

## ANNOTATION GUIDELINE

VERSION 2.2

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*Thank you for your help with data annotation! I will give you a short introduction to the data and the disease GIST so that you will understand the forum posts better.*

The messages that you will be annotating come from an online discussion forum for patients with Gastro-Intestinal Stromal Tumor (GIST). This is a rare type of cancer that forms in the stomach or intestine. The most common first treatment is surgery (also called a *resection* or a *whipple*) or a medication called Gleevec (generic name: *imatinib*) or both. Other common later treatments are Sutent (generic name: *sunitinib*) and Stivarga (generic name: *regorafenib*).

Patients often have severe side effects from using the medication, such as chronic tiredness, nausea, and diarrhea. The average survival is 12 years after diagnosis for these patients and unfortunately, often there will be metastases – i.e. the development of secondary tumors at a different site in the body like the liver. Please be aware that some of the forum posts can be shocking and/or very intimate. If you prefer not to annotate for this reason, please let me know.

For my research project on knowledge extraction from patient repositories I am investigating the type of information that is shared in forums such as these. For the purpose of insight, training data, and evaluation, I need manual annotation of the forum messages. You will annotate the messages according to four categories:

1. Sharing personal experiences as patients (yes/no)
2. Giving information based on own experiences (yes/no)
3. Providing emotional support (yes/no)
4. Is the author the patient being discussed? (yes/no)

These are defined on the next pages.

### General remarks on the annotation

- Multiple categories can be present in one message simultaneously. You do not need to choose. Fill in separately for each category if it is present in the message or not.
- Messages can address multiple topics. If a category is included somewhere in the message, it counts as a yes.

### **1<sup>st</sup> column: Sharing personal experiences as patients (yes/no)**

Sharing personal experiences as patients is defined as either:

a forum member sharing their disease history, their treatment history, or their experiences with the illness or treatment with others.

a forum member sharing how they cope with the disease or its treatment. These statements can be emotional or contain religious references.

**A personal experience does not need to be about the author – it can be about someone else.**

**If yes: fill in 1**

**If no: fill in 0**

#### Examples of sharing experiences:

1. *yes, bad chills at the beginning of my treatment that I end up at emergency, this happened about three times. After two years taken Gleevec still very cold, but not too bad.*

This post describes someone's experience with their treatment – specifically the side effects of taking the medication (e.g. *end up at emergency, still very cold but not too bad*)

2. *my copay was \$1600 a month for a year!!! its unbelievable!!!!!!: (*

This person describes their experience with their financial situation because of illness (copay = how much you need to pay for health costs out of your own pocket)

3. *All I can say is make really good lists. I couldn't remember ANYTHING to the point of tears sometimes. I've been much better off of Gleevec but still not 100% after 1 year without it.*

This post describes the personal experiences of someone as a result of the disease (e.g. *I couldn't remember anything*) and the consequences of taking medication (*been much better off*)

4. *My husband has bad indigestion every time he takes his meds before breakfast*

This post describes the personal experiences of someone's husband with side effects of medication (*bad indigestion*). The personal experiences do not need to be of the one writing but can be about someone else.

#### Examples of NOT sharing experiences:

1. *I feel blessed*

This post is about a personal feeling, not an experience. Also, it is unclear if it relates to the disease or not.

2. *I hope it's like that for me!!*

Same as for 1

3. *Most important: Consult an oncologist who is knowledgeable and experienced with GIST, specifically. Ask lots of questions, and keep asking until you get the answers you understand.*

This post gives someone advice but does not contain the personal experience of someone with consulting an oncologist. This is just an assumption we make.

4. *Someone asked me yesterday how cancer has changed my life. You said it much better than I did! Thanks.*

A personal experience of something that happened (*someone asked me yesterday*) but the experience relates to a conversation, not the disease, treatment or coping.

5. *I would kiss my wife's scar every night. Vit . E tastes terrible but I did not care!*

This is a personal experience of the author (i.e. something he would do) but is not an experience related to the disease or the treatment of the disease.

## 2<sup>nd</sup> column: Giving information based on own experiences (yes/no)

Defined as:

a forum member sharing “factual” information learned from their own experiences or factual information from external sources **to help or advise others**

The information can be about medical topics (e.g. the course and symptoms of the disease, medication, treatment) as well as about the consequences of being ill (e.g. restrictions in daily life, financial consequences, insurance).

**If yes: fill in 1**

**If no: fill in 0**

### Positive examples of sharing information:

1. *Most important: Consult an oncologist who is knowledgeable and experienced with GIST, specifically. Ask lots of questions, and keep asking until you get the answers you understand*

The author gives advice based on own experience: *consult an oncologist... & ask lots of questions....*

2. *A few folks were talking about insomnia and ways to help sleep better. Check this article out:*

The author gives an external source which can help others with sleeping and advises them to use it.

3. *The water retention is a pain in the ass. Can you do sports? It's what helps me most.*

The author with advises in question format others to do sports and relates to his/her own experience (*It's what helps me most*)

4. *The pharmaceutical companies have assistance programs. Inquire to see if you qualify.*

The author is giving information about the pharmaceutical companies and is advising others to *inquire to see if you qualify*.

5. *All I can say is make really good lists . I couldn't remember ANYTHING to the point of tears sometimes . I've been much better off of Gleevec but still not 100% after 1 year without it.*

The author is advising others to *make really good lists* based on their own experience: *I couldn't remember ANYTHING*

6. *Those cysts are quite common in just about everyone . However us GIST warriors it makes us worry . Always good to check and ask for an opinion.*

The author is informing others that *cysts are quite common* and advising to *check and ask for an opinion* in cases of cysts

Examples of NOT sharing information:

1. *I live in roswell ga 10 Minutes away....i have local oncologists but i take direction from Dr - NAME- in miami . Feel free to PM me*

The author does not give any advice, but just relates who his/her doctor is and where he/she lives

2. *yes, bad chills at the beginning of my treatment that I end up at emergency, this happened about three times . After two years taken Gleevec still very cold, but not too bad.*

The author shares a personal experience but does not give advice.

3. *If I were you, I would stay in bed*

The author gives advice but does not give any information based on their own experiences

### **3<sup>rd</sup> column: Providing emotional support (yes/no)**

Defined as:

a forum user who emotionally supports another, recognizes and understands the other's feelings, console them and by doing that help the other.

**If yes: fill in 1**

**If no: fill in 0**

#### Examples of providing emotional support

1. *I hope you feel better soon ...*
2. *May your surgery go really well, and your recovery even better!!!*
3. *Sending you healing thoughts and prayers that you start to feel better soon. Sorry to hear it's been a rough recovery ...*

All these examples are emotional support. One person wishes the other a fast recovery.

#### Examples of NOT giving emotional support:

1. *Absolutely brilliant news - Enjoy the journey now!*
2. *Thank you*

Simple responses such as 'Thank you' or 'Absolutely brilliant news' should not be marked as emotional support: these messages express a positive feeling but do not support another forum user emotionally.

#### **4<sup>th</sup> column: Is the author the patient being discussed?**

Not all forum users are cancer patients; some have a family member with cancer. Thus, some posts have been written *by* a patient while other posts have been written *about* a patient. Of course, there are also many cases where you simply do not know.

**If the author is a patient, fill in 1 (for 1<sup>st</sup> person)**

**If the author is discussing another patient e.g. his/her mother, fill in 3 (for 3<sup>rd</sup> person)**

**If you cannot tell from the post: fill in 0**

**If in doubt, fill in a 0.**

Example when the author is the patient him or herself (= 1) :

1. *It is wonderful. I travel 8 hours just to go there. Let me know if you have any questions anytime. I have been on Gleevec 400 mg, then Sutent and back on Gleevec but at 800 mg.*
2. *Being on gleevec left me in a cloud also and I have been off it for almost 2 years...I'm still in a cloud!*

For both examples, the fact that this person has been on Gleevec, which is medication for GIST is a clear indication he/she is a patient

Examples when the author is not the patient but discussing another person who is a patient (e.g. a husband, a brother, a friend etc.) (= 3):

1. *My Husband has Gist, but we travel to Oregon...Dr -NAME-, he's the best ...!*

The husband of the author is the patient being discussed.

2. *Thank you so much for your support! My mother was diagnosed back in March, and we want to support her and help her through out this process . So I am so thankful for being here for us! God bless you all*

*My mother was diagnosed* is a clear indication that her mother is the patient in this case.

Examples where you do not or cannot know (=0)

1. *I am so sorry for you both . Thoughts and prayers go out to you!!!*

The author could be a patient or not. The people he/she is referring to could be patients or not. There is no clear indication. They could have both just heard that their mother has died. Although it is logical to assume he/she is talking to patients, you cannot know for sure.

2. *A few folks were talking about insomnia and ways to help sleep better . Check this article out :*

Even though again it is logically to assume that if someone is giving this advice, he might have go through it himself, you do not know. Also of course both patients, partners, brothers etc. might all have sleeping problems.

3. *I hope it's like that for me!!*

Although it is logically to assume that the author is a patient and hopes that a certain outcome will happen for him/her, you do not know for sure. He/she could also be someone's partner and hope that their romantic relation will not suffer or even something completely different.

4. *I hope for your recovery*

This post includes a personal pronoun *I* but that does not mean that that author is a patient. In this case, you do not know.