Patient Voice: Motivations and Perceptions of Experienced Research Participants

Successful clinical trial recruitment requires a thorough understanding of the target patient profile, and a key factor within this profile is patient motivation. What drives a patient to consider, inquire, prescreen, and ultimately consent to participate in a trial? While these motivations will vary by study experience, indication, study type, patient demographics and other factors, common themes often emerge when one speaks to patients. The lesson? Always ask the patient. Their reasons can surprise even the most seasoned clinical research professional.

Patient Interviews

A series of interviews were conducted in the spring of 2018 as a pulse-check on what motivates patients to participate in clinical trials. All seven patients (4 men, 3 women) had previously participated in clinical trials and came from 5 sites within an integrated site network. They were interviewed by phone, after first being contacted by their study coordinator to determine interest in interview participation.

Patients interviewed had a median age of 66 and had participated in studies for Alzheimer's disease, blood sample collection, COPD, erectile dysfunction, gout, hypercholesterolemia, hypoactive sexual desire disorder, osteoarthritis, overactive bladder, smoking cessation, type 2 diabetes, and vaccine (c. Difficile and influenza).

Patients were asked the following questions, with responses summarised below.

- **How many trials have you completed, and have you done them all with the same organisation or with different organisations (site network/healthcare provider)?**

Collectively, the patients had completed 33 trials, and screened for an additional 7, with 4 patients actively randomised in a trial at the time of the interview. Patients had conducted the majority of their trial experience with the same site organisation, with the exception of one trial completed at an academic centre.

- **What made you consider research the first time?**

Six of seven respondents reported they first considered research because of a medical condition for which they were seeking relief or improved treatment outcomes, including COPD, type 2 diabetes, high cholesterol, and overactive bladder. One respondent shared that he began participating in flu vaccine studies on the recommendation of a friend so he could give back to the community, and then progressed to an indication-based study after a positive experience.

- **Has that reason changed the more you participated?**

Five respondents shared that the primary reason for participating continued to be for treatment or management of their condition, and the financial benefit was an additional reason shared by four participants. The financial benefit aligned with those respondents whose conditions required maintenance medication and other supplies and was particularly prevalent among retirees and those on fixed incomes.

Conversely, two of those interviewed made a point to mention that the money was not important to them, and was not a motivating factor in their decision to participate.

The altruistic benefits (advancing medicine, helping others, vaccine donation programme) and strong relationships with study teams and principal investigators were also mentioned as reasons for continued participation in research studies. Frequently, interviewees referred to study team members by their first names as though they were friends or family: "Holly knows my history, so she calls me whenever a study might work for me." "I got blessed when it came to Susie." "She is awesome; we talk about situations that impact my life and she is approachable."

- **Do you talk to others about research participation or is this something you view as a private choice not to be discussed?**

Responses to this question fell into two categories: Those who spoke only with close friends or family about their decision to participate in research (three participants), and those who claimed to be vocal advocates for research (four participants). For those who chose not to share their research participation with a broader audience, the reasons provided were around modesty and privacy, versus concerns that others may not share their views.

- **If you could change something about the research process as you've experienced it, what would that be and why?**

Responses to this question varied widely, yet all pertained to elements of logistics, study design or the overall drug development process. Interestingly, the patients that shared the aspect they wanted to change all acknowledged that they understood why it wouldn't be possible, or couldn't be changed as they suggested.

- For the arthritis study I was in, I had to go to a crowded orthopaedic place for my X-ray. It would be nice if the site had an X-ray machine, since I never have to wait there.
- The needles! Getting stuck all the time!
- If I could sit in my armchair and you came to me.
- I think if the hours were better you could get more people to join. I'm retired now, but when I worked, it was a lot harder to make appointments.
- Try to get the government to speed things up. They take too long to get things approved. They could also share with the patients when drugs do get approved, maybe a "congratulations!"
- The [Sponsor company] should let people who took part in the study have a break or discount on the medicine once it's approved. I gave my time and my body, maybe you could help me now.
- I was in a study that started with an e-diary, but they had to switch it to a "clunky and chunky" diary book. If the e-diary could have worked out, that was better. I was disappointed when they took mine away. It's hard to remember: counting hours, or if you're out – really inconvenient.
- I would like to know in between or half way through the study if I am getting the placebo, but I understand why they can't tell me.

- **If you could say something to someone considering research for the first time, what would it be?**

All patients interviewed expressed the message equating to "Do it!" in different ways. Many iterated that it was a positive experience, safe, well monitored, or carefully managed. In this question, six of the seven mentioned that it would help you, and three of the respondents also mentioned that participation would help other people, too.

Nearly half of those interviewed mentioned that participation in clinical research helps one become more educated about their own health or medical condition. One patient also reminded potential participants to "check your pride at the door and be prepared to do things in the interest of science."

Conclusion

Participants are driven to consider research for various personal reasons, but a primary reason remains a dissatisfaction with the current course of their condition and a motivation to find something better. However, only two of seven patients interviewed were told about clinical research by their physician (who also happened to be the Principal Investigator on the study referenced); the others sought it out on their own, reflecting a movement towards patient empowerment. Even when aware that the study may have a placebo component, uncomfortable procedures, or inconvenient visit schedules, the overall research experience outweighed the discomforts for many.

The importance of a positive experience with the study team was clear from feedback – from the receptionist, to the phlebotomist, to the research coordinator and investigators – the impact of this cannot be overstated. It is because of these meaningful relationships that patients chose to look past the challenges and find ways to participate. This is not to say, however, that a positive relationship at the site level can make up for a protocol designed without the patient in mind. One must wonder how many tertiary and exploratory endpoints caused patients to say "Too many needles!" while begging for an e-diary during a long-term outcomes study.

As research professionals we have a call to improve the clinical research ecosystem and implement truly patient-centric trials; we must listen to the patient and suggestions – even those given tongue in cheek – to advance clinical research and the long term challenge of access to patients.

An expansion of the research to a larger patient population is planned for Q318 to validate the common response themes that have been identified.

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