**Conversation Guide: Digital Health Modernization Discovery Research**

**Bold text identify the moderator’s questions.**

*Text in italics are Leanna's observations and interpretations of the participant.*

[Text in brackets are interpretations in participants’ direct quote.]

**Introduction (2 minutes)**

*Start recording.*

* **I have started recording**. I'd like to confirm: Are you comfortable if I record my screen and the audio as we talk today? I am okay with you recording it today.

**Background (5 minutes)**

**To get started, I’d like to get a little background information about you and your experience with the VA.**

1. **Can you tell me a little bit about yourself?**

I am in Denver, I was from MI, in was in the army for 25 years and I never had issues with the VA until recently I have more expensive extensive work so they are ignoring me and aren’t returning calls and being rude when they are on the phone. Horrible, it’s been horrible.

I have two German shepherds, I fostered the one because I was fighting myself, I have a bad hip (one of my issues but not the biggest one) so I got the dog because they get me out walking so she as been a blessing. I feel guilty if I don’t take her out if I’m sore they just give more pain pills instead of fixing me. “So you just want to get me hyped up on pain pills because that’s what it feels like?”

I stopped taking one pain pill and I read up it said it was addictive so I don’t take it so I suffer. I have gained 30 pounds since the pandemic because I am in constant pain. Those are my hobbies: the dogs, my animals, they bring me joy and get me out of the house. My grandkids were just here, I like to write, I have been writing a book about my time oversees for 10 years and it has been really raw. I sometimes have to take a few days off; I kept a lot of journals to remind me. I forgot a lot. I have 4 more months of my 17 month tour and then I’ll be done. I’m really excited.

1. **Where was your tour?**

It was in Iraq, Kuwait. I say Iraq because we were all around there but stationed a pretty safe place in Kuwait but it was still scary. We heard gunshots every day.

I had had a few TCNs, third world nationals, so we had a lot of third world nations and I was the only woman. I am left handed and that’s a bad thing if you are left handed they think you are evil because they wipe their asses with their left hands. I went in with a lot of obstacles. I had stalking issues people trying to get into my tent, I was constantly in fear and that ignited my PTSD. I have friends from all over and I have had them before and after and they tell me I’m a nervous wreck. So shaky.

I never realized that I startle easy, everything scares me and startles me but that’s probably why I have two German shepherds. It’s like having a man around and it makes me feel much better.

The biggest issue is my teeth. I have been grinding my teeth for years, I have developed a lisp because my teeth have gotten worse and worse and worse, I have lost caps. I am always falling in my dreams roller coasters, falling off cliffs, being in the water and flying 90 feet in the air, gritting your teeth. I know I grind my teeth in my sleep. I’ve ground them down to nothing.

It took 9 months to get to a regular dentist and he said “you’re all fucked up.” They told me I need to see a prosthodontist. I still get bills from him and no one at the VA is helping me. I saw an advocate - army advocate - because I thought it was the end of the line and they would help. Spent an hour, I brought bills, emails, he looked at my call log. Sees that I call over and over again.

I got one lady from the dental clinic and she literally laughed at me. I asked if she cared that I am in pain and do I need to go to the media. She laughed and told me to do what I need to do. I asked for the supervisor and she said she was busy. Then the next day they called and they were rude, condescending, and had me in tears.

I am afraid to call back, she ruined… I was screaming and throwing things out of frustration. It has went well over a year [It has been more than a year]. Now I need to see a prosthodontist they are saying too bad; I realize there’s a Pandemic and there’s people that are worse. Always someone worse. Always someone better. That’s just how life flows but it doesn’t excuse them acting as I am just a number. No body cares. I tried to make an appointment with the advocate but they are no longer taking appointments and not in the office. Am I just supposed to sit here?

I spit when I talk and now my friends make fun of me. I am just in constant pain and I don’t understand why I am being put on the back burner; I still need help but no one is helping because it is expensive. I am 100 percent disabled; that is my right.

I don’t understand this entire thing about President Trump lets you see who you want so why can’t I? *Mission Act*

I requested my regular doctor I had when I was working. He does face molds and splints but then the VA told me that I can’t go there, you need to come to VA. The VA doesn’t give nitrous gas, they don’t offer it in their clinics. I am horribly terrified of the dentist, I have to be gassed up or knocked out.

Dentist said I have to have all new caps, open up the back of your jaw, you’ve changed your whole mouth. I begged for them to let me go with them because I am comfortable with him but they said no I have to go off of this list. They publicly talk about going to who you want but then here I am. It took 8 months to get these ugly glasses that I can barely see you, big foggy mess, it took months of arguing with people. Then my hip, my doctor did the Xray then the VA did the MRI.

1. **My doctor, what do you mean?**

My VA doctor, my primary care. She has done what she can do but there’s only so much she can do. People tell me my primary care should be doing it but I am fully capable. I have been on the phone for hours while waiting so I get ready and put my makeup on. “You are number 55 in the queue.” I have to do something when waiting and it’s hours. When you get someone on the phone before you can say anything they say please hold and then they transfer you to someone else.

1. **Are you calling local VA medical clinic?**

The local VA then prompted through and then there’s a number for Community Care. Those are people that are supposed to be helping you get care. They have been the least helpful, rudest. I don’t know if they hate their jobs or find it thrilling to mock people. I am at their mercy and they make me feel that way. If I get angry they say they will hang up. I have been on hold for an hour of course I am mad, I have things to do. Or they answer and say they don’t have an idea about the clinic, they could be a volunteer. It took me months to realize I was sending all my glasses stuff to a completely different building.

After flipping out, I finally got someone on the phone. They said they are “tired of this.” I said “I thought your job is to help and get me to the right department.” They said “You don’t understand what we’re going through.” They just say that everyone is important and I don’t know who to give the information with. Then finally she said “screw it, I’m just going to give you the number directly” to this clinic.

She gave me the number to the clinic. I had an appointment within 2 days. Why didn’t you tell me that from the beginning? My eye doctor from the VA faxed my stuff over 12 times. It’s through the VA. Even though this person isn’t a VA eye doctor they are the community care. Affiliated, there’s a list. They have to be on a TriWest list to have people from the VA. Dentists, doctors can sign up.

Everyone I talk to says they don’t want to be on it because of the billing sucks and paperwork sucks and it’s confusing and it needs to be filled out every time. Even if you come in for teeth cleaning and X rays they are two separate services they have to do it twice then don’t want to fill it out to go someone else.

1. **Sounds like for your hip and your dental work, you’re taking on the job of finding a specialist that will take you on?**

Sort of, like with dental and eye glass thing. What I did was they send a list and I spent hours going to the websites to check out their reviews. I am scared of dentist so I need someone that knows what they are doing. The issue is the one that know what they are doing don’t want to be on the list because they have tons of patients. They don’t want to deal with the VA.

I begged my dentist and they said it is a huge pain in the ass they said its only new dentist or dentists trying to get new clients. So now I need a specialist, they sent the list of contacts for x-rays and cleanings but not prosthodontists. I’m still waiting for the list. You call, they won’t give the email, phone number or name. What am I supposed to do? They talk down to me and it has been a year in the making, I’m dying, it is going on two years and it’s getting worse.

If I am looking on someone on the list if you gave me one for the dentist and eyeglasses, where’s the one for the prosthodontist? They said “I have red flagged your file and sent it to a higher place,” and they won’t give me the information of the higher office so I am supposed to sit here and wait. So I’m just supposed to sit here and wait. It has been a month since it was put on alert to go higher. It is horrible.

1. **I’m sorry about that. I wanted to go back, previously you had employer based healthcare?**

Yes

1. **When did you apply for VA healthcare?**

I had a melt down at work and lost my job, I worked my whole life, part of why my mental health is so bad now because I feel lost, I have nothing to do besides eating and drinking. I used to work 14 hours a day. I always had BCBS or Delta Dental and had no issues.

I had a breakdown and went to a loony bin at the VA so I admitted myself to set an example at work, like you can’t treat people like that. He [my boss]moved me into a closet from a big office for the big wig.

I lost my shit, so I was forced to go to the VA. Instead of them doing anything they took me off of all my meds, which made me extremely vulnerable. I thought everyone was trying to kill me, full of depression and they diagnosed me I am 100% disabled, you can’t work anymore.

I didn’t know what they meant; I can work but not where it triggers me. Even doing this kind of stuff, can I do anything? I use to do mystery shops so I had to look up the tax laws. It says I cant make above poverty level. It basically says I can’t make too much and I cant be actually employed.

By this time of the month I was making 70K and now I make 30K. I still have the same bills; I gave up the extras like Starbucks and getting my nails done. I now spend all of my money on my bills just to survive and I have to go to food banks. It’s been horrible.

1. **You said you were diagnosed as 100 percent disabled. Can you tell me more about that process?**

I am not sure about the process. I thought it was time consuming. I was 70% since I got back from Iraq and I could still work. No problems. I got a little part-time check and it helped me live then I had the meltdown at work and I thought I would be able to come back with a letter telling them to stop messing with me. 33 days I got the letter that I am 100 percent unemployable. I don’t know how to fight that, I guess that’s what I am now. Everyone said I guess you don’t [fight it].

Everyone I talk to, all I said was hell yeah I wanted to kick him in the face and push him down the stairs. I don’t want to kill him. This is right after it happened. I want to hurt him a little not kill him. Those are homicidal tendencies. I don’t care who you are. Everyone wants to punch someone at a point. I wanted him to catch the flu and he shits for a week. I don’t think I said anything that horrific. I just said I can’t go back if he’s there, there are training him to be the owner, with him there I can’t go back to that job.

Well they decided that I couldn’t work again. It makes no sense to me, I was a great employee, I had way more friends then enemies. Everyone was coming for advice and I got a lot of raises. I am actually still friends with one of my bosses. [My previous boss] was a bad seed; he fired a lot of people. He didn’t fire me, but I am sure I was on the pecking order and it wasn’t good for my mental health. I realize that. But it was the best job I ever had.

Before he had come along I was there for 8 years, I felt important, I felt needed and I need that in my life. That’s why I have this dog, I have to feel like I am caring for someone. But I also feel sheltered and alone. This has not been a great experience.

Others are like great you never have to work again. I don’t feel that way. I am trying to feel that way but that’s why I started my book because I have to do something with my life. I can’t sit around and eat and feel sorry for myself but I can’t do it. I’m trying to live with this. When you take someone from 70K to 30K, that’s huge. It’s huge on your mental capacities.

My kids use to be able to ask for money but now I can’t. My daughter asked to go get nails done but I was like I haven’t been in a year but she’s paying. Wow, this is cool that my daughter is going to pay for it. It is kind of nice where my kids are at a nice age and time in their career they can do it.

1. **How old are your kids now?**

My kids at 27 and 32. My 32 year old is a mid-wife, she, too, is very “take care of people,” she always loved babies. Babysat my friends kids. My other daughter hates kids and loves dogs, never going to be in love. She was very affected by my mental breakdowns; she was just a kid, 13, when I went to Iraq. She was abused by her stepmom and I didn’t know until I got home. The stepmom monitored everything she did and what she said and she took everything from her room. I brought her computer, VCR, paid for a year of internet. They took everything and left her with a twin bed and dresser. She has been mentally scarred from it.

1. **When did you return from Iraq and then get your disability rating?**

It was the same situation, I was working with rain man, anytime you went near him he was cleaning, each time someone would leave the office he was cleaning. The one time I touched his arm he freaked out. I got along really well with my boss came into my office at my 1 year mark and I said I was done. I’m going to explode on this guy. The guy was making me have evil thoughts, they said they would get me another office but I said I am sorry. Normally I would never leave something without a replacement but I walked out that day.

I remember my boss because we stayed in contact for a while. She said you did 25 years in the military why don’t you use the benefits. [I said] “well more people need them”. I am working I don’t need the benefits and she said I deserve them and to get my mental health checked and one day you will be forced to address it.

Sure as shit, I ran out of my medicine so I reached out to the VA to see a counselor and I didn’t even ask. I was just venting doing what I did with the counselor. One day she said to me “you know you have PTSD”. I said no I don’t. She told me I am full of anxiety and always in fight mode. Well yeah I was in the Army and I have to be tough. She said you don’t have to be that way anymore. I told her I will always act that way it is bred into me to act that way.

I was forced into the medication because I ran out. Then basically if they are giving me medication they told me I need to better myself to see the counselor. Six months in she wrote a letter to the VA to get me disability pay because you deserve it. You went through a lot and I am still living it. It’s still a part of your life.

It has ruined my daughters ; we all have separation anxiety among many other things. Both of my daughter are like me, single because they watched me, and it saddens me very much because I hate I am this way at 55 and I have been in love one and that’s it.

Once someone raises their voice he’s gone, you scare me, you’re gone. You’re mean to my dog you're gone. I dump men for the frivolous of things one of the things was he had a big hairy back. One guy bit his nails. The common sense is that doesn’t make sense. Stupid thing I have broken up with men over, I am still friends with them and asked what’s wrong with you, we love you. I say get in line. I don’t know how else to be, if the starts and moon don’t line up you got to go.

My kids are now the same thing. I thought I was doing good teaching them. I had good Army friends and they came over for football, pizza and helping the kids. I thought I had enough of that they my kids wouldn’t be like me. Not be afraid like that. For years I never told my kids anything, only since I started my book, if something happens to me and I die I don’t want them to find out by reading. They are adults so they can handle it so I have shared 80 percent of what really happened to me. The other 20 percent they will have to find out about. I have used writing to escape pain. Pat Benetar poetry. Broken love, black hearts. I write dark poems; it gets me through, it makes me address my inner demons. I didn’t even mean for it to happen, she suggested her putting in the paperwork and I haven’t thought about it. So many people told me they would deny deny deny. Six months later, they sent me a letter for 70 percent.

1. **Did you have to do anything? Sign anything, show up anywhere?**

I had to sign a release form I’m sure. I can’t remember specifically, it was so long ago but I had to give her my permission and she suggested it. After a few meetings. There are people worse than me, missing legs and limbs, mine is all in my head, I look completely normal. I have always dealt with it. I have friends.

I am doing something right, I don’t know what, that I have had them from 5th grade 10th grade. That’s not common but that’s me. When yahoo and massager was a thing, that was Facebook of my time: I would do chronicles, it would be raw, dirty, and perverted. People were always like “my husband is waiting for it, my sister want to be part of the email group.” People wanted more. That’s what started it. Now I have a lot of followers on Instagram that I am doing for when I do go to sell my book.

I kept this buried inside, I’d share and then make a joke so they wouldn’t think it was real. I was captured, raped overseas. I found a way to talk about it in a real way without crying. I can talk about it without being messed up. I have always been the strong one. It is weird to address it. I need to be on medication, you’re not so strong, not so tough.

The stuff with the VA is what send me over the edge. I get off of the phone I cry and stay in bed. Once it gets dark I start to drink and I know it’s because of all of this. My kids were here for a week and I didn’t touch alcohol, today is the first time in 3 days I showered. I was so sad when they left. This shit isn’t normal, this behavior is not okay. This is not “why don’t you practice what you preach.” But I don’t.

1. **I’m so glad you’re writing and finding ways to get this out.**

It is raw. I almost forgot my daughter almost died after her tonsils were removed. She had them out then she did something to burst something and when in fact my journal entries are way worse, my mom called me, my friend called me, I wrote everything down. I want everyone to know what really happened because I never really talked about it. I have been writing about it for years but I biggest fear was something would happen and they would find it when they were too young. I had it in a box that said do not open until 18. I kept it for a long time. I had two kids, in the Army and owned a home at their age so they can take it. I am positive that all of this stuff with the VA is literally sending me over the edge. I wish someone were here to video me when I get off the phone. I am like a crazy person, kicking, screaming. Like they tell to do. You put your head in a pillow and scream and then crying into slumber. It takes days to get over. I went through all of it and have to do it again. Once a week I am putting myself through the mental abuse and know I will be neglected but if I don’t do something no one will. I wrote a letter to the federal trade commission. I was online one night, I was trying to find out who to talk to and I found the FTC under the military. One of the things was workplace this or that but then also being mistreated medically so I though what the hell so I wrote them a letter saying what I am saying to you. I am moments away from losing it if no one helps me soon. I hate this feeling. I hate feeling angry all the time. I feel sorry for people that are chronically depressed, that feel this way every day I don’t feel this way every day. It is becoming more frequent and I drink every day. I used to drink every Friday and Saturday. I functioned fine when I would only drink Friday or Saturday. And now I drink every other day and I make sure it is dark out before I have my first drink. I can’t be a daytime drunk. You have to draw the line somewhere. I want to take my pills but it makes you feel numb. I am constantly devil/angel [gestures to shoulders] and I know what I am doing is fucked up. I am so remorseful, I am angry at myself but angrier at the VA because they did this to me. It is hard, I started seeing the nut doctor every week on the phone and he just annoys me. It makes me mad. “How are you feeling between one and ten Ms. XXX?” Like ask me real questions, I can see you with your paper and pencil. That’s not helpful. Talking to a friend is more helpful. Then I vent and then they vent. Tell me something bad that’s happening in your life. I can’t be the only person that feels this way. I have had 4 throat surgeries from sand and shit. The last surgery they snipped one of my vocal cords, I use to sing like a queen. I talk like a guy; everyone says thank you sir. I never correct anyone. It makes me so self conscious. I try to do my hair and makeup and be girly but I feel like I am always being knocked down and it’s all related to the military. It is the best and worst thing that happened to me. How is that? How can it be the best thing and the worst thing? It doesn’t make sense to me but it makes the best.

1. **What makes it the best?**

Feeling empowered. Then you look back and it is like how abusive. I used my vagina was a golden nugget of love. I was a virgin, I was a tomboy, I remember going to the bar and this guy was just dying. Then you look back and you’re like it was abusive! I used my vagina to my advantage but it has also been detrimental.

This counselor wants me to take ownership but a lot of it was because I was a girl. I didn’t dress up, I didn’t wear makeup. I tried to be low key, like in sweats with paint on it in Kmart shoes. I didn’t try to be pretty in the Army. Just being a girl is all it took, much less.

A lot of the time it was very empowering I could be like “dig that hole, carry my bag.” I was very much in control. I met a lot of friends. It says something when you have friends that would die for you and you know they would. The only one on the outside is my kids. I would take a bullet for them. I don’t know if I would for my friends, but I would for my military friends. When you shit, shower, and shave with people, when you share personal space, you get really close.

I became quite a counselor, a lot of people came to me for advice. With every good thing something bad happened.

I got a lot of mistreatment/ “Nice tits, X,” A lot of attention. “Sorry they’re just nice” [imitating male colleague.] So much inappropriate stuff happened and it made me inappropriate. That’s what people love about me; it is a double edge sword. I only like people like me [blunt, honest] That’s why the counselor isn’t working because he is acting like a robot.

I am always trying to be better but then I am knocked back down. I was happy when the masks happen so I could cover my face. “I get to cover all this? Sweet!”

**Thank you and closing (2 minutes)**

Well we really appreciate you taking the time to share your thoughts with us today. Your feedback is so helpful to us as we continue to work on the site and make sure it really works for Veterans.

Lastly, do you know any other Veterans, caregivers, or service members who might be willing to participate in a future user research session? If Yes: Thank you! I'll have our team send you an email with a little blurb that you can pass along.

Great, well thank you so much again, and enjoy the rest of your day!