treatment.

I guess just greater follow-up with social workers in terms of getting access to EI for example and just ways to not use, not use the system but just like use the resources that
are available to you to your advantage because the regular person doesn’t, doesn’t know how to apply for things like, you know, Ontario Trillium what that even is. I didn’t, I didn’t know what that was until I was suddenly presented with all these pills that I had to take daily. And so yeah definitely greater, greater social work or whatever is involved in those kind of processes in health.

Participant #5

R: That could be, that could be nice to have. Just again because, because it is such a new thing any, any little, you know, different twinge or experience or, you know, whatever physical symptom comes up is like I would be paying attention to it and wondering about it. And, you know, it might be something simple that you could ask the forum...

Participant #1

Beliefs about Consequences

N = 12

Positive Consequences

Almost every participant (n = 12) identified positive consequences to participating in a CAR-T clinical trial pertaining to treatment, health and altruistic benefits.

Treatment Benefits

Participants were supportive of research that aims to improve current treatment options and contributes to developing a cure. Participants indicated that key benefits would include having a treatment option in the face of few alternatives (n = 7) and having the option of a more tolerable alternative to chemotherapy and transplants (n = 6). Three suggested that participating in a CAR-T trial meant gaining access to a cutting-edge technology.

R1: [laugh] If there’s something that is that works as well or better than the, the strains of the chemotherapy well then it’s an easy [laugh] an easy answer to hear that you want to see that.

Participant #3

R: Well it’s, you know, if a person qualifies for the trial, right and then and does it I mean [laugh] it’s, it’s cutting edge, right and it’s, it’s an option that is looking promising and may work...

Participant #7

Health Benefits

Several participants (n = 8) believed that CAR-T cell therapy could lead to health benefits like achieving remission or even a cure and saw that as a key reason to participate. One participant indicated that improvements to quality of life were just as important as prolonging life.
If I go off the treatment and my specialist has told me, you know, I could be I could try to be off the treatment as of March and see how my body responds but the word cure was never brought to my attention [laugh] or said to me. So, if this treatment this new treatment CAR T-cell can actually cure me I’d, I’d be willing to give it a try, right. *Participant #9*

R: Oh okay I see well the I guess the first benefit would be potentially lifesaving and then, and then if not lifesaving at least increasing longevity of, of life and maybe and again I don’t because I don’t know, maybe there’s a quality that’s enhanced also. In other words even if you, if you don’t get all the results that you sort of look forward to if you don’t get remission at least if you have quality of life or a period of time I think that would be, I think that would be important to people. *Participant #13*

**Future Benefits (Altruistic Consequences)**

The most often cited benefit to participating in a CAR-T trial was improving treatments for future generations (*n* = 7) and generally contributing to science (*n* = 6) and the advancement of cancer treatment and technology.

And so they went through trials to get here and so and if the parameters are careful which I’m sure they are about what the impact on patients would be I’m, I’m all for the concept of this type of testing. Because it can end up I’m a perfect example it literally saved my life. And so work was done, research was done in order to arrive at that place. *Participant #2*

Two participants in particularly, indicated they would be willing to participate in a CAR-T clinical trial for the good of others because they have “nothing to lose but lots to gain.”

And I again, you know, I think that being a test subject is beneficial long-term for future generations. So I’m at a point in my disease that I would be a good test subject because I’ve already been through, you know, through so much. That, you know, I think I, I would be beneficial, you know, to, to this to the trial... *Participant #4*

R: I would be feeling more like what have you got, you know, you don’t have anything to lose but you have lots to gain. I, I think is what I would feel like and like I said well hopefully, you know, the, the trial is, you know, is a positive thing and it’s for the better of, you know, myself and if not for myself at least it’s for maybe other people down the road. *Participant #7*

**Negative Consequences**
Although interview participants were hopeful regarding the potential of CAR-T cell therapy, many indicated they were concerned about negative consequences like short and long-term side effects and the dearth of evidence regarding treatment efficacy.

Participants were most concerned about the potential safety and side effects associated with participating in a CAR-T clinical trial and indicated that perceived risk played a part in their decision to participate. Seven participants mentioned the risk for negative side effects, six expressed concern about long-term effects, four were concerned CAR-T cell therapy might lead to a worsened quality of life, and two were explicitly concerned about the risk of death.

R: Negative aspects hmm one that, you know, it doesn’t respond, you know, the way it was supposed to or, or the way they thought it may to yourself or, or to the group whichever. Unknown, you know, side effects unknown side effects potentially to, you know, maybe do more harm than good to, to the patient or, or myself. Yeah long, you know, that being either short-term or, or long-term. That’s about it, yeah other than that I mean there’s not, you know, I know I’m just trying to think here [laugh]
Participant #7

R: Well the unknown, you know, evidently. I think after all of, you know, the chemotherapy treatments and protocols that I’ve been through we still don’t know long-term effects. I think that is probably primarily the setback in, in clinical trials. It’s you just don’t know, yeah so the unknown.
Participant #4

So the, the relatively large chance of dying from the treatment is still a big barrier to me for participating.
Participant #1

Five participants expressed concern about the unknown efficacy rates and suggested that was a deterrent to participating in a CAR-T trial. The ability to provide participants with efficacy data may impact whether participants decide to participate.

R: Yeah because it’s not like we’re test driving a new car it’s test driving something in my body and it could be life and death. Because we’re all different and this could work for a hundred people and kill one and I could be that one so I would be nervous about that.
Participant #2

Two participants also expressed concern that participation in CAR-T cell therapy may exclude them from other available treatments. Implications for other treatment eligibility should be clarified for prospective trial participants.

**Neutral and Ambivalent Expectations**

When it came to evaluating personal risk and chances for survival, participants expressed a variety of beliefs reflecting different levels of acceptance and willingness to gamble. For
example, four participants acknowledged that CAR-T cell therapy may work for some but not everyone and that they could among the unfortunate.

R: I, I’ve read people refer to it that way as well, but again as you say it’s kind of early to say. And also the response can be different, different from person to person. So, one person may get a fantastic response another person may not.

Participant #8

Some were willing to accept a certain level of risk ($n = 2$) while others were distressed at the thought of making a high stakes decision that could be life saving or fatal ($n = 4$).

R: But that’s the same with like chemo or a bone marrow transplant or anything it’s like confidence like oh it’s this like thing that could potentially like cure me and it could be like really good for me but also like I could die from it, you know, like it’s, it’s freaky to think like oh this could cure me it’s like Russian roulette. It’s like this could be the bullet or this could not, you know, so just that pretty much.

Participant #11

Importantly, participants acknowledged that taking risks was part and parcel of receiving cancer treatments and that what may sway their decision to participate in a CAR-T clinical trial is how the risk reward ratio compares to that of standard treatment. Efforts to inform patients should, therefore, include comparative rates detailing how the risks and rewards of CAR-T cell therapy compare to bone marrow transplants, chemotherapy, and no treatment.

Finally, just as perceived risk is an important consideration, so is the perception of possible benefits. In other words, according to one interviewee, patients who consider participating must believe they stand to benefit from CAR-T cell therapy.

R: Hmm that’s an interesting one because I guess I would have to, I would have to have a pretty strong feeling myself that that the chances are good that the, that the treatment was gonna work. So, you know, in even though what they’re looking for is the safety, you know, if the if it made sense that it’s likely gonna work then I’d be more interested in being involved as part of the safety side. If, if there was just too many doubts as to whether or not there was gonna be a positive benefit to the treatment, then I’d have to, I’d have to wonder about, you know, is it worth participating.

Participant #8

Goals

$N = 13$

Personal Benefits

Survival

When it came to exploring patient priorities, it was clear that while helping others and contributing to the advancement of treatment options was considered a valuable goal, most
participants were primarily interested in what they stood to personally benefit from their participation. The most important goals interviewees wished to achieve by participating in a CAR-T trial were increased chances of survival, remission, and even a cure \((n = 12)\).

Certainly it’s something that you’re, you know, we all want to be here for as long as possible.

*Participant #3*

R: You know I’m still gonna I’m fighting, I’m fighting tooth and nail and, you know, I’m gonna do whatever I can and hope that, you know, some, somewhere, some, sometime that we come up with something that will, you know, give a person a better survival rate and time, you know, so about time.

*Participant #7*

So if this is something that for instance has the possibility of them saying okay you go through this and maybe you won’t need treatment again in the future or the chances of you needing treatment again in the future is reduced significantly then that would be, that would be a real positive for me. That would be something I’d want to know from the haematologists. Because again every time like when they talk about it they say every time you have to have treatment the expectation is that your remission the second or third time a subsequent time will be only half the length of time of your first remission. So it gets to the point where they can’t really treat you it’s not worth treating anymore because if you’re only gonna have a remission that’s, you know, so incredibly short what’s the point? So if, if a CAR T type of therapy if it’s, you know, if you can get a response like the, the so-called cure where you essentially have such a good remission that you’re not worried about it anymore then that’s something that’s worthwhile.

*Participant #8*

Survival as a priority was additionally demonstrated by what participants were willing to endure. For example, some spoke of travelling long distances, attending frequent appointments, and risking side effects.

R: Yeah [laugh] that’s a big word, right. Yeah knowing, knowing that with treatment there are possible side effects, to me as I guess as a younger adult I don’t have any other type of disease concurrently so for me I’d be willing to take the risk of more aggressive kind of treatment I guess if I can use the word [laugh]

*Participant #9*

**Quality of Life**

Not everyone prioritized survival or the potential for a cure above all else. Five participants were especially vocal regarding the importance of quality of life. One participant in particular, indicated that he would prioritize quality of life over survival given his older age.

… it seems to me that there are a lot of people and it’s good for them who will do the, the, you know, different things to stretch out the, stretch out life. And I think that’s, that’s
your choice, but, but I think quality of life is more important than the quantity the actual timeline.

Participant #13

Others talked about wanting to reduce the experience of pain and discomfort \((n = 4)\) and that their well-being was more important than contributing to research \((n = 2)\).

Just that unknowing that it’s new and when you’re in like a life-threatening situation you want something that is proven to work and not like, like in theory you’re like oh yeah I’d want to help research and test and everything. But when you’re in that situation and your life is literally in, in the cards you’re less willing to actually like use yourself for that when you know you have an option that’s more likely to work.

Participant #11

**Benefits to Others**

Though survival was the highest priority, many interview participants recognized they may not live long enough to benefit directly from CAR-T cell therapy. Thus, many spoke of the merit of contributing to CAR-T research because of the benefits to future generations and the general advancement of cancer treatment. Specifically, nine participants mentioned that helping others was important to them.

R: I think primarily to know that it’s advantageous for, for people that have, have just been newly diagnosed. And, of course, survival, you know, I’ve got a grandson. Yeah, yeah but I think, you know, I think a big part of me just wants to see in that there’s a benefit for, for people. I’m gonna cry now. For people, you know, in the future yeah. Yeah, yeah not have to go through what I went through, yeah.

Participant #4

And also the other motivation like I said earlier is to help others and to help the research and, and but my greatest motivation would be probably like I said if my cancer comes back and they ask me to participate and if they could help me that way I will, I will definitely go for it.

Participant #12

Though many were in favour of participating in order to help others, most mentioned this goal as secondary to personal benefits. That is, participants were first motivated by personal gain and second by the appeal of helping others. One participant indicated that he was not at all motivated by altruistic considerations.

R: Hmm I think, I think the way in which it’s framed to me the way in which it’s presented. And like, like if it’s presented as a way to help other people and to kind of, kind of me to be an experiment essentially then I wouldn’t feel so good about it.

Participant #5

Participants also shared that they valued advancing the science and technology of cancer...
treatments \( n = 9 \), that participating in research \( n = 7 \) was important, and that finding a cure \( n = 5 \) was a priority, even if they did not stand to gain from it.

R: Well let me relate it to my situation with APL. The treatment that I’m getting with the Atra and arsenic is relatively new over the last few years. And so they went through trials to get here and so and if the parameters are careful which I’m sure they are about what the impact on patients would be I’m, I’m all for the concept of this type of testing. Because it can end up I’m a perfect example it literally saved my life. And so work was done, research was done in order to arrive at that place.

*Participant #2*

R1: I, I think just generally having gone through what I’ve gone through I think I’m more open to the idea of wanting to be part of clinical trials for, for the betterment of the whole process.

*Participant #3*

R1: My participation in any research is the best outcome is further advancement to eliminating cancer well not, children or grandchildren or just, just the advancement of beating cancer.

*Participant #10*

Participants also indicated that improving current treatments options by finding alternatives to chemotherapy \( n = 4 \) would be important as was testing for safety \( n = 4 \) to ensure risks are diminished.

And just this idea that there is an alternative I think that’s very comforting because like chemotherapy does terrible tings to the body and it yeah it, it’s crazy.

*Participant #5*

R: No because I, I think the safety I think, I think years ago the chemo got as many people as the cancer did, you know. Just so it’s very important to, to make sure that, that not just, you know, you’re making somebody, you know, you’re, you’re helping cure perhaps a disease but you’re but the chemical itself has taken the person out. So, no I think that would be very important.

*Participant #13*

**Environmental Context and Resources**

\( N = 12 \)

**Enabling Financial Resources**

When asked what resources participants would need to participate in a CAR-T clinical trial, most \( n = 11 \) responded that having parking and transportation provided or paid for would alleviate the burden of attending frequent appointments.

R: Sure I mean obviously any, you know, any benefits is more than welcomed. You know, as I, I’ve mentioned to you before, you know, I’ve the parking, of course, is, is
a bit of a financial burden but, you know, we do have mechanisms in place. But yeah just knowing that you can come and go without that sort of, you know, burden would be beneficial for sure.

*Participant #4*

R: That would, that would help parking fees anything to subsidize my expenses if I would need to visit the hospital or the medical facility that would be helpful.

*Participant #9*

In addition to parking and transportation, participants mentioned a host of other resources that could be helpful to prospective trial participants including, covering trial medication (n = 3), caregiver costs (n = 3), child care services (n = 2), accommodations (n = 2), and helping participants and caregivers access alternative sources of income (n = 2).

R: Mm hmm definitely caregiver and transportation. I was lucky that I had my mom but if things had gone even remotely differently and she hadn’t been able to get time off from work and if she hadn’t had another alternative source of income which she does. She gets a pension from, from Columbia where she worked for a few decades. That’s where we’re from and that’s where I was born and that is a very stabilizing source of income in her life and in the family, family’s life, but like if she hadn’t had that then things would have been different.

*Participant #5*

R1: I mean if you’ve got people with kids that need childcare to be able to be part of the process well you do have to think of those, those aspects.

*Participant #3*

R: Well I, I’m not sure just like is this a daily thing that is done or weekly or every 2 weeks that would make a difference. I’d have to look at housing and for my wife as well. She would travel with me in all likelihood anyway. So housing would be a big thing. Yeah eat, of course, but you have to eat wherever you are so that’s, you know, of.

*Participant #6*

Some interviewees (n = 6) indicated that they would not need any resources because they lived close to the hospital and did not mind paying for transportation. Resources should, therefore, be allocated according to need to ensure that those who require greater assistance are not excluded from trial participation because of financial barriers.

**Appointment Frequency and Availability**

Participants were also asked about appointment frequency to determine whether appointment schedules might be a participation barrier. The majority (n = 7) indicated that they would be willing to attend as many appointments as necessary. Some indicated that weekly (n = 1) monthly (n = 3) and long-term follow-ups (n = 1) were feasible and manageable.

like people can be quite strong. You know I don’t think they always, you always see yourself that way but I think it’s like okay this is, here’s something where we like we
need you for 2-3 hours like one, one day in 3 weeks can you do that? Yeah, yeah, I could do that.

*Participant #13*

Only two participants indicated that frequent appointments may be a hassle.

*R: I don’t know how the whole procedure goes but I, I guess I’m imagining that I have to visit the hospital quite often to have the procedures done on me. Right now as a patient it’s pretty simple and manageable for me. I take a pill every day but if that if a new treatment means I have to go into the hospital and quite frequently to, to continue with the procedures then maybe that’s a hassle.*

*Participant #9*

Others (*n = 3*) indicated that flexible appointment hours may be helpful. One participant shared that because they were retired they could be available whenever needed.

*R: Not covered but maybe like add appropriate times like if someone like to be able to have flexible hours almost. Like if say somebody is like I don’t know how but they’re well enough to still be in school or in work, part-time or whatever, while they’re doing this it needs to be like you can’t just all of a sudden be like oh I’m at work but I have to leave at this time to go to this trial and come back. Like it needs to be after their work or on weekends or stuff like that whereas usually like clinical and medical appointments are like cut off at 4 or even like before 5 o’clock where that’s when people are getting off work, right?*

*Participant #11*

**Access to Information and Medical Experts**

Finally, a few participants (*n = 4*) indicated that they would appreciate access to medical experts during the clinical trial. For example, one participant suggested a 24-hour hotline.

*R: Definitely my specialist and the medical team for any questions that I have like if I’m feeling some side effects right away I could get someone to look at me and maybe monitor in the hospital. But because I find that trying to reach a medical team is pretty tough here. [laugh]*

*Participant #9*

I think like a 24-hour phone number to call with any questions would be a really important one.

*Participant #1*

**Behavioural Regulation**

*N = 12*

Participants were asked about strategies they use to keep track of appointments so that any barriers or enablers to attending follow-ups could be identified. While five participants said they were satisfied with reminder phone calls, most participants (*n = 9*) indicated that they used and
preferred electronic methods for tracking appointments like email, text, Google calendar or mobile phone calendars.

So I, I try to have a couple of things in place here so that I know okay and then generally we get a phone call from the facility wherever either the treatment or the appointment is we get a phone call usually ahead of that as a reminder. So for me that those are the things that I would use I guess.

Participant #6

R: No but yeah an e-mail or a text would be, would, you know, it would be nice. I usually have it in my phone, but then again, you know, if when you’re feeling awful and sick sometimes you make mistakes entering things in your calendar or whatever so a reminder is a good idea then.

Participant #1

Some participants indicated they also used physical calendars and more than half ($n=8$) shared that they often use multiple methods for keeping track of appointments. Four participants shared that their caregivers were instrumental in scheduling and tracking appointments.

R: Well I, I’m pretty organized myself so just having a list of all of the appointments and having a clear timeline helps because then I jot that down, like I use a Google calendar and I have an agenda and then I have a big kind of board that I write it on in my room. So I think just having all the dates set out. Like I get phone calls every so often just the automated phone calls with a reminder

Participant #5

R: Yeah so my, my husband he’s been really good. He whenever we, we go to an appointment he’s there with me so he would put down the next appointment on his calendar as well so he, we remind each other basically. [laugh]

Participant #9

Given the increasing use of electronic devices and tools, providing electronic reminders in addition to phone call reminders may help patients keep better track of their upcoming appointments.

Three participants indicated that attending appointments was a priority. One participant described how he and his wife “make a day of it” as a way of integrating appointments in their daily life. Another three characterized themselves as well organized, suggesting they were unlikely to miss an appointment. One participant shared that while missing appointments during acute treatment was unlikely, it was possible to once in remission. This suggests that reminder emails and phone calls may be more important for long-term follow ups than during acute care.

Other than, other than that I don’t know, I mean it’s for sure going through treatment of sorts is a busy, a busy a very busy time but it also becomes somewhat the focus of your life so I think it’s easier for me to forget appointments now that I’m in more of a maintenance—I’m not doing maintenance treatments but I’m more in that remission maintenance kind of thing.
Participant #8

In other words, what would, what would it, would it be a daily, would it be a weekly, would it be a monthly. You’re probably like every 3 weeks we live out in [name of town] so it’s about 45 minutes or so but it’s we don’t even think about it. We just make it part of our every 3 weeks we just make it part of our it’s, well right or wrong, it’s become part of our life. And we tie it into other things.

Participant #13

Intention

N = 12

Four participants indicated that they would participate in a CAR-T clinical trial. Three suggested they would participate because it would help others.

R2: …I think we can make our voice known right now that yes, definitely we’d be interested in participating.

R1: Yes, mm hmm, yeah either way we’d want to know the status and where what stage it’s happening and you could benefit being part of the process.

Participant #3

R: Well with the research that is already out there that definitely has swayed, you know, my desire to be part of the, you know, a clinical trial. And I again, you know, I think that being a test subject is beneficial long-term for future generations. So I’m at a point in my disease that I would be a good test subject because I’ve already been through, you know, through so much.

Participant #4

Three participants indicated they definitely would not participate because they believed the technology is not advanced enough and the therapy is too risky.

Most participants, however, wavered in their intentions and suggested they would participate if they knew they would benefit from doing so (n = 8), if they had no other treatment options (n = 7), if their doctor asked them to (n = 3), if they knew it would benefit others (n =2), and if they believed their health was good enough to endure the therapy (n = 1).

I’m game to try it but at the same time it’s like well if I’m not gonna get, you know, if I’m not gonna be getting the drug say in like the what is it randomized ones where you don’t get or you’re just getting something that looks like the drug. Would I really want to do something like that?

Participant #7

R: Yeah hmm I’d say if I didn’t have any other decent options I guess like if I’m told after this next round whatever it is and it doesn’t work if I’m told we [participant's name] I’m sorry that’s really all we can do for you, I’d probably be very inclined to go into a
Two participants suggested that they would be more willing to participate in an efficacy trial than a safety trial. Another two were unsure.

R: I, I think I’d honestly feel much less comfortable because safety I feel like is just it just has more negative connotations with devastating side effects or minor side effects whereas effectiveness is more associated with change for the better and growth and recovery. And yeah I, I would feel much less confident if it was phrased as testing the safety of this because then you think oh what’s going to happen to me?

Participant #5

R: Hmm the safety of CAR T-cells yeah that’s that might be the only reason that I might hesitate to participate, especially when I feel okay right now. I don’t know if participating in that stage of the trial would benefit me.

Participant #9

While motivation to participate was variable, this is likely to do with the patients that were sampled. Many of the people we interviewed were currently receiving treatment or were in remission. However, those who will be eligible for CAR-T cell therapy will relapsed after having tried all available treatments (i.e., chemotherapy and transplants). Under these conditions it is likely that many more patients will be motivated to participate in a CAR-T trial as is suggested by the intentional condition of having no other options.

Emotion

*N* = 13

When asked how they feel about potentially participating in a CAR-T trial, most participants (*n* = 11) indicated they would feel positive, excited and hopeful at the potential to benefit from CAR-T cell therapy. Two said they would feel grateful for the opportunity and two said they would feel fulfilled knowing they had contributed to improving cancer treatments.

And especially because there’s, there’s also so much of a huge range in terms of what kind of side effects and the degree of side effects that people get. So, nervousness would be in there but I would also say that probably overriding that would be hopefulness.
Because I can’t see the point of participating in something like that unless you’re hopeful that it’s gonna work.

Participant #8

Participants also suggested they would feel anxious and scared \( n = 9 \) because of the unknown outcomes and threat of side effects. One participant shared that she would also feel financially stressed.

R: Yeah because, you know, it even it I shouldn’t say even but it, it takes an emotional toll as well when you’re faced with the decision of can I afford this or can I not afford this? And, you know, that can put a lot of stress on, on a person.

Participant #6

Many participants \( n = 9 \) also described feeling mixed emotions of feeling hopeful and positive but also fearful and nervous. One participant described his ambivalent feelings as bittersweet.

R: Oh and also fear, you know, like it’s almost like confidence but also fear because it’s like what if it doesn’t work? What if I have these side effects?

Participant #11

R: Hmm kind of a sense of helplessness. Definitely helplessness and lack of agency because by that point everything else would have not necessarily have gone according to plan. And like it definitely like I feel bittersweet at the thought of that because it’s sweet that, you know, you’re getting access to a ground breaking treatment that could be it very much seems to be the future of, of the, the field. But bitter that you have to be in that position at all. And so, so yeah but I feel that by that point it would, it would be different your, your mindset because it’s like at that point you just want to survive and make it through it at all so yeah.

Participant #5

Despite the range of emotion participants described feeling, they indicated that these emotions would likely not impede them from participating.

But I think, you know, I think I will, I will probably like I said I will probably be afraid but I will be probably willing to do that anyway.

Participant #12

Memory, Attention and Decision Making

\( N = 9 \)

Participants discussed additional factors that contribute to their decision making including assessing their current age, health and prognosis \( n = 8 \), the impact it may have on their families and caregivers \( n = 3 \), comparing available treatment options, like BMTs, to CAR-T \( n =1 \), and considering what there is to benefit from participation \( n =1 \).
Those that considered health and prognosis indicated that if they were young and healthy they may be more willing to try aggressive treatments. Those with poor prognoses were likewise willing to try experimental therapies.

R: I believe in, in that you are perhaps a test subject and my individual opinion on that is, you know, I’m fine with it because of where I’m at in, in my prognosis.

Participant #4

R: Yeah [laugh] that’s a big word, right. Yeah knowing, knowing that with treatment there are possible side effects, to me as I guess as a younger adult I don’t have any other type of disease concurrently so for me I’d be willing to take the risk of more aggressive kind of treatment I guess if I can use the word [laugh]

Participant #9

However, those who were older (70+), in remission, or currently receiving treatment, were less inclined to risk clinical trial participation.

R: Hmm I guess it would be if for instance if the and since I’m, I’m in a good partial remission. They said look like, if it does look like my own situation was sort of like the, the remission was starting to fail then that would definitely be something I would consider regardless of the position I was in.

Participant #8

Participants also discussed how their illness affected their attention and memory. Six patients described decreases in their capacity to retain information, remember and attend to different stimuli. They described having trouble understanding what was being said to them and feeling overwhelmed by the amount of information that was provided.

R1: Yeah well you’re the caregiver I’l be a lot of times I’m sitting back and unable to take in everything that’s going on because it’s happening so quick when I’m so weak with everything that you can see everything or explain it to me or understand what’s being said.

Participant #3

When a bunch of information like that is thrown at you, you don’t really absorb all of it especially when you’re in kind of just like this trauma, scared state of just like oh you’re body’s trying to kill you, you know.

Participant #11

Several discussed the importance of having caregivers who were willing to listen, take note of critical information, and help them keep organized (see Social Influence and Behaviour Regulation).

Skills

N = 11
When asked how they would go about enrolling in clinical trials, participants described using a variety of skills that enabled them to search for information, speak to their doctors about their treatment plans and available trials, and generally advocate for their care. Specifically, eight interview participants described the different ways they knew how to find information about CAR-T cell therapy and clinical trials. They described doing Google searches, visiting national websites like the Leukemia and Lymphoma Society or the National Institutes of Health, speaking with their doctors, reading news articles and directly emailing clinical trialists.

R: Hmm if I found out there was one sort of in the area or that I could have access to I would probably, you know, getting somebody’s e-mail address and, and reaching out to them by e-mail to just see what the scoop is and if I would qualify.
Participant #1

So, I would go about getting a hold of either like the Leukemia/Lymphoma Society. They do have, you know, some support, right, to look for clinical trials but I believe it’s a 1-800 number. I believe it’s in the States.
Participant #7

Others indicated they would ask their doctors about their eligibility for CAR-T trials (n = 7) and would notify their hematologists of their interest in participating. One suggested she would wait for her doctor to approach her.

R: I think I would tell Dr. [name]. I think they pretty much know [laugh]. Dr. [name] has been my haematologist for many, many years but because I went to an allo stem cell I’m now I’m part of the bone marrow transplant team. They’re very good at letting you know and I, I’ve been very verbal that, you know, I’m not there yet. And I haven’t put my name or anything out there but when I did see Dr. [name] giving that, that session on CAR T-cell I was very interested. So yeah I would, I would research it myself and, and put my name in but I’d also let the doctors know that I’d be interested.
Participant #4

A couple (n = 2) participants described how they approached speaking with their doctors. One described seeking out second opinions and the other shared that he prepares for his visits with his physician.

R: I would bring it up to my doctor first and I would also Google it. I’m bad sometimes because I’ll always Google and like see the worst case scenarios happening and then get psyched out because of it. But that’s what I would do just sort of read about it and be informed because I find that sometimes doctors they kind of—and like obviously not maliciously but like mine like simplify it and just kind of brush over it. But then when you’re informed then when you have specific questions and specific terminology that catches their attention that’s kind of like mostly reserved for those in the healthcare profession. That’s when you can get more detailed answers which I’ve found has very much been the case in my experience. Like I have to come armed with, you know, a good set of specific questions to get specific answers.
Participant #5

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Two participants indicated that familiarity with a healthcare setting is helpful and that navigating the healthcare system and advocating for their own care may have been challenging if they had been unfamiliar with a hospital setting and medical language.

I’m fortunate, again the wife, daughter, father-in-law’s a doctor, mother-in-law was a nurse. So, you know, it’s sort of around the tables and discussions even some of this discussion, you know, different discussions would come up. And you actually get comfortable where, you know, just sort of simple going to the emergency room can be intimidating.

Participant #13

One participant explained that while he was familiar with a hospital setting, he had to learn how to advocate for himself.

R: I mean I did understand how hospitals work because as I said I volunteer and that so I was a bit familiar with overall environment of a hospital but I was utterly unfamiliar with being an inpatient and, and a sick patient in a severe condition that was very new.

Participant #2

R: And I got asked that a million times while I was here both by the nurses and by the doctors. And when I came to realize that I could ask questions and get an answer they would answer. And back to the point I made earlier that if I were part of the upcoming trial I’m an equal part.

Participant #2

These experiences suggest that newly diagnosed cancer patients may benefit from training on how to search for trustworthy information regarding their diagnosis and available treatments as well as training on how to approach physicians and specialists with questions and concerns.

Nature of the Behaviour

N = 11

Most participants reported never having participated in clinical trials or research (n = 8). Four indicated they had experience either participating in a clinical trial or trying to enroll in one. One participant that tried to enroll did not meet the study criteria and was unable to participate. Two participants were sure they had participated in clinical trials and one suspected but was not sure.

R: I’m not, I’m not exactly sure if it was clinical but at that point they were they stopped using R-chop. And they’d started to which was the rituximab.

Participant #4

Two other participants believed they had participated in research but were not sure regarding the details. One described having participated in a patient panel that may have been part of a patient engagement imitative.

R: And I was also I was involved in, in a panel that was technically some research but it was a patient and patient and family sort of feedback type.
Participant #8

Regardless of their experience, participants were unable to provide details about the research they participated in. A couple mentioned “signing something” and allowing their blood and other samples to be tested but knew little about what they were consenting to or what would become of biological samples.

Only patient seemed sure of the details regarding the clinical trial they participated in and why they chose to do so.

R(2): But she did for the FLT3 she did take midostaurin which was a clinical trial drug.
...

R: The purpose was a FLT3 inhibitor because the FLT3 makes the AML more aggressive and harder and more likely to come back and harder to, to get rid of. It just is just a bad thing and so the midostaurin like inhibited and [4:28] _______ like the FLT3 until I could get the leukemia under control and it has stopped that.

Participant #11

Social, Professional Role and Identity

N = 13

When asked whether participants had any moral or ethical objections to CAR-T cell therapy, most patients (n = 11) indicated they did not. A few offered explanations and indicated that CAR-T cell therapy, and technological advancements in general, were not in conflict with their religious beliefs or values.

R: No. If it was gonna, you know, if it was gonna improve my, my life, you know, with cancer and, you know, I’m a religious person. You know I have faith and, and stuff, but at the same time I believe in science too and, you know, I entertain naturopathic ways and, and consulted with some naturopathic doctors. I like I said I believe in science and I wouldn’t have a problem with, you know, using a genetically altered cell to kill cancer that is, is growing, you know, inside living inside of me and growing and potentially, you know, life threatening to me. I wouldn’t have a problem with doing it, no.

Participant #7

A couple mentioned they did not have any ethical problems with CAR-T and actually preferred immunotherapies to chemical therapies or BMTs that expose patients to host vs graft disease.

R: I think it would be great. You know I don’t, I don’t have any like moral or ethical qualms about engineering my own cells and putting them back into me to fight cancer. I think that I think it’s great if we can, if we can not we, if humanity can do that I think we need doing the cells. I, you know I would way rather have my own reengineered cells than but, you know, I am a bit nervous about something like a bone marrow transplant or
stem cell transplant because of the risks of [16:05] [graft vs host] disease and all that stuff.

Participant #1

Five participants also mentioned aspects of their identity that may influence their decision to participate in a CAR-T clinical trial. Three mentioned that helping others was part of their identity and drew connections between their altruistic self-concept and their willingness to participate in clinical trials for the good of others.

Not only to yourself, about yourself think to others and we are all everybody in my family we’re all like this, you know. Like we, we put ourselves in second we always put others in front, before us. Like for us it is very important and we have good values in that way, you know, like generosity is very important and to give others it’s very important and also to help, you know. And that’s why I think I will, I will not hesitate to participate and to, you know.

Participant #12

Other \((n = 4)\) participants discussed how the experience of having and treating cancer has changed them forever. They discussed wanting to participate in research and clinical trials because they had a difficult time with their treatment and wished to make the process easier for others and suggested that fighting cancer was a group effort that required the involvement of patients and health care providers. Finally, one young man described how cancer changed his life dramatically and how that instilled a commitment to continue fighting.

R: I think I guess just like thinking about the context in which I was diagnosed it was very difficult. It was a very difficult age for it to happen to me. Because I was 20 years old in my 3rd year of university, doing well in school and I think just the time in which it happened was very—and obviously there’s no perfect time to get cancer but it was just devastating. Particularly just because everyone continued to achieve their goals, get internships, go around the world and then I guess my personal growth and my reputation in some ways became about my recovery and my comeback which happened. And so I feel like I would very much be in favour of that trial because not only would you be possibly helping yourself but you like I would be paving, helping in paving the road for, you know, more people to not go through what I went through. And even like worst experiences as well and I feel like that’s something very much that I would love to do just because yeah, yeah I, I’ve been just very defined by it. Just because I like I’ve worked with different departments that with like a lot of different students and when I got sick like everyone knew about it. And so, and so yeah I would want to do as much as possible to continue fighting and helping others yeah.

Participant #5

Optimism

\(N = 10\)
Participants were generally optimistic about the prospect of a CAR-T clinical trial indicating that they expected more positive outcomes than negative outcomes. Eight participants expressed optimism regarding general treatment outcomes, survival, alternatives to chemotherapy and transplants, and advancing science. Three participants expressed optimism about improving treatment options for future patients. Three participants indicated they were cautiously optimistic given the toxicity and mortality risks and believed that most clinical trials go well.

R: Absolutely. Absolutely yeah it’s almost a decade that I’ve, I’ve seen what’s gone, you know, what’s happened. And it’s always evolving which is just—I, I think we’re in very exciting times, very exciting times. I’m just thankful I’m along for the ride. [laugh]

Participant #4

R: Feelings let’s see well you feel well you feel like you’re [laugh] I would be feeling more like what have you got, you know, you don’t have anything to lose but you have lots to gain. I, I think is what I would feel like and like I said well hopefully, you know, the, the trial is, you know, is a positive thing and it’s for the better of, you know, myself and if not for myself at least it’s for maybe other people down the road.

Participant #7

R: Yeah, you know, I think that there’s so much to be gained by, by studying it more in people and just increasing the end, the sample size. And, you know, the yeah I do think that there’s a lot of positives to be gained but the negative’s a big negative.

Participant #1

Beliefs about Capabilities

Beliefs about Capabilities

N = 9

Seven participants indicated they would feel confident participating in a CAR-T cell therapy trial. They cited a variety of reasons including their trust in the health care system (n = 3), being in good enough health to participate (n = 3), feeling they had enough information (n =1), and based on their past experience (n =1).

So, I think it’s a really good idea and I have con, you know, pretty serious confidence in our system of monitoring as you’ve just described. How it gets set up which is how careful you’re being now and then how it’s monitored stage by stage. So there are places in the world where I wouldn’t be confident in doing this but in this country I do feel confident.

Participant #2

Five indicated they did not feel confident in participating in a CAR-T trial because the technology is not advanced enough (n = 2), they would need more information (n = 2), they felt their type of blood cancer might be too rare (n = 1), and they did not feel comfortable participating in a safety study (n = 1).

R: I, I think I’d honestly feel much less comfortable because safety I feel like is just it just has more negative conations with devastating side effects or minor side effects
whereas effectiveness is more associated with change for the better and growth and recovery. And yeah I, I would feel much less confident if it was phrased as testing the safety of this because then you think oh what’s going to happen to me?

Participant #5

Reinforcement

N = 5

A few participants discussed how the outcomes of their past experiences influenced their current decision making. Two participants indicated that because they had experienced a lot of complications and side effects, they were not eager to participate in experimental therapies.

R: Right yeah, it might be a different story had I not been in so much pain all the time and having all the unknowns of like not even being on like a trial thing but having all these complications like for a long time. Like my cortisol level was 17 and it’s supposed to be between like 200-600 and that took them 3 weeks to figure out. And all it is, is a checkmark on the blood test. So that like I just and that was like losing consciousness, like that was like it’s just like a lot of I went through a lot of pain and unknowns and difficulties that I we couldn’t figure out let alone something that wasn’t really tested. And, you know, but say like, like some of like the people I’ve met they were a little nauseous maybe puked a couple or 3 times their whole treatment and were fine, you know. Like they might, they might have been way more open to like oh yeah like, like to something like this.

Participant #11

Four participants discussed their positive experiences with research and indicated that they believed contributing to finding a cure was rewarding.

R: I will like to help and I will hopefully achieve, hopefully not me but hopefully that the researcher will achieve the, the cure and will they will find a cure that would be. And you know, also probably be rewarding when you participate to a research and then they the cure is, cure is found or they find a way to, to treat cancer. I think it’s probably rewarding for the person who participate to that research, yeah.

Participant #12