



Portrait of the clinical trial participant

What motivates clinical trial
volunteers to take part?

In collaboration with:



For additional resources, including further analyses of the data collected from this survey, please visit: <https://www.antidote.me/antidote-whitepapers>.



Introduction

Every time we use blood pressure medication, get an allergy shot, or take many other treatments that improve our daily lives, we have clinical trial volunteers to thank.

But considering how many approved drugs many of us rely on every day, most people haven't ever participated in research – and may not even personally know anyone who has. For example, only 8% of cancer patients participate in research, and clinical trials often languish without enough volunteers.¹ In some ways, volunteers are a rare breed. They're also critical to bringing us closer to more and better treatment options. That's why we asked one more favor of former volunteers: To help us understand their motivations so we can find better ways to engage patients in research.

In 2018, Antidote worked with eight leading health organizations – American Kidney Fund, Allergy & Asthma Network, Healthline, JDRF,

Lung Cancer Alliance (now GO₂ Foundation for Lung Cancer), Lupus Research Alliance, Melanoma Research Alliance, and Multiple Sclerosis Association of America – to survey nearly 4,000 patients and caregivers about their attitudes towards clinical research. The initial survey work and analysis were conducted in partnership with SCORR Marketing.

Of the patients we surveyed, 1,033 had participated in research. Based on our findings, we're able to paint a portrait of the clinical trial participant: What matters most in their decision-making process, what demographic factors they might have in common, and what factors set them apart from those who have never participated.

Highlights of our findings (see table 1) include:

- In our prior survey-based whitepapers, we shared that patients prefer to hear about research opportunities from their doctors. But for patients who have already participated in research, we found that taking their doctor’s recommendation was not the reason most patients participated. This held true across conditions, with one exception: 83.5% of oncology patients say that their doctor’s recommendation was the reason they took part.
- “I joined to extend my own life” is a major reason oncology patients participate in research: 55% said this was “the major reason” for participating, compared with just 8.8% of chronic/acute patients and 11.1% of chronic disease patients.
- In total, 33% of respondents said that “I want to improve my quality of life” was the major reason they chose to participate in research, and 34% of

those surveyed said that wanting to help patients who come after them was the major reason they participated in research.

- Our findings suggest that improving quality of life is one of the key reasons patients participate in research, and should be included as an endpoint in clinical trials.

While the percentage of people who have participated in clinical research may be small, there’s plenty to glean from their experiences – both as a whole and on the individual condition level. In this whitepaper, we’ll share details on the factors that motivate patients to join trials, and the aspects of decision-making that matter less. In our previous whitepapers, we’ve offered insights into how patients think about clinical trials, regardless of whether they’ve ever participated in clinical trials themselves. The patients in this whitepaper took that significant step and signed up for research – we’ll help you understand why.

Table 1: Overall responses re: motivations for participating:

Race	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
I joined to extend my own life	393	38.0%	220	21.3%	211	20.4%	209	20.2%
I was following my doctor's recommendation	502	48.6%	198	19.2%	195	18.9%	138	13.4%
I wanted to help future patients who come after me	58	5.6%	202	19.6%	424	41.1%	349	33.8%
I wanted to improve my quality of life	124	12.0%	194	18.8%	374	36.2%	341	33.0%
I wanted to receive the best care possible	154	14.9%	234	22.7%	328	31.8%	317	30.7%
I wanted to receive the most up-to-date therapies without the high expense	247	23.9%	245	23.7%	285	27.6%	256	24.8%



Methods and respondent profile

Nearly 4,000 individuals (n=3,942) responded to an online survey between June 18, 2018, and August 21, 2018. The survey sample included individuals living with various conditions in the U.S. Survey participants were recruited through leading patient advocacy organizations.

Overall, the sample we collected was predominantly female and non-Hispanic white, though multiple races were represented. We compared answers from white versus non-white (including multi-racial) respondents. In addition, we collapsed the categories of conditions into (1) oncology, (2) chronic with acute onset of symptoms, and (3) chronic (see table 2).

We did this after noticing trends in responses by condition type and to better assess the relationship between condition and demographic characteristics on patients' willingness to participate in different types of trials.

We chose to ask the question of sex assigned at birth rather than gender as this is frequently the sex/gender assessment used to screen individuals for trial eligibility. Differences in education level or income level among groups were not statistically significant. As mentioned above, around a quarter of respondents (n=1,033) had participated in a clinical trial.



Relative to those in our survey who have not participated in research, trial participants had higher levels of education, were of higher incomes, and were more likely to be male (see table 3). Oncology patients were also more represented among participants than non-participants.

Age, race, and income are also significantly associated with condition – another detail critical to our analysis. Oncology respondents were nearly twice as likely to report earning more than \$100,000 compared with those with chronic conditions. Those answering for oncology were also more likely to be white, and older.

While our sample is relatively small, our findings are consistent with other research conducted on what factors make patients more likely to participate in clinical trials. For example, a study published in JAMA in 2016 found that cancer patients earning less than \$50,000 were 32% less likely to participate in a clinical trial compared with those who earn more.²

It’s also important to note that a layer of selection bias exists in this survey: respondents answered a 60-minute largely un-incentivized survey (some partners entered respondents into a gift card raffle). Both those who have and those who haven’t taken part in research are particularly engaged in the topic of research participation.

Table 2: Re-categorized condition areas

Oncology	Chronic with Acute Onset	Chronic
Lung cancer Melanoma	Asthma/allergy Gastro	Lupus Kidney disease Multiple sclerosis Type 1 diabetes

Table 3: Counts and frequencies of demographic categories of the sample (n=1033)

Condition	Clinical trial participants		Non-participants	
	Count	Freq.	Count	Freq.
Oncology	224	21.7%	471	16.2%**
Chronic/Acute	215	20.8%	598	20.6%**
Chronic	594	57.5%	1836	63.2%**
Age				
54 or under	473	45.8%	1480	51.0%**
55+	551	53.3%	1413	48.6%**
Prefer not to answer	9	0.9%	12	0.4%
Education				
Some high school/high school diploma	96	9.3%	383	13.2%**
Some college	262	25.4%	857	29.5%**
College degree	328	31.8%	917	31.6%
More than college	340	32.9%	694	23.9%**
Prefer not to answer	7	0.7%	54	1.9%**

*p<.05 **p<.01

Table 3: Continued

	Clinical trial participants		Non-participants	
Race/Ethnicity	Count	Freq.	Count	Freq.
Non-white	142	13.8%	453	15.2%
White	891	86.3%	2452	84.4%
Hispanic	42	4.0%	144	5.0%
Non-Hispanic	969	93.8%	2700	92.9%
Sex				
Male	235	22.8%	554	19.1%**
Female	794	76.9%	2337	80.5%**
Prefer not to answer	4	0.4%	14	0.5%
Income				
Less than \$50,000	334	32.3%	1127	38.8%**
\$50,000-\$99,999	290	28.1%	795	27.4%**
\$100,000+	227	22.0%	516	17.8%**
Prefer not to answer	182	17.6%	467	16.1%**

*p< .05 ** p<.01

“I was following my doctor’s recommendation”

In previous whitepapers, we’ve noted that patients prefer to hear about clinical trials from their doctors. But we also know that most doctors, particularly primary care physicians, don’t have time to talk with their patients about clinical research. Close to 70% of the public has never or rarely considered clinical trials as an option when discussing treatment or medication options with their doctor, according to a 2017 survey conducted by CISCRP.³

This trend also played out in our findings: Only 13.4% of respondents across condition areas said that following their doctor’s recommendation was the major reason they took part (see table 4 in the appendix). In total, 48.6% of respondents said “no, this wasn’t the reason” regarding their doctor’s recommendation.

Though not statistically significant in our sample, non-white respondents were least likely to say that following their doctor’s recommendation was a major factor in their trial participation. This trend makes sense in light of prior research that has found that non-white patients are just as interested, if not more so, in taking part in trials, but are less likely to be invited to participate.⁴

This trend held true across condition areas, with one exception: Those living with cancer. Oncology patients were more likely to report that following their doctor’s recommendation was “the major reason” or “one of the major reasons” they participated in research – by a wide margin. Only 16.5% of oncology patients said that their doctor’s recommendation was not the reason they took part.

Clearly, a doctor’s recommendation can make a significant impact on an oncology patient’s willingness to participate in research. At the same time, the fact that only 8% of cancer patients take part in clinical trials each year is a sign that not enough of these doctor-patient conversations are taking place.⁵

When researchers asked primary care physicians and oncologists about factors that prevent them from discussing research opportunities with patients, a few trends emerged: Lack of staff to support patient referrals to clinical trials was the most-cited structural barrier, and lack of awareness of clinical trials was the most common perceived barrier.⁶

Providing support for busy practices, along with information about available trials, could help facilitate these important conversations between patients and doctors regarding research. And while a doctor’s opinion may be particularly important for oncology patients, our prior research has found that patients across condition areas are interested in having these conversations.

Close to 70% of the public has never or rarely considered clinical trials as an option when discussing treatment or medication options with their doctor



“I joined to extend my own life”

In our survey, we asked whether the reason “I joined to extend my own life” rang true for survey takers. We found that this was the most important to oncology patients – 55% said this was “the major reason” for participating, compared with just 8.8% of chronic/acute patients and 11.1% of chronic disease patients (see table 5 in the appendix). Of course, cancer is more likely to be life threatening than many other conditions, and overall survival is a standard endpoint in cancer clinical trials.⁷

Other findings in regards to this question were perhaps more surprising. Women were much less likely to say they joined a trial to extend their own life – 40% reported “this was not the reason,” compared with 29.4% of men.

People earning more than \$100,000 were also more likely to say that extending their own life was a major reason for participating. Neither of these findings were statistically significant in sub-analyses, but both warrant further research.

While there is debate around whether survival is the only valuable endpoint, and if quality-of-life measures should also be included more often, it’s clear that extending life is a top priority for cancer patients. Our findings suggest that it is rarely the main motivator for those living with other conditions, however, and may also be less of an incentive for women considering participation, and more of one for those in higher income brackets.

55% of oncology patients said this was “the major reason” for participating compared with just 8.8% of chronic/acute patients

“I want to improve my quality of life” and other measures of care

In our survey, we asked how much three different measures of care mattered to patients: Improving quality of life, receiving the best care, and receiving quality care at an affordable cost.

Across condition areas and demographics, survey respondents said that the desire to improve their quality of life was a significant reason for participating. In total, 33% of respondents said that “I want to improve my quality of life” was the major reason they chose to participate in research (see table 6 in the appendix). Only 12% of respondents responded “No, this wasn’t the reason” in regards to quality of life, underlining its importance.

Quality-of-life measures are subjective, and can be difficult to capture. Our findings suggest that improving quality of life is one of the key reasons patients participate in research, and should be included as an endpoint in clinical trials.

The growth of electronic patient-reported outcomes (ePRO) gives researchers the opportunity to capture measures like mood and pain level in the moment. For example, two main therapies, pazopanib and sunitinib, are used to treat metastatic renal cell carcinoma (mRCC).⁸ They’re equally effective in terms of survival, but have frequent adverse events, making health-related quality of life the deciding factor for clinicians when selecting a treatment option. Researchers explored whether ePRO instruments could improve the patient-doctor conversation and lead to better quality-of-life outcomes for patients diagnosed with mRCC.

Patients may be interested in participating in this kind of research, and certainly benefit from its outcomes.

In our survey, when asked why they participated in a clinical trial, cancer patients were also the most likely to say “I wanted to receive the best care possible” (see table 7 in the appendix). This response may encapsulate both a desire for improved quality of life and a longer life. For cancer patients in particular, clinical trials are seen as one of the best places to receive the highest-quality care available. Those 55 and older were also more likely to say this option was important to them.

As for receiving quality care at an affordable cost, while this was less of a priority than other reasons for most survey participants, around 25% of respondents said this was the major reason for participating (see table 8 in the appendix). Those earning less than \$50,000 were slightly more likely to say this was the major reason for participating, though those earning more than \$100,000 were slightly more likely to say it was “a major reason” to participate. Overall, receiving high-quality care at a low cost in a clinical trial appeals rather equally to those across the socioeconomic spectrum.

For cancer patients in particular, clinical trials are seen as one of the best places to receive the highest-quality care available

“I wanted to help future patients who came after me”

As prior research has found, altruism is the top driver of clinical trial participation. In our survey, as well, helping future patients was the most popular reason for participation: 34% of those surveyed chose it (see table 9 in the appendix).⁹ Those living with chronic conditions in particular were the most likely to choose this option as the major reason they participated.

As we learn more about the genetic factors behind various conditions, patients may also be more interested in moving research forward for their families.

Patrick Gee, a patient advocate for Antidote’s partner the American Kidney Fund, is participating in an observational trial seeking to learn more about how an APOL1 gene mutation functions in people of African descent. Those with two copies of the gene are at an increased risk of developing chronic kidney disease. The gene has also been connected with lupus, which his daughter has.

“I know that whatever I find out, I just want to help the next generation,” Gee told Antidote.

Clinical trial recruitment campaigns may focus on altruism in outreach materials to connect with patients. In terms of trial design, it’s also critical to reward and respect patients who participate out of a sense of altruism. Patients are very interested in seeing the results of the studies they participate in: For example, 91% of the public considers it very important to receive a study summary after participation, but only 53% of those who participated received one.¹⁰

Following up with patients after a trial, whether it’s with a thank-you note, information on the published study results, or details on the next phase of the trial, helps close the loop with patients and can help them feel positive about the study – and encourage others to participate. As it stands, 91% of clinical trial participants would “probably” or “definitely” recommend participation to friends or family members, according to CISCRP research.¹¹ Paying it forward to patients can help amplify the value of research participation through word of mouth, and shows appreciation for the critical role clinical trial participants play.





Conclusion

As we work toward engaging more diverse participants in research, there's much to learn from those who have already taken part in research.

While we noticed some demographic trends and themes, these are only broad brushstrokes. Regardless of demographic backgrounds, participants in our survey were most motivated by the impulse to make the world better for those who come next. Those who participate in research understand the risks involved – they know the trial won't necessarily be successful, though they hope

it will improve their quality of life. But they also know that regardless of the outcome, their participation helps move research forward for everyone living with their condition.

As barriers to participation are reduced or eliminated, it's still important to drive home the core reason participants choose to take part. By keeping this noble purpose in mind, we can create clinical trial experiences that are comfortable and engaging for patients, and respectful of the priceless commitment they make.

To learn more about Antidote and our work, please get in touch

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- ¹ <https://www.forbes.com/sites/victoriaforster/2019/02/19/why-do-only-eight-percent-of-cancer-patients-in-the-u-s-participate-in-clinical-trials/#6b3df7ae77e9>
- ² <https://jamanetwork.com/journals/jamaoncology/fullarticle/2457394>
- ³ <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Decision-Making-Process.pdf>
- ⁴ <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Decision-Making-Process.pdf>
- ⁵ <https://www.forbes.com/sites/victoriaforster/2019/02/19/why-do-only-eight-percent-of-cancer-patients-in-the-u-s-participate-in-clinical-trials/#18f0dd177e9d>
- ⁶ https://pdfs.semanticscholar.org/287e/569e8546250d17872dba812cd70f3aa73d74.pdf?_ga=2.243146626.1016768126.1570805688-1476850538.1570805688
- ⁷ <https://www.cancertodaymag.org/Pages/cancer-talk/What-Do-Clinical-Trial-Endpoints-Really-Measure.aspx>
- ⁸ <https://www.cancertodaymag.org/Pages/cancer-talk/What-Do-Clinical-Trial-Endpoints-Really-Measure.aspx>
- ⁹ <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Participation-Experience.pdf>
- ¹⁰ <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Participation-Experience.pdf>
- ¹¹ <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Participation-Experience.pdf>

Appendix

Table 4: Demographic breakdown to responses: I was following my doctor's recommendation

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	502	48.6%	198	19.2%	195	18.9%	138	13.4%
Condition								
Oncology	37	16.5%**	36	16.1%**	87	38.8%**	64	28.6%**
Chronic/Acute	147	68.4%**	25	11.6%**	28	13.0%**	15	7.0%**
Chronic	318	53.5%**	137	23.1%**	80	13.5%**	59	9.9%**
Age								
54 or under	237	50.1%	105	22.2%	78	16.5%	53	11.2%
55+	260	47.2%	91	16.5%	115	20.9%	85	15.4%
Prefer not to answer	5	55.6%	2	22.2%	2	22.2%	0	0.0%
Education								
Some high school/high school diploma	45	46.9%*	15	15.6%*	19	19.8%*	17	17.7%*
Some college	116	44.3%*	54	20.6%*	47	17.9%*	45	17.2%*
College degree	172	52.4%*	67	20.4%*	48	14.6%*	41	12.5%*
More than college	167	49.1%*	59	17.4%*	79	23.2%*	35	10.3%*
Prefer not to answer	2	28.6%*	3	42.9%*	2	28.6%*	0	0.0%*
Race/Ethnicity								
Non-white	74	52.1%	32	22.5%	21	14.8%	15	10.6%
White	428	48.0%	166	18.6%	174	19.5%	123	13.8%
Hispanic	23	54.8%	3	7.1%	10	23.8%	6	14.3%
Non-Hispanic	468	48.3%	191	19.7%	182	18.8%	128	13.2%

*p< .05 ** p<.01

Table 4: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	104	44.3%	46	19.6%	47	20.0%	38	16.2%
Female	398	50.1%	151	19.0%	146	18.4%	99	12.5%
Prefer not to answer	0	0.0%	1	25.0%	2	50.0%	1	25.0%
Income								
Less than \$50,000	165	49.4%	74	22.2%	47	14.1%	48	14.4%
\$50,000-\$99,999	152	52.4%	50	17.2%	55	19.0%	33	11.4%
\$100,000+	104	45.8%	39	17.2%	57	25.1%	27	11.9%
Prefer not to answer	81	44.5%	35	19.2%	36	19.8%	30	16.5%

*p< .05 ** p<.01

Table 5: Demographic breakdown to responses: I joined to extend my own life.

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	393	38.0%	230	21.3%	211	20.4%	209	20.2%
Condition								
Oncology	25	11.2%**	16	7.1%**	59	26.3%**	124	55.4%**
Chronic/Acute	118	54.9%**	37	17.2%**	41	19.1%**	19	8.8%**
Chronic	250	42.1%**	167	28.1%**	111	18.7%**	66	11.1%**
Age								
54 or under	205	32.4%*	101	21.4%*	88	18.6%*	79	16.7%*
55+	184	33.4%*	118	21.4%*	122	22.1%*	79	16.7%*
Prefer not to answer	4	44.4%*	1	11.1%*	1	11.1%*	3	33.3%*
Education								
Some high school/high school diploma	34	35.4%	19	19.8%	22	22.9%	21	21.9%
Some college	92	35.1%	55	21.0%	51	19.5%	64	24.4%
College degree	138	42.1%	79	24.1%	55	16.8%	56	17.1%
More than college	127	37.4%	66	19.4%	82	24.1%	65	19.1%
Prefer not to answer	2	28.6%	1	14.3%	1	14.3%	3	42.9%
Race/Ethnicity								
Non-white	50	35.2%	28	19.7%	37	26.1%	27	19.0%
White	343	38.5%	192	21.6%	174	19.5%	182	20.4%
Hispanic	12	28.6%	5	11.9%	14	33.3%	11	26.2%
Non-Hispanic	376	38.8%	210	21.7%	193	19.9%	190	19.6%

*p< .05 ** p<.01

Table 5: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	69	29.4%	45	19.2%	57	24.3%	64	27.2%
Female	324	40.8%	173	21.8%	154	19.4%	143	18.0%
Prefer not to answer	0	0.0%	2	50.0%	0	0.0%	2	50.0%
Income								
Less than \$50,000	120	35.9%	82	24.6%	80	24.0%	52	15.6%
\$50,000-\$99,999	122	42.1%	58	20.0%	51	17.6%	59	20.3%
\$100,000+	83	26.6%	42	18.5%	45	19.8%	57	25.1%
Prefer not to answer	68	37.4%	38	20.9%	35	19.2%	41	22.5%

*p< .05 ** p<.01

Table 6: Demographic breakdown to responses: I wanted to improve my quality of life.

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	124	12.0%	194	18.8%	374	36.2%	341	33%
Condition								
Oncology	24	10.7%*	29	13.0%*	93	41.5%*	78	34.8%*
Chronic/Acute	25	11.6%*	32	14.9%*	81	37.7%*	77	35.8%*
Chronic	75	12.6%*	194	18.8%*	374	36.2%*	341	33.0%*
Age								
54 or under	64	13.5%	100	21.1%	159	33.6%	150	31.7%
55+	57	10.3%	94	17.1%	213	38.7%	187	33.9%
Prefer not to answer	3	33.3%	0	0.0%	2	22.2%	4	44.4%
Education								
Some high school/high school diploma	11	11.5%*	15	15.6%*	28	29.2%*	42	43.8%*
Some college	27	10.3%*	39	14.9%*	101	38.6%*	95	36.3%*
College degree	39	11.9%*	76	23.2%*	105	32.0%*	108	33.0%*
More than college	45	13.2%*	63	18.5%*	139	40.9%*	93	27.4%*
Prefer not to answer	2	28.6%*	1	14.3%*	1	14.3%*	3	42.9%*
Race/Ethnicity								
Non-white	19	13.4%	19	13.4%	54	38.0%	50	35.2%
White	105	11.8%	175	19.6%	320	35.9%	291	32.7%
Hispanic	4	9.5%	8	19.1%	13	31.0%	17	40.5%
Non-Hispanic	118	12.2%	183	18.9%	351	36.2%	317	32.7%

*p< .05 ** p<.01

Table 6: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	26	11.1%	43	18.3%	92	39.2%	74	31.5%
Female	97	12.2%	151	19.0%	281	35.4%	265	33.4%
Prefer not to answer	1	25.0%	0	0.0%	1	25.0%	2	50.0%
Income								
Less than \$50,000	35	10.5%*	58	17.4%*	116	34.7%*	125	37.4%*
\$50,000-\$99,999	40	13.8%*	52	17.9%*	111	38.3%*	87	30.0%*
\$100,000+	20	8.8%*	58	25.6%*	80	35.2%*	69	30.4%*
Prefer not to answer	29	15.9%*	26	14.3%*	67	36.8%*	60	33.0%*

*p< .05 ** p<.01

Table 7: Breakdown of responses to the statement: I wanted to receive the best care possible.

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	154	14.9%	234	22.7%	328	31.8%	317	30.7%
Condition								
Oncology	15	6.7%**	22	9.8%**	84	37.5%**	103	46.0%**
Chronic/Acute	46	21.4%**	52	24.2%**	62	28.8%**	55	25.6%**
Chronic	93	15.7%**	160	26.9%**	182	30.6%**	159	26.8%**
Age								
54 or under	83	17.6%*	120	25.4%*	148	31.3%*	122	25.8%*
55+	69	12.5%*	114	20.7%*	177	32.1%*	191	34.7%*
Prefer not to answer	2	22.2%*	0	0.0%*	3	33.3%*	4	44.4%*
Education								
Some high school/high school diploma	9	9.4%	24	25.0%	28	29.2%	35	36.5%
Some college	41	15.7%	48	18.3%	80	30.5%	93	35.5%
College degree	60	18.3%	83	25.3%	97	29.6%	88	26.8%
More than college	44	12.9%	77	22.7%	119	35.0%	100	29.4%
Prefer not to answer	0	0.0%	2	28.6%	4	57.1%	1	14.3%
Race/Ethnicity								
Non-white	24	16.9%	23	16.2%	50	35.2%	45	31.7%
White	130	14.6%	211	23.7%	278	31.2%	272	30.5%
Hispanic	6	14.3%	9	21.4%	16	38.1%	11	26.2%
Non-Hispanic	144	14.9%	221	22.8%	304	31.4%	300	31.0%

*p< .05 ** p<.01

Table 7: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	25	10.6%	42	17.9%	90	38.3%	78	33.2%
Female	129	16.3%	192	24.2%	235	29.6%	238	30.0%
Prefer not to answer	0	0.0%	0	0.0%	3	75.0%	1	25.0%
Income								
Less than \$50,000	51	15.3%	75	22.5%	96	28.7%	112	33.5%
\$50,000-\$99,999	51	17.6%	65	22.4%	98	33.8%	76	26.2%
\$100,000+	25	11.0%	51	22.5%	77	33.9%	74	32.6%
Prefer not to answer	27	14.8%	43	23.6%	57	31.3%	55	30.2%

*p< .05 ** p<.01

Table 8: Breakdown of responses to the statement: I wanted to receive the most up-to-date therapies without the high expense.

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	247	23.9%	245	23.7%	285	27.6%	256	24.8%
Condition								
Oncology	41	18.3%	55	24.6%	69	30.8%	59	26.3%
Chronic/Acute	51	23.7%	46	21.4%	61	28.4%	57	26.5%
Chronic	155	26.1%	144	24.2%	155	26.1%	140	23.6%
Age								
54 or under	120	25.4%	116	24.5%	127	26.9%	110	23.3%
55+	123	22.3%	128	23.2%	155	28.1%	145	26.3%
Prefer not to answer	4	44.4%	1	11.1%	3	33.3%	1	11.1%
Education								
Some high school/high school diploma	19	19.8%	21	21.9%	29	30.2%	27	28.1%
Some college	58	22.1%	62	23.7%	73	27.9%	69	26.3%
College degree	87	26.5%	71	21.7%	84	25.6%	86	26.2%
More than college	83	24.4%	87	25.6%	96	28.2%	74	21.8%
Prefer not to answer	0	0.0%	4	57.1%	3	42.9%	0	0.0%
Race/Ethnicity								
Non-white	36	25.4%	29	20.4%	45	31.7%	32	22.5%
White	211	23.7%	216	24.2%	240	26.9%	224	25.1%
Hispanic	10	23.8%	14	33.3%	13	31.0%	5	11.9%
Non-Hispanic	234	24.2%	224	23.1%	264	27.2%	247	25.5%

*p< .05 ** p<.01

Table 8: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	41	17.5%	57	24.3%	69	29.4%	68	28.9%
Female	206	25.9%	187	23.6%	214	27.0%	187	23.6%
Prefer not to answer	0	0.0%	1	25.0%	2	50.0%	1	25.0%
Income								
Less than \$50,000	71	21.3%	87	26.1%	88	26.4%	88	26.4%
\$50,000-\$99,999	67	23.1%	74	25.5%	80	27.6%	69	23.8%
\$100,000+	60	26.4%	44	19.4%	71	31.3%	52	22.9%
Prefer not to answer	49	26.9%	40	22.0%	46	25.3%	47	25.8%

*p< .05 ** p<.01

Table 9: Demographic breakdown to responses: I wanted to help future patients who come after me.

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
	Count	Freq.	Count	Freq.	Count	Freq.	Count	Freq.
Overall sample:	58	5.6%	202	19.6%	424	41.1%	349	33.8%
Condition								
Oncology	8	3.6%*	54	24.1%*	96	42.9%*	66	29.5%*
Chronic/Acute	18	8.4%*	46	21.4%*	87	40.5%*	64	29.8%*
Chronic	32	5.4%*	102	17.2%*	241	40.6%*	219	36.9%*
Age								
54 or under	22	4.7%	96	20.3%	193	40.8%	162	34.3%
55+	35	6.4%	103	18.7%	227	41.2%	186	33.8%
Prefer not to answer	1	11.1%	3	33.3%	4	44.4%	1	1.1%
Education								
Some high school/high school diploma	7	7.3%	20	20.8%	40	41.7%	29	30.2%
Some college	8	3.1%	47	17.9%	118	45.0%	89	34.0%
College degree	24	7.3%	60	18.3%	121	36.9%	123	37.5%
More than college	19	5.6%	73	21.5%	141	41.5%	107	31.5%
Prefer not to answer	0	0.0%	2	28.6%	4	57.1%	1	14.3%
Race/Ethnicity								
Non-white	7	4.9%	23	16.2%	61	43.0%	51	35.9%
White	51	5.7%	179	20.1%	363	40.7%	298	33.5%
Hispanic	3	7.1%	7	16.7%	17	40.5%	15	35.7%
Non-Hispanic	55	5.7%	190	19.6%	394	40.7%	330	34.1%

*p< .05 ** p<.01

Table 9: Continued

	No, this wasn't the reason		Yes, but this wasn't really why/it was a small factor		This was one of the major reasons		This was the major reason	
Sex								
Male	12	5.1%	48	20.4%	105	44.7%	70	29.8%
Female	46	5.8%	153	19.3%	317	39.9%	278	35.0%
Prefer not to answer	0	0.0%	1	25.0%	2	50.0%	1	25.0%
Income								
Less than \$50,000	21	6.3%*	46	13.8%*	146	43.7%*	121	36.2%*
\$50,000-\$99,999	18	6.2%*	61	21.0%*	111	38.3%*	100	34.5%*
\$100,000+	7	3.1%*	56	24.7%*	102	44.9%*	62	27.3%*
Prefer not to answer	12	6.6%*	39	21.4%*	65	35.7%*	66	36.3%*

*p< .05 ** p<.01