

## Supplementary Material

### Appendix 1: Discussion Guide – 1st Interview – Participant

Targeting improvements in bowel function and quality of life using epidural stimulation and training after severe SCI.

#### Motivations for Enrolling in Program

- Tell me how you came to be enrolled in this program.
  - o What motivated you to enroll in this program?
    - ▢ Why now?
    - ▢ Were any reasons related to bowel dysfunction?
  - o Did you encounter barriers or challenges that caused you to seek this program?
    - ▢ PROBE for barriers related to bowel dysfunction and bowel management
  - o Had you tried other therapies?
    - ▢ Explore other programs' advantages and disadvantages
    - ▢ Did any of the prior programs have an effect (positive or negative) on bowel function?
  - o What do you expect this program to provide that you have not found so far?
    - ▢ Do you think this therapy will improve your bowel function?

#### Goals, Hopes, and Expectations

- What goals do you hope to achieve while participating in this program?
  - o Top 3 goals
  - o Are there goals related to other systemic functions? For example, cardiovascular, walking, bladder, bowel, sexual function?

#### Concerns

- Is there anything that keeps you up at night (so to speak) as an individual with spinal cord injury—your most pressing concerns?
  - o PROBE for bowel function and management concerns

#### Participation in therapy

- How many sessions have you had?
- What do you expect this program to be like?
  - o Any expectation related to bowel function?

- What are your hopes for this program?
  - o Do you have any hopes related to bowel function?
  - o PROBE for examples including adult role, socializing ...
- Are your hopes for this program different than your expectations for it?
  - o PROBE for the area of bowel function and management
  - o PROBE for examples including adult role, socializing ...

## Appendix 2: Discussion Guide – 1st Interview – Caregiver

Targeting improvements in bowel function and quality of life using epidural stimulation and training after severe SCI.

### Baseline information

- How long have you been a caregiver for NAME?
- How are you related to NAME?

### Motivations for Enrolling in Program

- Tell me how NAME came to be enrolled in this program.
  - o What do you know about NAME's motivation to enroll in this program?
    - Why now?
    - Were any reasons related to bowel dysfunction?
  - o What do you expect this program to provide that NAME has not found so far?
    - Do you think this therapy will impact NAME's bowel function?

### Goals, Hopes, and Expectations

- What bowel function and management related goals do you hope NAME can achieve while participating in this program?
  - o Top 3 goals
  - o Are there goals related to other systemic functions? For example, cardiovascular, walking, bladder, bowel, sexual function?
- Do you have goals for yourself, related to bowel function and management that you hope to achieve while NAME is participating in this program?
  - o Do you have any goals related to other functions?
  - o Do you have any general goals?

### Concerns

- Is there anything that keeps you up at night (so to speak) as a caregiver of an individual with spinal cord injury—your most pressing concerns?
  - o PROBE for bowel function and management concerns.

### Perceptions of Caregiving/Caregiver Adaptation

- In what ways do you think this program can make a difference for you as a caregiver?
- In what ways do you think this program can make things **better** for you in your life?

PROBE for examples including adult role, socializing ...  
PROBE for bowel function and management

- In what ways do you think this program can make things **harder** for you in your life?

PROBE for examples including adult role, socializing ...  
PROBE for bowel function and management

### Appendix 3. Dedoose Software excerpts for “Motivation for Enrolling in Study”.

Pub ID	Excerpt	Code			
		Benevolence	Gain improvement in functioning	Gain independence	Other
B213	<p>I: What would be the advantages or disadvantages of those therapies?</p> <p>P: Um a lot of um outcomes it gets me preoccupied; um my mind clears, mm physical... hold on *coughs* sorry I had to drink...</p> <p>I: It's ok.</p> <p>P: Um what I was supposed to- um muscle, SCS bike it used to stimulate my muscles, I used to have like back on the standing frame and I used to do standing, it gives, I mean, body still feels um in a good shape, I would literally, my aim is um to do the much um rehab that I can, for my body, cause I'm not sitting on this wheelchair, honestly, up for the rest of my life. No, thank you.</p> <p>I: Ok. So that's your goal, to get out of the wheelchair.</p> <p>P: Yes.</p> <p>I: Ok. Um did you see- did you think that would happen with the previous types of therapies that you were doing?</p> <p>P: I mean I did see a program. Yes.</p> <p>I: I-I am sorry I didn't understand that.</p> <p>P: Um through the journey that I've been, I've seen like the um the amount of effort that I've put into my rehab I see the outcome.</p>			True	True
B213	<p>I: Ok. What are you expecting would happen in this-in this study, having the implant?</p> <p>P: Um I really wanna see my core to be um strong, up to the muscle and the erector spine, this is, like what I am aiming, if there is anything else it's gonna come um *inaudible* I'll be only happy and grateful for this, um yeah, for these things to come.</p> <p>I: Ok. Do you have um specific goals that you hope to achieve, for example, you mentioned um that you would like to um increase your core strength?</p> <p>P: Yeah.</p> <p>I: Are there things that you would like to accomplish because you have increased core strength?</p> <p>P: Yeah, I wanna start crawling...</p> <p>I: How can that change your day?</p> <p>P: I don't- I don't think, it doesn't-it would um it wouldn't really change my day, but it would change me mentally knowing, I wanna actually start crawling, and core and erector spinal I'd hope help me a lot with that, and because I'll crawl I still have movement in my legs, this is how I'm gonna remise soon *laughs* well not soon, but yeah. Now I need the trunk, and my triceps. The triceps it's on me because they wouldn't do *inaudible* on me because isn't-is not in this trial.</p>				True
B213	<p>I: Ok, ok. Um what are your-um as a person with spinal cord injury, what are your biggest most pressing concerns? What worries you the most?</p> <p>P: Um spinal cord injury, right?</p> <p>I: Yeah, as a person with spinal cord injury.</p> <p>P: Um I mean, I don't feel free, I feel like in a cage,</p> <p>I: Oh.</p> <p>P: And I feel like um, yeah. I feel like I am not free. This is yeah, how I can describe it, really.</p> <p>I: That sounds um.</p> <p>P: Yeah devastating, yeah.</p> <p>I: Yes, yes. That's a good word.</p> <p>P: Yeah.</p>			True	

	<p>I: I'm trying to imagine it, and it does, it sounds quite frightening.</p> <p>P: I mean, um definitely spinal cord injury gave me and still gives me a lot of lessons; be patient, be as good as you can be, like you have to long from um this .... Or otherwise you will become grumpy as, bitchful, screaming everyone, and no ma'am, I don't need this, so yeah, because yeah I guess because I've been traveling a lot and I move-I moved from ****, from home, since I was fifteen, I studied abroad in school, and um- and I feel like after accident asking this sort of like, it's just simple tasks which I used to do without asking anyone, and now, I literally have to ask like so many things and this is also like a lot of um yeah, I don't feel like free, I don't feel like that I can do and go there, and quickly do this, no, no; I become very slow and um, I don't know I feel like-I still feel myself depressed, 5 years past and I still feel like: what is going on?</p> <p>*laughs*</p> <p>I: Right.</p> <p>P: Yeah.</p>				
B213	<p>I: Are you expecting um the study to have any impact on your bowel function?</p> <p>P: Yes, for sure. And I-I feel like, I feel like it already gives me some um like, just by contracting the muscle I feel um, actually Wednesday, the first time they turned the chip on, um next same evening, I had my um period; which meaning yes, they pretty much effecting my organs down there.</p> <p>I: Ok, um had you been having periods before that?</p> <p>P: Oh, yeah, yeah, yeah. I mean, it came earlier, I wouldn't expect it, like it came 3 days early.</p> <p>I: Ok, ok.</p> <p>P: Yeah, I was like "Okay".</p> <p>I: *laughs*</p> <p>P: *laughs*</p> <p>I: Um do you expected to have any um effects on um your urinary program?</p> <p>P: Bladder, yes! I'm so fed up but with these supra-pubic catheters, I can't. I would love to pee myself, like, be able to pee when I want to, like from how it should be not from like having this tube... and Oh my God! The amount of infection it brings this tracking *sights* this is another lesson of mine, oh my God. But yeah, I would love to have improvement, like um, I actually feel spasms like, I used to train my bladder, I used to clump it, and then, and then the bladder would get full, and then this is when I'd have spasms, telling my brain "Ok you need to empty your bladder". You unclamp and um, this is how I used to train the bladder, the-um the skin? No, how do you say, the tissue of the bladder so it can be elastic.</p> <p>I: Mhm.</p>		True		
B213	<p>I: Ok, um let's see, what are your hopes for the study?</p> <p>P: The trunk movement, more stability in the trunk, let's say it that way. This is the minimum that I'm asking. If something else comes, I'll be so grateful, but I don't wanna like say; this and this, I just really hope the trunk they help me, the rest, on me *laughs*</p> <p>I: Ok, so it sounds like you're trying to kind of manage your expectations and keep them sort of low, so you don't...</p> <p>P: Yeah, expecta-yeah. It's another sort of psychological way of dealing with stuff.</p> <p>I: Ok um, if you did see changes in your trunk control, what types of things are you hoping to be able to do?</p> <p>P: Um</p> <p>I: How would that help you?</p> <p>P: Yeah, um li-like if you'd lie down on your back, you'll be able to um go on seating position without-without asking anyone to help you</p> <p>I: Ok.</p> <p>P: And then um reaching for something, that'll be very helpful</p>			True	True
A64	<p>I: Okay. Can you tell me over 30+ years, I'm sure you've tried several different therapies and programs, can you tell me what barriers or challenges you've faced in those programs? What was it in those programs that did not work?</p> <p>P: Well, to be quite frank, the only things I've really done for myself from a rehab perspective and research perspective have been on my own at home. In addition, I work at ****, I've been there for 30 years and had a career [and am]</p>	True			

	<p>still working now. So, going into Times' Square every day for the last 30 years to our headquarters building and not usually getting home till 6:30pm, that's usually when I would exercise, ride my bike, stretch, whatever for a couple hours and then dinner and do it all over again. That's been my normal for a while. I've done a few research projects along the way at Kessler Institute in New Jersey or the Bronx VA in New York, just for helping out with things like maybe a pulmonary study or something like that, low intensive. But I'm not one that has been chasing different therapies to get me out of this chair. I'm coming at this from a little bit of a different perspective; I came to terms with what I had lost in 1982 many years ago, I had to, that's what allowed me to move forward, go to college, get a job on ***, build a business. People kind of ask me why I'm doing this, why I wanted to be a part of this program. One, because I'm seeing the proof and the benefit to many people already with my own eyes and that's very compelling. But it's also [because] I want to try and help advance the research. At the risk of maybe not having great success and people going "I told you so, you shouldn't have ever worked with someone that many years' post-injury". But I think I'm in pretty good shape in all the MRIs that I've done of my lower spine have showed a very robust spinal cord. And all the working out I do every day on my bike. Back in 1983, by the way, I helped develop the functional electrical stimulation bike, which is a standard exercise equipment, out in ****, that was the last time I was a true guinea pig. And I developed a great exercise equipment for people who are paralyzed, and I've always used that. So, from a bone density standpoint and muscle mass, it's been okay, not stellar, but it's hung in there and I've never had any skin issues or fractures, knock on wood. So, been able to maintain a relatively healthy existence for the most part. But I think a lot about... If you thought about the polio community, they came up with a vaccine for polio, they eradicated polio, but they kind of forgot about those who were already paralyzed by polio. It's like, "we're done with this" and no research moved forward to try to improve those peoples' lives. I don't want that to happen to this field of research. I want people who have very long term, chronic injuries to still be a part of this research, and that's why I came down here to do this. With the hopes that... well, one, with the understanding that I may have zero benefit, but if I don't then we have some degree of success, that'll help to change the minds of the nay-sayers.</p>				
A64	<p>I: Okay. I know you have kind of managed expectations for this study, but what goals are you hoping to achieve? What would feel to you like it was a success?</p> <p>P: I look at this research as potentially life extending and if it can improve upon my autonomic functions such as normalizing blood pressure or improving the bowel or bladder activity, that to me would be an unbelievable success. I would love to be able to go home and have an exercise routine that is more intense than what I was currently doing with my bike, that would allow me to try to get into better shape and get my heart rate up and help me build and/or maintain bone density. I would love all that. I don't think, for me, it's realistic to think that I hope that I'm walking when I go home, that's not really my objective. I would love to have a piece of equipment that I could stand [in] with the stimulator on and have it activate my core and some of my legs muscles to allow me to stand independently. That would be mind-blowing to me. To me, standing is one of the best isometric exercise you can do. When you're standing in place, that's when you're driving the force down into your body, through your body and into the ground, and if I could do that a couple hours a day, as well as have improvements in my cardiovascular system, that's life extending.</p>		True		
A64	<p>I: Okay. So, from what you've told me previously, is you don't really have solid expectations, but you've thought about these things, you just haven't put real expectations on them.</p> <p>P: I won't go into it expecting it to happen because everyone is different and not everything happens for everybody. I've spoken to a lot of people who've gone through it; most people have had improvements one way or the other, but they're not all walking out of the lab. But I do look at and define a "cure" as any degree of improvement, be it your internal autonomic function—bladder, bowel, sexual function, ability to sweat if it's hot, cardiovascular—or more visibly, voluntary movement or the ability to stand and support your bodyweight. That's how I've always characterized this study, that it has the potential to do that and</p>		True		

	we're trying to learn if it has the potential to do that with someone 39 years post injury. So, I think we have a pretty good start.				
A64	P: Aging with a spinal cord injury isn't the easiest thing to do in the world, and aging in general isn't all that friendly. It's easy to put on weight if you have a spinal cord injury, there's high rates of diabetes in spinal cord injury, I hope to avoid that. Using an open catheter system, a suprapubic catheter, for 38-39 years and being colonized with bacteria for that length of time probably isn't the healthiest thing in the world. I come from a family that has a history of cancer; I had breast cancer in 2016, caught very early, thankfully. Brittle bones, skin issues, those are all the things that kill people with spinal cord injuries. Christopher Reeve died of sepsis from skin breakdown that he had that wasn't healed all the way and he thought it was fine, but unfortunately, some bacteria got in there and it went rampant. There's a lot of stress on our hearts because we have very low blood pressure and due to the lack of muscle activity, our hearts have to work harder to pump the blood. I'm also a tall guy, 6'3". So, those are some of my concerns. And a lot of those concerns can be improved upon through this research, I do believe it. Me in particular, I don't know, but I'll work hard to try to make it happen.		True		
A64	I: Yeah, yeah, I can see that. Those are all the questions I have, is there anything that you think is important for us to know about participating in this study? Just anything at all. P: I think it's super exciting and I know I'm honored to be down here and be a part of it. I hope to make people proud and gain some benefit and help move things forward. I've put my money and my effort towards this cause for many years now, I've put my body towards it, and I couldn't think of a better place to do it. I: Well, I feel grateful that you started what you started early on and got involved with Chris and Dana and are here today to hopefully see some fruition for your efforts, and not just for the program in general, but for yourself. P: Yeah, thank you. I mean, I was a catalyst which launched a community effort and I think my dad and many other friends of his and the torch being passed on to his kids, including myself and my sisters, to keep building this out.	True			
A133	I: Okay so not too far. Um, what motivated you to come to Louisville and participate in this program? P: The benefits of the stimulation...the stimulator				True
A133	I: Okay um...did you encounter any barriers or challenges um in your past therapy? Or even in your everyday life that caused you to seek out this study as opposed to other studies? P: Um...I mean yea. All the physical limitations that come along with quadriplegia make you want to find a way to overcome them. But there was nothing that was going to do that until epidural stimulation. I: Okay. Um, so...so your motivation was hopefully to gain some function um. P: Yeah		True		
A133	I: To your body. Um, what about function in relation to um, your bowels, and your bowel management program P: I mean...*sighs* that's the most awkward time of the day every day. Because I have to figure....so like...anything that would allow me to do that on my own would be worth doing like study wise or whatever. But I mean I don't know if epidural stimulation is going to be the thing that fixes that. From what I've talked or heard from other participants, is that they haven't seen much progress I guess with that area. But I know everyone is different. But yea I mean if like, if there was something that would give me bowel and bladder function control back, it would be worth jumping over just about every hurdle to do it		True		
A133	I: How important is that in terms of your overall uh progress? Where would you rank that? P: Like in terms of like if I could get this back, it would be more important than that? Or stuff like that? I: Yea. Whu- yea P: I could put control of my hands and fingers at the top of the list; way above everything else. Then I would probably put bowel and bladder second or third		True	True	



A133	<p>I: Okay; um do you have hopes for this program? For this study? I know you kind of managed your expectations, but do you have hopes?</p> <p>P: Well yea. I mean I hope that I can...you know... the ability to stand up and take some steps. I hope that I have...um they were talking today like they've seen how its effecting people's hands and arms or having some effects from it. Though you know, if I can have stuff there, you know all kinds of hopes but...I try not to set those in stone.</p>		True		
A133	<p>I: Yea, okay; what about goals. What goals do you have for this study?</p> <p>P: Uh, for the study...the goal I mean...however I can find ways to regain function to limit the needs I have with caregiving. You know, I uh...and I...</p>		True	True	
B42	<p>I: What was it about, now we are going to talk about the stim and um bowel movement and urinary functions, so all of that together? So, what was it about the-the stim program um that was interesting to you? That motivated you to want to partici-participate in that particular program?</p> <p>P: The opportunities that it presented.</p>				
B42	<p>I: Okay. So, what were your expectations coming into this- this study? The stim study and the bowel study?</p> <p>P: To get anything I could get and that- because Dr. **** has told me from the- from the get-go that I am the weirdest person he's ever met with my injury. He said he's been practicing for not telling how many years and he says, 'I've never seen anyone with an injury like you've got'. Because my hands continue to improve, um my strength continues to improve, and I have started out with triceps on one side, and biceps on the other, and now I've got a little bit of- a little bit of each one of the ones I was missing on the oth- on each side so those continue to improve. In fact, he told me about a week before- two weeks before my surgery that I ought to be a good candidate for them. Cause I'd probably definitely going to give them some wrenches.</p>		True	True	True
B42	<p>I: Can you just kind of name three things that you are really hoping to achieve? Out of this program.</p> <p>P: Well, I would like to be able to stand. I don't need to run a marathon. If I could stand up and adjust myself in the chair, I'm going to- I'm going expect- I'm going to say that's gonna be- a-b- a huge accomplishment. Because based on what on- what I normally go through every day. Um any uh- anything I could get to move that doesn't currently move, would be great. And anything I could get that would help my wife take care of me, would be that much more better as well.</p>		True	True	True
B42	<p>I: Um, what do you think this study can provide that you have not found so far?</p> <p>P: The u epidural stim?</p> <p>I: Sure.</p> <p>P: Um, more opportunity than anything else. I was determined I was going to do the program. You can ask ****. She'll probably tell you I am the most determined participant she's- she's ever had. Because she'll tell you- she laughs and says she knows more about my medical records than she does hers. Cause I kept- hi-hitting snags.</p>				
B42	<p>I: Yeah. Um, okay, do you have, in terms of this program, the-the stim study, do you have particular conter-concerns about say cardiovascular or sexual function, walking...bladder?</p> <p>P: As far as- well, I have particular concerns about all of those. But, you know, it's just more of that I really hope I gain something in some of those areas.</p>		True	True	
B42	<p>I: Do you have any expectations related to the bowel part of the study? What are you hoping that you can achieve with this bowel program- this- in this study?</p> <p>P: I really wish my bowels would start working again to where I could be- do more of it on my own.</p> <p>I: How would that make a difference in your life, your daily, you know, daily day-to-day routine?</p> <p>P: Well...*****'s needs are not what they use to be so I could save her a whole lot of- hey **** come here a minute. And- the um, that could save her a whole lot of wear and tear on her knees. So that would- that would help in a lot of other ways.</p>		True	True	
B42	<p>I: Um, I'm hoping the next time that we speak, you know, you're gonna be farther into the program so you'll have more uh hopefully new things to tell me.</p>				

	<p>P: Well, I hope so. And I'm- like I said I'm kind of excited about this. I- you know, I-I have got a weird injury and-and ever-every doctor that I've ever seen has told me that. And uh it was a bruise on the spinal cord, and they've seen people that had four times worse than what I got that didn't show any of the stuff that I did. The paralysis. So...I- Dr. *** says I'm going to be a real good one for them.</p> <p>I: Mokay well I hope so.</p> <p>P: Well, I hope so too. Hoping they learn a lot. Like I said I've already started out being the odd duck out so...</p> <p>I: It sounds like you like that.</p>				
A128	<p>I: Okay. Um, what was it about this particular program, the epidural program, that was interesting to you? That you wanted to try this? What was different from the other types of programs and research out there?</p> <p>P: Um, truthfully, I mean I even right now I'm almost 10 years into my injury, it was 2013, so really, I was just kind of stagnant. I mean I didn't... I had minimal coverage when it comes to my insurance when it came to physical therapy, things like that. Um, I really found it interesting, you know the technology part of it and how they're, you know, working towards getting people with...getting people movement below their injury level. Um, so they could, you know, possibly, move those limbs again or get, you know, some kind of improvement. And, um, it was.... even though it's...you know a two-year commitment, and I would have to move there...um, which was difficult for a couple of years...it was still in my mind possible. So, it was something that I, you know, continuously looked into and after a while tried to you know, work it out in my life to be able to move there for two years and take part in this.</p> <p>I: Okay. Um, when...when you...uh were looking into this study, was it the movement that you were most interested in? Or were you also interested...were their reasons related to bowel dysfunction or urinary dysfunction that had you interested?</p> <p>P: I mean it definitely does. I'm...I have a pretty good schedule and I'm really kind of farther into my...I don't want to say it like this...but like I said I've had my spinal cord injury for 9...almost 10 years so I'm a little further into this where I, you know, don't have as much problem with bowel or urinary issues or accidents. Um, but in my mind, any improvement with that would be huge. Um, but truthfully, that would be...that was mostly the movement that, you know, interested me when it came to the epidural stimulation study.</p>		True		
A128	<p>I: Okay, um...What do you expect this study to provide for you that you've not found yet?</p> <p>P: Truthfully, I don't expect...not expecting anything because as I was explaining, that you know, this is experimental so um...I'm expecting to, you know, hopefully help other individuals with spinal cord injuries in the future with, you know, the research they do with me. Um, I'm hoping I guess you could say, just um, to you know, get some movement back possibly below my level [of injury] and gain some strength</p>		True		True
A128	<p>I: Okay. So, you're not expecting any...anything from the study. What are your hopes? What do you hope to achieve?</p> <p>P: Ah, hopefully you know I...I um have a good kind of interaction with the stimulator. I get some movement that I haven't had before. You know whether that's um...in my...in my...in my hands cause of my nerve damage or below...my injury level. Increase my bone density strength...</p> <p>I: Okay.</p> <p>P: And overall yea, lower...lower body strength, um that I don't have use of.</p>		True		True
A128	<p>I: Do you have any goals...um...for improvement related to...um...cardiovascular...uh...temperature, blood pressure...</p> <p>P: Um...I mean...I know...yea...all that stuff I... I would definitely...would be a goal because it will improve my health but at the moment I don't have many issues with those types of things. I'm really kind of lucky that way where my...I do have, you know, fluctuating blood pressure but thankfully I don't get autonomic dysreflexia or...um...you know, something that happens negatively because of my cardiovascular or anything. It's very rare...</p>				True
A128	<p>I: Okay. Do you have any goals related to standing or walking?</p>		True		

	P: Yeah. I mean that would...truthfully, I mean, I'm willing to whatever it would take to do that.				
A128	I: Do you have any goals related to b...bladder, bowel function, or sexual function? P: Um...I...when it co...I...when it comes to like...um bladder function, I can...I have neuro-damage to my hands um...so I can...so I can actually cath myself. I've done it a few times. It's not the most...the cleanest because of...you know...UTIs and things. Um...I guess with that would be my han...the...the um...nerve damage in my hands doesn't allow me really to do either of those for myself. Um...so I mean eventually would be great to do those two things on my own with no help. But that...especially when it comes to the bowel care...I don't know if that's even, you know, a possibility. But um...I'm sorry I'm kind of confusing but it is definitely a goal of mine to be you know...more self-sufficient when it comes to those two things.			True	True
A128	I: The things that are most important to you. P: Um, gaining more independence. Uh, gaining function below my spinal cord injury level. Um, getting data and, you know, research, positive research for future spinal cord...uh pe-individuals, that are you know, taking part in this. And.... yea just improving uh quality of life.	True	True	True	True
A128	I: What are you, I know you said you have no expectations, but what are your kind of...thinking might happen in term of movement? Can you be more specific in that? P: Yeah. Yeah. Um, you know I'm definitely not expecting to [chuckle]...Ha...Um...let me start over here. Uh, I think, here you know hoping, that I will have...get some truck function in my...possibly be able to work my abs somehow or my trunk to be able to possibly, you know, sit up or...um...definitively get more movement in that area. And I mean just to be able to...even move my legs or any...any of that thi...point you know to continue to exercise those areas that haven't been um you know been able to move or anything the last 10 years. I: So, if you were able to gain um more core strength and some movement in your legs, what would that mean...in terms of your daily life? What kinds of things can you envision happening? P: Um, I mean, like I said it would just improve my independence substantially if I... if I could tran-, you know sit up a little bit or transfer myself from my bed to my wheelchair, um that independence, uh and even that confidence would, you know, be great. And I think those...those two things would help that. Um having more, you know, balance would...through my core would help me to be able to, you know, get out and um...You know I have a gr-- freedom chair, which [laughs] I don't know if you know what that is, but I...I...I'm not really able to use it because my...my lack of core strength. But get out and you know hike and do stuff like that. Um...Not, not literally but you know with my freedom chair and things. Just uh, just be able to get out and experience the world a little more		True	True	True
A128	I: Yeah. Okay. Well, those are all the questions I have. Is there anything that you think is important for us to know? Regarding, you know, looking forward to the study? Or...? P: No, I just um you know anything I can do help or to participant, you know, to help someone in the future that has a spinal cord injury...with anything, I'm definitely willing to do. And, um yeah, I just appreciate your time. And cause I know...I know everybody...you know in this is working towards, you know, a better quality of life for people with spinal cord injury so it's...it's awesome.	True			True
C237	P: Yeah. I'm being really cautious with-with you know, because I know that there are a lot of things that we don't-that we still don't know about how the neuron the nervous system works. And so, it's like I know that whatever they whatever-whatever happens with the study, they will learn something and that's kind of my mindset is whatever-whatever happens whether I regain much or not. They're still going to learn something and it's going to help someone else, and you know, I mean obviously I'm here, so it gave me some hope but that's my focus is more. What are they going to learn from me? You know, okay, so I'm a teacher so I'm a science and math teacher. So, this-this is just another teacher thing.	True	True		

C237	<p>: Yes. Okay, okay. Okay, so I guess, excuse me *clears throat*. Um, back to managing your expectations deep down underneath, is there I know it's baby steps, but is there something that you're hoping you can achieve in this program?</p> <p>P: I would-I would love to, eventually whether it's with this study or subsequent study or whatever, I would love to regain the ability to at least walk a little bit again. I know that I have a really long way to go before that's even a conversation. Although we did-we did stand me Friday and today and my left leg with the stimulator was supporting my weight today.</p> <p>I: That's exciting.</p> <p>P: Yeah. Yeah. I know that-that was really cool. And my left leg has been the more responsive so far. But even-even if I can just stand without necessarily having a standing wheelchair would be would-would-would be huge. Just to be able to reach things. I am 5'10, I was 5'7 when I got hurt. I don't even know how to be 5'10, you know? Like a little but I go to Walmart, and I look at the top shelf and I'm like if I could just stand up. I know I could reach it and instead I have to spend 15-20 minutes looking for somebody to help me reach something, you know? which is super annoying. So, but I am, I'm due for a new wheelchair. So, I'm actually in the, he is getting a new one, and we're going ahead and getting me a standing to just because, I thought it would be kind of helpful. I know that like, when I'm doing my training and stuff, I can't use the standing part and all that, but I thought it would also be helpful during the times when I'm not staying, you know, doing my training and whatever. Yeah, to be able to help cook or whatever. You know, do different things around the house or you know, make it easier to go shopping or whatever. So, and so yeah, there's like I said, there's a lot going on with all of this.</p>		True	True	
C237	<p>I: No. No, it's perfect. When you decided to be in this study were any of your reasons related to bowel or bladder dysfunction?</p> <p>P: I mean, I knew-I knew that that's part of the study when I was going into it and I'm like, yeah, that would be awesome. If I could regain some-regain some control over my bowel and bladder. That would be fantastic. You know again, it's one of those things. I'm just going to kind of see what happens and you know hope for the best but-but also the cautious with with my optimism.</p>		True		
C237	<p>I: Sure. Okay. What are you hoping or expecting this study to provide for you that you've not found so far with other therapies?</p> <p>P: Again, I'm just-I'm hoping that I regain some function because anything that I gain is going to be something that I wasn't going to get back home because there's just there's not a lot in the way of spinal cord injury research in Kansas. I mean, KU Med is focused on cancer research. So, it was either come here or go somewhere like Craig or you know, I'd have to go far away from home. Kick it. Any kind of real spinal cord injury, any kind of breakthrough treatments, you know?</p> <p>I: Sure. Okay, did you notice in early in your therapy previously, did any of that have an effect on your bowel or bladder?</p> <p>P: Not really. I mean basically, again, it was 25 years ago. The prevailing knowledge was yeah, you're stuck with this. So, let's just get you on a bowel program. Get you regulated and get you, you know, get your body used to having-to having to evacuate with hope, and-and so there really wasn't anything to try to-to try to re-establish those connections, you know nerve wise, right?</p> <p>I: Okay.</p> <p>P: Yeah, because it was quite a while ago. Yeah. Yeah, I mean and like I said 25 years. I've spent the last 25 years hearing. Yeah, you better learn to live with this, you know, and I'm like guys I'm going to walk out of this Hospital. Yeah. Yeah. You see how far that went. Obviously, I'm here so I didn't walk out of the hospital, but you know, we're not giving up hope.</p> <p>I: Right.</p> <p>P: No, I mean it's like I-I know that there's got to be people out there, you know, and so when I saw that, Dr. **** was doing this. I was like: Oh God! Somebody is doing, you know, something and I-I'll be honest when I saw those videos, I just was floored, I was like, oh my gosh that has to be a fluke, you know? And then as I've seen more videos and read more things since then I'm</p>		True		True

	like, okay. Well, you know, maybe-maybe I do have a shot at this, you know, and-and so I'm just going to give it whatever I can and hope for the best, you know, okay.				
C237	<p>I: Do you have any goals that you hope to achieve? I mean, what would be the most important thing for you to see some change in?</p> <p>P: I would really like to-I'd really like to regain some function in my lower body just to be able to help with dressing and control spasticity. I mean, if-if I could do that much that would be huge. Obviously if I could stand up that would be even better and if I could walk, you know, holy crap, that would be amazing. They even-even if I can just get enough function to help with dressing and with bathing and things like that and with transfers that would be-that would be huge.</p> <p>I: Okay. Well as you continue through this project will be talking about those changes, and I hope you see some I hope so too.</p> <p>P: I really do, and I hope I get to share, excuse me, share all of that with you, you know as it as it goes along so yeah, because you know, even-even the very small successes, are successes. Well, yeah, I mean my goodness I stood today, and my left leg supported my weight. That was like wow that was that was crazy. So yeah. Any of that that I can get will be-will be nothing short of a miracle to me.</p>		True	True	
C237	<p>I: Okay. You had mentioned transferring, that you would like to see some improvement and that, what about your first, let's talk about your work. Okay, so you're a teacher, what kind of changes would be helpful for you in terms of teaching?</p> <p>P: Being able to stand so that I can use the entire white board would be thin. Being able to go and grab supplies that I need without having to say: "Hey, can you go reach this for me?" Would be really cool, those and those are-those are issues that I've had throughout my career. You know, those are the two big ones that I can think of. Or like I can carry stuff, I pile stuff on my lap, so, you know, it would be it would be a change for me to figure out how to maneuver standing, and like holding into a book or you know, things like that. But I mean classrooms have usually, generally have enough tables and stuff around that I can I can move furniture if I have to, or whatever to make that work, but just-just being able to use the whiteboard and use the whole board, and just being able to reach things, you know, without having to tell a teenage student open your eyes and look up because it's right in front of you and the fall on your head. If somebody touched on it a little, you know, would be really-really nice.</p> <p>I: Yeah.</p> <p>P: Thankfully, I work with adults right now, so it's not so bad but, yeah, the-the times I've worked with teenagers, I'm just like pie and then when I work with little kids, I'm just like yeah, you can't reach anything either. So great, here we are.</p> <p>I: Yeah. So yeah, wondering if this study might have, if you're thinking this study might have an impact on-on your work life.</p> <p>P: I mean, I could see areas where it could certainly, I mean, you know, being able to stand, if by some miracle I'm able to walk, you know, I can look over our shoulders a little easier and see what people are doing. As far as work, when I'm going around the room checking on people, you know, there are things that I'm sure that I'm not even considering that could be impacted. But definitely being able to, you know, because again math and science teacher, I need the whole board and I can't necessarily do that right now. I'm teaching ESL classes. It would be nice to make a chart out of the whole board every once in a while to help students, see how verb conjugation Works in English versus Spanish or French or Swahili or whatever. So-so yeah, I mean just-just being able to utilize the space better would be wonderful.</p>		True	True	
B38	<p>I: Okay. So, prior to this study, were you in other studies or only in therapy?</p> <p>P: Yeah, I was in other studies too.</p> <p>I: Okay. What is it about this particular program with the stimulator that you found interesting? Or that... yeah.</p> <p>P: Basically, that it can help everyone and not just me. It's also cool to try new things that haven't been done yet, in my opinion.</p> <p>I: Okay, so you wanted to help out with the research, is that it?</p>	True			

	P: Yeah.				
B38	<p>I: Okay. What are your expectations for this program?</p> <p>P: Obviously to learn more about myself. Hopefully to get better and everyone else who might go through this same thing someday.</p> <p>I: Do you have specific expectations for yourself? Like goals?</p> <p>P: Just to get better overall. More function. Yeah, that's about it.</p> <p>I: Can you be a bit more specific about getting better? I mean, is it related to your hands, to your legs, to your core, to you know...</p> <p>P: Uh, everything. Not just one, but I mean I guess this specific one is not related to my hands, but basically everything else yeah. Just training and trying things I haven't done and working out more.</p>		True		
A97	<p>I: Okay. What was it about this particular study that interested you?</p> <p>P: Uh the epidural stimulating one would have to be the blood pressure, regulating my blood pressure is what was a big interest to me. Uh mainly cause my blood pressure will either drop really quickly or I'll get dysreflexic. You know either from my bowel programs or things like that. So, the idea of being able to regulate my blood pressure was a big thing.</p> <p>I: Okay. Um, were any of your reasons related to the bowel dysfunction?</p> <p>P: Not necessarily. The only thing that bothers me with my bowels is when I'm having a bowel program, I'll get dysreflexic. Um, other than that my bowel programs I've got them worked out pretty well. I use a mini enema in the morning, and it only takes me about a half hour so to have a bowel program and then cleaned up so that parts really not that big of an issue for me form day to day. But getting dysreflexic from the bowel program is one thing that kind of bothers me.</p>		True		
A97	<p>I: Okay. Um, so since you had used an external stimulator, with no effect, what...how did you feel this in-</p> <p>P: They were stimulating like my upper body, my arms, and stuff whereas this is a...this epidural...you know stim implant is supposed to actually effect my blood pressure, keeping me at regulated. As well as potentially getting um movement in my legs and stuff like that. Being able to do like voluntary movement and uh so from my understanding, this epidural stimulator, being implanted in me is much different than just hooking up some electrodes to my biceps or my back to do anything like that.</p> <p>I: Okay. Did that explanation make a difference to you? In terms of doing this study?</p> <p>P: Oh yeah. Cause like I said, when they start talking about *cough* excuse me *clears throat*, once they mentioned about being able to regulate my blood pressure with this, having a device that actually works to regulate my blood pressure, depending on, you know, what activity is going on, that's what really interested me.</p>		True		
A97	<p>I: Okay. Okay. Um, in addition to regulating your blood pressure um, are yo- do you have any hopes or goals for this to affect your bowel function?</p> <p>P: Beyond not getting dysreflexic during my bowel program, maybe...maybe something that would help...cause sometimes I do struggle, even with a mini enema, where I might have to be digitally stimulated. So...it would yea I can-, it would be nice to see if it helped push my bowels out better than what it does right now with just using the mini enema and digitally stimulating.</p> <p>I: Okay. Um, so the...the blood pressure and helping with the bowel function, do you have any other goals or hopes for this program?</p> <p>P: Nah, not with this one specifically. Cause my biggest thing other than blood pressure and stuff and helping with my bowels, would be getting finger and wrist movements. Which I know this, currently won't happen so...</p>		True		
A102 CG	<p>I: It sounds beautiful. Um, what? Um, when she enrolled in this study, what was her motivation in terms of recovery, and also in terms of her bowel and bladder function?</p> <p>C: Um, well, we, um, early on we had different friends with um first patients who had the implant surgery. Um, so, he had explained to us, like, what functions and stuff that he got back from having the implant. And uh, **** um, you know like three years out they say that probably, I mean there's still possibility of getting recovery, but it just gets slower and slower. So, um, she</p>		True		

	<p>was working out three hours a day five days a week at Journey full, which is an NRN site in **** and then, um, she was also doing FES rowing twice a week and some. So, she's been building her muscles and getting everything stimmed the whole time but, um, she really likes to get, you know, kick start it and get her spinal cord excited enough so that the signals are going past her injury site and that she could actually use those muscles below the injury site including respiratory, bowel program, other functions.</p>				
A102 CG	<p>I: Right. But ultimately, you would prefer that she'd be in a therapy program or a study that focused...</p> <p>C: Not a therapy program, she's been in that and that was great to get all her muscles working and stuff like that with stim. But if this study was specific to, for what **** needed, she would be having more electrodes put in and she would be... her training after the stimulation would be for other things...</p> <p>I: Right, okay.</p> <p>C: ...that **** needs. She doesn't need just to fix her respiratory function or improve her bowel program as a, you know, a bonus.</p> <p>I: Mmkay.</p> <p>C: She needs to have improved bowel function, she needs to have improved bladder function, she needs to have improved sensation, she needs all those things. But this is just targeting one thing, with the hope that other things will come along, like a side effect, a side effect in a positive way.</p> <p>I: Okay. How do you feel about that?</p> <p>C: Uh, like I said, I feel as though whatever she gets out of this, that's what's gonna happen. And then the next step would be to, you know, like I said put another implant in, put another electrode, then down the road there's also the possibility of doing external stim and internal stim, those things just aren't approved right now. So, she definitely has to do this now to reach the end goal, for not only her, but for everyone else in the community. Cause like I said, if she doesn't do it and you know, the next person doesn't wanna do it, the next person doesn't wanna, like you're not gonna move forward as a whole.</p>	True			
C193	<p>I: No that's okay. Um, so when you were contacted about this study, what was it that uh interested you in this particular study?</p> <p>P: Well, I know that one of the- like uh cutting edge kind of things that they were doing was with uh epidural stimulation. So, I have heard about it and saw what they were doing. Um so when they told me that was like what they were going to be working with, um yeah I thought like I mean whatever can improve my quality of life and that might give me a little bit more of independence, like if I gain some more um like con- more strength, or more control even of my upper body and If I'm able to assist uh a little bit more like my mom who's taking care of me or whoever will be my caregiver, that to me is already a gain. So, when they described the whole purpose of the study, uh I said yes immediately. I mean like whatever and whatever I can do you know to be part of something that might impact and change the life of other people, that's- that was a yes for me.</p> <p>I: Okay. Um...did-did you have any reason related to bowel function for um joining this program? Was there something about that that interested you?</p> <p>P: Well actually thank God i-it's not usual for me to have accidents. But I would love to see if that- if would be able because we do um my bowel program is through digital stimulation and so I have to like help, like well no not me, my mom. She needs to help the sphincter to open up for me to be able to have that bowel movement. So, if I'm able to have a little bit more of strength or if something changes in those muscles, that will allow me to you know, to do that um without, you know, having to have that digital stimulation or that um- that would be wonderful. So that was also something that really uh caught my attention.</p>		True	True	

C193	<p>I: Okay. What do you expect this study to provide that you've not found so far?</p> <p>P: Um, well I- as I said overall uh improvement in quality of life in general, to gain a little bit more of independence, um and yeah if I was able to-to gain that uh like yeah if my muscle function in my bowel improved that would be wonderful. So...yeah whatever helps improve the quality of life is just a gain for me.</p> <p>I: Okay, what goals do you hope to achieve in this study?</p> <p>P: Uh one of my main goals, I know- this one in particular focus on cardiovascular function, so we are not going to be uh addressing locomotion, as a- as a thing. But uh for example, I need to use a hooyer lift to transfer. But if I am able to stand with some assistance, that would probably mean that um someday I might be able to get rid of the hooyer lift for my transfers. That would be amazing. Uh and also as they said, um through the voluntary movement through my legs if I am able to help a little bit more my caregiver, um and assist them with like, you know, making them easier for them to help me get dressed, and everything, that's also something that would be amazing. And of course, um improve the bowel uh function. And I also have some leakage during the night um in my bladder. So, if that was something that I was also able to change that would be wonderful.</p>		True	True	
B194	<p>I: Okay. How did you find out about the study and what motivated you to participate?</p> <p>P: I found out about the study on the news. I saw them talking about it on the news...about this big, like, breakthrough. And then I wanted to be a part of it because I want to better my life and become more independent and be healthier.</p>		True	True	
B194	<p>I: Okay. Um. Were any of the reasons, uh why you wanted to enroll in this study, did anything have to do with your bowel function?</p> <p>P: Uh, not at first because I wasn't aware that that was something that they were focused on, I thought it was just recovery and movement. But, I mean, yeah definitely it's something that I would be a part of. I want to improve every function. If that includes bowels, then I want to do it.</p>		True		
B194	<p>I: Alright, well you might not be able to answer a lot of these questions. But the next time we talk you will. What do you expect from this program?</p> <p>P: I...I'm kinda coming into it with not having any high expectations. I just want to get everything I can from it. My goal is to just be as independent as possible and to gain as much back as I can.</p>		True	True	
B194	<p>I: Okay. What are your top three goals that you would like to achieve, participating in this study?</p> <p>P: Um. Top three? I would like to be able to transfer without needing a sliding board. I would like to not need any help at home anymore. I would like to be completely independent. And third, is just to regain as much function as possible.</p>		True	True	
B194	<p>I: Okay. What are you hoping to achieve in terms of things like your roles as an adult or socializing? Independence...what are you hoping to achieve?</p> <p>P: I'm hoping to not need a caregiver.</p>			True	
B42 CG	<p>I: Okay. Um, were any of the reasons that you, that want- that he wanted to, and you wanted him to enroll in this study, were any of the reasons related to the bowel dysfunction?</p> <p>C: Not directly but if that's something that he can get back, that would be great for him.</p> <p>I: Okay, what do you expect this study to provide for your husband that you've not found so far?</p> <p>C: We are hoping that it will give him a little bit more freedom.</p> <p>I: In what way?</p> <p>C: We are hoping I-I... What I'm hoping, I-I what I'm kind of hoping for is for it to get him enough, I'm not saying to go jump up and run the Boston Marathon tomorrow, but if this program could help him to get his bowel and bladder function back, you know. E-e-even if he could just stand up, just enough to, you know, adjust himself so that he's comfortable, so he doesn't have to rely on someone to do it for him.</p> <p>I: Right. Just...</p>		True	True	



	C: The-the more things for him to become more independent and less dependent upon me.				
B42C G	<p>I: Okay, okay. What- what are your top three goals for this, that you hope he can achieve in this study?</p> <p>C: I am really hoping for just truly more independence for him. Because I do work part time, uh I've taken a leave of absence currently just so we can uh, you know, be more available for the trainings and the physical therapy and all that kind of stuff. Um, so, you know, i-it would make it much easier if he was a little bit more independent. So that he can, you know like I said, if he gets uncomfortable, and I'm not home, he has to wait for me to get home.</p> <p>I: Yeah.</p> <p>C: So that to me is very important. Um, I'm really hoping again, the bowel and bladder function, I can't imagine what it would be like to have to depend on somebody else to even just go to the bathroom.</p> <p>I: Yeah.</p> <p>C: And quality of life. I mean being- just to know that he's able to do things without me literally watching over him.</p> <p>I: Right. Do you have goals for yourself related to this program?</p> <p>C: To learn as much as I can.</p>		True	True	True
B40- CG	<p>I: Ok, ok. Um what... ok, were you-were you listening while I was doing his interview?</p> <p>C: Yeah, somewhat.</p> <p>I: Ok *laughs*</p> <p>C: *laughs*</p> <p>I: Ok um, so what do you think was his motivation for enrolling in this study?</p> <p>C: I guess is the trunk, is a big issue, I mean is a small one, what I see his trunk issue, cause he is always laying into his um left and um, he has spasms, if he go to try moving on the night, you touch his leg, he's all over the bed, is just, the spasms are a big fact, meaning if we try to roll him over it just lock out, it just every muscle of the bottom it just locks out.</p> <p>I: Wow, does that keep him up at night?</p> <p>C: His spasms does, yes. Cause **** we gotta get him moving around because his legs are moving, and he can't sleep. Because just if something touches his legs, just keep jerking...</p> <p>I: Yeah, ok. So that affects your sleep as well.</p> <p>C: Oh yeah, yeah. I mean, like I said, whoever gets up, if she gets up, we always check on him. To see if that pillow is between his knees; so, we don't want him to get pressure sores, because, if you put your hand between his knees and it locks up, you're not gonna bringing that out.</p> <p>I: Ok</p> <p>C: So much pressure.</p>		True		True
B40	<p>I: Okay. So about five years. Um, what was it about this particular study that motivated you to enroll? What was it that was interesting to you?</p> <p>P: The uh bladder- or not bladder. The uh blood pressure? A lot of uh the people that were in the study and from what I read that most people get their blood pressure to regulate better for them.</p> <p>I: Uh-huh.</p> <p>P: So, it doesn't drop all the time and has it maintain steady when they are standing or doing activity. So that stood out on me and also um, some are able to do their core better and get movement in their legs. Um, so that was interesting to me. And since I've got so much ton and spasms, uh there was also a program that they can kinda try to control that too. And that would make my life a lot better from, you know, being uh stiff all the time plus regulate my blood pressure.</p> <p>I: Okay. Um, how is this study different from other programs? So, why this program and not another program?</p> <p>P: Uh, just because of the reviews I've heard from other patients that's went through the program.</p> <p>I: Okay. So just kind of word of mouth?</p> <p>P: Right. Mhm.</p> <p>I: Okay. Um, were any of your reasons related to bowel disfunction?</p> <p>P: No, it was mainly just movement and blood pressure.</p>		True		True

B40	<p>I: Okay. Okay. Um, what do you expect out of this study?</p> <p>P: Um hopefully positive re-results of uh the blood pressure being regulated and uh movement in-in some of the limbs that I have that are the lower limbs and uh bowel and bladder hopefully if that starts working again.</p>		True		
B40	<p>I: Okay. Okay. Um, so you're hoping for better blood pressure control and what else?</p> <p>P: Uh voluntary movement in my limbs and lower extremities.</p>		True		
B40	<p>I: Okay. Um, do you have, when it comes to movement of your limbs, is there...are there certain things that could be helpful for you? I mean obviously I know there is but kind of what is your goal, you know, are you hoping to be able to feed yourself, or uh brush your teeth, or uh control spasms. What is it that you're hoping will come out of this?</p> <p>P: Hopefully I can start doing transfers um by myself. Being able to transfer in and out of bed, in and out of the chair, and into a seat or something. Uh hopefully I'll be able to stand. Uh with maybe a walker or a cane, or something. That would help to where, you know, being out in public I'll be able to stand up, you know, to get- to be able to stand and uh mainly just to get around easier for me you know. Um...uh...that's pretty much about it I mean really.</p> <p>I: Okay. Okay. Um, let's see.</p> <p>P: Just-just like the stabilization of being able to control my trunk, you know, for leaning forward and leaning back. Sitting up straight to be able to control my trunk to be able to do certain things.</p>		True	True	
B40	<p>I: Okay. Uh what are you expecting the program to be like?</p> <p>P: Uh it should be like the, the first time whenever I had my session before my implant. Where um *inaudible* activity if I'm able to move uh certain joints on my own. Uh to be able to move to certain areas. So, I'm looking to see if that will be happening and hopefully, with the stimulator, there will be some difference between before the implant and after impact.</p> <p>I: Okay. Okay. Um, are you hoping for any changes in your bowel management?</p> <p>P: Yes, that would be nice. Um, I-I haven't heard too many people uh talk about that area. But, you know, to know if- when to go that would be awesome. Uh, to be able to void on my own. Uh or to know that, you know, there's pressure that needs to be released from the bladder area, um that would be a plus.</p>		True		
B40	<p>I: Okay. Um...what are your hopes for this study?</p> <p>P: Uh to help people with spinal cord injuries also because I know they're getting the information and, you know, maybe something happens. During my study, they're different from others that, you know, they haven't found before or that can help other people also and then they'll also benefit me to where um...to where I'll be able to stand and be independent on my own.</p>	True	True		
B40	<p>I: Okay. Is that something that um you would like to do but you're not able to do?</p> <p>P: Yeah, I'd like to-to be able to do some-some type of work down the road if I'm able to be a bit more independent.</p>			True	
A12-CG	<p>I: Ok-Okay so...okay so you don't have hopes for-for the study just expectations?</p> <p>C: I don't- I have hopes that ***** will gain more function than what she does have. What she does have I feel she does a lot of stuff, but she will be more independent also like what she wishes</p>		True	True	
A12 CG	<p>I: Um, so in terms of her bowel function and management....um...what are you hoping she can achieve in this study specifically? In terms of that uh bowel program.</p> <p>C: So...like that she'll be able to, you know, uh be able to go without- without help.</p>		True	True	
A12 CG	<p>I: Um, what are your top three goals for her specifically for this study? What are the most important things that you're hoping that she will achieve?</p> <p>C: Well like I mentioned just uh just like what she wishes, just more being more independent.</p> <p>I: Okay but what- what would she need to be able to do for herself to be more independent than you think, you know, like if you're thinking about goals for</p>		True	True	True

	<p>this program what are the top three? I know independence but what would she have to do- what would have to happen for her to gain that independence?</p> <p>C: Well, just off of my head I'm thinking, like, you know, she wishes to drive. Okay so, she- we have a ramp- a van with a ramp I mean. She-she can't put herself all the way up even if she pushes the wheel she then will fall back. So, maybe more, you know, more strength up, you know, upper body. Like I mentioned earlier, um upper more- upper strength so she's able to move herself maybe from a wheelchair to a chair, you know.</p> <p>I: Okay.</p> <p>C: Um, um b-b-bowel function and urine function. Feeling, being able to feel um the areas that she can't feel. She can't feel anything from her chest down. Even in some of her arms. Uh, she can't open her hands so maybe being able to feel some areas-areas in her arm, you know, just – uh- just a lot- there's a lot of things. Top three would be um, you know, being able to maybe move herself, not have someone to spot her you know. Like when I transfer- she transfers out of the bed, you know, after I dress her, after bowel, after shower. Our you know she-she'll move herself, but someone has to be right there because she could fall over</p>				
B38 CG	<p>I: Okay. So, what were the main motivations to enroll in this program?</p> <p>C: Well, of course, recovery is one of the main things. I just did this yesterday, I'm on a committee for the North American Spinal Cord Injury Consortium, and this is exactly what I was talking about. Of course, with a spinal cord injury, and as a parent, everyone wants to recover, even though there's not necessarily a cure. But that's, you know, part of the study and part of being part of it, to help find more ways to... for spinal cord injury patients and the community to have a better quality of life, not only for ***, but you know, for others in the community. So as a mother, I was, you know, searching for such a traumatic event, you just kinda start to look for everything and every possibility. And the most promising procedures that were going on was typically the epidural stimulator and so that was typically what we were looking for. Is something to not only help possibly with recovery of any mobility, but also with bowel and bladder and blood pressure and just quality of life.</p> <p>I: Okay, you were hoping for something that was kind of all-encompassing or address multiple issues?</p> <p>C: Yes.</p> <p>I: Okay, and Frazier does this?</p> <p>C: Yes.</p>	True			
B38 CG	<p>I: What do you expect this program to provide that he's not had so far?</p> <p>C: That's a hard question because he's had, we've had everything that we could possibly need almost through Frazier. He's really not been without any type of therapy at all since the injury. Pretty much he's been, had physical therapy or occupational therapy pretty much every day since his injury, which is a blessing for us.</p> <p>I: What do you expect it to... what kind of differences do you expect it to make in his life?</p> <p>C: More independence. I'm hoping that it will bring him more independence, so that he cannot depend on me as much, give me a break haha. You know, for him to live his own life, and to be able to take care of himself basically.</p> <p>I: And so, does he currently require 24/7 care?</p> <p>C: He says he doesn't, but yes, I mean, we cath him and bowel and bladder. I mean, he could be left alone, but I'm just not really comfortable with it. We kind of live out in a rural area, so anywhere that I would go as far as stores or anything, I'm not 5 minutes away, so but he is able to... you know, get his own stuff and take care of himself to that extent, but not like as far as going to the bathroom, he could not.</p> <p>I: Okay, but in terms of living by himself, would he be able...?</p> <p>C: No.</p> <p>I: Okay, okay. So, is that something that you are hoping for through this program?</p> <p>C: Yes, yes.</p> <p>I: Okay. Do you think that this study, this therapy will impact his bowel program?</p>			True	

	<p>C: I hope so. He's uh, he... He does probably fairly well with the bowel program but, I guess, I hope it impacts more of the natural feeling, the way he felt before the accident.</p> <p>I: Mhmm.</p> <p>C: He knows when he has to go, he can feel when he has to go, but he can't stop himself from going.</p>				
B38 CG	<p>I: Okay. So what changes are you hoping to see through this program?</p> <p>C: [laughing] How much time do you got?</p> <p>I: I have all the time in the world.</p> <p>C: I'm kidding, I'm kidding. Any change would be a blessing, in the positive, but you know, I would love for him to regain any sensory or motor function anywhere. I know it's for the lower level and it doesn't affect his upper body, he still has issues with his hands, so I know it doesn't affect that part of it, so I do hope that it would affect that where he could naturally go to the bathroom on his own, where he wouldn't need to cath himself or you know, be on a bowel program because that's where a lot of the issues of independence-wise also. We always say it would be great to walk, but if he had his hands our lives would be completely different as far as his independence. And a lot of that has to do too with you know, going to the bathroom and stuff, even just getting dressed and a lot of things of that ability for his legs... he wouldn't need his hands... his hands wouldn't be as big of an issue if he had some function in the lower part if that makes sense. And vice versa.</p> <p>I: Well, okay, I can see that... excuse me... I can see that if he had function in his hands or arms, but if he has function in his legs but not in his hands and arms, how would that help with him....?</p> <p>C: He does have function in his hands and arms, it's limited in his fingers.</p> <p>I: Oh, I see.</p> <p>C: His legs can move up to where he can at least put his leg through a pant or shorts, you know, he can hold onto it with his hands. But lifting his legs and holding onto the pants and doing a lot like that with his hands he's not able to do. He's not able to do multiple functions with his hands.</p>		True	True	
B38 CG	<p>I: Got it, okay, okay. What, for you, are the top three goals that you hope he achieves in this program?</p> <p>C: Specific or overall?</p> <p>I: Let's do both.</p> <p>C: Well, for this particular study, this is a cardiovascular study... So, I'd love for him to, with this particular study or if he moves onto step or stand, I would love for him to be able to of course walk, stand on his own, sit on his own, go to the restroom, we don't really know about his sexual function because he's single, so we don't know. I mean, it works as far as what we can see when we're cathing him, but we don't know if he's, what else he can do as far as that goes. Bowel and bladder, he has issues I guess with his blood pressure, but none that really affects our daily life. UTI's affects our daily life, so going to be able to pee on his own would be life changing for him as far as health-wise. But overall, it's all independence, him gaining his own independence and... I guess UTI's, cause I think his fear is him becoming antibiotic-resistant, that's how you know, a lot of spinal cord injury patients die is becoming antibiotic resistant, and that's something I always think about so if he was able to pee on his own we wouldn't have to worry about that.</p>		True	True	
B38 CG	<p>I: Okay, good. In what ways do you think this study can make a difference for you as a caregiver?</p> <p>C: I guess this is the same thing I said before, if he regains any function whatsoever, for him to, you know... Not only for... As a mother, if he's happy, I'm happy.</p> <p>I: Right.</p> <p>C: If he's prosperous, I'm good. If he's taken care of, I'm good. So, anything that benefits him, benefits me. So, anything that helps him will help me. Because I mean, right now, I could... you know, I could be the type of mother that says "Ok, see ya, I'm leaving" and leave him here, but I... like I said, I'd turn around and come back cause it'd be a waste of my time cause I wouldn't enjoy myself because I would not... If he's not happy, I wouldn't be happy. So, if he's good, I'm good.</p>			True	

	<p>I: Is there anything about this study that you think might make your life harder or more difficult?</p> <p>C: Um, if we get in a bad group. [laughing]. I'm just joking, cause it's all part of a good thing, so I'm not gonna say that. No, no, I don't really think so. Like I said, if we weren't meant to be here, I don't believe that we would be here. So, trust me, having faith is where we're supposed to be.</p>				
A102	<p>I: Well, I understand that probably walking is a very long, long, long term goal, but for instance, I do another study. It's for pediatrics, and it's also spinal cord injury, and so for them, a lot of the mother's goals are just for them to be able to sit upright in their wheelchair and have that core control, which many of them don't have early on. So you know, they're smaller goals, but still a lot of effort involved. So if you had to think of it in that way, your smaller goals, what would be the most important ones for you right now to work on and try to improve.</p> <p>P: [pause]... So I'd say any smaller goals that would grant me some of that independence, so just a lot of hand goals I would like to see, that would be important, like being able to pick things up. I just went through the process of doing adaptive driving, so that was one of my big goals. I think like with hand function might come being able to, a lot of bowel, bladder stuff also comes with not being independent enough to do that, so I mean, I think these are all big, big goals, but also the domino effect.</p>			True	
A102	<p>I: You've lost some independence with that.</p> <p>P: Yeah.</p> <p>I: And control.</p> <p>P: Yeah. So yeah, the independence and control, being on time, that weighs on me. Also like, just getting to do the things that I want to do like professionally. I was preparing to go to law school when I got injured, I worked at the district attorney's office, but all that is on hold, just because logistically it's all very challenging. So just ever getting back on track with that stuff weighs on me too.</p>			True	
B192	<p>I: Um, what was it about this particular program that you thought you wanted to do?</p> <p>P: Well, I just thought there were like a lot of benefits from it. Um, it looked like something, like I said, like something that I thought about myself and, you know, why not? I'm always the kind of person like that. Like why not try it? I'm not scared of anything really. Um, I don't know I just thought that like if it could improve anything, you know, why not go for it? What do I have to lose? I have everything to gain but nothing to lose.</p>		True		
B192	<p>I: Ok. Did you have specific um, barriers or challenges that caused you to seek out studies or um, you are just always searching?</p> <p>P: Well, like I said, I mean, you heard it on the call like being athletic, and being a mover, and being a goer, and just not wanting the way around, or feel sorry for yourself, and just having that drive, I don't think that you ever give up hoping wanting something that is going to make you better. I don't think that it's in your mind say that's all the way. So, I am always looking for something, it's never been even like a second thought, I mean like, it's just doing something that's always been in my mind, meaning like I don't really want to live my life, during my whole life like this, you know? Like there is more that I want, and there is more that I want to do, so um, that being looking for something was, it was- it was always there, it was in there but not... you know, not a thought in my head.</p>		True		
B192	<p>I: What do you expect the study to provide, that you have not found so far?</p> <p>P: Well, I mean, I think everyone wants to come in and be like... I can move! You know? Or whatever now, and like I like to feel better and um or want to be stronger, me... I want to be able to transfer on my own, um, cause I'm still on my balance, I always get scared of falling, um I want to be able to do that, I want to be able to utilize my core, and transfer and do those things, and wanna be standing on my own, and it would be amazing if I can take steps alone, but um I am also realistic, you know? However, like I said, just me working with C*** and seeing my knee being able to move and pull up, and you know... that to me it's like amazing. So, I mean, you want it all but you are going to be happy as wherever you get.</p>		True	True	True

	<p>I: Ok, um. Do you think the um the therapy or the stimulator would have any effect on your bowel function?</p> <p>P: I think all I can hope is probably going really, really well, I feel like when she it turns on like, yeah, yeah.</p>				
B192	<p>I: Ok. What are your top 3 goals for this program?</p> <p>P: To get... like I said to get stronger. Obviously to build you know, to build muscle tone and get stronger, and my core and stuff and to be *inaudible* u and be in my vehicle on my own, I want to, I want to be, I mean, who wasn't want to be unlimited and, like do things like that on their own or I really, really want to be able to stand up on my own, or stand up and just feel like me again, um but, overall, I just want like... better overall health I guess, I mean, you know? Like anything that can improve like your longevity or just like improve your quality of life whatever that may be to you as an individual um I don't know I just want... I want to be more independent, if that makes sense; I don't want... I hate having people, having had people to help me do things, I hate it. Like that's the one thing that eats away out me, more than anything...</p> <p>I: Yeah.</p> <p>P: Anything else, you know? I can do it whatever, but I do... like, I hate having people do things; it drives me crazy. But sometimes it's like easier if someone helps you; if you're on a hurry, doing like day to day activities and just go with it, you know you hate it, go with it, suck it up and just do your thing</p> <p>I: Right.</p> <p>P: I mean, I've always... I think I've been very blessed because I had always had like a great support system; like my great family members, that been there, you know... my aunts, my cousins, and I have the best friends in the world, like they would do anything for me, they cry when I'm not even crying, so... I mean, I've been very blessed in those ways; because I do know of other people that their family just doesn't take it in the way mine did.</p>			True	True
B192	<p>I: Do you have any goals related to bladder, bowl, or sexual function?</p> <p>P: Um I wish I had sex right know, I mean, I was talking to a guy just talking to a guy back home, when we started talking was before I came out here. So um, or dating, whatever you want to call it um we've been talking for February... seven months? And um, you know that would be great; but that's never been a problem with me, the sex part.</p> <p>I: Ok.</p> <p>P: As far as bowel and bladder; it would be amazing... to not have to use enema, you know?</p> <p>I: Mhm.</p> <p>P: I mean, that would be amazing... because, and that's another thing, it's like, in relationships, I... I really don't, like I said, I try to keep that separate from romantic relationships just because I am a private person when it comes to that, and I just don't feel like, I don't know, you don't want to someone looks at you differently...</p> <p>I: Wh..?</p> <p>P: Even when it's different you don't want them to view it that way. And... is kind of embarrassing I mean, honestly, for me, it is. Like, I just don't want it, no. Like, you don't have to go to another room, but it would be amazing to those m... muscles to be able to not need to use a catheter, or... I don't know, the belly button thing, like I said, is the most freedom loving thing I've ever had done. Um that really doesn't bother me, but the enema... I don't really like it... this thing in my butt everyday</p> <p>I: Right</p> <p>P: Cause, I have to go like every day. Like I mean, I go... like, I feel like I am like a guy. I go at the same time every day and I have to go. Like I wake up, and I am like... oh my God, I got to go to the bathroom, you know? That just, I don't feel right if I don't.</p> <p>I: Yeah</p> <p>P: Like I feel miserable if I don't go every day. First, my doctor said I need to go every day. Because I did, like I did suffer from um when I first had my accident, they had me on schedule where I went every other day, then I got to the point where I was like... I can't do this anymore like I am constipated, I am not like... I am like hurting, and I had a hemorrhoid. And I did have those</p>		True		

	<p>removed, and he told me there is like a 2% chances it will ever come back, but talk about painful, that is painful...</p> <p>I: Yeah</p> <p>P: Like I am talking, painful. And then only after having removed, you have to si- six weeks, and when they tell you six weeks, they are not lying, is not going to be four weeks, it's going to be six straight weeks to start jerking out of your body, like you know, like I mean, just mucus, fluid, whatever, and then, you are so constipated after the surgery that you'll literally have to ask to get it out of you. Is the most horrific thing I have ever had gone through.</p> <p>I: Yeah, that's pretty bad.</p> <p>P: Of all the surgeries... Oh yeah, and that's what they said. They said like, if um because it was one it gave me Oxycontin, when I had, this is back in 2008 I think, and I was like no, I am not taking that, there's no way. Cause I've always been, you now? Dot not take drugs, do not take pain pills, nothing. And so um, he is like no, you are gonna want it; I still refuse to take it. I think still like maybe two purges, and I was like... I am taking no more pain pills or anything, I'm going to suck it up and just go through, you know? Get through this, and it was horrific, it's a horrific surgery.</p> <p>I: Yeah</p> <p>P: Because, I will tell you this, is one of the most painful things I have done.</p>				
B192	<p>I: What as a person with spinal cord injury, what are your most present concerns? The things that just kind of are always in the back of your mind</p> <p>P: Hu... well, what, what I don't... I'll tell what I don't like; for the spinal cord injury, I hate the fact I have to worry about that damn wheelchair, excuse me if I am cursing but that's one thing I don't, because it's always in the back of my mind, I have to worry about that, because mine recently had a part that came off of it, my friend's husband has to mess with that or fix it, and I... I ca cannot take it until fix it on Friday, but that um is always in the back of my mind you know? Like... having to worry about that thing and then, just like reliability when it comes to someone helping you, and not been able to like, you know... laying there in bed and not knowing if that person it's going to show up, or you know... not knowing like what that day is going to bring you up, not having the freedom to get you out of that bed, that's a, that a scary feeling. Like I have done that like you know, several times and um... that would be amazing to not have to have someone, to not have to depend on someone, so I think that a thing that is always a concern is the reliability that you have um, maybe you're always thinking about, like you know... I got to bring myself to pee, I got to worry about this chair, I got to make sure there are plenty catheters, I got to um, you know, do those things... alone. You know, and then I got to go. And then is like, like I said, from me, myself like... I got to make time to work out today, I got to do this, and I got to do that, just to keep my body into shape. Because I've always said that I always wanted my body to be in good enough shape so if anything ever come about regards to like signs like this right here that I want to be in enough good shape to be a candidate, I want to be in good enough shape to make progress, I want to good enough shape to you know, to be healthy...</p> <p>I: Right.</p> <p>P: As well. So, I mean, that just always been my mindset. I don't know about other people, I've not really... have really anyone is hard too, because you know? I don't really find... other people that have the same, same thing...</p> <p>I: Sure</p> <p>P: And, you know, I don't know. But yeah... those are...</p> <p>I: What about finances and insurance, do you have any ...?</p> <p>P: Oh god! Hu, I aint think about that... oh yeah! That's another thing... and that's what I told the guy social security, is an embarrassment, and this is the truth... literally for me, it's an embarrassment that I have to have those services. I hate it, I don't want the government tell me how much money I can make. I want to be free, and that's another thing, I'm glad you said that. Um that I want to get out of this, I want the freedom to be able to be healthy and independent that and I don't have to need those services. I don't want to be on social security, I don't want to have Medicaid. I don't want Medicare. I want to be able to capitalize on my own finances, make as much money as I want, not</p>			True	True

	be told what I can do, how much money I can make, if I can get married, if I am gonna lose something, I don't want to have to deal with all that, honestly. I really don't. So... that is like a... that's a... yeah, that's a major concern, major concern.				
B52	I: Okay, okay. Let's see. What were your primary reasons for wanting to enroll in this study? P: Uh, you know, to get movement back. Well, that's primarily the reason. I: Okay. Were any reasons related to bowel or bladder? P: Uh, not initially, but then when I read more about it yes, specifically bladder.		True		
B52	I: Okay. What are your goals for this program? P: I have set a very low bar. If I could just, if I could get even small improvements like, this might sound small to other people but it's big to me, is being able to sit up independently without, you know, straining my neck and my shoulders and my, you know, everything else. I would be very happy I would call that a complete success. I: Okay. Why, how would that affect you in your daily life? Why is that so important to you? P: It's just hard to sit in your chair and not have a lot of trunk support and it just affects neck, shoulder, it just makes daily living a lot easier when you're not struggling to keep yourself up. I: Okay. Does it cause soreness or pain? P: Neck pain, yeah. Could be neck pain, I get, you know, some kinks in my neck every once in a while. I just get tired, my posture, I feel like my posture is horrible even though actually my posture is pretty good, considering. I just like to be very tall and sit up straight. I: Okay. How would that help you in your daily activities? P: Working. You know, if I'm working on a computer, if I'm doing stuff in the kitchen you get so exhausted, you know, keeping yourself up. I: Okay, okay. So that's your primary, your biggest hope. Do you have another? P: Oh, well, of course. I mean, voluntary movement, yes. Being able to stand independently, yes. But I mean, those are, those are aspirational.			True	
B52	I: And specifically, when you talk about more movement, is there... are you looking for more movement where in your body? What would be the most valuable movement for you? P: Moving my legs, I guess.		True		
B212	I: Limited, ok. Um what motivated you? What was it about this study that you were like "Oh yeah, I wanna do this". P: Um that it was sponsored, or paid for, or whatever by the Christopher Reeve Foundation. I: Ok. And what do you know about them that made you feel comfortable with that? P: That I figured anything they've been involved in was probably very pretty legit. I: Yeah. Ok. Um where, are you having any particular problems that you're most interested in seeing some change? For example, um you know, it could be bowls, urine, sexual function, it could be um temperature, body temperature, or heart rate, you know, all the way up to walking, so... kind of, what are your expectations? P: Better movement, better movement is what I'm looking for. I: Better movement, so that... P: To gain, to gain back as much movement as possible, yes.				True
B212	I: Um so in terms of your expectations for this program *coughs* excuse me, um I know you said you want better movement, but if you had to home in on two, or three or four particular things, what would be that you would most like to see some change in? P: Um definitely better fingers cause I have limited use of my hands, um definitely being able to at least stand up or better use of my legs just to help me dress better, um better transfers, I'll have to say um just like all along just any steps I can take to improve quality of life			True	True
B45	I: Okay, alright. So, coming into this program, what were your expectations, your goals?			True	



	<p>P: Well, I've had a long time to think about it since my injury and everything like that. So it's from the beginning, one doctor will say you'll never walk again and one of the lead doctors and the first, one of the first PT lead doctors that I talked to said just, literally said to me train, nobody's gonna tell you if you'll walk or you'll get better in certain pace (?), he's like if you train like it's your personal Olympics and you just, if you're ready at certain times for things that become available down the line, you never know. When you hear something like that, you get encouraged, and it's all about building the engine, for me it's building the engine, so I'm just, my output is I just want to keep building every day and get stronger in each aspect and so whatever happens happens.</p> <p>I: Okay. Did you have expectations for this study?</p> <p>P: My expectations was that it was gonna put me in a better situation to a) get stronger in things that you can't do at home on your own, and my expectation is, my biggest expectation is that when people from home come down and see me, they're just like damn, you are getting stronger in all aspects of how you were before versus when they see me the next time.</p> <p>I: Okay. Did you have goals that were different than your expectations?</p> <p>P: My goals... I think it's hard to say to have goals like that, but my goals would be just to be well... I don't know how to say that, I guess, my goal would be just to perform well in the eyes of the doctors, the therapists, get good feedback from them, and the same from my family and friends. It's... that's it.</p> <p>I: Okay, okay. So in relation to bodily systems or functions, did you have any focus on any particular one such as cardiovascular, walking, bladder, bowel, sexual function?</p> <p>P: For me, I do it [inaudible], I think if you talk to anybody similar to me or in my situation, it's like if you can do one thing then just keep going, like I want, the more things they throw at me I'm gonna attempt to do it.</p>				
B45	<p>I: Okay, alright. What are... what do you think... what are you hoping will happen with that implant?</p> <p>P: I'm hoping I see improvements across all levels from my bladder to sexual function to standing to muscle activation to seeing different things quicker to feeling the sensation of different things like I've experienced already since I've been down here.</p> <p>I: Okay. Any expectations related to bowel function?</p> <p>P: Yeah. Like I said, I just wanna get better, being more aware of it, giving more of a heads-up cause I know when it's coming, but depending on what it's made up of, like if it's a regular one, I can hold it for a bit, but if it's loose or something like that I'm gonna have an accident.</p> <p>I: Yeah.</p> <p>P: Along that, I guess, I would want to improve that aspect of it.</p>		True		

(\*\*\*) Personal information removed.

Interrogator (I); Caregiver (C); Participant (P).