

Appendix 2. Coding guide for questions: List of terms used to code questions with examples.

Theme	Subtheme	Definition	Example
Type of Question	Homework	Question asks for help on work assignments or homework questions.	“HELP! Research Paper!?”
	Application	Question asks about potential applications or uses of a given intervention, treatment.	“Is it possible to use brain pacemakers to treat autism disorders?”
	Opinion	Question either asks or offers an opinion on a given matter.	“Do you believe in mental illness, ie bipolar, ADHD, ect are real?”[sic]
	Information-sharing	Question shares information or presents facts/ideas.	“Did you know that psychosurgery is making a big come back?”
	Access	Question asks about how to gain access or how to obtain a certain treatment, intervention.	“How can I have Deep Brain Stimulation done for Depression that is NOT part of a Clinical Trial?”
	Health advice	Question asks specifically how to act or how to approach a health decision.	“Is Deep Brain Stimulation advisable for Parkinson's Disease?”
	Information-seeking – procedure	Question asks about the details or specifics of a procedure or intervention.	“What is deep brain stimulation surgery?”
	Information-seeking – disease	Question asks for information about a disease.	“Is Tourettes Syndrome similar to OCD in any way?”
	Information-seeking – treatment	Question asks for information specific to the treatment, such as details about that treatment, how it works, as well as what treatment might work for a given problem.	“Are there any herbal remedies for Tourette's syndrome?”
	Information-seeking – charity/financial coverage	Question asks how to obtain money/financial support or how to offer money/financial support.	“Would Medicaid pay for any brain stimulation therapy?”
	Experience	Question describes or asks for personal experience with a disease, intervention or other topics.	“Has any one received ECT treatment before?”[sic]

Asking for Self/Other	Self	The information the questioner asks for is directed at an issue they are dealing themselves.	“Why do I continue to want to kill myself?”
	Family/Friends	The information the questioner asks for is directed at issues that a friend or family member is dealing with.	“Please help..My dad is getting worse very fast?”[sic]
Emotions Expressed	Helplessness	The questioner expresses an inability to change the course or outcome of the situation and may need help.	“Parkinson's disease??? I need an advice plz? Hey, my grandmother has this disease. She is 65. Its getting worse and worse. She's taking Antiparkin, but it's not helping. I live in Georgia so health care isn't very good... Do u have any advice about what medicine should she take? or is there new way of treatment? or any updates?thank u so much!!!!” [sic]
	Hopelessness/D espair	The questioner foresees only negative outcomes from their situation and/or expresses a desire to explore any course of action regardless of its consequence.	“My doctor said my wife might be a vegetable... is there a cure? Please tell me! Im desperate! I love my wife so much, and I cant live with her being a vegetable! Please tell me if there is a cure...”[sic]
	Fear/Worry	The questioner expresses fear or concern about the outcomes of their situation.	“Has anyone out there had Deep Brain Stimulation procedure done and how did it go..? my 33 yr old son needs this procedure and is terrified that something will go wrong so any input I can get may help me encourage him to have it done.”[sic]
	Frustration	The questioner expresses anger over their inability to change their situation.	“will my tourettes syndrome ever be cured? I hate it. I hate how it makes me feel...”[sic]
	Suffering	The questioner describes or expresses a state of discomfort or pain.	“Can anyone talk to me about Parkinsons? My wife, age 58 has parkinsons. It advanced from level 1 to level three to advanced stages in a matter of months. I am having a very hard time. The doctors will not talk to me about it, because of Privacy rules. Which I think are crap. I am the sole care giver. I am totally distraught. I just need to communicate with someone.[sic]
	Disappointment	The questioner expresses a level of disappointment over what they expected of	“Is there anything to do about tourettes? I've had it for as long as I can remember and I'm 19 now and it doesn't seem to be

		the outcomes of their situation versus what has actually occurred.	going away. Are there any methods or exercises or anything I can do about it? My doctor had always told me it would go away when i got older but... it hasn't? :/”[sic]
	Pleading	The questioner repeatedly requests for help or more information.	“how long can a person live after being diagnosed with parkinson's disease? please help.. i really need to know this... inform me of family members or friends who have had this incurable disease and let me know the average length of time PLEASE”[sic]
	Sadness	The questioner expresses sadness about a situation.	“can anyone help me? Hi friends, I am 32 yrs old suffering from Tinnitus for the last one years. I have shown to many E.N.T specialist but fail to restore my peace of mind. I am very depressed. can anyone help me. how can i get rid of this disease. I wud b very gratefull.take care you all here.. virendra”[sic]
	Coping	The questioner describes some form of managing the discomfort of their situation.	“Tardive Diskanisia treatments? I am looking for ways to deal with TD. What can I do in addition to any medication I may take for it?”[sic]
	Urgency	The questioner describes a situation where immediate or extreme attention is required.	“i want an urgent help regarding parkinsons disease my uncle is in advanced stage.any one have any suggestion? do any know any doctor please give an advice”[sic]
	Hopefulness	The questioner is optimistic about the potential outcomes from a situation.	“hopefully someone can help me with getting my dad help?”[sic]
	Love	The questioner expresses love towards another person.	“Any advice on what I should do about my Dad... I'm afraid to say anything to him right now, but I still love him and want him to be as happy as possible.”
	Anger	The questioner expresses general anger about their situation.	“I think my brother is controlling my thoughts with a brain implant, what are my options?... I have never been an angry person before but now I have a really short fuse. I need to talk to someone independent but how do I even begin to explain this and how can I trust them?”
DBS Codes	Approval	The questioner mentions whether the treatment has been approved/allowed or talks about it being	“travelling to india for my son treatment? my son is 4 years and 4 months and he has severe generalised dystonia no medication has worked on him i found out about a

		approved (for a certain treatment, etc.).	procedure called dbs deep brain stimulation just wanted to know how to convince the doctors for that in uk as they said that is the last option.And can i take my son there ?will there be any objection over here if i show them a official professional letter stating that is the best treatment for him” [sic]
	Risks	The questioner mentions that there are risks involved in DBS treatment.	“what is parkinson? my father is suffering from it.his full body is shaking when he is sitting, walking, doing something.? We consult a doctor he suggested to operation for BRAIN .but we think its quite Risky for person of age 55. He suggest AIMS hospital for such operstion.” [sic]
	Electrode	The questioner mentions the use of an electrode in DBS treatment.	“Why is Deep Brain Surgery only performed on people with Parkinson's disease later? Why aren't these electrodes set into the brains of those afflicted by parkinson's disease earlier on? At the moment the procedures are done at the end-of dose period of L-Dopa... why?Thank you!” [sic]
	In child	The questioner discusses the use of DBS in children.	“What is your opinion on deep brain stimulation for severe tourette's syndrome for a 15 year old?”
Impact of Illness	School	The illness affects a person's ability to attend, succeed in or complete school.	“24 years old and depressed, how to deal... I want to get back into publishing and go back to college as I originally planned. How do I get out of this depressive rut?”
	Work	The illness affects a person's ability to find employment, to successfully perform their duties or to attend work.	“Another question - Parkinson's this time? Hello again. A year or two ago, my dad was diagnosed with Parkinson’s disease. I've been trying to find things out about it on the internet like how long it takes before it will stop him working, things like that. All I know is it's a degenerative condition. Any help appreciated...”
	Mobility	The illness has an impact on a person's ability to move their body.	“I am 27 & I have Parkinson’s? Is there any possible way of not ending up in a wheelchair, I am devastated.”
	Activities	The illness has an impact on a person's ability to properly perform or complete day-to-day tasks.	“can deep brain electrical stimulation restore piano facility like prior to parkinson's onset ? facility loss onset noticed ca.1985,diagnosed Parkinsons 1993. Sinemet//comtan//requip work, now max doses.age 78. Would love to again be

Social isolation	The illness impacts a person's ability to meet or interact with others.	as lousy at piano as I was 25 years ago.” [sic] “Is there any way I can change my sexuality? I feel like I am dying? Ungodly depression, no acceptance with anyone, few friends, and I am a very handsome man, but never dated or had a boyfriend/girlfriend before. I am sick and tired of this.”
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Appendix 3. Coding guide for answers: List of terms used to code answer stems with examples.

Theme	Subtheme	Definition	Example
Type of Response	Personal experience	The answerer describes some personal experience of theirs.	“My movement disorder neurologist keeps mentioning it for my dystonia (different type). I'm not desperate enough for brain surgery. It is a common treatment if botox and meds are not sufficient”
	Sympathy	The answerer expresses sympathy for the questioner.	“...my heart goes out to you and your Grandmother. Parkinson's is not an easy disease because it is such a shape shifter...”
	Unreferenced content from website	The answerer repeats website content without referencing the website.	
	References content from website	The answerer repeats website content but references the website.	
	Links	The answerer provides links to other sites.	
	Refer to physician/specialist	The answerer suggests the questioner contact a physician.	“If medication is not working for you there are limited options. There is an implant that releases electrical impulses to your brain to control seizures (kinds like a pacemaker to your brain). There is also a surgery (fairly risky) that includes removing a portion of the affected area. Talk to your neurologist about options.”
	Refer to organization	The answerer suggests the questioner refer to information from or contact a primarily profit-based organization.	“...Some good information can be found at the... Medtronic company's page. Medtronic is the company that produces the stimulators and electrodes...”
	Refer to clinic	The answerer suggests the questioner refer to information from or contact a centre where healthcare is provided.	“There are doctors at Butler Hospital in Rhode Island who have done this procedure...Have you looked into attending residential treatment? All these things are necessary before any doctor will try brain surgery. You can

		also look into Deep Brain Stimulation. This has just been approved by the FDA. This surgery is also done by doctors[sic] at Butler.”
Refer to institution	The answerer suggests the questioner refer to information from or contact an organization that is not primarily profit-based.	“For more information, explore the following sites: Obsessive compulsive foundation National Institute for Stroke and Neurological Disorders Yale Child Study Center & OCD”[sic]
Affirmative	The answerer responds "yes" or affirms what the questioner asks.	
Negative	The answerer responds "no" or disagrees with what the questioner asks.	
Diagnosis	The answerer diagnoses the questioner with a condition.	“Yes, this is OCD. Yes there is treatment. Congratulations for recognizing that you have a problem...”
Awareness/clarification	The answerer is unaware of what the questioner is talking about and may ask for clarification.	“Your wife should be able to waive her privacy with regards to you...Do you know what medications she is on? Has she been tested for similar diseases such as progressive supranuclear palsy? That seems to be a fairly quick progression for straightforward Parkinson's disease. What medications is she on? Is there anything that can be added to her medication? Have you researched deep brain stimulation as an option? If your doctors are being unforthcoming, I would find a different neurologist.”
Information-sharing disease	The answerer shares information about a disease, disorder or condition.	“Parkinson's disease is a neurodegenerative disorder which leads to progressive deterioration of motor function due to loss of dopamine-producing brain cells. It's this that leads to the shaking (tremors) that you see in your father. You've probably noticed

			stiffness, slowness, impaired balance, and a shuffling gait, too..."
	Information-sharing Treatment	The answerer shares information about general interventions designed to treat a condition.	"The most common, up-to-date surgery for the treatment of Parkinson's disease is called Deep Brain Stimulation. Even this is not a very common surgery. Normally, patients are prescribed oral medications to deal with it."
	Information-sharing procedure	The answerer shares information about a specific intervention, and may details about that intervention.	"There isn't a cure medication may control the tremors. there is an experimental procedure where the doctors implant something in the brain that has showed promise. but is not FDA approved yet." [sic]
	Opinion	The answerer makes a value statement about a topic.	"...It never ceases to amaze me as to why people judge without knowing all the facts. I'm not saying you are, but the people who say that [Michael J. Fox] is not having this procedure because he wants to remain a poster boy. What utter nonsense."
	Health advice	The answerer provides suggestions for how to approach or resolve the questioner's health decisions.	"As far as I know the surgery involves injecting electrodes into the brain and then the tics diminish after a number of months. I'm not sure if you're old enough, but it definitely sound like the Tourettes is significantly impacting your life and you should try to get the surgery if possible. I don't think it's 100% successful though."
	Soliciting contact	The answerer encourages the questioner to contact them or offers them their contact info.	
	Seek info	The answerer encourages the questioner to look for more information.	
Features Of DBS	Effective (by disease)	The answerer describes DBS as effective or "works" for a certain disease/condition.	"...I read an article that said that [DBS] was found to be effective in children, some as young as 10, so you should be fine. If I am wrong, then I think it would probably be for people over 18.

			<p>However, each person should be assessed individually as to their stamina and overall health before considering surgery.</p> <p>Good luck and I hope I helped! :)”</p>
	Non-effective (by disease)	The answerer describes DBS as non-effective or "doesn't work" for a certain disease/condition.	<p>“I doubt it, the "missing" signals in autism (check out "theory of mind") are far more complicated and require far more adaptability and refined tuning than [brain pacemakers] would be able to deliver. It's not just about raising/regulating activation levels or neurotransmitter levels.</p> <p>It might potentially help the types of autism spectrum disorder that are caused by overstimulation from one of the senses - (I assume their role in epilepsy is to regular/lower activation levels)”</p>
	Experimental (by disease)	The answerer describes DBS as being used for treatment, but only in experimental conditions.	<p>“...as far as I know, deep brain stimulation has never been a widely-used depression treatment. Actually I think it's more of a new treatment that's still being tested and hasn't been used much at all yet (maybe will be used in the future)...”</p>
Evaluation of DBS	Strong positive (e.g., amazing, miracle)	The answerer unreservedly recommends DBS as a treatment.	<p>“My husband had the surgery 7 years ago and it took between 6 and 9 months to get the programming at the optimal settings...My husband is 62 years old and has had PD for 18 years. The surgery was nothing short of a miracle for him.”</p>
	Worth trying	The answerer acknowledges the value of DBS and recommends they look into it or consider it.	<p>“...It is certainly a serious consideration, but, if it's a promising choice and the only choice for some then go for it.”</p>
	An option to consider	The answerer acknowledges that DBS is an option that must be compared with other	<p>“...Be sure to do your research on this procedure. Look at all the pros and cons. Know what you are getting into. There</p>

	treatments or evaluated based on one or more factors but does not provide a recommendation either way.	are side effects, which are different for every person."
Last resort	The answerer recommends the reader consider all other options before considering DBS.	"If all else fails, and your dystonia is still severe, there have been some promising results recently with a new type of brain surgery called Deep Brain Stimulation that has been shown to improve various types of dystonia. If you really have tried everything, DBS... might be a realistic option for you."
Not worth, too risky	The answerer expresses that the risks are too high to ever consider DBS.	"Surgically invading the brain seems like an extreme way to solve such a problem. Would not counseling be safer? There are MANY potential complications of placing hardware into the brain, none of which are nice."
Expresses reservations	The answerer acknowledges that there are limitations to DBS treatment or is hesitant to recommend the treatment.	"There is no cure for Parkinson's disease...There are also some experimental treatments, such as deep brain stimulation, that are only tried on specific cases and with limited positive results."
New/Radical	The answerer describes DBS as new or extreme treatment.	"...There is a new technique which has been working for folks. It's rather drastic: deep brain stimulation..."
