

What It's Like to Volunteer in a Research Study – Ep 32

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JESSICA GANGA 00:06

[music] Welcome to our Kessler Foundation Research Recruitment Roundtable, an extended Fast Takes episode. My name is Jessica Ganga, communications and digital media coordinator at the foundation, and I'll be hosting the discussion where our panel will talk about research recruitment here at Kessler Foundation. Ever wonder what it's like to participate in a research study? Do you know what the process is like to be a participant? Those questions and more will be answered today. Before we get started, I'd love to introduce our panel to you. Today, we have with us Rachel Byrne, Senior Research Coordinator in the Center for Spinal Cord Injury Research and the Center for Outcomes and Assessment Research, Kate [inaudible], Research Coordinator in the Center for Mobility and Rehabilitation Engineering Research, Jenny Masmela, Senior Research Coordinator in the Center for Stroke Rehabilitation, Sam Schmidt, Research Recruitment Manager, and Angela Smith, Senior Research Coordinator in the Center for Neuropsychology and Neuroscience Research. Thank you, ladies, for joining. We're looking forward to hearing your insight about research recruitment here at the foundation. I'd love to start with you, Sam, directing some questions toward you. Could you please give a brief explanation of your role at the foundation?

SAM SCHMIDT 01:27

I'm the research recruitment manager. I've been with Kessler Foundation for about five years now. I'm usually the first point of contact when someone is interested in a research study and wants to enroll. People either sign up through our website, or they can call. I'll typically start by creating a profile for them in our secure database. During this call, I will gather some information about them, some personal information and medical information to see which studies they qualify for. So once I create the profile, it goes into our secure database, and then we're able to see which studies they're eligible for. I also help identify new ways of reaching people that qualify for our studies. So I work with a lot of local community groups and organizations that help people with disabilities and debilitating diseases to help get the word out about our research studies.

GANGA 02:25

For our listeners, can you please talk about what research recruitment is at Kessler Foundation for anyone that might not know?

SCHMIDT 02:33

So all of our research studies have specific criteria and demographics for people they're looking for that qualify for the studies. So our research studies are grant funded, and our researchers must adhere to the strict guidelines of who qualifies for the research study. So that might mean somebody who has a brain injury who is between the ages of 18 and 65 who is right handed, for example. So my job is to help identify people that qualify for these studies and help them get enrolled.

GANGA 03:09

If somebody would like to participate, what can they expect as they enroll in a study and then begin the participation?

What It's Like to Volunteer in a Research Study – Ep 32

SCHMIDT 03:17

Typically, people can find out information about which studies are enrolling participants by going on our website. You can go to kesslerfoundation.org and click on the join a study button, and then you'll see a listing of all of our actively recruiting studies, and you can select a study that you're interested in and then sign the form on the website. And then I receive an email with the contact information, and I'll give you a call and then create the profile for you in our database. And then, we'll see if you qualify for that study. So if you do qualify, I will provide your contact information to somebody on the research team for that study, and they will give you a call, and they'll generally have some study specific questions for you. And then if you do qualify, you can work out scheduling directly with them. Participation looks different depending on the type of study. So we have what we like to call tele-studies, which are research studies that can be completed remotely from home. So these are typically survey or questionnaire studies where everything is done either on the computer or over the phone, so it doesn't require any visits to our local offices. These studies tend to be shorter. You can often complete these studies in one day, and we also have studies that require visits to our offices. And that could be a one day study or an intervention study that requires multiple visits to the office over a period of time. So depending on what the study is, it looks very different. So we have studies that focus on improving cognition, so they might be testing out an intervention that improves memory. So you might complete some tests of thinking skills. We also have studies that focus on improving mobility, so regaining function after an injury. So you may enroll in a robotic exoskeleton study, which is intended to help you regain function and improve your mobility. We also have studies that focus on improving quality of life after an injury, so it really depends on what study you're enrolling in. It looks very different depending on the study.

GANGA 05:39

It sounds like there's a little bit of something for everyone if they would like to join. You mentioned that people can come into the office here at Kessler Foundation for studies. COVID-19 is still happening. There are protocols still in place. What are the protocols at Kessler Foundation that are in place to ensure the safety of participants and the researchers involved in the study?

SCHMIDT 06:06

Yeah, so we take safety very seriously at Kessler Foundation. Our offices have actually been open since June of 2020, with lots of safety measures in place. We have thermal scanners at both our East Hanover and West Orange location. The thermal scanners will take your temperature prior to entering the office. If your temperature is over 100.4, we will ask you to go home, and you would only be able to enter if you don't have a fever. We are also requiring that everyone wears masks. If the study requires the participant and the researcher work very closely together, we require surgical masks or K95 or KN95 masks as an extra safety precaution. We're also continuing to social distance in the office as much as we can, and we have HVAC air purifiers throughout both offices and sanit-- I'm sorry, sanitation stations as well.

GANGA 07:13

Another thing people might want to know about is privacy of their personal information since data is being collected. How does the foundation keep the data and personal info secure?

What It's Like to Volunteer in a Research Study – Ep 32

- SCHMIDT 07:28 At Kessler Foundation, we take HIPAA very seriously. So we ensure that everybody's information is private and protected. Once someone is enrolled in our participant database, they are provided with a unique number to identify them. We use that unique identifier in lieu of their name. So instead of using personal information to identify someone, we will use the number instead, and only members of our research team have access to our database, and everything in our database is tracked. So we do take it very seriously, and we ensure that no information is shared and everything is protected.
- GANGA 08:10 Thank you so much, Sam, for introducing what research recruitment here is at Kessler Foundation. Now I'm going to direct some questions to our panelists. First question is for everybody, what can an overall day look like for someone who is participating in a study? Angela?
- ANGELA SMITH 08:30 I always say similar to what Sam was saying that every study is very different in terms of what participation might look like. And when we first make contact with somebody who's interested on the phone, we'll go over all of the details of the study, how many visits, the amount of time that they might have to be here, what they will be doing. And it ranges anywhere from a one day study that might take a couple of hours to what we call clinical trials, randomized clinical trials, where that's going to involve a lot more visits, where they're going to come in, maybe up to 15 to 16 times during the course of the study over, say, a six to eight month period of time. So that's the minimum range to the maximum range of what participation might look like. Every lab is going to be different, too, in terms of the type of data that they're collecting and what they're going to have the participants doing in our lab. I mean, it's cognition primarily that we're looking at. So we're going to be doing a lot of tests that are looking at memory, learning how quickly you can process information, things of that nature.
- GANGA 09:53 Thank you so much, Angela. The next question is actually for you as well. For folks who aren't in the world of rehabilitation research, they may picture researchers as people in lab coats that poke and prod at folks, but we know that this is not the case. Can you explain what a research study is like from the perspective of a senior research coordinator?
- SMITH 10:15 Recruitment is relationship, and that begins, I mean, with Sam definitely as kind of the first point of contact and just being empathetic and understanding to their concerns about maybe participating in a research and what they might be doing and try to allay some of the fears to answer the questions that they will not be poked and prodded at - I'm going to use this in quotations - "as a guinea pig." We are very much committed to the mission to improve the lives of people with disabilities here at Kessler Foundation. So I ensure or I kind of comfort people when I'm talking to them on the phone that we have their best interest in mind. A lot of people do participate because they want to give back to other people who have the type of disability that they have, whether it might be multiple sclerosis, traumatic brain injuries, spinal cord injury. So a lot of research is also doing that. We're collecting data to help people who might have

What It's Like to Volunteer in a Research Study – Ep 32

these injuries in the future, and it is a give back to help others who might be in that situation in the future.

GANGA 11:37

Sam?

SCHMIDT 11:38

Participating in studies is completely voluntary, and if at any time anyone is uncomfortable with continuing the study, they are allowed to withdraw. We don't make anyone do anything they're uncomfortable with.

GANGA 11:49

Thank you, Sam. That was a great point to bring up. Kate, the next question is for you. In the center that you work for, I know that there is sometimes robotic equipment or machines used during studies. How are participants made aware of the equipment's function and use before the study?

KATE GOWOREK 12:06

We have a team of, depending on if it's like one of the robots that we're using, a physical therapist will explain to them how it works, what to expect, they'll be trained on how to use it. Any questions they have will be answered by them. With a lot of our other equipment, we do have biomedical engineers who specialize with this equipment, and they'll explain the same thing along with our research assistants. So before anything is done, we explain. We put these markers on. They're like stickers. The cameras we use basically, like how you make video games or movies now where it just captures you and turns you into a little stick figure. So everything is explained in very simple terms so that everyone can understand exactly what we're going to be asking them to do.

GANGA 12:46

And if anybody doesn't want to use a particular machine or a robotic equipment, I know that Sam made the point previously that things are voluntary, are people allowed to back out, or do you offer a lot of time for people to ask questions?

GOWOREK 13:02

Everything is explained prior to bringing in the participants of what's going to be expected. A lot of our studies, depending on what equipment we're using, if there is certain equipment that can potentially make a patient uncomfortable, a lot of the studies do have the option to skip using that piece of equipment, so it does vary if it's an equipment specific study. So, for example, an exoskeleton study that we're doing, a robotic exoskeleton study, the person would have to be in that in order to participate, but they do have the option of whether they would like to participate or not. So, like Sam had said, they can choose to-- if they get in it, and they're uncomfortable, they feel like it's not a proper fit for them, they can choose to withdraw. And obviously, if we get something else that comes in that may be appropriate for them, we'll give them a call to come in for that.

GANGA 13:50

Thank you, Kate. The next question for everyone is for the centers that use MRIs during some studies. This is also something that can be a little intimidating for people, especially children participating in pediatric studies. What are some common misconceptions about MRIs, and how do you prepare participants to use them?
Angela?

SMITH 14:11

I think one of the biggest misconceptions is that MRIs use radiation, and an MRI does not use radiation. It's using a magnet to be able to get the images that we need. So

What It's Like to Volunteer in a Research Study – Ep 32

there's no radiation involved. We also don't use any contrast in our lab anyway, in the studies that we are doing. So there's no IV contrast that's being given. The effect of repeat MRIs, sometimes some of the studies that we have, they might be doing three MRIs over the course of a six to eight month period of time. So we do say that the safety of repeat MRIs has been established. Although long term effects are always unknown. We have a consent form that the person will go through with the researcher who is consenting them into the study so that they know all of the potential risks that there might be. But as far as misconceptions, that's probably one of the biggest ones is that there is radiation involved.

GANGA 15:11

Thank you. And Sam, would you like to add to that?

SCHMIDT 15:13

Yes. We also have a mock scanner for our pediatric patients that helps kind of familiarize them with the scanning experience. It's a device that is much smaller but looks very similar to our actual scanner or actual MRI scanner. So typically for the pediatric MRI studies, we'll have the parent bring their child in to do one visit in our mock scanner where they have the chance to use the mock scanner and kind of get used to what the experience is like, what noise they would expect to hear, what it looks like. And this helps kids feel a lot more comfortable before they go into the actual MRI scanner.

GANGA 15:55

Angela?

SMITH 15:56

A lot of the studies that we do that have MRIs, the MRI portion is optional, so the person could participate in the study and not do the MRI part of it. Also, if they do decide to do the MRI, and they're in the MRI, and they're uncomfortable, and they want to be taken out, they can be removed from the scanner at any time, and that would not affect-- obviously, we wouldn't be able to collect MRI data on that particular person if they say, "Hey, this is a lot for me to handle at this moment," but they would still be able to remain in the study in general and do neuropsych testing, exercise testing, whatever else is involved in the study, even though they might not be able to complete the MRI portion.

GANGA 16:45

It's really good to note that at the end of the day, the participants' safety and well-being and what they would like to do is kept in mind. So thank you for bringing that up. Rachel, can you please talk about tele-studies here at the foundation and how they work, especially for those with SCI who would like to participate?

RACHEL BYRNE 17:06

Our studies that involve phone surveys are a very convenient way for people to participate in our research studies. They can do it from the comfort of their own home, especially if they have concerns about COVID or travel to the foundation. When we enroll participants for a study that's completed over the phone, we do still review the consent process with them, and we always ensure that we have another staff member on hand just to make sure we can cover everything and answer everyone's questions. And we do also give the option to break up the sessions, so particularly for people with spinal cord injury, they might have upper limb impairment. So it's harder for them to hold the phone or set up a headset, so they

What It's Like to Volunteer in a Research Study – Ep 32

might want to split up the session over the course of two days. That is another convenience to our tele-studies.

GANGA 18:06

Are any of the tele-studies done via video, or is it all on the phone?

BYRNE 18:13

So most of it is over the phone. There are some studies that involve group sessions. So based on the design of the study, there might be a group therapy session or more like a support group session or focus group session. And so some studies are designed so that people are joining via Zoom or something similar to that as well.

GANGA 18:34

Sam?

SCHMIDT 18:35

We do have several studies that do use Zoom and other online platforms to do video conferencing. For example, we have a study that's focusing on improving job interview skills in people with TBI and pediatric autism. And this study uses virtual reality and an online platform too as part of the intervention in this study.

GANGA 19:01

Thank you, Sam. Would anybody like to add any thoughts about tele-studies here at the foundation? Sam?

SCHMIDT 19:08

Yeah. So one other thing about the tele-studies is that it allows us to reach people we wouldn't have been able to reach before. Most of our studies used to require visits to our offices and couldn't be completed from home. So you had to live close by West Orange or East Hanover, New Jersey, in order to participate. But now we're able to reach people all across the country.

GANGA 19:31

Has anybody seen - and anyone can answer this - how the tele-studies has affected their research in terms of, I guess, the point that Sam made that now you are able to reach a broader, I guess, span of participants? Rachel?

BYRNE 19:51

Like Sam said, there are a lot more people that we could open our research to. So, for example, one of our studies had been completely in person prior to COVID pandemic, and we adapted during that time frame and switched over to our virtual sessions using Zoom. And previously, whereas it was hard to enroll people because the time it took to travel to Kessler, particularly if it was during a rush hour or other family obligations they have, this now opened it up to them that they could attend. And we could also recruit people who were living out of state. So we did find that to be very helpful to our research as well.

GANGA 20:36

Angela?

SMITH 20:37

A lot of the ways that we do recruit kind of getting the word out about the studies involve social media or a website that the US government runs called ClinicalTrials.gov. And those are national. I mean, we can tailor our social media to somewhat of this area, but we would get in the past many inquiries from people who lived outside of our regional area, from ClinicalTrials.gov or from a site called ResearchMatch. And they were really interested in participating. They had heard about the study, but they couldn't participate because they were living too far away. So now when we get those inquiries from sites like that, depending on the studies that they're interested in, we have that option to offer them. And for me, one of the

What It's Like to Volunteer in a Research Study – Ep 32

things I do not like having to do when people are so interested in participating is telling them, "No, we don't have anything for you because you live too far away." And now, we have that option to be able to give people the options through tele-studies. And I love that.

BYRNE 21:45

Rachel. There's actually two other things I wanted to mention. So I briefly touched upon transportation being an issue, especially for people in the spinal cord injury community. Sometimes they have not gotten back to driving or don't have a vehicle that's been adapted for them. And some of our studies do provide the transportation, can set up transportation and reimburse for that. But a lot of studies cannot. So using the tele-studies is very helpful for that as well for people who wouldn't otherwise be able to come here. And the other thing I wanted to mention is we could adjust our hours a little bit better. For example, our data collectors might want to leave for the day a little bit early and head home and complete a later session with a participant from home because they're working and they can only talk to us maybe at 07:00 O'clock. And it definitely opens up more opportunities in that respect as well.

GANGA 22:44

Rachel, you actually brought up a good point and touched upon one of my next questions, which is about transportation to the studies. So for the folks that can make it to our offices, is there transportation available to and from the studies? And if so, what are some ways participants can overcome this barrier if this is one? Sam?

SCHMIDT 23:09

Just as Rachel mentioned, a lot of our participants are unable to travel to us because they no longer drive or don't have a means of transportation. So we do have some different ways of handling this. We offer Uber, Lyft, or they can use the compensation from the research participation to pay for travel.

GANGA 23:29

Thank you. This next question is for everyone as well. For people, again, that might not know what goes into the research here at Kessler Foundation, can somebody please explain what a healthy control is and how having healthy controls and research is important to the studies? Sam?

SCHMIDT 23:49

So healthy controls are used as a comparison group in our studies. So healthy control basically means somebody who does not have the condition that we're studying in that research project. So we may be looking at an intervention to improve cognition or mobility in people with traumatic brain injuries or spinal cord injuries. Our healthy control group would be individuals that don't have a TBI or spinal cord injury, and they're basically enrolled in the study as a comparison to test out the same treatment.

GANGA 24:21

Angela, did you want to add to what Sam had to say?

SMITH 24:24

A lot of what we do is not testing out different medicines, but that's usually the framework that a lot of people understand when you are enrolled in a study that involves looking at the effect of a medication. So some people would be getting the medication, and some people would be getting a placebo, and they don't know which one it is. So the healthy controls are pretty much our placebo group. So they're our comparison group to the other group that we're studying that is getting the

What It's Like to Volunteer in a Research Study – Ep 32

treatment, and we can look at the difference, make sure that what we're seeing in terms of the effects of the treatment are not just due to, say, interaction with the researchers, things of that nature, other things that would be outside of the scope of what we're looking at for the effect of the treatment.

- GANGA 25:19 Thank you, Angela. One thing I wanted to point out is the 64 year old cap for most studies. Is there a particular reason for that, why there's an age cap? Kate?
- GOWOREK 25:32 So I know from my department specifically because we do do motor research, which mainly includes walking and balance. As all people age, balance starts decreasing. And specifically, once you're 65 and over, there's one and-- sorry, I'm echoing, let me start over for that part. Once you are 65 or over, studies have shown that one in three people will have a fall every year. So in order to eliminate an outside effect of balance being an issue, we have an age cut off. So this way we are only treating people who have balance problems because of an injury such as a stroke or a traumatic brain injury and not something that's age related.
- GANGA 26:19 Jenny?
- JENNY MASMELA 26:20 Yes, for my center, stroke, the ages that we are testing is from 18 to 100. So for us, it doesn't have any limit on the age.
- GANGA 26:34 Rachel?
- BYRNE 26:35 I agree. A lot of our studies don't have an age limit, but some do. And there are a couple of reasons for that. So, for example, there are various studies that are looking at employment. If it's a study that's looking at employment, they're looking more at a working age group, which tends to cut off around age 65. And another reason could be that as people age, other medical conditions or health conditions could start to arise. So if people have other health issues or are using certain medications, it's harder to see any beneficial results or improvements. They're not as great. So in the end, it looks like there might not be improvement due to the treatment from a study.
- GANGA 27:22 Thank you, ladies, for clarifying that one point. That was very useful information. Rachel, what are you and other researchers doing to ensure that studies here at the foundation are inclusive and diverse?
- BYRNE 27:37 We do approach our studies to maximize inclusivity and sensitivity. We know that some groups of people have historically been disadvantaged when it comes to healthcare access or might not have trust with medical community or scientific professions. So what we try to do is build trust with our participants. We use sensitive language in our consent forms and our recruitment procedures, and we also try to involve family members as well. And we also have our staff members participate in cultural competence training when it's available through certain studies. We also have tried to build an inclusive team of our staff members who represent different backgrounds and bring different perspectives in regards to race, or age, sex, or socioeconomic status. One of our largest studies in the Center for Spinal Cord Injury Research enrolls both English and Spanish speaking participants, so we include consent forms and questionnaires that have been translated into Spanish. We also

What It's Like to Volunteer in a Research Study – Ep 32

include study team members who are Spanish speaking as well, so we can make sure that they can communicate with our Spanish speaking participants.

GANGA 28:53 Thank you. Again, it sounds like the participants' best interest is always kept in mind with each study. Jenny, how would you say your work translates to real world outcomes? And in your opinion, how does it change peoples' lives?

MASMELA 29:13 Well, in my center, we are studying spatial neglect, which is a disorder after stroke. And we are testing the KF-NAP and KF-PAT. The KF-NAP is the assessment that identifies the disorder, and the KF-PAT is a device that help us to treat the disorder. So at this point, there are many rehab clinics utilizing this device and also identifying the disorder.

GANGA 29:54 Could you talk about, briefly I guess, what spatial neglect is and how that research is helping folks that may have spatial neglect?

MASMELA 30:06 Okay, spatial neglect is a disorder after a stroke. It's mostly when someone has a stroke on the right side, they tend to neglect the left space. Everything that is on the left side of the body is neglected. So that's why we use the KF-NAP to identify this disorder and the KF-PAT to treat it.

GANGA 30:35 Thank you for clarifying what that was. So I can definitely see that this is really important research that you're doing and why it would be important for people to participate in these types of studies.

MASMELA 30:47 Yes, it is very important. And the most important is that this has been translated into clinical, which gives the opportunity to declinations to treat this disorder. In a few years-- not many clinicians know about this disorder. So my center has been implementing this KF-NAP and KF-PAT to many different rehab centers, even though this assessment and device is around the world.

GANGA 31:32 Sam?

SCHMIDT 31:34 Yes, I just wanted to add something about spatial neglect. It's a visual impairment that happens after a stroke that isn't an issue with the eyes. It's actually an issue with the visual processing center in the brain. And it causes people to not be able to see one side of their visual field. So this can impact people in their everyday lives in numerous ways. So, for example, a man may only shave one side of his face and not see the other side, or somebody may be eating breakfast, and they'll only eat the right side of the plate. So the treatments that Jenny and her team in the stroke center are helping people with everyday function, so helping them in amazing ways.

GANGA 32:24 Angela?

SMITH 32:25 One of the most important things for translating the research into the clinic is insurance coverage, and a lot of what we do, we're establishing what they call class 1 evidence that the treatments that we are using and that we're testing work, and unless we have that evidence to support what we're doing, a lot of insurance companies will not cover cognitive rehabilitation or some other type of rehabilitation. So it's one of the most important things. And a lot of the case managers over in the

What It's Like to Volunteer in a Research Study – Ep 32

cognitive rehabilitation area over at Kessler Institute actually use publications that we've had to send to insurance companies to try to justify to them, "Here, you might say that this treatment isn't working or that cognitive rehabilitation isn't justified for this particular patient. But here is a research study that's been done that shows otherwise."

- GANGA 33:24 Jenny, could you explain why identifying spatial neglect is important using the research done at Kessler Foundation?
- MASMELA 33:35 It is very important for the daily life because some of those persons who suffered the stroke, they would like to go back to normal life. That implies driving, navigating in the open field. And if the spatial neglect is not treated, then these persons cannot go back to normal life, be able to drive, be able to navigate, be able to go back to work because they will be neglecting either side of the body, of the space of the body.
- GANGA 34:21 Another barrier may be the length of a study. What is a typical length for most studies? And for those studies that span a longer amount of time, how do you make this a smooth process for participants? Sam?
- SCHMIDT 34:39 Our research studies vary as far as how long it takes to complete them. We have some studies that can be completed easily from home or completed in one day, and then we have long term or longitudinal studies that require multiple visits or multiple calls or remote sessions over time. So the quicker studies are a little bit easier to complete. But if a study requires multiple visits or the hours for each session are long, we do allow participants to break that up. So if a study is typically completed in one day, and let's say it's four hours, if somebody prefers to split that up into two visits, we can usually accommodate that. It really depends on the study since they are also different. But again, we have the participants-- their best interests in mind, and if they're more comfortable doing things a little more slowly, that's completely fine, and they can take frequent breaks if they need to as well.
- GANGA 35:46 So essentially, with some studies, it can be tailored to their schedule.
- SCHMIDT 35:51 Absolutely. We don't necessarily operate in a traditional 09:00 to 05:00. Some of our studies can be completed after hours. Some research assistants are able to accommodate weekend hours. That isn't always the case, but it varies from study to study, but we are as accommodating as possible.
- GANGA 36:13 Jenny?
- MASMELA 36:14 Some of the protocols take longer than others. So for us, sometimes the testing process takes one hour to four hours every visit, and the way that we make them feel comfortable is providing transportation, in offering sometimes lunch, in trying to make their stay here during the visit very productive.
- GANGA 36:55 Angela?
- SMITH 36:55 The longer studies obviously are the ones that people might have more difficulty time wise committing to in the center that I work in, even if it's in, say, a six to eight month study. The majority of the participation of the visits are going to come maybe in the

What It's Like to Volunteer in a Research Study – Ep 32

first six weeks, and then there's going to be a time where there might be no contact or a couple of phone calls or something like that. And then we'll have the person come back at the very end at that six to eight month period and do another visit. So I always explain that when I have a participant on the phone and telling them how long the study is. Eight months sounds like a long time to be coming in the whole time. That's not always the case. And in most cases in our center, that is not the case with our longitudinal studies.

SCHMIDT 37:48 I also want to mention that if for any reason, a participant can't complete a long term study, and they aren't able to do all of the visits, we still do provide compensation for their time. So typically, the compensation is delivered on a schedule, so you receive, let's say, \$50 after visit one, an additional \$25 after visit two. That's just an example. So you would receive compensation even if you don't complete the whole study. It just might not be the full amount.

SMITH 38:22 The person who enrolls in a study that's longer term, they can withdraw at any time. So just because they are consenting to participate in a six to eight months study, and they find that something happens in their life, something comes along and they can't continue to commit to that length of time, they are always allowed to withdraw themselves from the study.

GANGA 38:51 Thank you, Angela. You both touched upon my next question, which was about compensations. Sam, for people that have listened to this episode and are interested in being part of a study, how can people start that process of participating?

SCHMIDT 39:10 So I think the easiest way to get involved is to go to our website that's kesslerfoundation.org and click on the join a study button. Once you click on that, you'll see a listing of all the different conditions and different types of studies that we have, and you can learn more there. And we'll have a full listing of all of our studies that are actively recruiting on our website. So that's the easiest way to get more information. And then you can complete the join a study form on our website, which is on every study page, and you'll just fill out your information, and then either me or somebody from the recruitment team will reach out to you, and we'll help you get enrolled.

GANGA 39:53 Thank you, Sam. As a wrap up question for anybody that would like to answer, why, in your own words, is it important for people to participate in research studies? Kate?

GOWOREK 40:07 For us, because we are doing mobility research, a lot of the technologies we're using can then be introduced into inpatient and outpatient hospitals where they can reach a broader population of people. So with the research we've done, we currently have FDA approval to use these robots for people who had a stroke, who had a traumatic brain injury, who had a spinal cord injury, and these devices can then be used in hospitals. It can be billed by insurance to be used with therapists and will provide more tools for therapists to use for future patients.

GANGA 40:42 Angela?

What It's Like to Volunteer in a Research Study – Ep 32

SMITH 40:43

A lot of our participants, they're looking to give back to others who are going through similar things, and that brings purpose to what they're doing. They might not gain an exact personal benefit from the study that they're in. But what we're looking at and what we're studying in the long run, could bring tremendous benefit to people who are dealing with the same type of disability that they have. And so, I hear that so many times from participants that I'm doing this as a give back and to help those who are in the same situation that I am or might be in the same situation that I am. So I think that's a really important thing that I've heard from participants in terms of the importance of being in a study.

GANGA 41:29

Rachel?

BYRNE 41:30

Yeah. I also think that in order for our research to make an impact, we need to include people who are experiencing certain issues, people who have the most knowledge, for example, with spinal cord injury. They're living the experience of spinal cord injury. So it's important to have our participants give feedback about things that are important to them. So our research centers on issues, for example, like navigating the community after finishing their rehabilitation, employment, wheelchair problems, managing pain. So a lot of these real world problems, and we can't understand that without actually involving people who are living with that injury.

GANGA 42:21

Thank you, Rachel, and thank you to all our panelists for a thoughtful roundtable and all of the information shared. For those that do have an interest in learning more about research, study participation, our panelists, and the research currently being conducted at Kessler Foundation, links are in the program notes. [music]

JOAN BANKS-SMITH
42:45

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