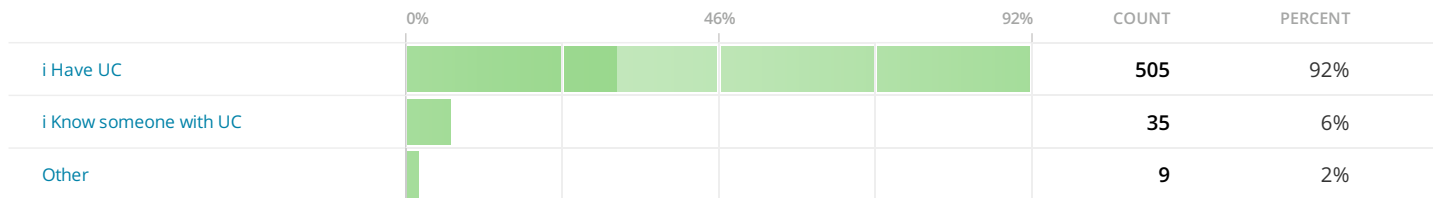


Survey Results

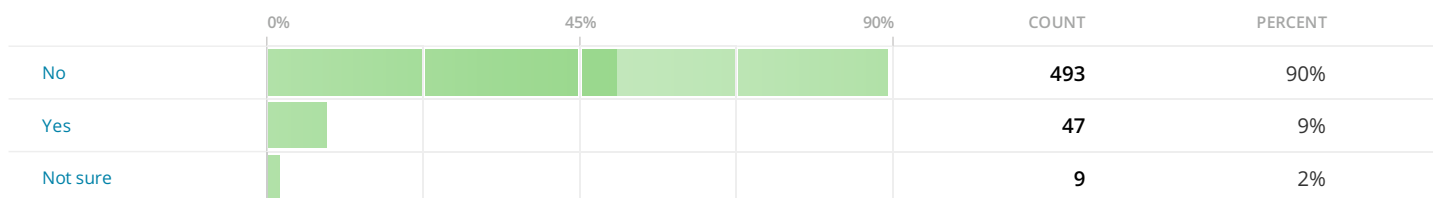
Question 01 To Start off, how would you describe yourself? *(Mandatory)*

Answers **549** Skips **0**
100% 0%



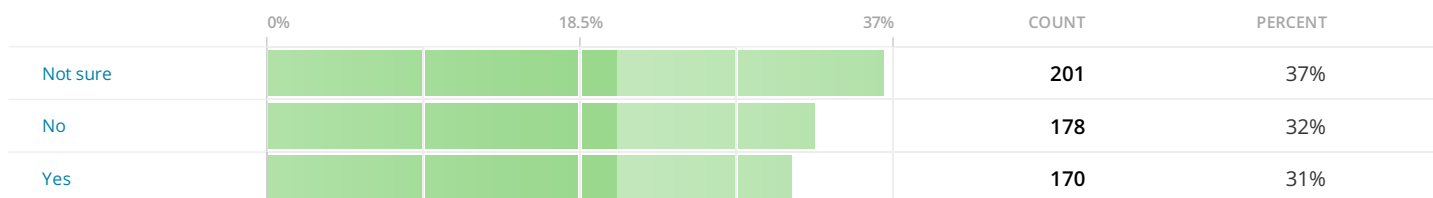
Question 02 Have you ever participated in a UC related Clinical Trial? *(Mandatory)*

Answers **549** Skips **0**
100% 0%



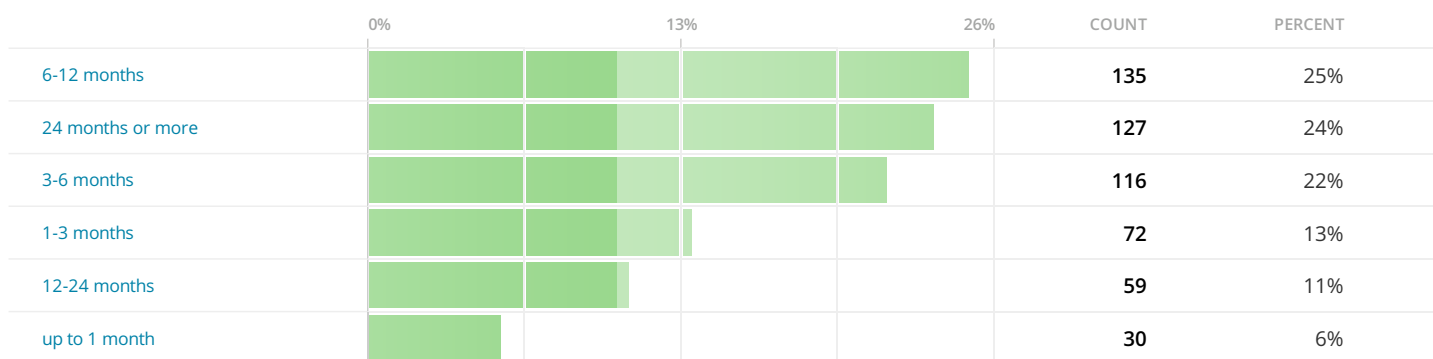
Question 03 Would you expect to be paid some money for participating in a clinical trial? *(Mandatory)*

Answers **549** Skips **0**
100% 0%



Question 04 Some clinical trials require a lengthy time committment from beginning to end. What is the maximum time period you be willing to be involved with a clinical trial?

Answers **539** Skips **10**
98% 2%



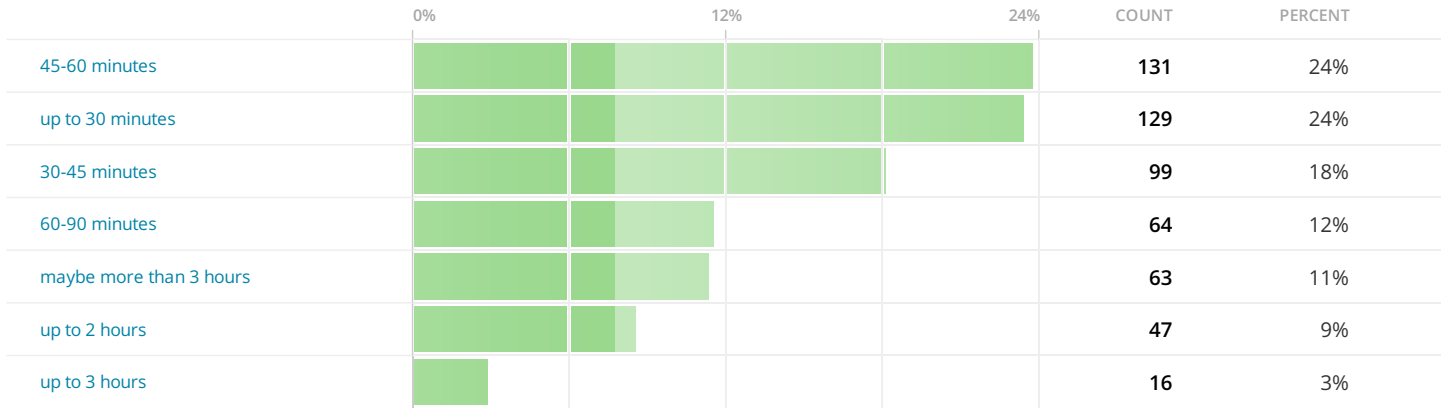
Question

05

Some clinical trials or "studies" require UC patients to travel to a specific doctor's office, university laboratory or other clinical site...How far would you be willing to travel from your home to a location like this for a clinical trial that you were interested in? (Mandatory)

Answers
549
100%

Skips
0
0%



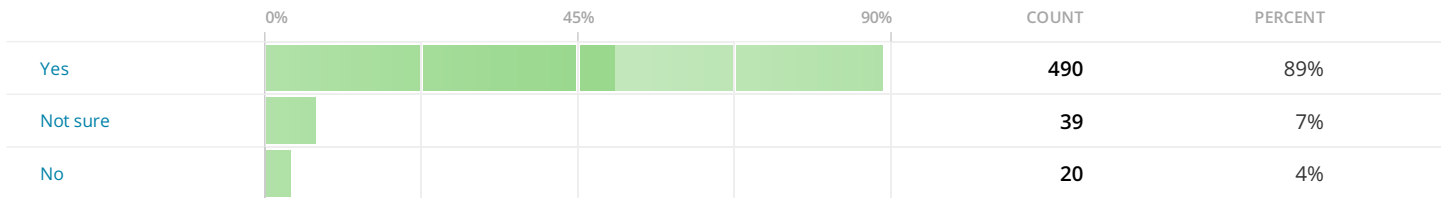
Question

06

Would you expect to meet with a doctor at the clinical trial to explain what is going on and answer your questions? (Mandatory)

Answers
549
100%

Skips
0
0%



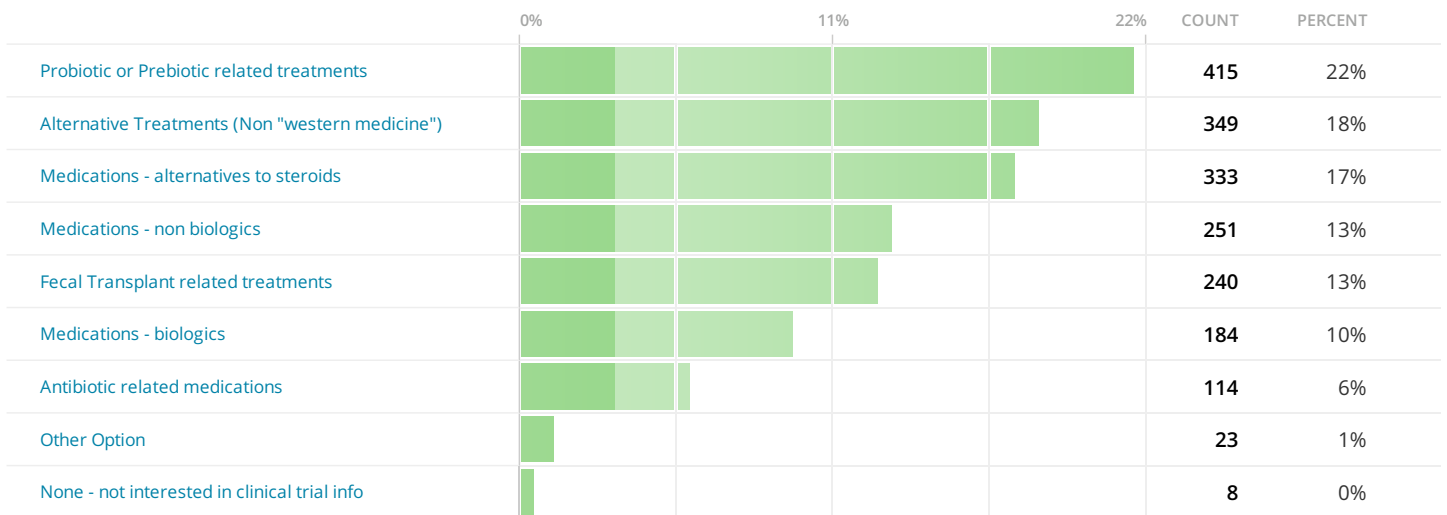
Question

07

What types of potential Ulcerative Colitis medications or treatment solutions would you be most interested in learning about with regards to clinical trials? (Mandatory)

Answers
549
100%

Skips
0
0%



Question

08

If you have experience with any UC related clinical trial, please feel free to share what your experience was like.

Answers
61
11%

Skips
488
89%

154,651,199

I've done a few. The last time was for a medication (pill) that was already approved by the FDA for other health issues... It was a double blind study to record the results of how it affected people with UC.

Wednesday, May 18th
12:00PM

154,605,383	I started Entyvio right after the clinical trial and have been in full remission for the past year. The professionals who give me my infusions are very competent, caring individuals who monitor my care carefully. Though the drug is out of clinical trial attention is given to the long term effects of this drug.	Tuesday, May 17th 10:54PM
154,530,121	FMT TRIAL SYDNEY AUSTRALIA. AWESOME GOT 11 MONTHS REMISSION. DRS ALL TOP OF FIELD. DR ALICIA WALSH, DR PARASOTHOMY SUDARSHIN, DR BORODY. I WOULD DO IT AGAIN TOMORROW. Not paid, didn't matter. felt really cared for not just a number. got a lot bloods and scopes done then referred to specialist ongoing care at the end of trial. trial was honest I was never promised results and because it was double blind at the end of trial those who were on the placebo then got access to real Fmt.	Tuesday, May 17th 4:46AM
154,526,422	I participated in a very early UC trial around 1985 in Glasgow, Scotland. The trial lasted for 3 months and at that time I was only monitored by my GI consultant. I just recall the drug didn't work for me and I was on the new trial drug not a placebo. It was related to sulfasalazine.	Tuesday, May 17th 3:13AM
154,525,949	I participated in FMT trial. It lasted for a couple of hours. People doing it were very professional. They answered almost all my questions or they admitted what they didn't. It's the safest option to treat UC. Go for it.	Tuesday, May 17th 3:16AM
154,514,314	I haven't been involved with a trial.	Monday, May 16th 8:38PM
154,507,640	No experience.	Monday, May 16th 5:56PM
154,500,558	have not taken part in any trials	Monday, May 16th 3:03PM
154,498,077	I participated in one trial which was looking into the occurrence of raised liver enzymes when taking mercaptopurine. It involved one visit to hospital for a simple blood test. I was treated very well and the administrator gave me so much time and information.	Monday, May 16th 2:14PM
154,479,891	I've taken part in two clinical trials for psoriasis. I traveled once a week, 45 min one way, for 3 months, for them to check my progress... and I got paid!	Monday, May 16th 7:16AM
154,475,899	FMT trial in university hospital setting. Short term success. DNA study through 23&Me, DNA study through UMass/Harvard.	Monday, May 16th 7:22AM
154,474,086	Trial involved a steroid. I was given placebo during a flare up instead of cortisone. After a few weeks my doctor took me off the trial and gave proper cortisone to stop the flare up.	Monday, May 16th 6:45AM
154,468,025	Immune suppressive medication	Monday, May 16th 3:50AM
154,465,689	N/a	Monday, May 16th 2:16AM
154,463,871	n/a	Monday, May 16th 1:02AM
154,463,862	I participated in one. It was, I believe, cancelled and I never heard about The results which was frustrating	Monday, May 16th 1:03AM
154,463,265	Have not participated in any trial	Monday, May 16th 12:27AM
154,462,416	nothing to add	Sunday, May 15th 11:44PM
154,462,406	I think I was part of a clinical trial with Garden of Life products which were given to me by my doctor. It lasted about a year (?) So long ago, that I do not recall. Dr. Joseph Brasco was my Gastro at the time in Huntsville Alabama. (2007-2016)	Sunday, May 15th 11:38PM
154,462,394	N/A	Sunday, May 15th 11:43PM

154,461,416	N/A	Sunday, May 15th 10:45PM
154,461,283	N/A: Haven't participated yet	Sunday, May 15th 10:39PM
154,460,742	I attempted to join a fecal transplant clinical trial. It required me to travel 7hrs one way and at the time my personal home situation would not have worked for me to be away from home that long.	Sunday, May 15th 9:56PM
154,459,859	No experience	Sunday, May 15th 9:30PM
154,459,010	I did one with 23 and me. It was simple and didn't require travelling, and allowed me to have DNA testing by means of a spit test, which enabled me to find out my ancestry. I was notified of the results.	Sunday, May 15th 8:51PM
154,458,861	Have not	Sunday, May 15th 8:44PM
154,457,157	None	Sunday, May 15th 7:27PM
154,455,626	I've tried but after answering all the questions the computer result is always I'm not a candidate.	Sunday, May 15th 6:05PM
154,455,119	Non threatening. Very easy.	Sunday, May 15th 5:39PM
154,453,473	I went through a trial that my GI Doctor was connected to so I was able to stay connected to him and his team. They were very accessible. I did 16 weeks of asacol hd and 1x/week methotrexate self injection. After the 16 weeks the injection went, "double blind" so neither my doctor nor his team nor I knew if I got the methotrexate or the placebo. I was able to get into remission. At the end of the study I could choose to stay on the 1x/ week injection with the asacol hd or just take asacol hd alone. Since I didn't know if I had the placebo or not, I opted to not continue the injection and just take the asacol hd. I think the trial is still going on or closing to an end so I will eventually find out if I had the placebo or not. The meds were free during the trial but now I pay \$50/ month after ins for the asacol hd.	Sunday, May 15th 4:29PM
154,452,732	Na	Sunday, May 15th 4:18PM
154,451,503	Not really a clinical trial, but I have submitted DNA to 123 and Me for a study on UC.	Sunday, May 15th 3:35PM
154,450,706	N/A	Sunday, May 15th 3:02PM
154,450,399	I was involved in the adacolumn trial at St Marks in London. It involved a weekly visit where I had a kind of dialysis cleaning the white blood cells. It did help me a bit - but took a huge toll on my veins and involved a long journey.	Sunday, May 15th 2:53PM
154,449,243	N/a	Sunday, May 15th 2:14PM
154,449,040	Several years ago I took part in a trial which looked at the effect of hypnotherapy on Ulcerative Colitis. It took approx 3 months and required my attendance every 2 weeks. I had incredibly thorough care, follow up and was given material to use at home. Whilst hypnotherapy is not something that has managed to maintain my UC alone, the practice proved incredibly beneficial at the time when I came off azathioprine and is a method I have returned to during times when I have flared as I find it incredibly calming.	Sunday, May 15th 2:08PM
154,445,516	N/A	Sunday, May 15th 12:10PM
154,444,888	I'm early in the trials, not sure what to think yet. Ask me in a few months.	Sunday, May 15th 11:53AM
154,443,989	Not applicable	Sunday, May 15th 11:31AM

154,443,596	N/A		Sunday, May 15th 11:23AM
154,443,542	<p>WHI , described above, I have been doing for over 20 years. It is all by mail and personal response surveys. Very professional, and of course, I get no feedback personally unless I goof up on the surveys. Requires results of medical tests, but not actual results from doctors.</p> <p>We get a token gift about every 10 years (:D).</p> <p>I have also donated my body to UC Irvine Medical School, as has my husband.</p>		Sunday, May 15th 11:18AM
154,443,092	No experience		Sunday, May 15th 11:10AM
154,442,797	<p>All the trials I've participated in have been great. Most try to be extremely accommodating to me. If they need a biopsy they will wait years until I next need a colonoscopy for example. They will work around my schedule if we need to meet. Everyone was professional. I have done studies focusing on the effects of diet on UC, childhood experiences (stressful events around the time of diagnosis, were you breastfed), and iron supplementation.</p>		Sunday, May 15th 10:47AM
154,442,451	No I don't have		Sunday, May 15th 10:45AM
154,442,365	I tried Vedolizumab and it didn't work		Sunday, May 15th 10:40AM
154,442,155	N/A		Sunday, May 15th 10:23AM
154,442,142	None		Sunday, May 15th 10:32AM
154,441,900	None		Sunday, May 15th 10:25AM
154,441,810	I am taking medicine since 2 years		Sunday, May 15th 9:38AM
154,441,543	Was just asked my a company last week to participate in a trail. Waiting to hear back what's next.		Sunday, May 15th 10:11AM
154,441,245	<p>Fecal transplant was only for an 8 week trail it did help minimize my active disease but unfortunately after the trail the treatment was no longer provided so sadly was not given the opportunity to continue with the treatment. I also believe the focus study should of been trailed a lot better. And treatment continued as it was helping me and others who participated in the fecal transplant focus study</p>		Sunday, May 15th 9:58AM
154,440,986	<p>I only was contacted by the trial in Toronto/Canada for the SSI (I have Crohn's), but just had switched biologics at that point of time and moved to another country simultaneously (from Germany to the UK), so was not interested in the first appointment in Toronto. Otherwise I would have traveled there (they cover the flight) after some lab tests in my home country Germany.</p> <p>I saw a doctor at a specialist centre in the German capital Berlin to hear a second opinion to choose a new biologic as the old one is not effective as well and heard about many different studies I could apply for. I'm currently taking another biologic, not participating in a study, waiting for it being effective.</p>		Sunday, May 15th 9:56AM
154,440,650	<p>My experience wasn't a good one. The doctor that headed the trial was arrogant and more interested in the results than the patients wellbeing. I had terrible side effects and seemed to get worse rather than better. Unless the trial is for alternative meds or pre/probiotics then I'm not interested in subjecting myself to that again.</p>		Sunday, May 15th 9:48AM
154,440,568	N/A		Sunday, May 15th 9:48AM
154,440,367	None		Sunday, May 15th 9:45AM
154,439,921	Both trials were through my doctor's office MANY years ago - Dipentum and a type of enema - separate trials		Sunday, May 15th 9:27AM
154,439,556	No experience with clinical trials, but with all the medications I have taken it sure feels like one.		Sunday, May 15th 9:18AM

154,439,379	I have just started a trial at the Mayo clinic. It is an 8 week trial of a new biologic. There is a cohort of placebo, study drug every other week, and study drug weekly.	Sunday, May 15th 9:16AM
154,439,024	N/a	Sunday, May 15th 9:04AM
154,439,012	N/A	Sunday, May 15th 9:05AM
154,434,993	N/a	Sunday, May 15th 7:16AM

Question

09

If you'd like to add a picture, feel free to do so here.

Answers

19

3%

Skips

530

97%

154,566,625	mecurly2.jpg (168 kB)	Tuesday, May 17th 1:18PM
154,562,062	IMG_20160423_191951~2.jpg (62 kB)	Tuesday, May 17th 12:24PM
154,511,098	amazonpic.jpg (42 kB)	Monday, May 16th 7:28PM
154,507,640	Betty 1015.JPG (459 kB)	Monday, May 16th 5:56PM
154,473,703	image.jpeg (1 MB)	Monday, May 16th 2:04AM
154,457,541	image.jpeg (187 kB)	Sunday, May 15th 7:45PM
154,456,189	me.jpg (2 MB)	Sunday, May 15th 6:36PM
154,449,953	Image 4.jpg (91 kB)	Sunday, May 15th 2:32PM
154,449,243	image.jpg (2 MB)	Sunday, May 15th 2:14PM
154,445,907	image.jpeg (2 MB)	Sunday, May 15th 12:26PM
154,445,516	ME IN HAT AFTER CROPPING.png (68 kB)	Sunday, May 15th 12:10PM
154,443,374	2015-08-25 18.34.13.png (717 kB)	Sunday, May 15th 11:11AM
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154,440,543	image.png (1 MB)	Sunday, May 15th 9:48AM
154,438,833	image.jpeg (146 kB)	Sunday, May 15th 8:56AM
154,438,766	image.png (780 kB)	Sunday, May 15th 8:56AM

