

IN4MATX 153: CSCW

Class 16:
Health Forums

Professor Daniel Epstein
TA Dennis Wang
Reader Weijie Du

Announcements

- A2 grades out after class today
 - Average 13.9/15, 93%
- No class Monday, May 27 (Memorial Day)
- Dennis will take the lead on Wednesday, May 29 to share some of his research!
- A3 due on Wednesday, May 29

Today's goals

By the end of today, you should be able to...

- Articulate the range of motivations for participating in online health forums
- Describe how these platforms leverage technological capabilities to scaffold effective conversation and support
- Reflect on how health forums operate relative to the formal medical system, and tensions between them

What is a health forum?

Forums

- Pre- social media, many online communities operated on forums
- Longer messages, archived, threaded, users with a post history



The screenshot displays a phpBB forum interface for 'yourdomain.com'. The header includes the phpBB logo, a search bar, and navigation links like 'Board index', 'User Control Panel', 'FAQ', 'Members', and 'Logout'. A status bar shows the current date and time, and the user's last visit. Below this, there are links for 'View unanswered posts', 'View unread posts', 'View new posts', 'View active topics', and 'Mark forums read'. The main content area features a table for 'YOUR FIRST CATEGORY' with columns for 'TOPICS', 'POSTS', and 'LAST POST'. The table shows one topic titled 'Your first forum' with 1 topic and 1 post, last posted by 'Meow' on Wed Oct 21, 2009 12:09 pm. Below the table, the 'WHO IS ONLINE' section indicates 1 user is online (1 registered, 0 hidden, 0 guests). The 'STATISTICS' section shows 1 total post, 1 total topic, 1 total member, and the newest member 'Meow'. The footer includes a 'Board index' link, a 'The team' link, and a copyright notice for phpBB.

phpBB yourdomain.com
creating communities A short text to describe your forum

Search... Search
Advanced search

Board index

User Control Panel (0 new messages) • View your posts

FAQ Members Logout [Meow]

It is currently Wed Oct 21, 2009 12:15 pm
[Moderator Control Panel]

Last visit was: Wed Oct 21, 2009 12:09 pm

View unanswered posts • View unread posts • View new posts • View active topics

Mark forums read

YOUR FIRST CATEGORY	TOPICS	POSTS	LAST POST
 Your first forum Description of your first forum.	1	1	by Meow  Wed Oct 21, 2009 12:09 pm

WHO IS ONLINE

In total there is **1** user online :: 1 registered, 0 hidden and 0 guests (based on users active over the past 5 minutes)
Most users ever online was **1** on Wed Oct 21, 2009 12:15 pm

Registered users: **Meow**
Legend: **Administrators**, **Global moderators**

STATISTICS

Total posts **1** • Total topics **1** • Total members **1** • Our newest member **Meow**

Board index

The team • Delete all board cookies • All times are UTC

Powered by phpBB © 2000, 2002, 2005, 2007 phpBB Group
Administration Control Panel

Health Forums

- Forums, but specifically for topics related to health and wellbeing
- Some specifically topical
 - Babycenter: all things parenting
 - Surviving antidepressants: discontinuing use of antidepressants
- Some more general
 - PatientsLikeMe



Health Forums

- Still widely used for discussions related to health and wellbeing
- Alternatives include Facebook groups, dedicated Discord servers, Subreddits

Discuss: Why might someone today still prefer a health forum over a Discord, Facebook group, Subreddit, etc.?

Why might someone today still prefer a health forum over a Discord, Facebook group, Subreddit, etc.?

Nobody has responded yet.

Hang tight! Responses are coming in.

Health forums over social media

- Avoiding context collapse
 - Health is a tricky topic, people might not want reminders while they're browsing Reddit for fun
- Cultivating community
- Forum-specific features

Why do people participate in online health forums?

Why do people participate?

- Better understanding of their condition
- Informational or logistical support
- Emotional support
- Recognition
- Helping others

Why do people participate?

Better understanding

- Seeking out resources to better understand your condition, such as after diagnosis
- *“Nearly half of patients (n = 559, 42%) agreed that the site [PatientsLikeMe] had helped them find another patient who had **helped them understand what it was like** to take a specific treatment for their condition.”*

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., ... & Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe. *Journal of medical Internet research*, 12(2), e1549.

Mamykina, L., Nakikj, D., & Elhadad, N. (2015, April). Collective sensemaking in online health forums.

In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 3217-3226).

Why do people participate?

Better understanding

- Building up scientific understanding among conditions which are less well-understood
- People share their experiences, through deep discussion they build up understanding
- People may not always agree

Reaction to previous perspectives. Many posts in threads with a high degree of collective sensemaking began with *reflection on previously stated perspectives*. For example, below are two replies in the “How Soon to Insulin?” thread, one that reinforces a previously proposed solution, and another that contradicts it:

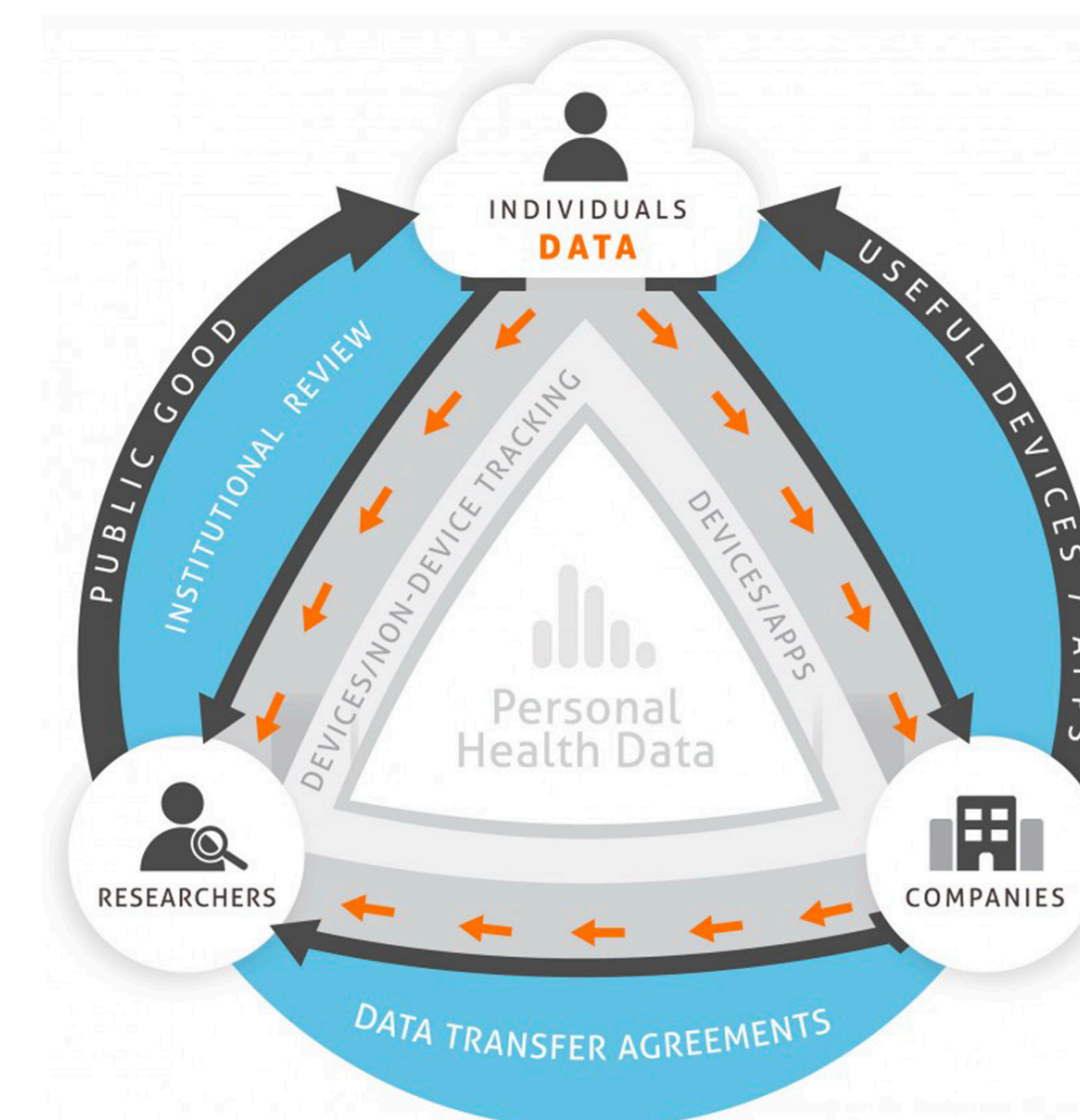
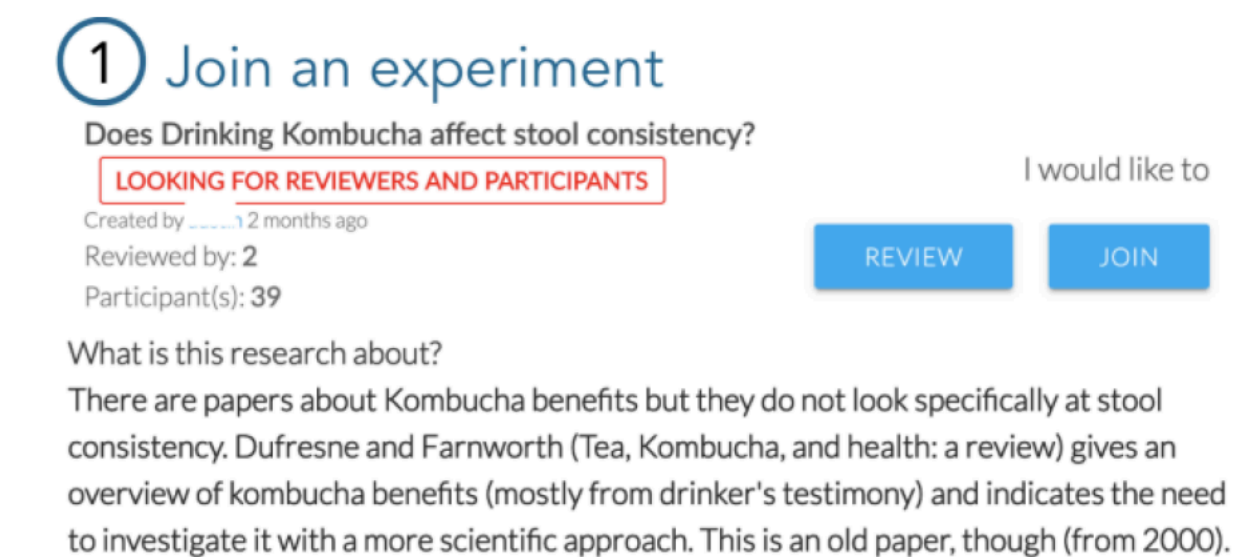
M1: I agree with what everyone else has said; you need to be antibody tested to see if you are T1.

M2: I second everything that has been said here ... except the criticism of Humulin.

Why do people participate?

Better understanding

- Efforts are sometimes more explicit, like encouraging forum members to donate tracked data to help build up scientific understanding
- Or encouraging people to run experiments



Pandey, V., Koul, T., Yang, C., McDonald, D., Price Ball, M., Greshake Tzovaras, B., ... & Klemmer, S. (2021, May). Galileo: citizen-led experimentation using a social computing system. In Proceedings of the 2021 CHI conference on human factors in computing systems (pp. 1-14).

Bietz, M. J., Bloss, C. S., Calvert, S., Godino, J. G., Gregory, J., Claffey, M. P., ... & Patrick, K. (2016). Opportunities and challenges in the use of personal health data for health research. Journal of the American Medical Informatics Association, 23(e1), e42-e48.

Why do people participate?

Informational or logistical support

- Beyond understanding their conditions, people also seek out logistical advice
 - Example: How to communicate with doctors around your condition
- Decision-making advice
 - For example, in pregnancy care: advice for handling nausea, strategies for labor and delivery

Papoutsaki, A., So, S., Kenderova, G., Shapiro, B., & Epstein, D. A. (2021). Understanding delivery of collectively built protocols in an online health community for discontinuation of psychiatric drugs. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW2), 1-29.

Gui, X., Chen, Y., Kou, Y., Pine, K., & Chen, Y. (2017). Investigating support seeking from peers for pregnancy in online health communities. *Proceedings of the ACM on Human-Computer Interaction*, 1(CSCW), 1-19.

Why do people participate?

Emotional support

- Health is serious, and we rely on others to support us through challenging moments
- Hard to find others in your personal life who can relate
 - *“Some [friends] want to be there for you, but they are so scared that they don’t even know how to talk to you. . . When shit hit the fan, some of the people who you thought would really be there actually weren’t”*

MacLeod, H., Oakes, K., Geisler, D., Connelly, K., & Siek, K. (2015, April). Rare world: Towards technology for rare diseases. In Proceedings of the 33rd Annual ACM Conference on human factors in computing systems (pp. 1145-1154).

van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative health research*, 18(3), 405-417.

Why do people participate?

Emotional support

- Community members are often at different stages of their health support journey
 - For example, cancer support communities have members with new diagnoses, as well as members in remission
 - For newer members, hearing how others persevered can be helpful

Why do people participate?

Recognition

- People seek out validation that their experiences are normal
 - *“I once [posted] about the nausea, like hey, who else feels sick? Honestly, in one day I already received 25 reactions to my first [post]. Well **it’s just good to hear you’re not the only one**”*
 - *“in SA I found acceptance and validation that **what I am going through is real**. Both the medical community and my social support network fail to recognize withdrawal syndromes”*
- Particularly in light of complex relationships with the formal medical system

Papoutsaki, A., So, S., Kenderova, G., Shapiro, B., & Epstein, D. A. (2021). Understanding delivery of collectively built protocols in an online health community for discontinuation of psychiatric drugs. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW2), 1-29.

van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative health research*, 18(3), 405-417.

Why do people participate?

Helping others

- Health communities rely on people with past experience sharing their story and their strategies
 - Someone has to give support
- Many people get their support and then leave the community
- These communities are therefore reliant on the altruism of their members
 - E.g., they are not obtaining any more support

How the design of online health communities fosters good communication

Structuring support

- In order to offer informational support, forum members often enforce structure in what people post
- *“we’ve asked you many times for your symptom pattern. **We can’t tell anything from these isolated posts [...]** To get anything out of peer support, you will need to take responsibility for tracking your symptoms, communicating them clearly and accurately”*

6 a.m. Woke with anxiety
8 a.m. Took 2.5mg Lexapro
10 a.m. Stomach is upset
10:30 a.m. Ate breakfast
11:35 a.m. Got a headache, lasted one hour
12:35 p.m. Ate lunch
4 p.m. Feel a bit better
5 p.m. Took 2.5mg Lexapro
6 p.m. Ate dinner
9:20 p.m. Headache
10:00 p.m. Took 50mg Seroquel
10:20 p.m. Feeling dizzy
10:30 p.m. Fell asleep
2:30 a.m. Woke, took 3mg Ambien (NOT "took 1/2 tablet Ambien")
2:45 a.m. Fell asleep
4:30 a.m. Woke but got back to sleep

Communicating health experiences

- People use their signature field to share aspects of their health experiences
 - Medication history, kids & ages, stage of treatment, etc.
- Posts often lack context, signatures help

FOR READABILITY, SHORT LINES ARE BEST.

- A **list** is easier to understand than one or multiple paragraphs
- Include **ALL drugs, doses, and dates (starting and stopping)**
- Any drugs prior to 24 months ago can just be listed with start and stop years
- Use actual dates or approximate dates (e.g. mid-June 2018) rather than relative time frames (e.g. 3 months ago)
- Spell out months (e.g. "January" or "Jan" as 9/1/2016 can be interpreted as 9 Jan 2016 or 1 Sept 2016)
- Please leave out symptoms and diagnoses

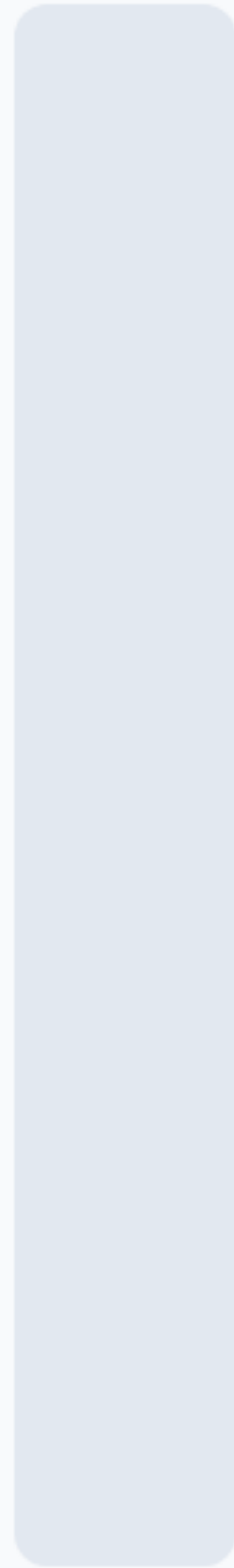
Example:

2001–2002 paroxetine
2003 citalopram
2004 paroxetine
2008 paroxetine slow taper down to 2016 Aug off paroxetine
2016 citalopram May 20mg Oct slow taper down
2018 citalopram 13 Feb 4.6mg 15 Mar 4.4mg 29 Apr 4.2mg

Relationship with formal healthcare infrastructure

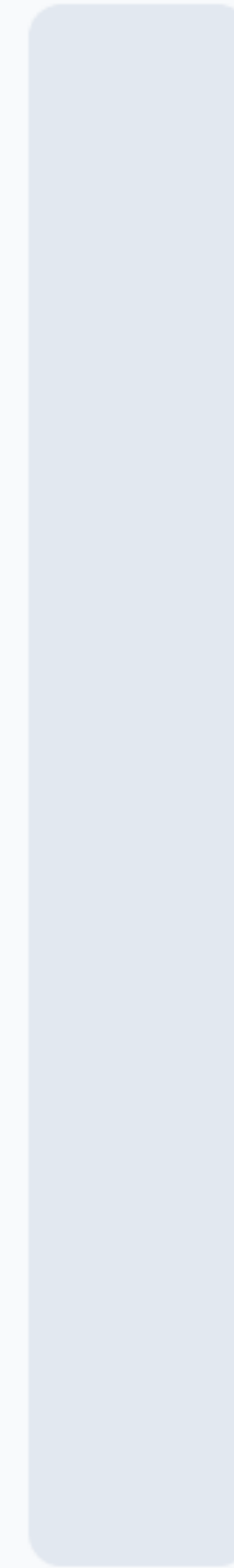
Which would you trust more for medical advice?

0%



A health forum

0%



A doctor

Relationship with formal healthcare

- People share the advice they receive from doctors
 - Helps extend the reach of medical advice
- Doctors occasionally participate in forums and give advice
 - Helpful for people who don't have access to a specialist, for example

Gui, X., Chen, Y., Kou, Y., Pine, K., & Chen, Y. (2017). Investigating support seeking from peers for pregnancy in online health communities. *Proceedings of the ACM on Human-Computer Interaction*, 1(CSCW), 1-19.

Gatos, D., Günay, A., Kırlangıç, G., Kusu, K., & Yantac, A. E. (2021, June). How HCI bridges health and design in online health communities: a systematic review. In *Proceedings of the 2021 ACM Designing Interactive Systems Conference* (pp. 970-983).

Relationship with formal healthcare

- A potential concern: is the advice on online forums credible?
 - Studies generally suggest that yes, the advice is high quality
- But, like with any online community, there are fringe groups
 - More on misinformation in a few weeks, though not so much in the health realm

Relationship with formal healthcare

- But, the unstated goal of health forums is that **they are filling in the gaps of the formal medical system**
 - Informational gaps: lack of description of how to approach treatment
 - Treatment gaps: lack of recognition of certain health experiences
 - Emotional gaps: lack of empathy
- Peer networks can help, but can only go so far
- Many communities explicitly exist because people feel they need support that formal healthcare systems do not provide

Relationship with formal healthcare

- So overall, there is often tension between these forums and the formal medical system
 - These forums offer support and information
 - But, for liability reasons, they do not want to be held responsible

Completion of your registration for SurvivingAntidepressants.org means you understand and agree to the following:

This site does not provide medical advice. For medical advice, see a trusted medical caregiver. Information presented here is intended for discussion with your doctor.

As documentation of psychiatric drug withdrawal is one of the missions of the site, the content you post may be preserved as a pseudonymous case history for study.

Relationship with formal healthcare

- SA: take what was discussed here to a trusted doctor
 - But what if you don't have a trusted doctor?
 - *"I can't help but feel extraordinary anger towards the prescribing doctor, and the thought of pursuing legal action crosses my mind frequently. In regards to earning potential and quality of living, I feel like these things have been robbed from me."*

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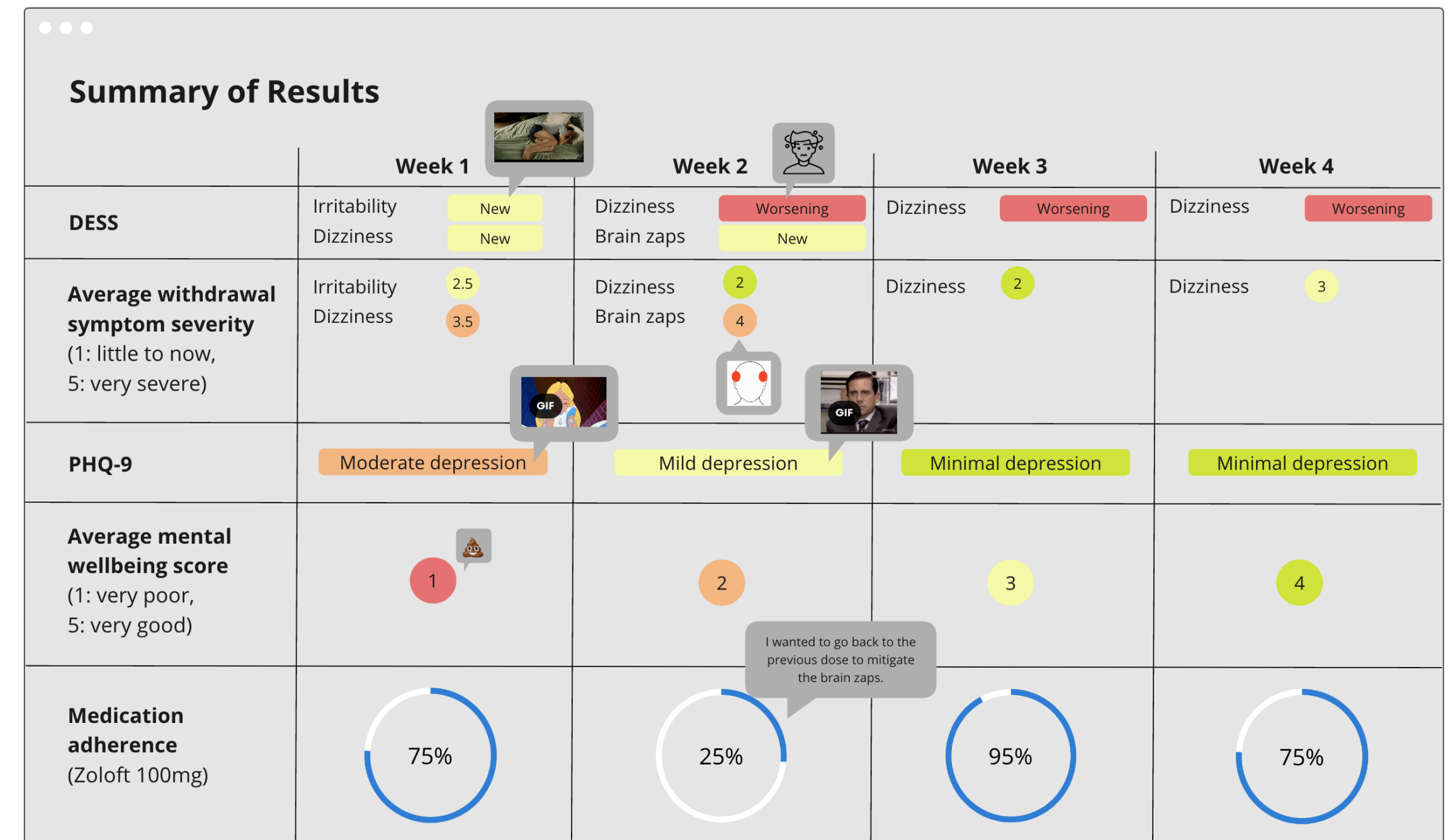
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Relationship with formal healthcare

What can we do?

- Give people better tools for communicating what they've learned from forums back to their doctors
- Help people better convey their symptoms, or experiences
- Help forums run more rigorous experiments, to help them produce scientific knowledge



Relationship with formal healthcare

What can we do?

- But the gap might be too far to bridge.
 - People turn to forums because of bad experiences, and might not want to go back
- Or, trying to integrate health forums with formal healthcare might undermine trust
 - If people see health forums as an alternative, trying to integrate might result in them not trusting the forums either

Today's goals

By the end of today, you should be able to...

- Articulate the range of motivations for participating in online health forums
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