React19 Persistent Symptoms Survey #2 Highlights

Second survey 9/30/2021 - 3/4/2022

Key findings from 967 surveyees experiencing Post COVID Vaccination Syndrome

1. The number of symptoms correlates with the severity of vaccine injury.
2. Autoimmunity may be a risk factor for COVID vaccine injury.
3. New-onset autoimmunity seems to appear at *very* high rates in the vaccine injured.
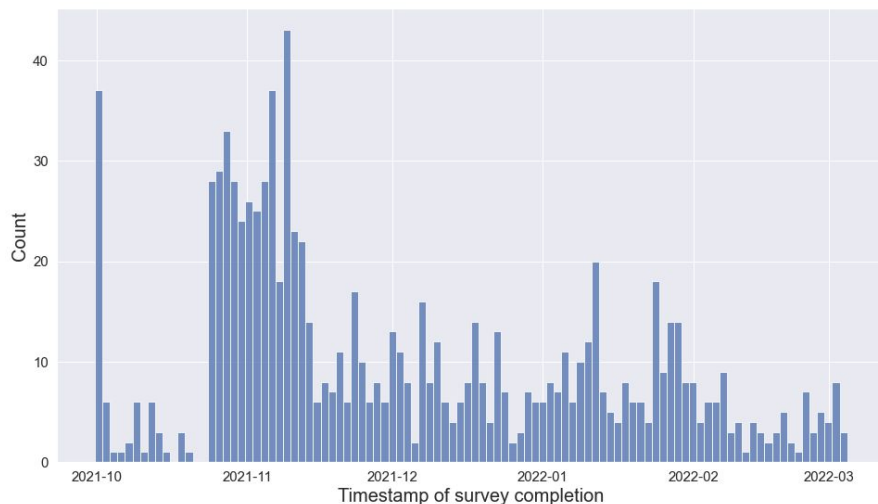
The autoimmunity connection is exciting as it may help us better understand vaccine injury and how to treat it.
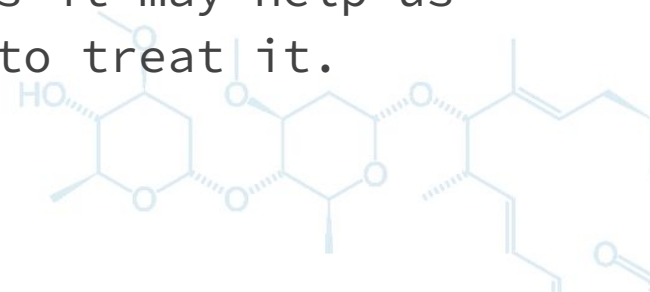
Part 1: Methodology and limitations

Survey participants

A Google Form was used to collect responses from visitors to the React19 website. Survey questions are available via this link to the Google Form.
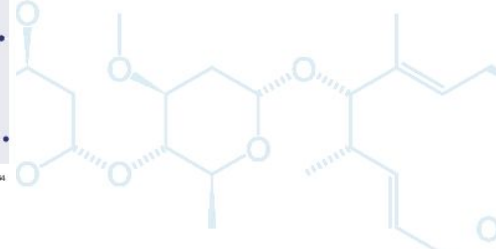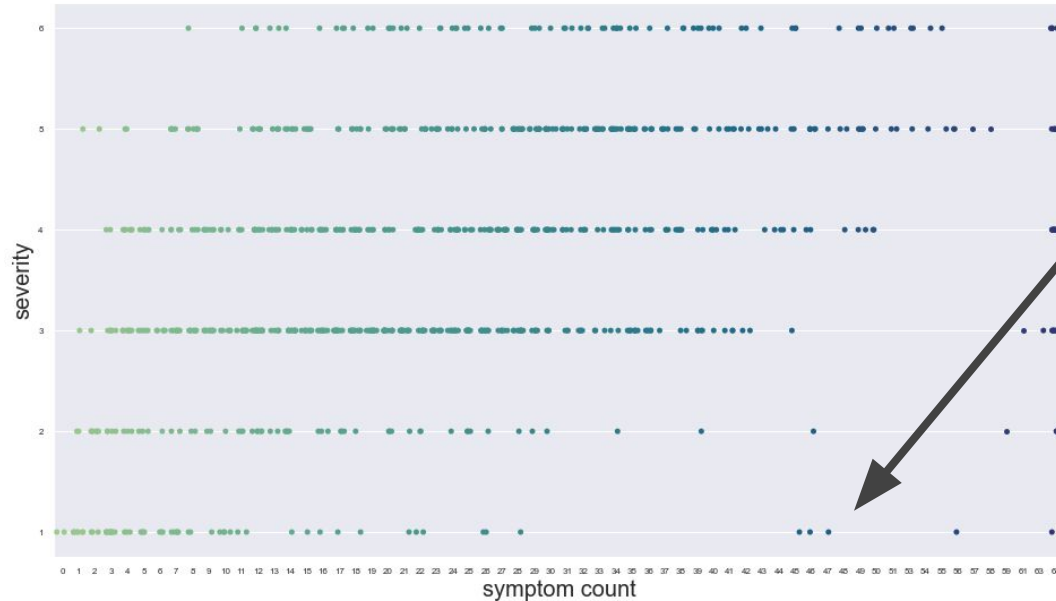
Limitation #1 - Surveyees have a diversity of interpretations

967 completed the survey by 3/4/2022.

4 responses were removed for various reasons (e.g. duplicate, unvaccinated).

A few reported having over 44 symptoms but reported the lowest severity.

Limitation #1 - Surveyees have a diversity of interpretations

51 reported having *all* 64 of 64 symptoms on the survey. That includes *both* high and low blood pressure.

One interpretation is that going from *no fatigue* to *no fatigue* is "staying the same" rather than "not applicable".
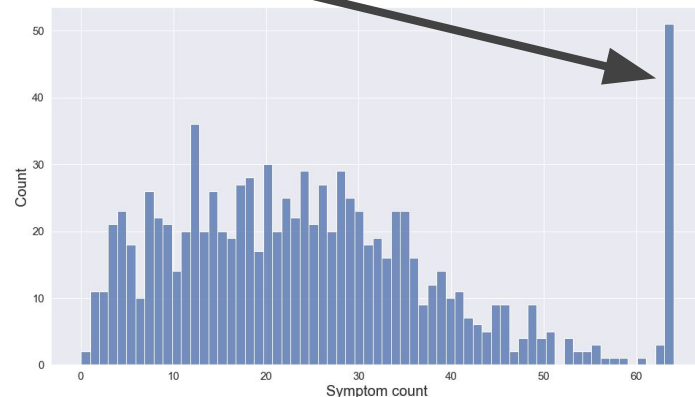
Please indicate which symptoms are Improving, staying the same, getting worse, or not applicable *

	improving	getting worse	staying the same	Not Applicable
Fatigue	○	○	◉	○
Brain Fog	○	○	○	○
Burning Sensation on Skin	○	○	○	○
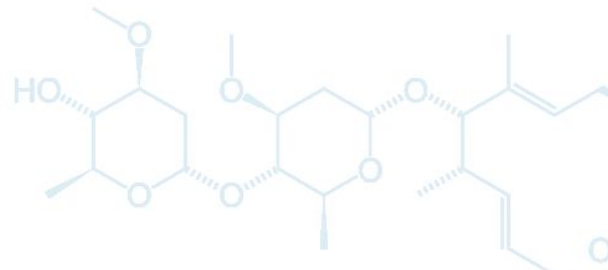
Limitation #2 - Freeform text responses were not analyzed manually

Please list all pre-existing issues below *

Regular expressions in Python were used to look for particular words (e.g. "autoimmune") in the free-form response. This method takes less time than going through thousands of entries. However, it is less accurate than manual interpretation.

```python
AUTOIMMUNE_LIST = HASHI_LIST + CELIAC_LIST + RHEUMATOID_LIST + LUPUS_LIST + MS_LIST + [r"\bautoimmune\b", r"\bSjogren\b", r"\bGBS\b",
r"\bGuillain\b", r"\bGuillan\b", r"\bAnkylosing\b", r"\bspondylitis\b",
r"\baddison", r"\balopecia\b", r"\bcrohn", r"\bbasedow", r"\bgraves\b", r"\bgrave's\b", r"\bInflammatory bowel\b", r"\bibd\b", r"\bMyasthenia\b", r"\bgravis\b",
r"\bPernicious anemia\b", r"\bPernicous anemia\b", r"\bPolymyalgia rheumatica\b", r"\bPsoriasis\b", r"\bType 1 diabetes\b", r"\bT1D\b", r"\bType I\b",
r"\bulcerative colitis\b",  #Colitis is common response, we'll assume it isn't autoimmune
r"\bUveitis\b", r"\biridocycltis\b", r"\bCIDP\b", r"Chronic inflammatory demyel", r"\bVITT\b", r"\bADEM\b", r"Acute disseminated enceph",
r"Aplastic anemia", r"Transverse myelitis"
```

Limitation #3 - Some vaccine injured have difficulty filling out surveys

Some vaccine injured have cognitive difficulties or are unable to tolerate computer/smartphone screens. Those people may be underrepresented in our survey.
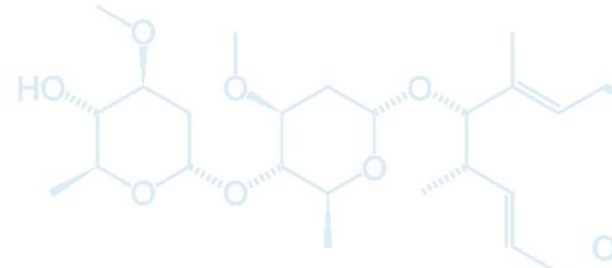
Part 2: Symptoms are diverse and many

The most common symptoms

While some of the vaccine injured have well-known symptoms such as myocarditis and allergic reactions to the vaccine, most do not have those symptoms.

The most common symptoms include 'brain fog', fatigue, and exercise intolerance. Those with brain fog have difficulty remembering to do something, multi-tasking, or concentrating on a task. Those with fatigue can have problems with walking more than a few minutes or having long conversations.

The next slide lists all of the symptoms asked about in this survey.

The most crippling symptoms include pain, brain fog, fatigue, and tinnitus.
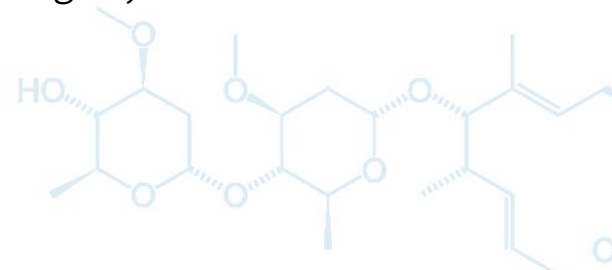
Symptom prevalence list

Top 10 most common	
[Fatigue]	82.0%
[Exercise Intolerance]	76.3%
[Brain Fog]	71.5%
[Heart Palpitations]	64.8%
[Muscle Weakness]	63.2%
[Tingling (numbness) in Extremities]	63.0%
[Dizziness]	60.0%
[Muscle Aches]	59.4%
[Sleep Disturbances]	58.4%
[Joint Pain (Arthritic)]	57.6%

[Fatigue] - 82.0%
[Exercise Intolerance] - 76.3%
[Brain Fog] - 71.5%
[Heart Palpitations] - 64.8%
[Muscle Weakness] - 63.2%
[Tingling (numbness) in Extremities] - 63.0%
[Dizziness] - 60.0%
[Muscle Aches] - 59.4%
[Sleep Disturbances] - 58.4%
[Joint Pain (Arthritic)] - 57.6%
[Anxiety / Adrenaline Surges] - 56.9%
[High Heart Rate] - 55.5%
[Insomnia] - 55.5%
[Shortness of Breath] - 55.4%
[Nerve Pain] - 52.0%
[New Persistent Headaches] - 50.5%
[Feeling off balanced, or motion at rest] - 48.7%
[Muscle Twitching] - 48.5%
[Heaviness in Legs] - 47.6%
[Memory Loss] - 45.6%
[Tinnitus] - 45.2%
[Severe Anxiety] - 44.2%
[Visual Disturbances] - 41.6%
[Abdominal/Stomach Pain] - 40.0%
[Sound Sensitivity] - 39.0%
[Nausea] - 37.9%
[Frequent Urination] - 37.0%
[Chills] - 36.3%
[Muscle Loss] - 35.9%
[Burning Sensation on Skin] - 35.6%
[Light Sensitivity] - 35.0%
[Heartburn, Indigestion] - 34.9%

[Internal Vibrations] - 34.9%
[Increased Thirst] - 34.3%
[Excessive Sleep] - 33.9%
[Heat intolerance] - 33.6%
[Dry Eyes] - 32.8%
[Diarrhea] - 31.8%
[High Blood Pressure] - 31.6%
[Dry Mouth] - 30.0%
[Tremors] - 29.7%
[Swollen Lymph Nodes] - 29.3%
[Skin redness, hives, petechiae, or rashes] - 29.3%
[Hair Loss] - 26.4%
[Excessive Gas] - 24.0%
[Constipation] - 23.8%
[Sore Throat] - 22.0%
[Swelling of Extremities] - 21.3%
[Irregular Menstrual Cycle] - 20.2%
[Low Blood Pressure] - 20.0%
[Persistent Cough] - 19.5%
[Bulging Veins] - 19.0%
[New Food Allergies] - 16.1%
[Disturbances in Glucose Levels] - 13.4%
[Myocarditis] - 13.3%
[White, or blue finger tips (digital ischemia)] - 10.4%
[Paralysis] - 8.1%
[Bloody, or black tar-like stool] - 7.3%
[Loss of Bowel Control] - 7.1%
[Anaphylaxis] - 6.4%
[Yellowing of skin, (or yellowing in whites of eyes)] - 5.5%
[Temporary Blindness] - 4.2%
[Glaucoma] - 3.2%
[Seizures] - 3.1%

*This survey's methodology may overreport some symptoms.

Each vaccine injured person is unique

The vaccine injured seem to draw from a common pool of symptoms. The combination of symptoms tends to be unique from patient to patient.

It may be the case that some patients draw more heavily from particular clusters of symptoms. However, more research is needed to verify if there are distinct clusters of symptoms.
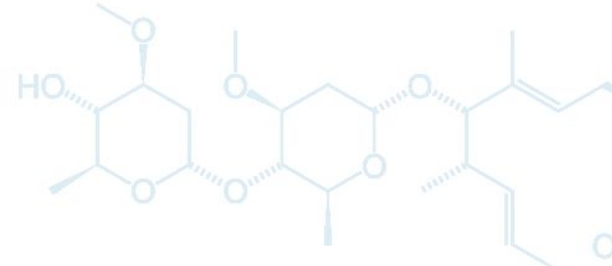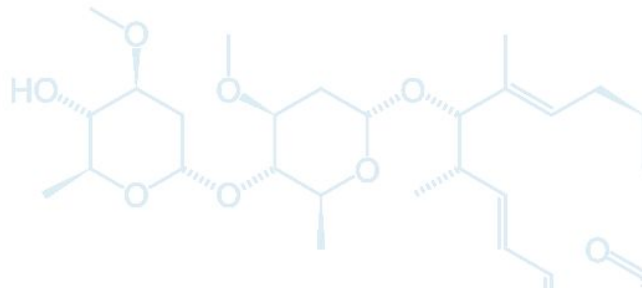
Part 3: Severity

Severity is a spectrum from mild to bedbound

- **54.9%** (501/913) reported being unable to exercise.
- **30.7%** (280/913) reported being unable to work.
- **9.6%** (88/913) reported being bedbound.

Part 4: Symptom count correlates with severity

The chart below shows the correlation between symptom count and severity of vaccine injury. The total number of symptoms is a fairly objective measurement that strongly correlates with severity.

*Note: the data on the right side of the chart is distorted by participants' diversity of interpretations.

Severity scale

6 = "I am unable to work and bedridden most days"
5 = "I am unable to work but still doing chores"
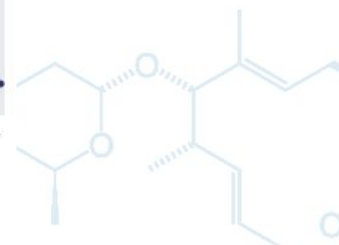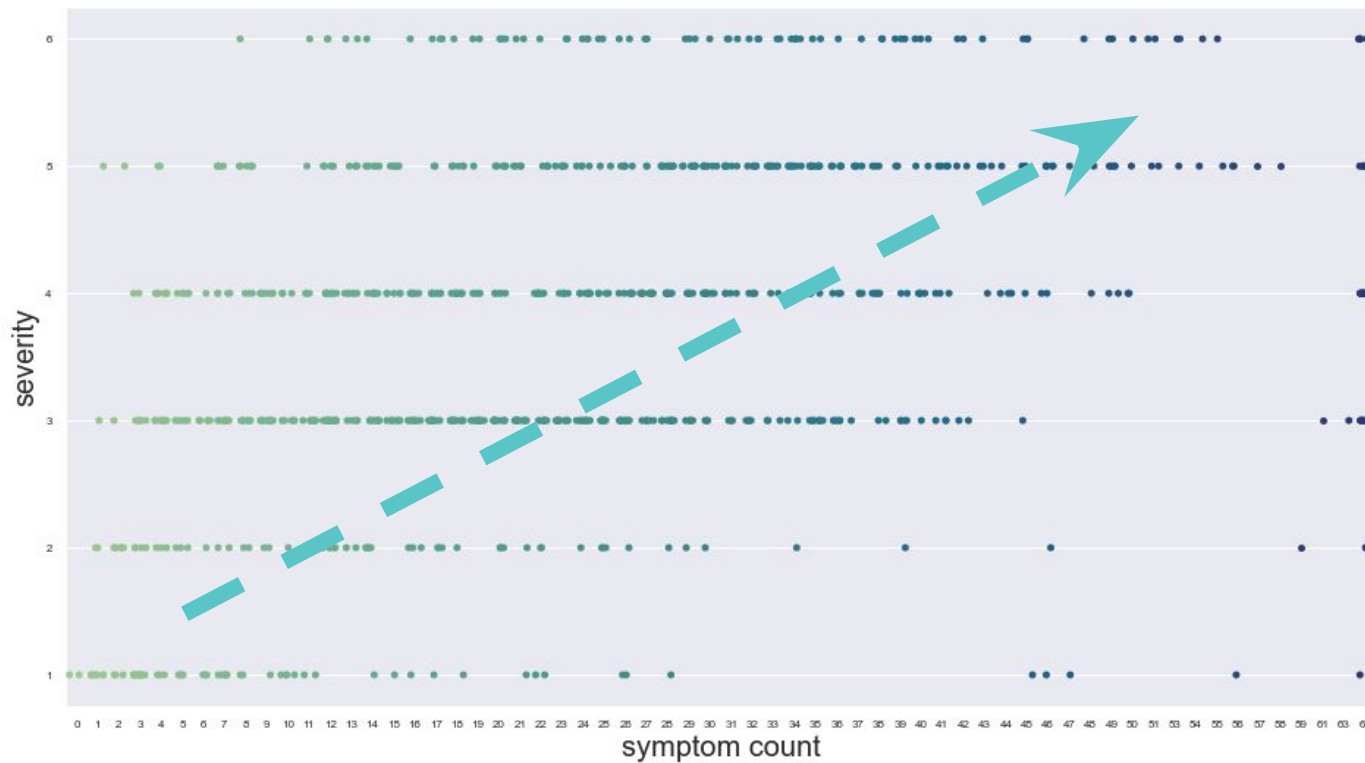4 = "I work or do chores but can't exercise"
3 = "I work or do chores and do light exercise"
2 = "I work and I am exercising normally"
1 = "I can live life like i did before"

*severity data missing for 50 participants

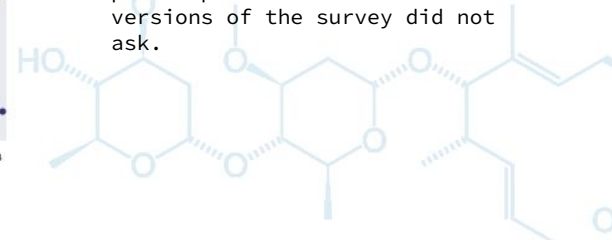The number of symptoms trends with severity.

Most surveyees with 30+ symptoms (out of the 64 surveyed) are severity 3 or higher. They have limited physical activity and can only handle light exercise.
Most surveyees with >50 symptoms are unable to work (severity 5 or 6), if outlier data points are ignored.
While vaccine injury is poorly understood, symptom count may provide evidence of bodily dysfunction.
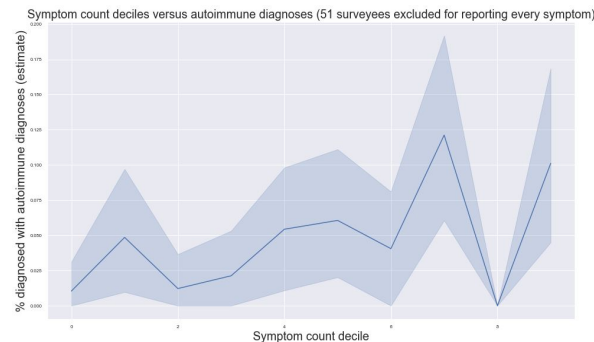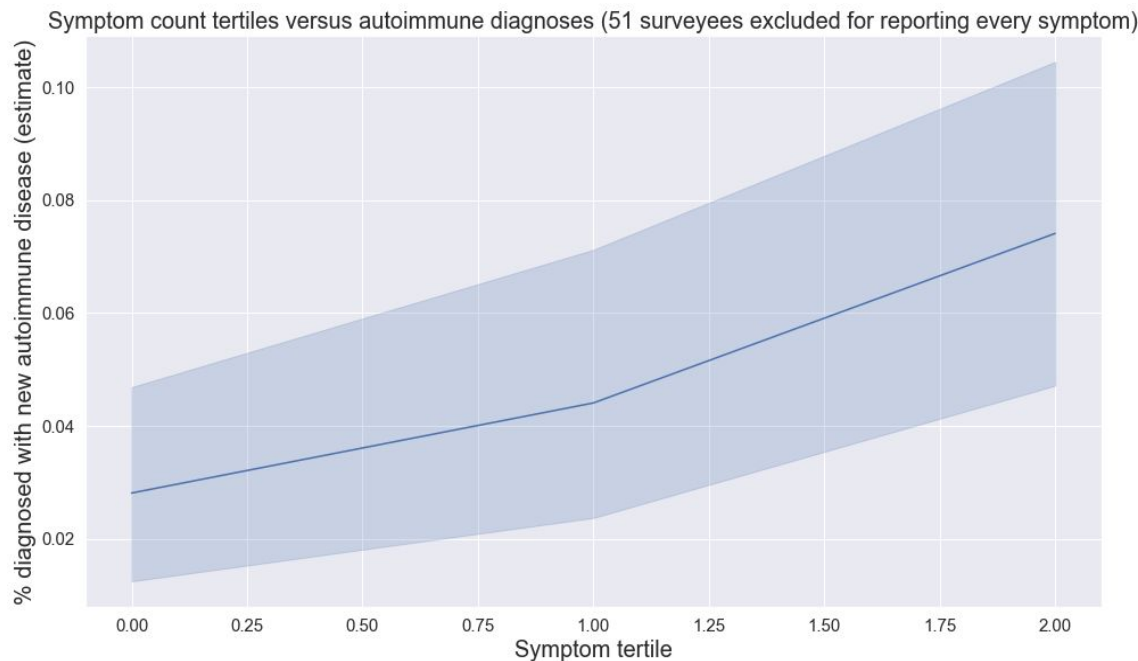

Severity scale

6 = "I am unable to work and bedridden most days"
5 = "I am unable to work but still doing chores"
4 = "I work or do chores but can't exercise"
3 = "I work or do chores and do light exercise"
2 = "I work and I am exercising normally"
1 = "I can live life like i did before"

*Severity data missing for 50 participants because the earliest versions of the survey did not ask.

Symptom count has a correlation with formal diagnoses of autoimmune conditions

Symptom count tertiles versus autoimmune diagnoses (51 surveyees excluded for reporting every symptom)

Symptom count deciles versus autoimmune diagnoses (51 surveyees excluded for reporting every symptom)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Symptom count has a correlation with formal diagnosis of dysautonomia
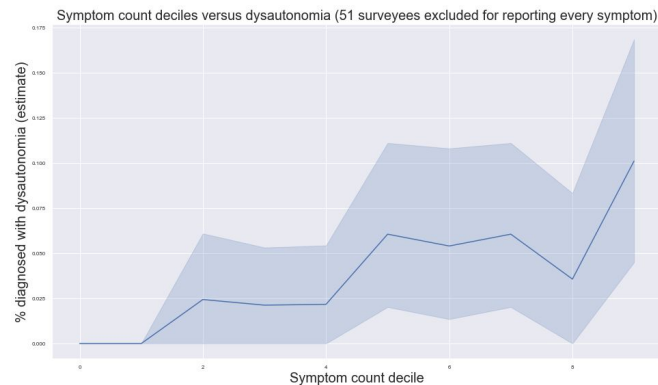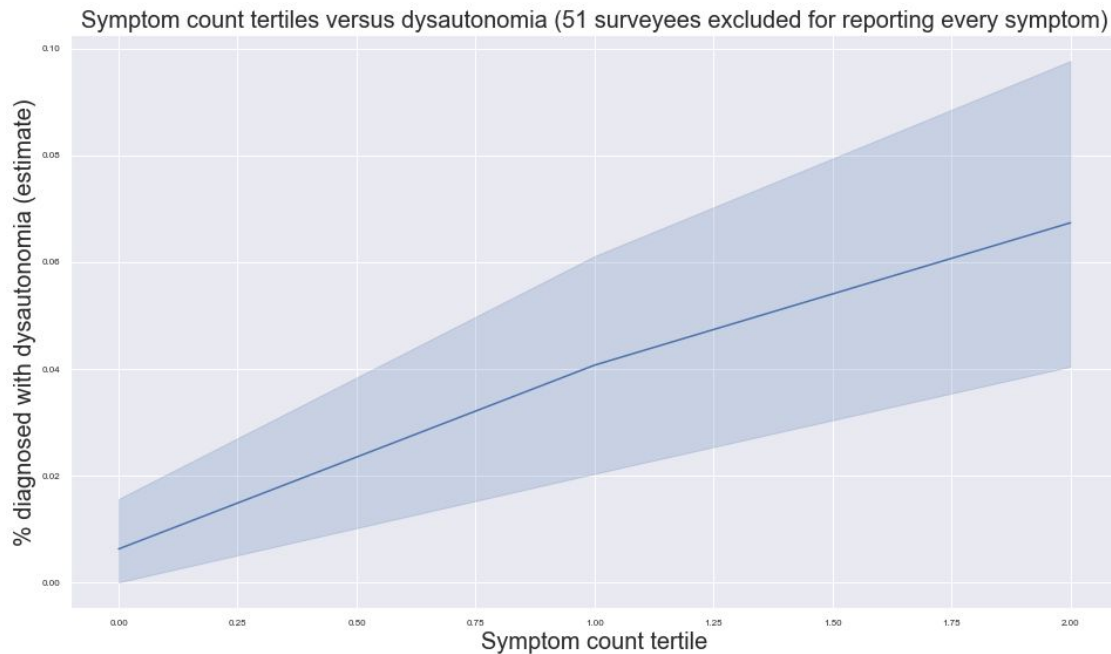
Symptom count tertiles versus dysautonomia (51 surveyees excluded for reporting every symptom)

Symptom count deciles versus dysautonomia (51 surveyees excluded for reporting every symptom)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Part 5: Symptom evolution over time

Do you feel you are getting better?

The surveyees with the lowest severity mostly feel like they are getting better. The severest surveyees are the opposite and are more likely to report getting worse.
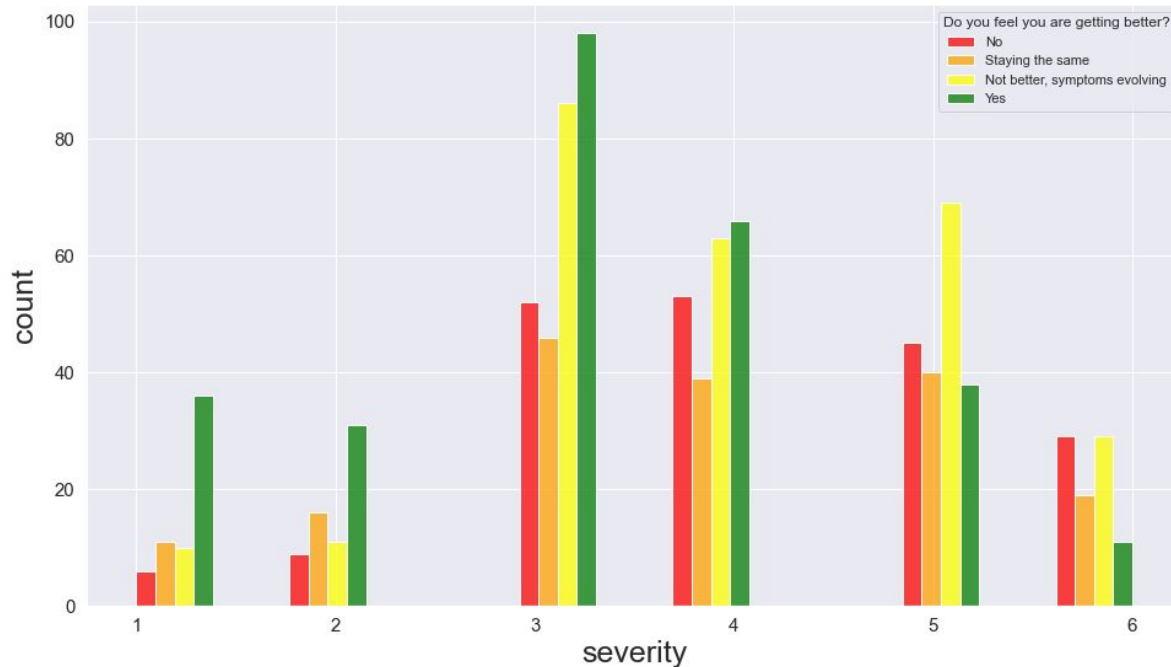
Severity scale

6 = "I am unable to work and bedridden most days"
5 = "I am unable to work but still doing chores"
4 = "I work or do chores but can't exercise"
3 = "I work or do chores and do light exercise"
2 = "I work and I am exercising normally"
1 = "I can live life like i did before"

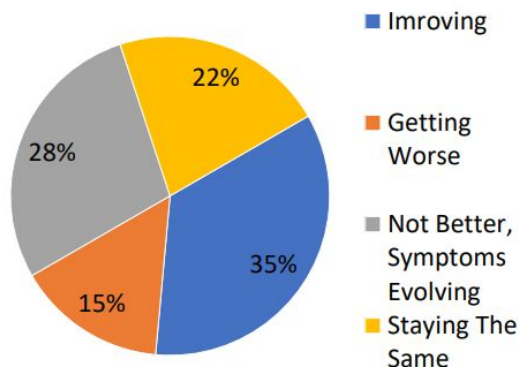*Severity data missing for 50 participants

Surveyees are more pessimistic than the first survey
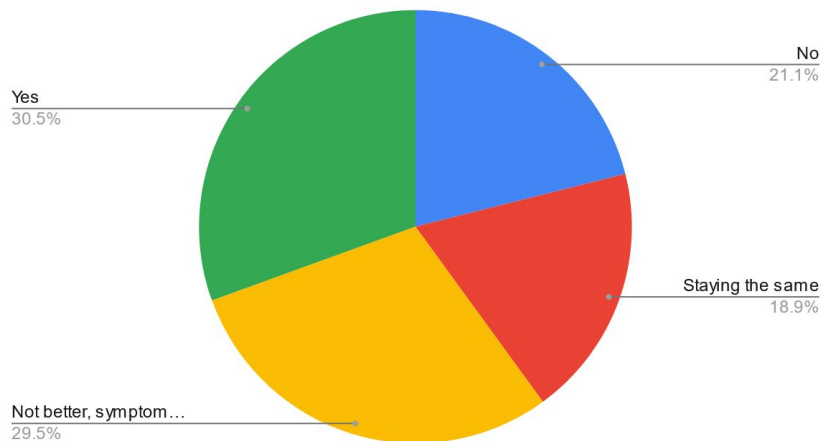
Improving fell from 35% to 30.5%
Getting worse rose from 15% to 21.1%
This might reflect healthy people returning to 'normal' life with chronic patients continuing to participate in surveys.

Are you improving?
Staying the same?
Getting worse?

- Imroving
- Getting Worse
- Not Better, Symptoms Evolving
- Staying The Same

22%
28%
35%
15%

Do you feel you are getting better?

No
21.1%

Yes
30.5%

Staying the same
18.9%

Not better, symptom…
29.5%
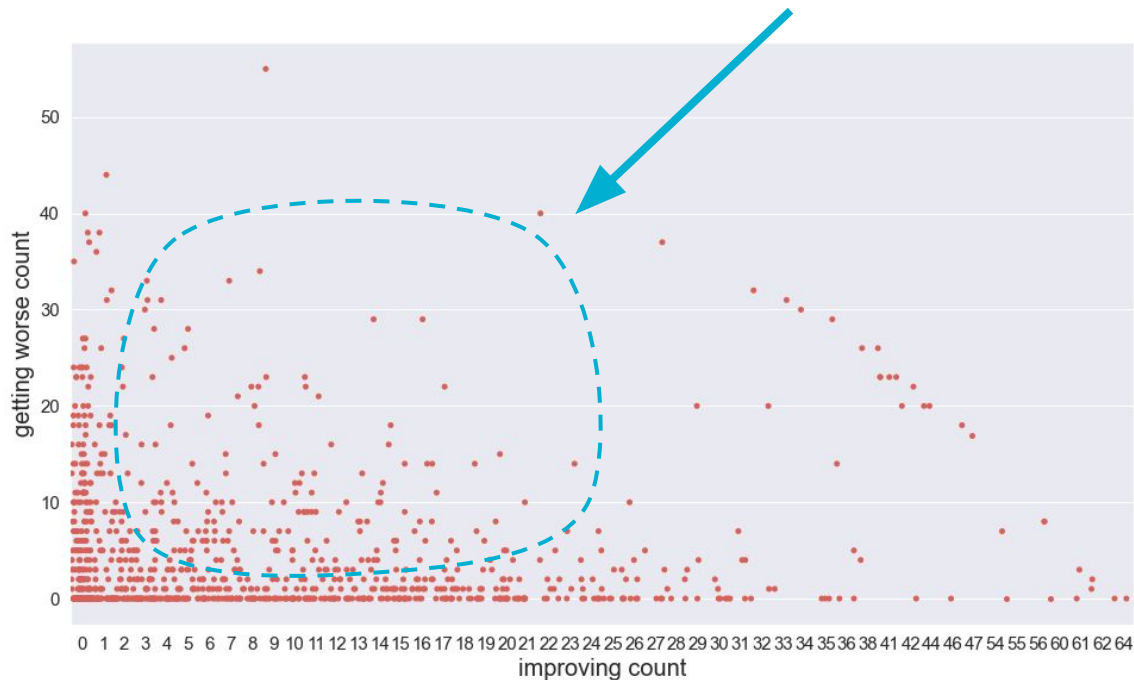
# The rotating cast of villains

Some patients find that they develop new symptoms over time as old symptoms go away. This can be seen in the patients who report symptoms that are improving **AND** symptoms that are getting worse, as seen in the middle portion of the chart below.
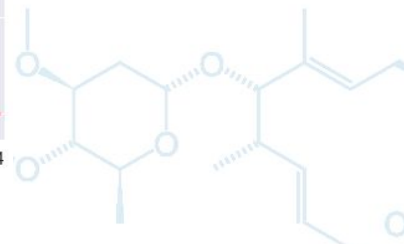
The rotating cast of villains (continued)

29.5% of surveyees reported that they are "Not better, symptoms evolving".

Do you feel you are getting better?

No
21.1%

Yes
30.5%

Staying the same
18.9%

Not better, symptom…
29.5%
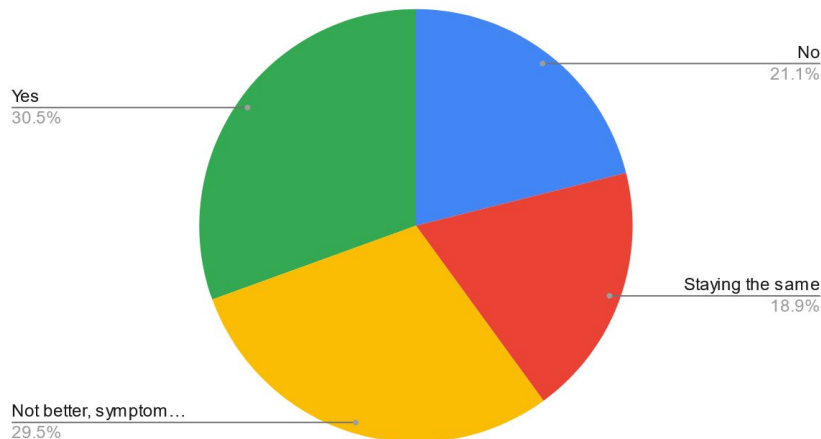
This suggests that cumulative symptom count can go up over time even if severity does not change. More research is needed to understand symptom count measurements to avoid distortions from this effect.

Part 6: Pre-existing conditions, autoimmunity, and formal diagnoses

Pre-existing conditions

Pre-existing autoimmunity was fairly common among surveyees (**11.2%** or 108/963). Hashimoto's thyroiditis and hypothyroidism were reported by **5.1%** (49/963).
Autoimmunity may be a risk factor for COVID vaccine injury.

Percentage of patients with pre-existing conditions, estimated via regular expressions (n=963)
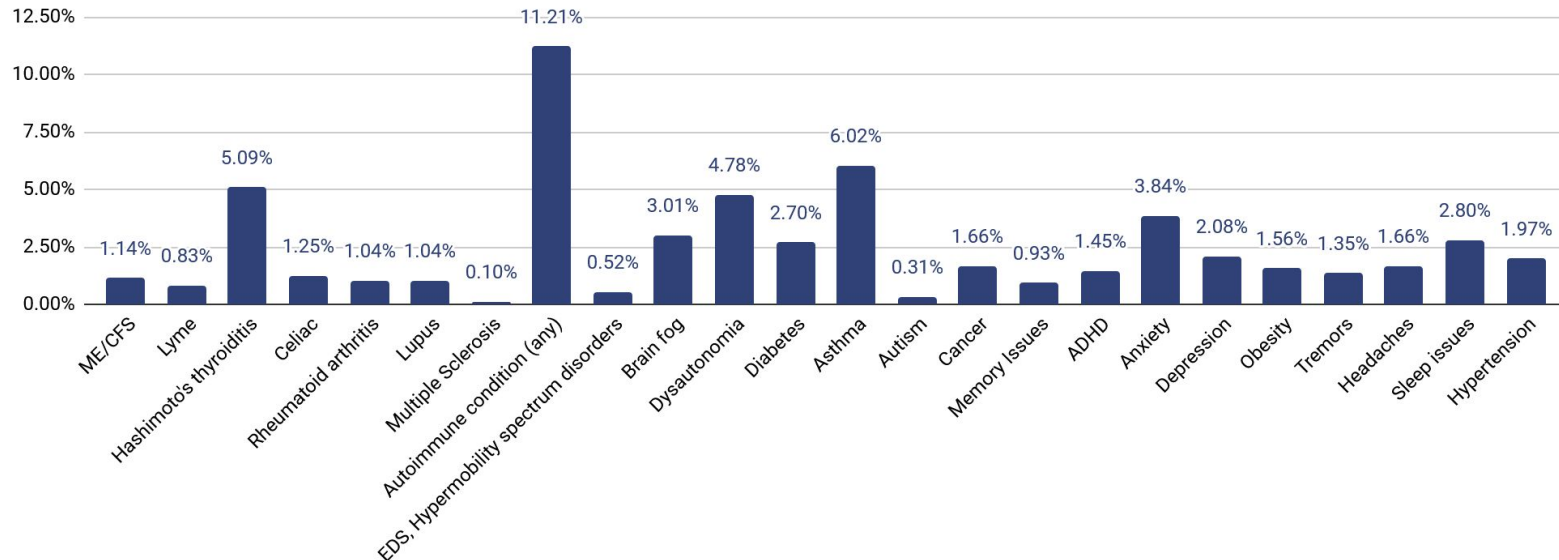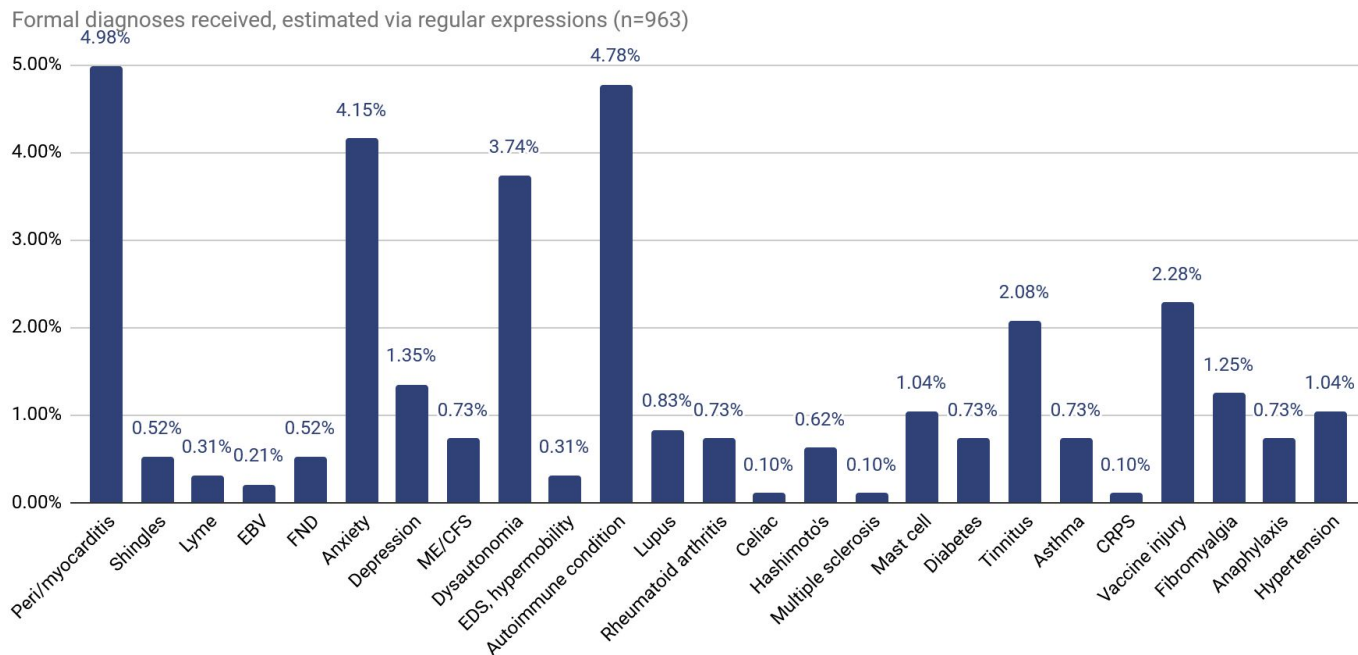

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Formal diagnoses received

The rate of newly-diagnosed autoimmunity was very high (~4.8%).
Many surveyees reported being formally diagnosed with anxiety and depression, which seems to be one of the most common ways in which doctors gaslight their patients.
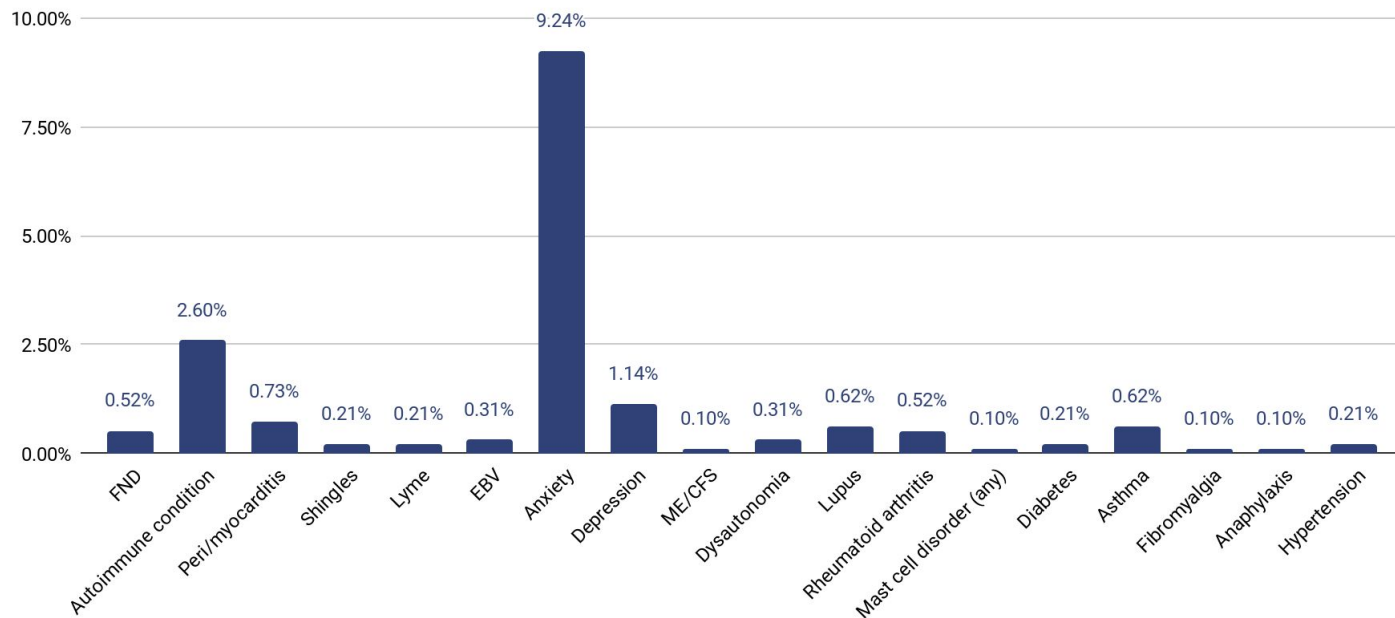
Formal diagnoses received, estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Misdiagnoses, *as determined by a medical professional*

Anxiety was the most common misdiagnosis reported, followed by autoimmune conditions.

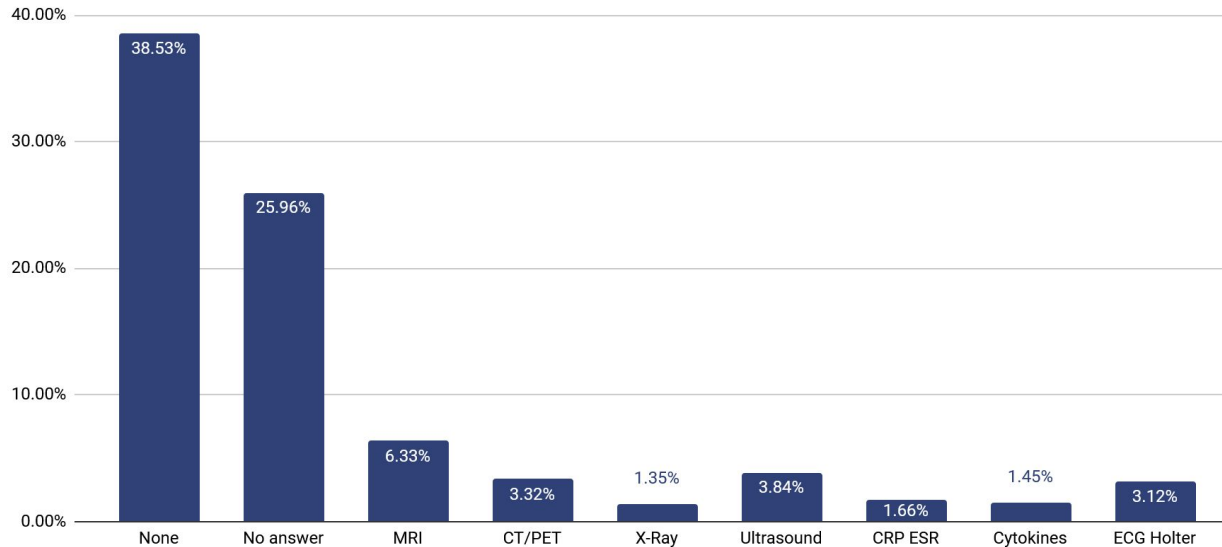Misdiagnoses as ruled by another medical professional, estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Part 7: Other findings

Abnormal lab results

Many surveyees reported that none of their tests found anything unusual. This is a major barrier to medical care as some doctors try to get rid of patients that they don't know how to treat, e.g. by blaming the patients and their 'anxiety'.

Labs/tests that came back abnormal, estimated via regular expressions (n=963)

*No answer = surveyee did not answer this survey question
**These results are likely biased towards medical tests that are frequently used. This data cannot reliably find tests that are useful for finding abnormalities in the vaccine injured.
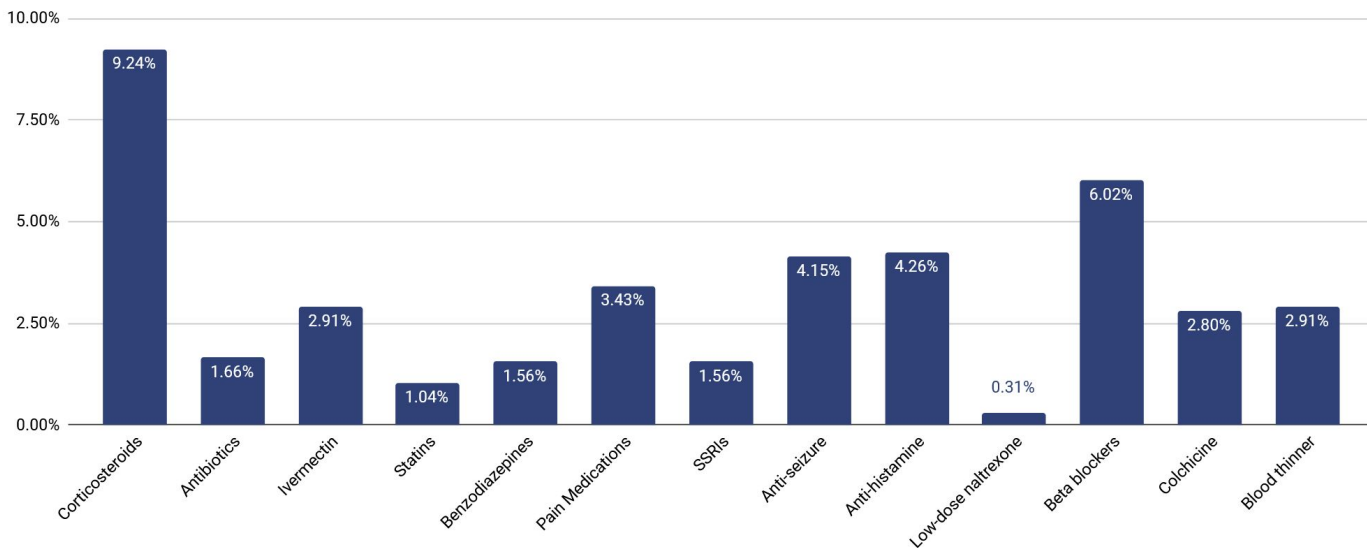***Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Medications that helped (doctor-prescribed)

The survey asked participants about which drugs helped, which biases the data towards drugs that are prescribed often.
45% of survey participants (438/963) reported that none of their doctor-prescribed medications helped (not shown).

Medications that helped (doctor-prescribed), estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Repurposing drugs used for autoimmune conditions

Corticosteroids are commonly used to treat autoimmune conditions. Their limited success in the vaccine injured suggests that other autoimmune treatments could be useful. Autoimmunity treatments include diet (e.g. gluten-free for celiac), ?antibiotics?, DMARDs, biologics, etc.
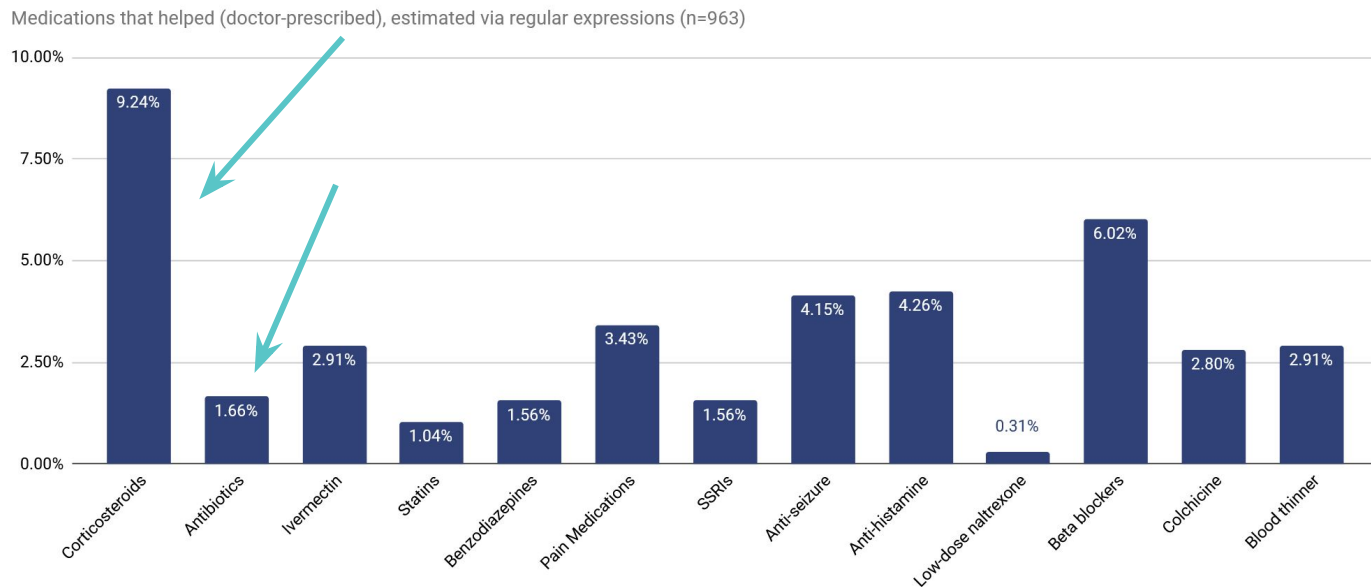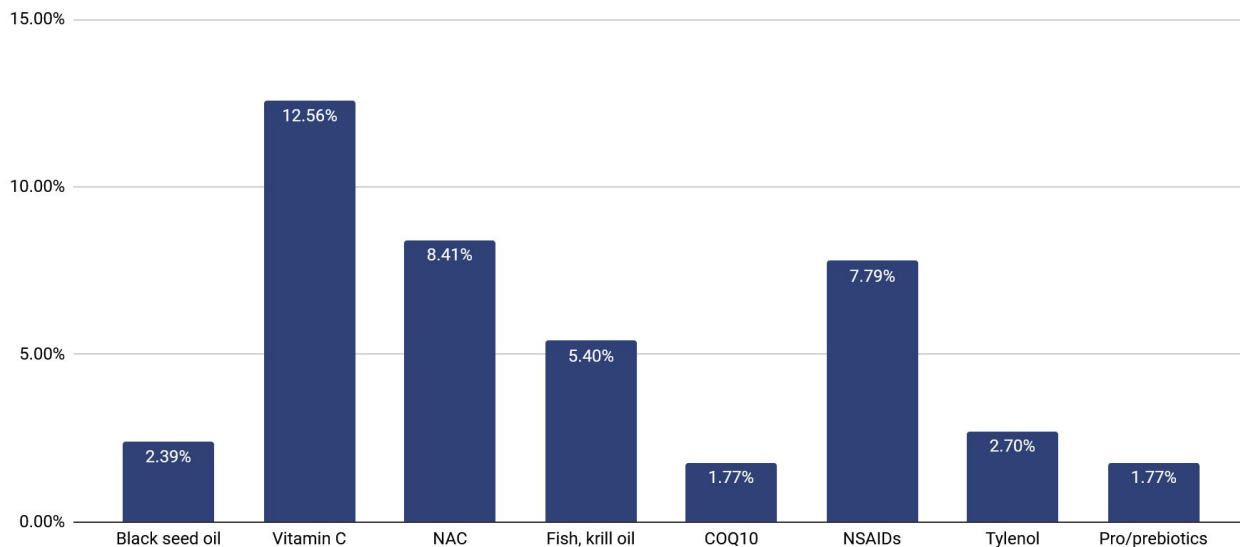
Medications that helped (doctor-prescribed), estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Over-the-counter medications that helped, part 1

The survey asked participants about which drugs helped, which biases the data towards drugs that are prescribed often.
46% of survey participants (442/963) reported that none of their over the counter medications helped (not shown).

Medications that helped (over the counter), estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

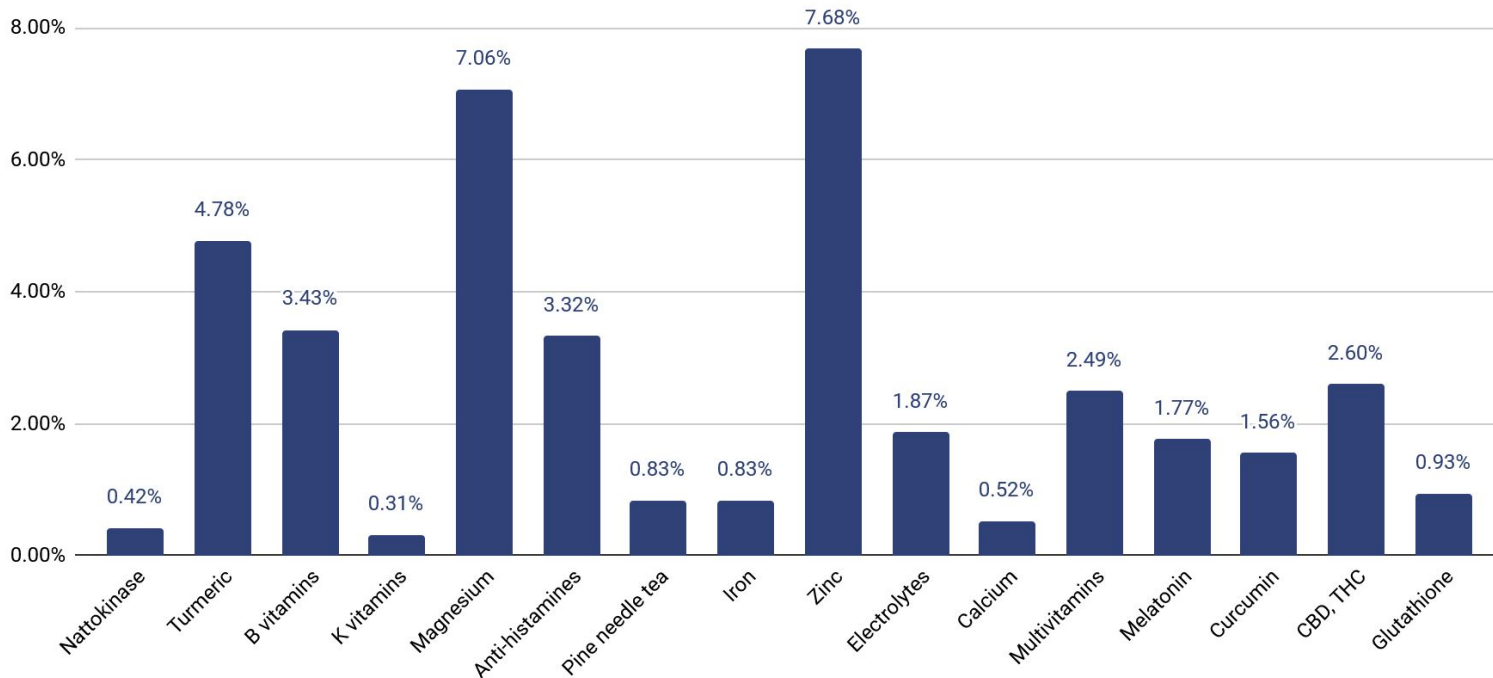# Over-the-counter medications that helped, part 2

Medications that helped (over the counter), estimated via regular expressions (n=963)

*Free-form poll responses were analyzed via Python regular expressions, which are less accurate than manual analysis by a human.

Part 8: A call to action

How do we move forward?

1. Recognize that vaccine injury is real and connected to biological symptoms, not patients having health anxiety.
2. More research should be performed on treatments that were successful in treating autoimmunity and inflammatory conditions- biologics, DMARDs, etc.
    - We will be publishing a morsel of data on corticosteroids soon.
3. We need more researchers to investigate vaccine injury and its uncanny parallels to long COVID (and ME/CFS). Helping the chronically ill- all of them- is the right thing to do, even when it is the unfashionable thing to do. Patients need science to heal them, not politics.

    - We will be publishing a long COVID + vaccine injury survey soon.

Thank you!
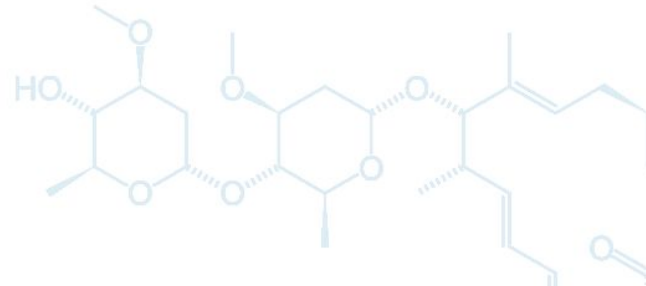
Collaborators

Survey Design
React19 volunteers

Analysis
Glenn Chan LongHaulWiki.com
Shaun Barcavage, NP
Brian Dressen, PhD
Spiro Pantazatos, PhD Columbia University

Correspondence
Please send correspondence to
glennchan /at/ gmail ● com

REACT 19
RESEARCH • EDUCATION • ACTION • THERAPEUTICS