

Online Supplement

Appendix 1. Mental Health Patient Interview Topics and Questions

Topic Area	Question
Reading Mental Health Notes Practices	<ul style="list-style-type: none"> • What motivated you to sign up for MyHealtheVet access? • How did you find out about the online health records feature of MyHealtheVet? • When did you first begin viewing your notes online? • How often do you view your notes? • When was the last time you viewed your notes? • Where do you typically view your notes? • When do you typically view your notes? • What are some of your reasons for reading your visit notes? What expectations did you have when you first started reading them? • Prior to online access, had you requested a copy of your health notes from the Record of Information office before?
Impressions	<ul style="list-style-type: none"> • What do you think about what you have read in your mental health notes? • What are you learning from reading your mental health visit notes? • What do you like about reading the mental health notes? Dislike? • Were they surprising, upsetting, confusing, and how so? • Were they helpful in any way, and how so? • What are your thoughts about the level of detail in your notes? Are there things you feel are important to put in the notes or leave out? • Having read your notes, what do you feel is the purpose of a medical note? Who do you feel the clinician is writing to? Who should the note be written for? • What, if any, differences have you noticed between visit notes regarding your mental health care and other visit notes?
Experiences	<ul style="list-style-type: none"> • Have you discussed the content of your notes with your clinician, and, if so, what did you talk about and how did the conversation go? • Have you discussed content of the notes with anyone else? • Have you shown or given anyone else access to your notes? Reasons? • Have you found what you've read to reflect what happened in session? • Have you ever had questions about what you read in the notes?
Impacts	<ul style="list-style-type: none"> • Has online access to your health notes had any impact on your life or health? • Has viewing your notes affected how you view or relate to your clinician? Has your relationship with your clinician changed in any way? • Have there been any benefits from having online access to your mental health notes and, if so, what are they?

	<ul style="list-style-type: none"> • Do you have concerns about having online access to your mental health notes and, if so, what are they?
Advice and Resources	<ul style="list-style-type: none"> • What advice would you give your mental health clinician to help make health notes more useful for you? For other Veterans? • If you could change your notes in any way, what alterations would you make? • If you could receive more information about what to expect and how to understand your mental health visit notes, what would you find helpful? • What would be the best format or delivery for this information? • What additional skills or information would help you discuss your notes or their content with your clinician? • Do you have any advice for other veterans about reading and understanding mental health progress notes? What have you learned or found helpful?

Appendix 2. Quotes in Support of Key Themes

<u>The therapeutic relationship and trust</u>	
	<ul style="list-style-type: none"> • “I’m able to trust her, so that’s fantastic. Being able to do that, I am able to open up more. That just opens all doors, and so it’s fantastic. So that encompasses all that: communication, being able to trust her and being able to open up. That just makes for a very good relationship.” • “I actually discuss with anybody I see through the VA system. I tell them that if they’re going to work with me they need to be upfront and truthful even if they have an opinion that differs from mine. Like if they think I’m over exaggerating or if they think that I’m making excuses to go ahead and openly tell me and we will discuss it and try to make my situation better through that. And that I do read my notes. And, you know, I’m like, either you guys work with me or you don’t. It’s your choice.” • “I reamed her out about making a mistake. I didn’t ream her out, but I was not happy. So I think we’re in a trust building stage; so she’s writing her notes carefully and I’m reviewing them carefully.” • “It affects me in the way that I will approach that person in the future. Either I’ll be very professional and, you know, just the facts ma’am, just the facts. Or do I have liberty to be a little more open, a little more jovial.” • “I haven’t had really a reason to check because my last mental health provider I actually trusted a lot.” • “It started to try to and I—so I stopped reading them. Yup. I was like, ‘I’m not going to read this anymore. I don’t need to – I don’t need to read this, I don’t need to look at her with suspicion.’... Because you’re seeing your most secret self laid out in just black and white in someone’s most cursory terminology and it’s demoralizing.” • “I watch what I say. So, I guess it changed the relationship.” • “I’m a little more hesitant on what I’m saying... I just don’t trust.” • “I feel like I’m going to be on guard now when I go to my next appointments. Maybe it’s not a good thing for them to show their notes, because now I feel like I will have to have kind of a persona or something for while I’m in there. To try and ignore the fact that I’m very uncomfortable in her sessions, and make sure that there’s content for her to write about that

doesn't just make me sound like a whiner that's wasting 45 minutes of her time.”

- “That way you can keep track of what's going on... You can compare and find that doctor that's going to be there to help you.”
- “And I started to read it more carefully. It was empowering. It was like, ‘No, that did not happen.’ And here I went and talked to the patient advocate, and they told me you have, these are the procedures you follow. So now when I read the notes, it's empowering. It's like I'm participating in this. In a way that I don't think I that I could participate if I didn't have access to the notes. Because I wouldn't remember.”
- “And because of MyHealthVet and that Blue Button, I have other people now that actually care and that actually want to help me and that I get to be truthful with.”

Transparency

Strengthening Patient-Clinician Relationships

- “I think being open and saying, ‘Well this is what I'm going to put in your note.’ Rather than having it come as a surprise. Because once I discovered that, maybe that was put in the note, and maybe they have a different perspective on it than I do. Yes, they have the doctorate, but I'm the person living through it, so who has the right perspective?”
- “I like the way the way that [my clinician] puts them in because he's very blunt and honest. He pretty much says exactly what I've said. And what I really like about it is that he also puts in there what we've talked about and what I said I would do. So then I can review and make – I look at it, it holds me accountable for what I said I would do because I tell myself I'm not firing on all cylinders, and I don't have a very good short-term memory and I know that. So having his notes there helps me a lot to remember to do what I need to be doing.”
- “So there's nothing that's derogatory, or blame, or stuff that's in there that we didn't talk about it. It's all straight-forward and to the point of what we talked about and what the plan is.”
- “If I'm doing lousy, tell me and I'm doing lousy and write in your notes that I'm doing lousy.”
- “She writes the way she talks. She is very honest, you know. There wasn't any hidden agenda like I thought.”
- “I think as long as they're professional, honest, and they don't try to inject their own story and opinion without discussing it with me first, I think it's completely fine.”
- “What I find helpful is finding out if we're on the same page. Something that a provider may key in on as an important issue, seeing if that's important to me as well. You know the – we have a therapy session, and I take away stuff, and I like seeing what she takes away from it as well, what she thinks the key points were because they don't always match what I thought was key to the session might not be key to the session for her. And to see that other perspective is kind of, it's interesting. It makes me think more about what's going on.”
- “When she found out that I was reading the notes and stuff, she would ask me if there was anything that was unclear, if I needed clarification on anything, if there was something that wasn't addressed, you know, she'd go out of her way. And I know that a lot of providers don't always take that time.”
- “To be honest with you, I think it made me closer to my therapist. It made that relationship stronger, the trust was there, because they were open to talking to me about it... they were willing to break it down with me, help me work through the issue, instead of stuffing it under the carpet... And I'm not saying every therapist is like that. I consider myself very, very lucky.”

Straining Patient-Clinician Relationships

- “You don’t know what’s going to be put in your record. Are they going to tell the truth? Are they going to say what you said?”
- “I found a lot of incorrect information. And things that just never happened. And I also found a lot of pattern of cutting and pasting. Where somebody would write something in one note and then three months later another person would want to make a quick entry and would just cut and paste. And that’s okay to a point, but it doesn’t accurately reflect what was said in that session, right?”
- “I just feel like my time should be respected. And I understand their burden and they have a lot of people to see, but it goes both ways. I’m giving up a lot my time and people to see as well.”
- “I had a negative experience at the [local] clinic where, you know, they had a behavioral flag but it had never been explicitly discussed with me. And at some point the provider was trying to take a note or to do something that set off an alarm of some type and people burst into our, into the interview room and it was really upsetting to me. I became interested in my notes from that point forward. I never threatened this person, I just went, ‘Well, whatever this is it’s not a healthy environment.’ I mean that just ruined my trust with them. I should say it created a real barrier to working through therapy.”
- “If a clinician assigns a diagnosis to somebody, that diagnosis should be thoroughly explained to the client. And so I think that, like me, who was surprised by having a borderline personality diagnosis all-of-a-sudden slapped on my records. I think providers will get better at describing that type of thing to their clients.”
- “I noticed that on my mental health chart they put in that I had, you know, that there was a borderline personality disorder. And I went in to the medical library and I looked up the BPD and I looked up the different case scenarios and I talked to my mental health provider about it... I didn’t know of this diagnosis at all. At all.”
- “Just all of the sudden, bi-polar disorder comes up as a diagnosis and we’ve never talked about it. It’s like, what’s this? When I questioned him about it, he removed it... I said, ‘Well you didn’t talk to me about it.’ So let’s have a conversation about this before giving me a diagnosis. But then again, even though it’s corrected, it’s now in my record.”
- “There are some things that they put in there that you didn’t even talk about. Some of the things I was like, holy cow.”
- “It was a couple items that were put down differently than they were discussed, and I can get upset pretty easily. And that upset me because the way they were reworded is not the way that I said it. And the way that I was reworded, the way it was reworded made it differently than it was implied.”
- “Sometimes what you say in sessions doesn’t necessarily correlate [with] what they think should be in there. I was just looking for more detail, more information, I guess.”
- “Oh my God I was born in 1937 and I am in remission from alcoholism. Who the hell is that? That’s not even me. So somebody had copied a note in somehow.”

Respect

Strengthening Patient-Clinician Relationships

- “I expect to be respected in person and in notes. Treat me with dignity, treat me with respect. I gave my life and my health for my country. So when I read notes, I expect them to be respectful. One of the ways that they’re respectful is not making me just a diagnosis, like I said. I’m a human being, I have given my life. So I want to be respected.”

- “I felt now that I can see a year’s worth, I can see kind of where we started, the progression that’s been made and where we’re at. I feel pretty good about where we’re at. Like I haven’t wasted a year of my time.”
- “With ADHD sometimes I get busy and move around a lot or jump from subject to subject and it’s kind of hard to stay focused. So it’s nice to know when I read the notes that the doctor noticed that I was staying on task, because I was really trying to stay on task. So yeah, it’s positive feedback for me, definitely.”
- “It’s good to know that there are some therapists that will actually see beyond what you project.”
- “[My doctor’s] entries are long. He gives it thought and consideration. ... I’m not just a repeat from the last PTSD person you talked to. I’m an individual with PTSD.”
- “Once you get used to talking to someone about the positive things that are going on and seeing them reflected back to you, it increases the number of things that you want to tell them that are positive, that are changing. Whereas if I see something like a new diagnosis, I’m like, ‘Oh my god.’ I have this symptom, and I’ve got that symptom, instead of seeing progress, and somebody noticing the progress.”
- “I think what his gift is he doesn’t pathologize me. He’s not trying to force a pathology onto me. He sees me as a human being and I’m going through this stuff, and he focuses on seeing my strengths.”
- “I expected to find very brief, very brief mentoring notes with just Axis information and I don’t know if they’re still using GAF scores but I basically expected, ‘Saw patient on this date, la di da di da, refilled medications.’ And there was actually a lot more information in there than I had anticipated. Kind of reassured actually. I’ve had problems in the past with continuity and I would rather have a more fleshed-out note than something like that. Because it provides a better picture of where I am. Especially when you’re dealing with mental health.”
- “He’s not just sitting there going, uh-huh, uh-huh, uh-huh, but that he’s really listening.”
- “It’s good to hear that you’re being heard... You can’t fix some things. You just need to be heard sometimes.”

Straining Patient-Clinician Relationships

- “You’re not listening to me as a person. You’re just seeing what I want you to see. It’s like, you need to dig a little bit deeper.”
- “Some days just, because I feel like I really worked hard or I put a lot out there, and then nothing’s said about it [in the notes]. You know?”
- “Well what does a civilian good note look like? SOAP, S, O, A, P. Subjective, that’s me. Objective, that’s you. But they don’t do that. They put just his notes in there. There’s not one word of what I said in there.”
- “The other doctor that I don’t feel as comfortable with... It comes across more unfriendly, more like, she has to be there and I’m a whiner. That’s what it feels like, is kind of very negative. ‘This is the things that I had to listen to today,’ kind of a tone. Again, that’s just probably my perception or I’m reading into it.”
- “And in the course of reading my notes, like I said, I was a little disturbed at times. I was like, you know, that’s not quite, I’m not quite sure if they actually understood what was going on. And it was good be able to see the notes to go, ‘Well this is what I think happened.’”
- “When I first started seeing the lady [at the VA] I told her, ‘I don’t do well with the medication. I have what they call the paradox effect.’ It sends me to my dark places, I don’t like that. I try to avoid those places. And then to look in my notes and to see that she wrote, ‘I think she would do well on anti-depressants.’ ‘What part of I don’t do well did you not understand?’ So I was really surprised, it’s was like, you’re not listening to me. I just want

somebody to listen and talk with, and not provide me a bunch of medication. I just don't do well with medications. I either forget to take it or have adverse reactions to it. That was a really big surprise, the fact that she said this and I'm going, 'Nooo.'"

- "Wait a minute, they have this written down. Wow. Did they actually listen to me and do they know who I am sitting in there? It seems like a very different person written in the notes at times. That's really not an accurate portrayal of me."