## Knowledge

<table>
<thead>
<tr>
<th>TDF Sub Category</th>
<th>Subtheme</th>
<th>Belief Statement Examples</th>
<th>Example Quote</th>
<th>Frequency</th>
<th>Total Instances</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRIALS</td>
<td>Familiarity with clinical trials</td>
<td>I know clinical trials test the efficacy of new therapies</td>
<td>R: Yeah a clinical trial is just a medical, you know, procedure to test new, new drugs and then therapies, right, any disease or many diseases, right. And a clinical trial is something that has proven to be shown in research then tried on, you know, in laboratories and on animals and appeared to be, you know, safe to research and stuff. Seems to be safe and worth to try on humans and, you know, in a setting that tries to prevent, protect patients as well as possible and to see if it’s actually gonna work on, on human beings. Participant #7</td>
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<td></td>
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<td>Trials try to increase control and minimize bias</td>
<td>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</td>
<td>10</td>
<td>17</td>
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<td></td>
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<td>I know a bit about how clinical trials work (not specific)</td>
<td>R: What do I know about clinical trials? Hmm it’s generally a new procedure or procedure that is being thought about being used and certain people are chosen to go in that trial and then may be given the full medication or whatever it is and others, other people in that trial are given a placebo. That’s kind of what I know about it. [laugh] Participant #6</td>
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<td>I know trials have different phases</td>
<td>R: I know I’ve been on the researcher side but not as a participant. [laugh] I: Okay. So as a researcher side then I’m sure you’re familiar with, are you familiar with clinical trials or what kind? R: Somewhat [laugh] Participant #9</td>
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Patients are followed very closely. 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 my prognosis. And that you’re followed pretty, pretty closely for a number of years following the trial. Participant #4

Knowledge of CAR-T Cell Therapy

<table>
<thead>
<tr>
<th>Somewhat familiar</th>
<th>Not familiar</th>
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<table>
<thead>
<tr>
<th>CAR-T CELLS</th>
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<tr>
<td>Patients are followed very closely</td>
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<tr>
<td>I find the existing research is convincing.</td>
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<tr>
<td>I have heard about CAR-T cell therapy</td>
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<td>8</td>
<td>13</td>
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<tr>
<td>I know about efficacy and side effects</td>
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<td>3</td>
<td>5</td>
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<tr>
<td>I do not know a lot about clinical trials</td>
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<td>I asked him about clinical trials but when I heard about the CAR T trial and he went online there, you know, and looked on the website. I forget which one it was. I looked on it after myself when I come home. You know, looking for clinical trials so I would because I know for the most part a lot of them won’t they’re not aware at least they’re not looking for them for you. And basically my best information has come from the Leukemia &amp; Lymphoma Society, you know, about clinical trials and, and this is where I’m at right now with you guys so [24:22] ________ with this one. Participant #7</td>
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<td>R: 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</td>
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<td>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... but just what’s out there the information and research that has already been done is, is very promising so that definitely is, is attractive. Participant #4</td>
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<td>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</td>
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<td>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</td>
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I know CAR-T cells are modified T cells that attack cancer cells. I thought I’d read somewhere about whether it’s the same thing or not you can tell me, where, where cells would be taken from the body but not, not like stem cells where everything is blasted but it was taken and maybe modified. In other words we’re gonna take a cell and let’s say weaken the cell wall so that if you put it back in the body if it, if it then interacts with the cancer the cancer itself would be weakened. So that’s kind of, kind of what I’ve read. Participant #13

<table>
<thead>
<tr>
<th>Knowledge Gaps</th>
<th>I did not know about CAR-T cells before this interview</th>
<th>Have you heard about them before?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I did not know about CAR-T cells before this interview</td>
<td>R1: No Participant #10</td>
</tr>
<tr>
<td></td>
<td>Yeah and I guess that would be the main thing and, how long a period of time would need to go pass along until it was known if this was effective or not? Participant #6</td>
<td>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</td>
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<tr>
<td></td>
<td>I would like to know more about the logistics of participating in a CAR-T trial</td>
<td>R: Basically, you know, the, the trial timeline and then projection line like, you know, the steps of, of the trial. The length of it and yeah possible, you know, projected outcomes like what we’re trying to, trying to do which I know, you know, everybody’s quite aware of. Participant #7</td>
</tr>
<tr>
<td></td>
<td>I would like to know more about the logistics of participating in a CAR-T trial</td>
<td>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</td>
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<tr>
<th>Total</th>
<th>8</th>
<th>29</th>
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<tbody>
<tr>
<td>Not familiar</td>
<td>5</td>
<td>8</td>
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</table>

Knowledge Gaps

I would like to know more about treatment efficacy

Yeah and I guess that would be the main thing and, how long a period of time would need to go pass along until it was known if this was effective or not? Participant #6

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

Knowledge Gaps

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I did not know about CAR-T cells before this interview

Have you heard about them before?

R1: No Participant #10

Yeah and I guess that would be the main thing and, how long a period of time would need to go pass along until it was known if this was effective or not? Participant #6

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

I would like to know more about the logistics of participating in a CAR-T trial

R: Basically, you know, the, the trial timeline and then projection line like, you know, the steps of, of the trial. The length of it and yeah possible, you know, projected outcomes like what we’re trying to, trying to do which I know, you know, everybody’s quite aware of. Participant #7

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
<table>
<thead>
<tr>
<th>Preferred Qualities</th>
<th>TRIAL INFORMATION DELIVERY</th>
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<tbody>
<tr>
<td>Online</td>
<td>I would like to know more about the safety and side effects of CAR-T</td>
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<td></td>
<td>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.</td>
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<tr>
<td>Written</td>
<td>I would like to know more about the long-term effects of CAR-T cell therapy</td>
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<td></td>
<td>R: I think lack of information like in terms of what the side effects could be and what how long the trial would last for and the long-term what that would look like. And, and I say that, you know, knowing full well that it’s like that’s what you’re looking for and the answers that you’re trying to find.</td>
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<tr>
<td>Accessible</td>
<td>I would like to know more about the global CAR-T research literature</td>
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<tr>
<td></td>
<td>R1: Yeah mm hmm and what you end so that yeah the history of what other countries’ stages are at, you know. What they have done and how much coordination there is between, between the various countries too. So whether each, each country deals independently and or not.</td>
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Total 12 81
**Enough to Feel Well-informed**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Participant #2</th>
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</thead>
<tbody>
<tr>
<td>I would want to be well informed about all aspects of participation</td>
<td>7</td>
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<tr>
<td>R: Who’s making the decisions and where, where are we in the whole test?</td>
<td>19</td>
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<tr>
<td>So I know this is gonna be the third time I’ve said this but I’m an equal</td>
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<td>partner in it. I don’t need to see all the data because I wouldn’t</td>
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<td>understand it but in terms of decision making I would need to be</td>
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<td>talked to and I need to be respected and, kept informed. <strong>Participant #2</strong></td>
<td></td>
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</tbody>
</table>

**Total instances in domain = 204**
### Social Influences

<table>
<thead>
<tr>
<th>TDF Sub Category</th>
<th>Subtheme</th>
<th>Belief Statement Examples</th>
<th>Example Quote</th>
<th>Frequency</th>
<th>Total Instances</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influential Stakeholders</td>
<td>Hematologists and Oncologists</td>
<td>I trust my hematologist or oncologist and would want their opinion</td>
<td>R: My haematologist 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</td>
<td>13</td>
<td>38</td>
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<td></td>
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<td>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</td>
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<td>R: I would say at this point probably my oncologist at the [hospital] in [town]. Participant #6</td>
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<td></td>
<td>I want information from specialists</td>
<td></td>
<td>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</td>
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<td></td>
<td>I would likely do whatever my doctor recommends</td>
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<td>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</td>
<td>3</td>
<td>7</td>
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<tr>
<td>Total</td>
<td></td>
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<td>13</td>
<td>49</td>
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<tr>
<td>Healthcare System</td>
<td>I can count on the healthcare system when things are tough</td>
<td></td>
<td>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</td>
<td>11</td>
<td>19</td>
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<tr>
<td>Total</td>
<td>I trust medicine and the healthcare system</td>
<td>Friends and Family</td>
<td>Total</td>
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<td>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. <em>Participant #12</em></td>
<td>I would want and value my family’s opinion</td>
<td>11 27</td>
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<td>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. <em>Participant #7</em></td>
<td>R: I, I would definitely bring my family members into account. Their, their opinions would be strong and strongly involved. <em>Participant #8</em></td>
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<td>R: 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. <em>Participant #3</em></td>
<td>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] <em>Participant #2</em></td>
<td>10 18</td>
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<td>Research Staff</td>
<td>I would want trial information from a member of the research staff</td>
<td>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. Participant #1</td>
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<td>Research and medical staff that are positive will influence my decision to participate.</td>
<td>And, and perhaps you have, I’m gonna say, you have been very positive. I think that’s important in other words there’s well, you know, maybe, maybe this will help maybe not but we’re gonna try it anyway. It’s like no the more positive like if I can see you as being positive it’s like oh okay well you know if she thinks there’s a good chance for some benefit and it may be... Participant #13</td>
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<td>Total</td>
<td>I trust experts who are not part of the clinical trial</td>
<td>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</td>
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<td>R: But I would wonder, you know, how much is the science perhaps overriding the attention that I got, for example. This wasn’t a test when I got here it was standard procedure so I felt confident in that. But if it wasn’t that if it was a test well just repeating myself I’d be questioning what their focus is. Participant #2</td>
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<td>Total</td>
<td></td>
<td>10 20</td>
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<tr>
<td>Trustworthy Healthcare Staff</td>
<td>I trust and value the opinion of my family doctor</td>
<td>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. Participant #13</td>
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<td>5</td>
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<td>I value trusting and honest relationships with healthcare staff</td>
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<td>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.</td>
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<td>I: So they would influence your decision whether to?</td>
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<td>R: Definitely yeah Participant #5</td>
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<td>Total</td>
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<td></td>
<td>5</td>
<td>13</td>
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<tr>
<td>Other Participants</td>
<td>I would want to hear from past participants</td>
<td>R: I think the, the, you know, the doctors, the researchers all of them would be very important. 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 Participant #12</td>
<td>2</td>
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<tr>
<td>SOCIAL SUPPORT</td>
<td>I do not value nor trust other patients' knowledge and opinions</td>
<td>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. Participant #8</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Diverse Perspectives</td>
<td>I would want to hear diverse opinions</td>
<td>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</td>
<td>4</td>
<td>6</td>
<td></td>
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<tr>
<td>Total</td>
<td></td>
<td></td>
<td>3</td>
<td>3</td>
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<tr>
<td>SOCIAL SUPPORT</td>
<td>I have family and friends who can support me through treatment</td>
<td>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</td>
<td>6</td>
<td>19</td>
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<td></td>
<td>I rely on my family to gather information and help me make decisions</td>
<td>So I’d need to take all of that into account that the impact isn’t only me and what happens to me. So it would be such a joint decision. It would be all of us 100% all of us and my professional team here to talk about it. Participant #2</td>
<td>5</td>
<td>9</td>
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<td></td>
<td></td>
<td>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</td>
<td>6</td>
<td>19</td>
<td></td>
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<tr>
<td>Desired Social Supports</td>
<td>I accessed a patient support group</td>
<td>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</td>
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<td>Total</td>
<td>Having a health advocate or support person is critical</td>
<td>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</td>
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<td></td>
<td>Access to support and resources post treatment (long term)</td>
<td>R: Yes that is my biggest, biggest advice for improvement is post. Because once the doctors see that you are well the, the resources, you know, as, as a patient you have to go and find them yourself. You know, I as I said I’ve been exposed to, to, you know, this, this world for quite a while so I was fortunate to have doctors, you know, to give me that information. But a lot I did no my own and I think yeah it really needs to be improved upon, yeah because there’s so much more that you want to know post. So there’s, there’s wonderful information pre, during, you know, shortly thereafter but post there’s not a lot. Participant #4</td>
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<th></th>
<th>Total</th>
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<td></td>
<td>Desired Social Supports</td>
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<td>I accessed a patient support group</td>
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<td>Having a health advocate or support person is critical</td>
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<td></td>
<td>Access to support and resources post treatment (long term)</td>
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Supplemental material placed on this supplemental material which has been supplied by the author(s)
<table>
<thead>
<tr>
<th>Access to social workers, counselling, social supports and resources</th>
<th>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</th>
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</thead>
<tbody>
<tr>
<td>R: With the BMT there’s not a lot of psychological follow up nor is there I mean there’s the resources out there, yes but for the doctors to incorporate that as part of their research is I think is really important. And not just be a test subject because, you know, the mind affects the body. The body affects the mind and maybe exploring that a little bit more. Participant #4</td>
<td></td>
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<tr>
<td>Online participant and caregiver forum</td>
<td>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</td>
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Beliefs about Consequences

<table>
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<th>TDF Sub Category</th>
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<th>Belief Statement Examples</th>
<th>Example Quote</th>
<th>Frequency</th>
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<tr>
<td>NEGATIVE OUTCOMES</td>
<td>Side Effects and Safety</td>
<td>I am concerned about the potential side effects and safety of CAR-T</td>
<td>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</td>
<td>7</td>
<td>26</td>
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<td>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</td>
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<td></td>
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<td>I’m concerned about the long term effects</td>
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<td>I: Yeah</td>
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<td></td>
<td>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. I: Yeah</td>
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<td>R: 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</td>
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<td></td>
<td>I’m concerned about the risk of death</td>
<td>So the, the relatively large chance of dying from the treatment is still a big barrier to me for participating. Participant #1</td>
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<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Diminished Treatment Opportunities</td>
<td>I would be concerned that participating in CAR-T cell therapy will exclude me from other treatments</td>
<td>R: #1 would probably be just like no obstructing like if I hadn’t gone and did the trial like what say like my chances—like say I went on the trial and it didn’t work and then like I’m not eligible for like these things now or now I have the worst chance of if I get a bone marrow transplant will it work and things like that? And so, like pretty much just like will I have the same like, is it like a try this it might not work but it will screw up your chances for other things to try in the future. So, that and also just safety like the side effects and yeah. Participant #11</td>
<td>2</td>
<td>2</td>
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<tr>
<td><strong>Unknown Efficacy</strong></td>
<td>I am concerned about treatment efficacy</td>
<td>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</td>
<td>5</td>
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<tr>
<td>I am concerned CAR-T cell therapy may worsen my quality of life</td>
<td>R: I, I think it’s like first it would be the unknown. In other words, you know, cancer of course has a reputation for not just the disease itself but, but for being ill for, for causing pain, for causing discomfort, for a variety of different things. And participating is the, is the participation gonna cause more of that? In other words, it’s a participation by taking the, by doing the, the trial is it going to cause or how much more? Participant #13</td>
<td>4</td>
<td>10</td>
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<tr>
<td>Treatment Benefits</td>
<td>CAR-T cell therapy may be a more tolerable alternative to chemo and BMTs</td>
<td>R: [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</td>
<td>6</td>
<td>12</td>
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<td>R: I think just the possibility of not relying on chemotherapy and radiation only. Like I guess obviously for people going through this it would have failed on some ways or not, not done what doctors were hoping for it to do. 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</td>
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<tr>
<td><strong>Health Benefits</strong></td>
<td><strong>Future Benefits</strong></td>
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<tr>
<td><strong>CAR-T cell therapy provides an alternative to having no treatment options</strong></td>
<td><strong>Participating provides early access to cutting edge treatment</strong></td>
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<td>And but also there’s, you know, depending on where you are with your disease it’s maybe that okay you’ve also opened, opened another door for me that says I didn’t think I was gonna have that but, but I now have something else to perhaps to look forward to.</td>
<td><strong>R:</strong> 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... <strong>Participant #7</strong></td>
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<td><strong>Participant #13</strong></td>
<td><strong>Participant #7</strong></td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>Health Benefits</strong></td>
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<tr>
<td><strong>CAR-T cell therapy may help achieve remission or find a cure</strong></td>
<td><strong>CAR-T cell therapy may improve my quality of life</strong></td>
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<td><strong>R:</strong> So and, you know if you can achieve remission and it just doesn’t come back then, you know, that’s to me that’s a huge benefit and, and, you know, like the chemo I have only been doing it for 5 months and it’s taken a big toll on my body. And, you know, I’m way weaker than I was and way less energy and all that stuff. It’s it’s still got another, you know, almost 2 years left of it. So yeah I guess that would be the biggest benefit being cured of leukemia without the long-term effects of chemo. <strong>Participant #1</strong></td>
<td><strong>R:</strong> 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. <strong>Participant #13</strong></td>
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<td><strong>Participant #1</strong></td>
<td><strong>Participant #1</strong></td>
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<td><strong>Total</strong></td>
<td><strong>Future Benefits</strong></td>
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<tr>
<td><strong>Participating in CAR-T will benefit others in the future.</strong></td>
<td><strong>R:</strong> 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. <strong>Participant #7</strong></td>
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<td><strong>Participant #13</strong></td>
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<thead>
<tr>
<th><strong>Health Benefits</strong></th>
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<td><strong>Participant #7</strong></td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>Health Benefits</strong></td>
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<tr>
<td><strong>CAR-T cell therapy may help achieve remission or find a cure</strong></td>
<td><strong>CAR-T cell therapy may improve my quality of life</strong></td>
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</tr>
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<td><strong>Participant #1</strong></td>
<td><strong>Participant #1</strong></td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>Future Benefits</strong></td>
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<tr>
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<td><strong>R:</strong> 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. <strong>Participant #7</strong></td>
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<td><strong>Participant #13</strong></td>
<td><strong>Participant #7</strong></td>
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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**

R1: I’m not so certain of whether it will help me necessarily, but it might help others. I don’t know but it’s the length of time from step 1 to it might be 5 years or 20 years well it may not necessarily benefit me but it may get to others **Participant #3**

### Participating in CAR-T will contribute to advancing science

<table>
<thead>
<tr>
<th>Participant</th>
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<tbody>
<tr>
<td>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. <strong>Participant #2</strong></td>
</tr>
<tr>
<td><strong>Participant #5</strong></td>
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CAR-T cell therapy is the future of blood cancer treatment

<table>
<thead>
<tr>
<th>Participant</th>
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<tbody>
<tr>
<td>And yeah and how it’s very much the future of treating like blood cancers and lymphoma. <strong>Participant #5</strong></td>
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</tbody>
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| **Total** | 10 | 35 |

### Total

| **Total** | 12 | 76 |

### Evaluating Risk

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<tr>
<td>I expect and accept some level of risk</td>
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<td>I’m sure they and I the I would be, I would be aware of the risks for sure. Like I know if, if I participate to a research I know it would be some risk and, you know, it’s, it’s expected I suppose. But yeah, I don’t think you, I don’t think you get into the something like this without some, some fear I suppose, you know. <strong>Participant #12</strong></td>
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<td><strong>Participant #2</strong></td>
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### "It’s like Russian Roulette" participating is a high risk, high reward situation

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<thead>
<tr>
<th>Participant</th>
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<tr>
<td>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. <strong>Participant #11</strong></td>
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<td><strong>Participant #2</strong></td>
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### Evaluating Efficacy

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<tbody>
<tr>
<td>CAR-T cell therapy may work for some but not everyone</td>
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<td>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. <strong>Participant #8</strong></td>
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<td><strong>Participant #2</strong></td>
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<tr>
<td>Category</td>
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Total instances in domain = 152
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<th>Example Quote</th>
<th>Frequency</th>
<th>Total Instances</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONAL BENEFITS</td>
<td>Survival</td>
<td>Surviving is important to me (self-preservation)</td>
<td>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</td>
<td>10</td>
<td>21</td>
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<td></td>
<td>Achieving longterm remission or a cure is important to me</td>
<td>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</td>
<td>5</td>
<td>8</td>
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<td><strong>Total</strong></td>
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<td><strong>12</strong></td>
<td><strong>29</strong></td>
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<tr>
<td>QoL</td>
<td>Quality of life is important to me</td>
<td>R2: But if we knew that it was bringing longevity and quality of life and reduce the costs of potential of relapse. R1: Mm hmmm R2: Those are all huge indicators that would R1: Important factors R2: make a difference in the decision here to participate if ever that was a possibility. R1: Mm hmmm Participant #3</td>
<td></td>
<td><strong>3</strong></td>
<td><strong>13</strong></td>
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... 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

Reducing the experience of pain and discomfort is important to me

R: Whereas I was just like in the beginning I remember like before the chemo kicked in I was like oh yeah do whatever yeah and then it was like okay I’m done with this we’re gonna do what works and do what’s gonna cause me the least pain and in the least amount of time. And then I’m gonna get out of here, you know.

Participant #11

My well being is more important than the research outcomes

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 than what the outcome would be although I’m not unconcerned about that because I would have volunteered. Participant #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

Total 5 26

Altruism

Helping future generations is important to me

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

Participant #11

TS FOR OTHERS
<table>
<thead>
<tr>
<th>BENEFIT</th>
<th>Description</th>
<th>Participant(s)</th>
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<td></td>
<td>And also the other motivation like I said earlier is to help others and to help the research 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</td>
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<td>R: Hmm I would think that it like I said before it’s nothing no treatment is working for me right now, not that it’s the case, but I would be willing to try it to for my own benefit and also to for other patients who have the same disease. Participant #9</td>
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<td></td>
<td>I am not motivated by altruistic considerations</td>
<td>Participant #5</td>
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<td>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.</td>
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<tr>
<td>Science</td>
<td>Advancing the science of cancer Tx and CAR-T cell therapy is important to me</td>
<td>Participant #2</td>
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<td></td>
<td>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.</td>
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<td></td>
<td>R: Hmm like fulfilment a little bit because it’s like, like you could yeah help yourself but also you’re in the trial even if it doesn’t work that gives information and that can help just in the long run whether like the trial works or risks of the trial, not the trial but of the CAR T-cells thing or anythingParticipant #2</td>
<td>9 21</td>
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<tr>
<td></td>
<td>Participating in research is important</td>
<td>Participant #11</td>
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<td></td>
<td>R: 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</td>
<td>7 11</td>
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<td></td>
<td>Finding alternative treatments to chemo is important to me</td>
<td>Participant #1</td>
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<td></td>
<td>R: And no just death but the other side effects you were talking about too. But again I would take, I would take being sick for a little while from a cytokine storm or something like that over 2 years of chemo, you know. If I’m gonna get better I’m gonna feel wiped out for a month that’s okay and then you get better and continue with your life, you know. Participant #1</td>
<td>4 15</td>
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</table>
R: I think just the possibility of not relying on chemotherapy and radiation only. Like I guess obviously for people going through this it would have failed on some ways or not, not done what doctors were hoping for it to do. 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

Fighting cancer and finding a cure is important to me.

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

Testing for safety is important

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

Total instances in domain = 144
## Environmental Context and Resources

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<th>TDF Sub Category</th>
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<th>Example Quote</th>
<th>Frequency</th>
<th>Total Instances</th>
</tr>
</thead>
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<tr>
<td>Enabling Resources</td>
<td>Having parking and transportation paid for or provided would help me attend appointments</td>
<td>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, 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</td>
<td>11</td>
<td>32</td>
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<td></td>
<td>Having medication covered would be helpful</td>
<td>R: Yeah just OHIP coverage really it’s just the only thing like I could possibly think of. Participant #11</td>
<td>3</td>
<td>5</td>
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<td></td>
<td>It would help to cover caregiver costs</td>
<td>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</td>
<td>3</td>
<td>4</td>
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<td></td>
<td>It would help to have child care services covered</td>
<td>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</td>
<td>2</td>
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<td></td>
<td>I would need to have accommodations covered to participate in a CAR-T trial</td>
<td>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</td>
<td>2</td>
<td>5</td>
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<td></td>
<td>Alternative sources of income are helpful resources</td>
<td>R: Okay. Well right now I’m off on disability so I’m pretty flexible like all I, all I do is get to my appointments right now. Participant #1</td>
<td>2</td>
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<td><strong>Total</strong></td>
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<td>50</td>
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<tr>
<td>TIME AND AVAILABILITY</td>
<td>Not Needed</td>
<td>I do not need any expenses covered</td>
<td>R1: Yeah fortunately we’re 10-15 minutes away from the hospital so it’s not as if we’re, we’re travelling from the country to be, to be doing this so that’s, that’s one aspect it’s, it’s much easier for us so. Participant #3</td>
<td></td>
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<tr>
<td>Availability</td>
<td>Flexible work/appointment hours would help me participate</td>
<td>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</td>
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<td></td>
<td>Frequent appointments may be a hassle</td>
<td>I have to go into the hospital and quite frequently to, to continue with the procedures then maybe that's a hassle. Participant #9</td>
<td>2 2</td>
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<td></td>
<td>I have the time needed and am available to participate in a clinical trial</td>
<td>I mean at the moment I'm retired and I have a lot of free time and I would be able to, to participate I mean I would be available when they need me. Participant #12</td>
<td>1 1</td>
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<td>Total</td>
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<td>10 27</td>
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| ACCESS TO INFO | Access to doctors and medical appointments | 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 | 4 11 |
| --- | --- | --- |
| | Long-term follow up care would help me participate | R: You know, it's one thing to achieve remission but then it comes back in 18 months or something like that or you end up developing I don't know what kind of a side effect within, you know, 3 years later or 5 years and stuff like that. Participant #1 | 1 2 |
| Total | | | 4 13 |

Total instances in domain = 103
### Behavioural Regulation

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<th>Total Instances</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCHEDULING METHODS</td>
<td>Existing systems work well for me</td>
<td>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.</td>
<td>Participant #6</td>
<td>5</td>
<td>10</td>
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<td></td>
<td>I use a physical calendar to keep track of appointments</td>
<td>R: Yeah I will, you know, put it in my calendar and, and make sure I don’t take any other make sure I’m free to; make sure, you know, I don’t have any commitment that day. Participant #12</td>
<td>7</td>
<td>7</td>
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<td></td>
<td>I prefer electronic methods for tracking appointments</td>
<td>I had a ton of appointments to deal with. Realistically speaking if I lost my phone I’d be in trouble because I had, you know, I was using my calendar on my phone. Participant #8</td>
<td>9</td>
<td>18</td>
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<td></td>
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<td>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</td>
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<td>My caregiver helps me keep track of my appointments</td>
<td>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</td>
<td>4</td>
<td>5</td>
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<tr>
<td>BELIEFS ABOUT SCHEDULING</td>
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<td>I use multiple methods to keep track of my appointments</td>
<td>R: Well, 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</td>
<td>8</td>
<td>10</td>
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<td>Total</td>
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<td>Attending treatment appointments is a priority</td>
<td>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</td>
<td>3</td>
<td>6</td>
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<td>I am an organized person</td>
<td>R: Well and I told you this at the beginning I’m pretty thorough so I and I’m very organized even when I was sick. Participant #4</td>
<td>3</td>
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<tr>
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Total instances in domain = 63
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<th>Example Quote</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>Intent</td>
<td>I would participate in a CAR-T clinical trial.</td>
<td>R2: Well if it’s a possibility I’d adhere more than what we have now, I think we can make our voice known right now that yes, definitely we’d be interested in participating.</td>
<td>4</td>
<td>9</td>
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<td></td>
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<td>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</td>
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<td>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</td>
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<tr>
<td>No Intent</td>
<td>I would not participate in a CAR-T clinical trial</td>
<td>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.</td>
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<td>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</td>
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<td>I would be willing to try CAR-T cell therapy if I stand to gain from it</td>
<td>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</td>
<td>9 15</td>
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<tr>
<td>I would only participate in a CAR-T clinical trial if there were no other options</td>
<td>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 study like that. Participant #6</td>
<td>6 20</td>
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<td>I would participate in a clinical trial if my doctor asked me</td>
<td>If my own haematologist felt that it was a worthwhile thing to try I'd probably, I'd probably consider it. Those are probably the 2 main things. Participant #8</td>
<td>3 3</td>
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<td>I may participate if it will help others</td>
<td>I got lots of blood when I was here and, and platelets and everything and so I would I, I feel an obligation and not a negative obligation but a positive obligation to give back and contribute. So that would motivate me a lot. Participant #2</td>
<td>4 4</td>
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<td>I would rather participate in an efficacy trial than a safety trial</td>
<td>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</td>
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<td>R: Hmm the safety of CAR T-cells yeah that's 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</td>
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<td>I might participate in a CAR T clinical trial</td>
<td>R: At the moment I, I would say I would have to give it some additional thought. Participant #13</td>
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Total instances in domain = 65
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<tr>
<td>Positive and Hopeful</td>
<td></td>
<td>I feel hopeful about the possibility of CAR-T cell therapy</td>
<td>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</td>
<td>7</td>
<td>11</td>
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<td></td>
<td></td>
<td>I am excited about the possibility of CAR-T cell therapy</td>
<td>R: But I just I think it’s really exciting, I’m really happy to hear that you guys are working on it. Participant #1</td>
<td>1</td>
<td>2</td>
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<td>I would feel fulfillment knowing I am helping myself and others</td>
<td>R: Hmm like fulfillment a little bit because it’s like, like you could yeah help yourself but also you’re in the trial even if it doesn’t work that gives information and that can help just in the long run whether like the trial works or risks of the trial, not the trial but of the CAR T-cells thing or anything. Participant #11</td>
<td>2</td>
<td>2</td>
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<td></td>
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<td>I would feel grateful for the opportunity to try CAR-T cell therapy</td>
<td>I got lots of blood when I was here and, and platelets and everything and so I would I, I feel an obligation and not a negative obligation but a positive obligation to give back and contribute. So that would motivate me a lot, gratitude for what I was—so I’d have both of those things. And the gratitude stuff would be overwhelmed by the nervous stuff when I would be coming in. [laugh] But I would get through it, you know. Participant #2</td>
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<td>18</td>
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<tr>
<td>Anxious and Nervous</td>
<td></td>
<td>I feel anxious</td>
<td>R: 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</td>
<td>5</td>
<td>11</td>
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<td></td>
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<td>I feel scared and fearful about participating in a clinical trial</td>
<td>R: You know, maybe the fear will, will probably temper my, my enthusiasm... Participant #12</td>
<td>5</td>
<td>11</td>
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<td>I feel overwhelmed when I think of how my family is affected</td>
<td>R: Because I hate to say this one of the things I learned being here might have been my body that had this but it impacted my wife and my 2 sons I’m emotional about this. So I’d need to take all of that into account that the impact isn’t only me and what happens to me. Participant #2</td>
<td>1</td>
<td>1</td>
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<tr>
<td>I would feel financially stressed</td>
<td>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</td>
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<tr>
<td><strong>Total</strong></td>
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<td>9</td>
<td>24</td>
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<tr>
<td>I have mixed feelings about the possibility of a CAR-T trial.</td>
<td>R: [laugh] I would say positive but nervous at the same time because there’s a lot of unknown. Participant #9</td>
<td>9</td>
<td>12</td>
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<tr>
<td>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</td>
<td>1</td>
<td>2</td>
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<tr>
<td>I feel bittersweet that I am in this position at all.</td>
<td>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 groundbreaking 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</td>
<td>1</td>
<td>2</td>
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<tr>
<td>I would feel disappointed if it didn’t work</td>
<td>R: You know it could be very disappointing if that doesn’t work. Hopefully it will work but the, the unknown things... Participant #12</td>
<td>2</td>
<td>2</td>
<td></td>
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<tr>
<td><strong>Total</strong></td>
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<td>9</td>
<td>16</td>
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<tr>
<td>Neutral</td>
<td>I would feel indifferent about participating (just another day)</td>
<td>I: Feelings so how would you feel if you were to participate? I know we've had people mention they would be worried, happy, stressed, nervous. R1: If you didn't tell me that there was a bunch of needles or IV then it would just be the standard course of my days being receiving treatments and tests. Participant #10</td>
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Total instances in domain = 60
## Memory, Attention and Decision Making

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<th>Example Quote</th>
<th>Frequency</th>
<th>Total Instances</th>
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</thead>
</table>
| DECISION MAKING  | Factors Influencing Decisions | I would consider my age, health, disease stage and prognosis | 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 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 | 8 | 22 |
<p>|                  |          | I would need to consider alternative treatment options before deciding to participate in a CAR-T clinical trial. | R: I would be more inclined towards the effectiveness trials yeah. Being involved in the safety again if I was in dire straights and, and it held some promise then I’d be making a decision in a different direction probably. Like I might, I might participate then, but if I was where I currently am on a protocol of chemo that’s working and all that stuff I don’t think I would go be a safety tester. Participant #1 | 1 | 2 |
|                  |          | I would consider the impact on my family when deciding to participate in a clinical trial | R: At the moment I, I would say I would have to give it some additional thought. It’s also in other words if you were calling today saying, you know, [patient says own name] we have, we have something going on right now that we could use your help with then 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. So, if I’m gonna put them in that position and maybe that’s, that’s an important part of it is like what, what else does it do aside from the individual, what else does it do for, or to, the family?Participant #13 | 3 | 3 |
|                  |          | I would need to consider what the benefits are for myself and for others | R: I would have to know more about it. Like I, I read as much as I could about the stem cells before deciding not to do that. I mean it was kind of a, I’m gonna say it was kind of unusual because of my age but, but I specifically said I’m, I’m so it would be a matter of what, what is, you know, what is, what is the benefit to me? Or even is there a little bit more benefit to others who like even if I don’t see, specifically see the benefit is, is will somebody, will somebody see the, see the benefit from that? Participant #13 | 1 | 4 |</p>
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<tr>
<td>Cognitive Overload and Disease Related Strain</td>
<td>Being sick affects my judgment, attention and memory</td>
<td>R1: Yeah well you’re the caregiver I’ll 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</td>
<td>6</td>
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<td></td>
<td>Too much information can be overwhelming</td>
<td>Nothing can be too difficult because if people, if people are ill it’s, it’s it is more of a challenge to, to try and keep track of, of sort of those things. Participant #13</td>
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Total instances in domain = 52
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<tr>
<td>Familiarity and Experience Advocating for Treatment Needs</td>
<td>I know how to find information about CAR T, blood cancer and clinical trials</td>
<td>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</td>
<td>8</td>
<td>28</td>
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<tr>
<td></td>
<td>I know I can ask my doctor about available trials</td>
<td>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</td>
<td>7</td>
<td>10</td>
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<td></td>
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<td>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</td>
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<td></td>
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<td>And if you heard about an available clinical trial of CAR T-cells how would you go about enrolling or participating in one?</td>
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<td></td>
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<td>R: I think I would bring it up to my specialist and ask him for his opinion first as he’s probably on top of a lot of the research out there. Participant #9</td>
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<tr>
<td>Learning to Advocate for Healthcare Needs</td>
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<tr>
<td>I know how to talk to my doctor about my treatment plan</td>
<td>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</td>
<td>2 2</td>
<td></td>
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<tr>
<td>I am familiar and comfortable with healthcare settings</td>
<td>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</td>
<td>2 3</td>
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<td>I did not know I could ask HCP questions</td>
<td>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</td>
<td>1 1</td>
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<tr>
<td>I would wait for my doctor to ask me to participate in a trial</td>
<td>how would you go about enrolling in it?</td>
<td>1 1</td>
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Total instances in domain = 45
### Nature of the Behaviour

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</thead>
<tbody>
<tr>
<td>PAST EXPERIENCE</td>
<td>Experience with Clinical Trials and Research</td>
<td>I have no experience participating in clinical trials</td>
<td>R: You know what off, off the top of my head no. Like I said, you know, I’ve never been in one or around one or even known anybody that’s, that’s done one so all of this is new to me. Participant #7</td>
<td>8</td>
<td>10</td>
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<td></td>
<td></td>
<td>I have some past experience enrolling and participating in clinical trials</td>
<td>R: Yeah you know it was a research earlier which I wanted to participate but I was unable to because I think I was too old. It was about anyway and, and it was I’m getting [laugh] I don’t know if I’m getting tired, but I’m looking for my words already. But anyway, I didn’t participate because of I was kind of not rejected but I was not I didn’t meet the criteria to participate that’s, that’s why. Participant #12</td>
<td>4</td>
<td>6</td>
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<tr>
<td></td>
<td></td>
<td>I have experience participating in research</td>
<td>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</td>
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<td>21</td>
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<tr>
<td></td>
<td>Experience with Intensive Procedures</td>
<td>Experiences receiving treatment.</td>
<td>So, you know, a feeling of I don’t know probably—I know I’ve been grateful to have a stem cell transplant, you know, I was grateful and thankful because I know a lot of people don’t get that opportunity. Even though mine, you know, did not work I had the opportunity, you know, to benefit and, and I’m very grateful even to this day. Participant #7</td>
<td>6</td>
<td>10</td>
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<tr>
<td></td>
<td></td>
<td>Being severely ill is a new experience for me</td>
<td>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</td>
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Total instances in domain = 32
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</thead>
<tbody>
<tr>
<td>VALUES</td>
<td>Values and Ethics</td>
<td>I do not have any ethical or moral qualms about using CAR-T cell therapy</td>
<td>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</td>
<td>11</td>
<td>15</td>
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<tr>
<td></td>
<td>Personality and Identity</td>
<td>Fighting cancer is part of who I am now</td>
<td>R: There aren’t any that I, I can think of. 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</td>
<td>4</td>
<td>6</td>
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<tr>
<td>Helping others is part of who I am</td>
<td>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</td>
<td>3</td>
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**Total instances - 25**
### Optimism

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<tr>
<td>Optimism</td>
<td>am optimistic</td>
<td>And do you expect that participating in a CAR T-cell trial for blood cancers will result in more good things than bad things? 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</td>
<td>8</td>
<td>16</td>
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<td></td>
<td>am optimistic for others more than myself.</td>
<td>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</td>
<td>3</td>
<td>4</td>
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<td></td>
<td>am somewhat optimistic</td>
<td>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</td>
<td>3</td>
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<td></td>
<td>I think most clinical trials turn out well</td>
<td>R: I would expect it. I mean the way how science is these days there’s so many checks and balances, you know, Ethics Boards and all sorts of things. I, I think by the time you get to clinical trials there should be enough knowledge out there that the likelihood of it turning bad is poor. Participant #8</td>
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Total instances in domain = 24
## Beliefs about Capabilities

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<tbody>
<tr>
<td>Level of Confidence</td>
<td>Confident</td>
<td>I am confident I can participate in a CAR-T clinical trial</td>
<td>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</td>
<td>7</td>
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<tr>
<td></td>
<td>Not confident</td>
<td>I am not confident I can participate in a CAR-T clinical trial</td>
<td>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</td>
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**Total instances in domain = 17**