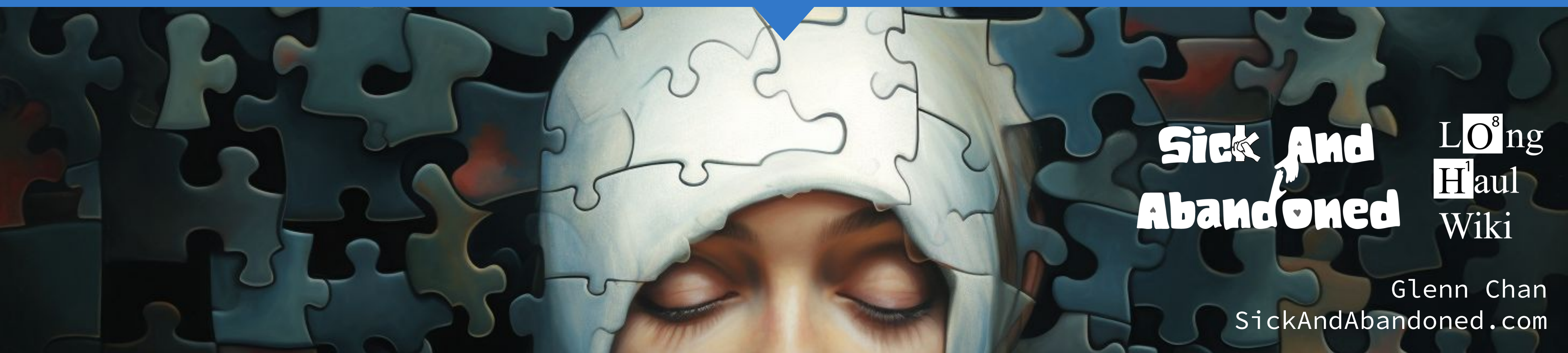


Jan 2024

Version 1

What Worked For 36 People Who Recovered

Patient Experiences Survey Data



**Sick And
Abandoned**

LOng
Haul
Wiki

Glenn Chan
SickAndAbandoned.com

Highlights of the Patient Experiences Survey

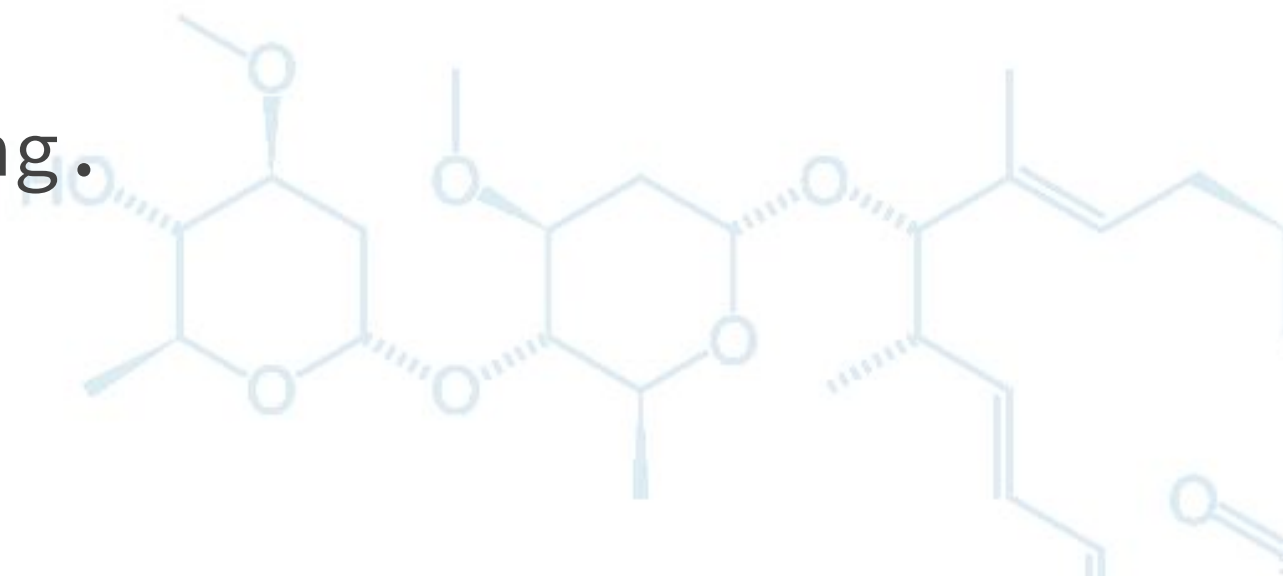


The data suggests that the following groups of treatments are promising:

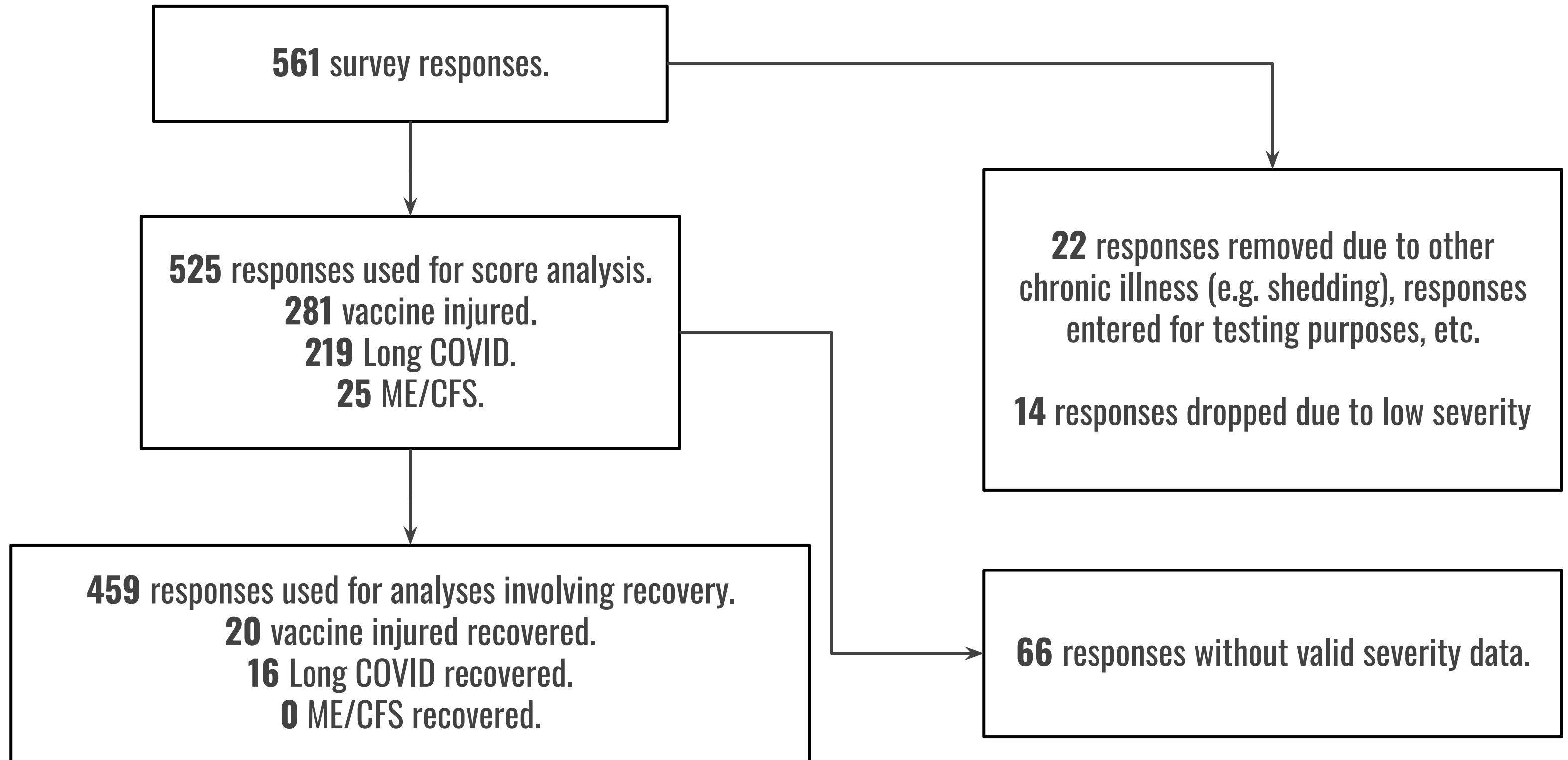
- **HBOT**
- **Fasting** (preferably extended)
- Certain supplements – **nattokinase**, **serrapeptase**, ?cat's claw?, ?NAC?
- Certain prescription drugs – **ivermectin**, **statins**, colchicine, LDN?

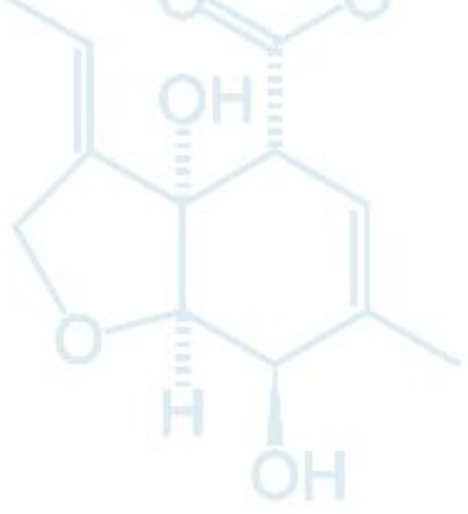
The double-edge nature of most treatments provides some support for taking a conservative, risk-averse approach to treatment:

- Discontinue treatment if symptoms are worsening.
- Start with low dosages before increasing.



525 responses analyzed across 235 treatments





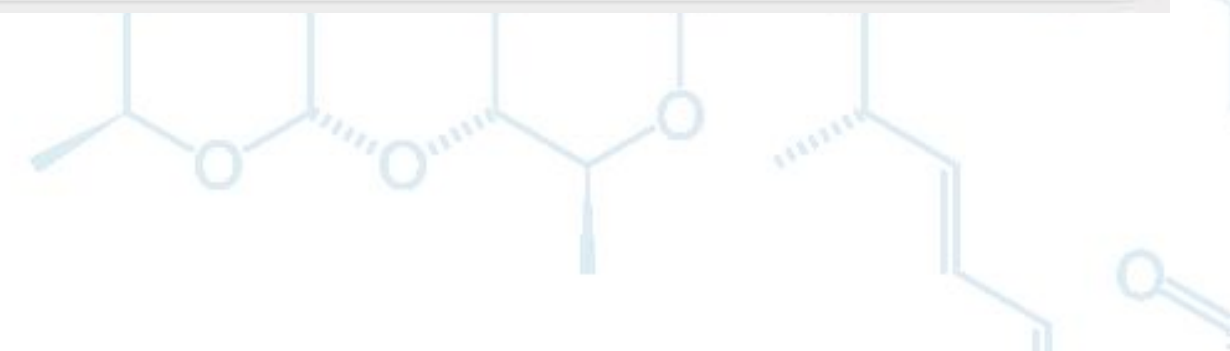
**Disclaimer: using experimental treatments to fix chronic illness is not always a good idea!
Almost all of the treatments discussed in this presentation have risk.**

Survey design



Surveyees were asked to rate the treatments they tried on a Likert scale. The addition of “Tried this, effect was unclear” takes some responses away from the other columns if the surveyee is not confident. Thus, low-confidence answers are less likely to lead to spurious conclusions.

Anti-depressants - SNRIs						
Serotonin–norepinephrine reuptake inhibitors	Significant improvement	Mild overall improvement	Not much benefit or harm	Mild overall worsening	Significant overall worsening	Tried this, effect was unclear
Duloxetine (Cymbalta)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Venlafaxine (Effexor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



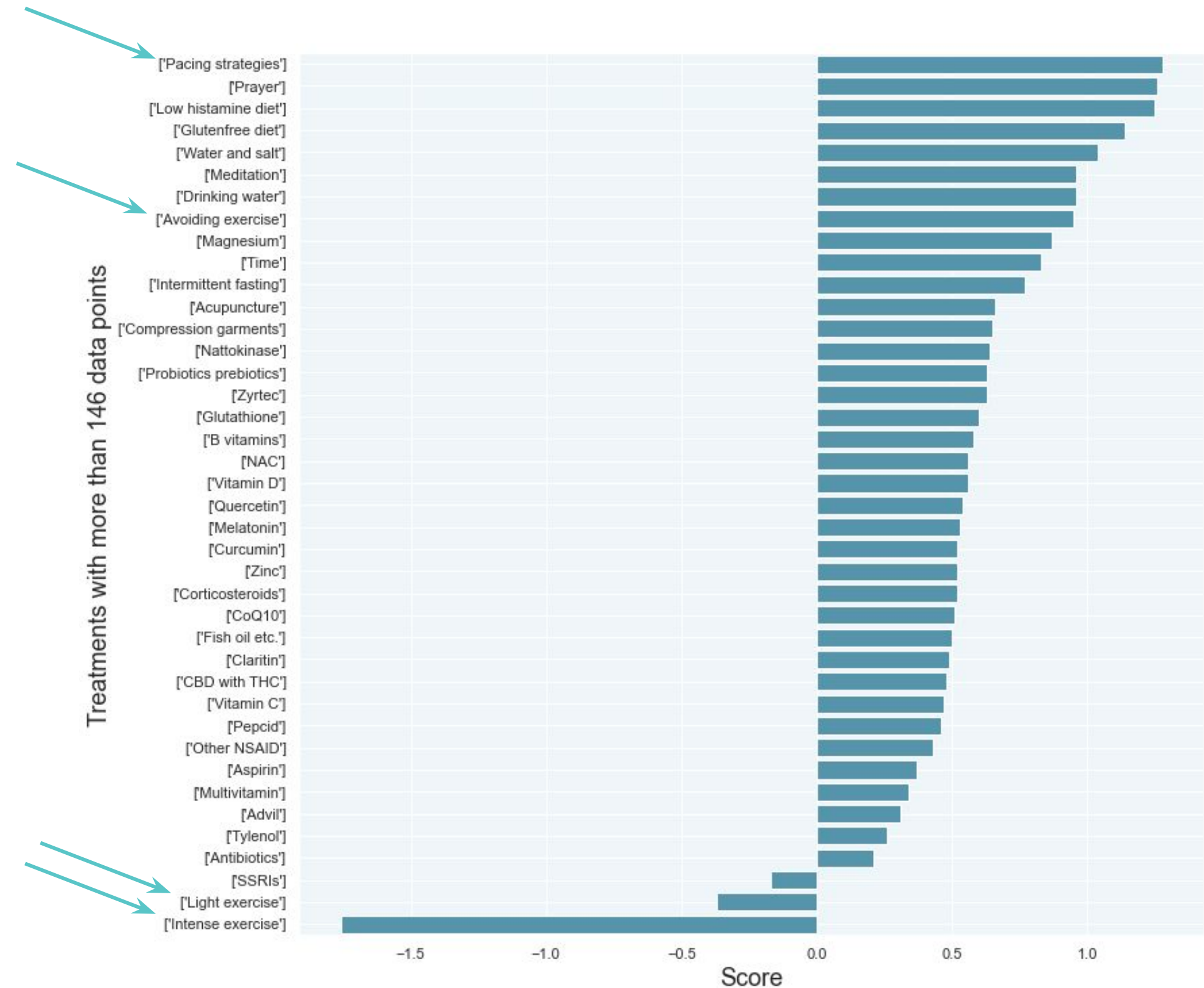
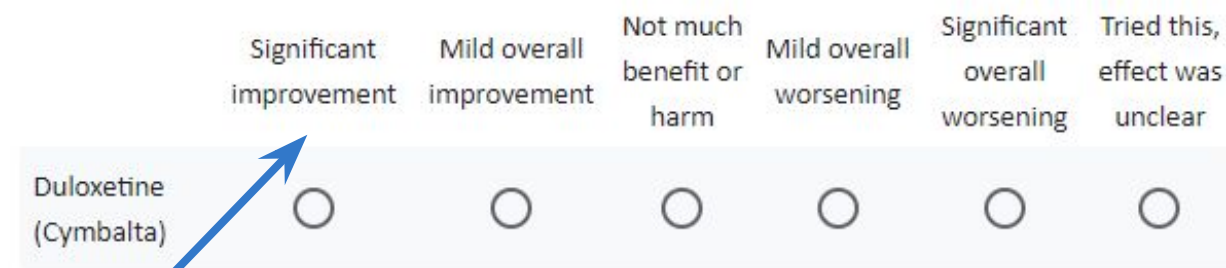
Popular treatments ranked by score



Scores of +3/-3 were given to significant improvement/worsening and +1/-1 for mild. 0 points for effect was unclear.

Exercise-related treatments (such as limiting exercise through **pacing strategies**) were outliers and took both the top and bottom spots.

This ranking system is *not the most reliable* as it often measures how surveyees answer surveys rather than medical outcomes. It does however measure patient satisfaction.

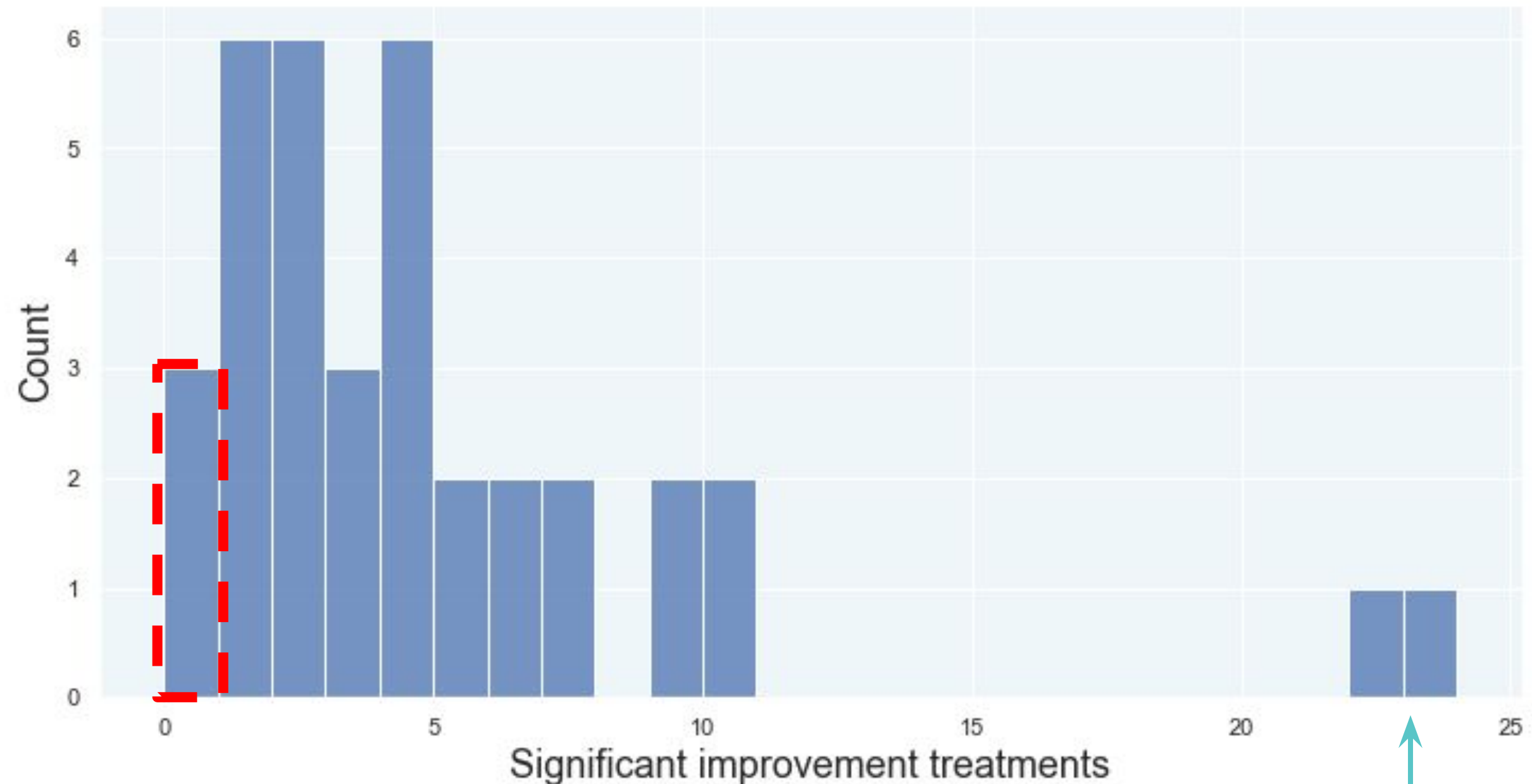


Some people did not identify *any* great treatments



3 surveyees did not report that any of the 235 treatments on the survey resulted in *significant improvement*.

The most 'significant improvement' treatments reported were **23** and **22**.



Analysis of mostly recovered patients - 20 vax injured, 16 Long COVID

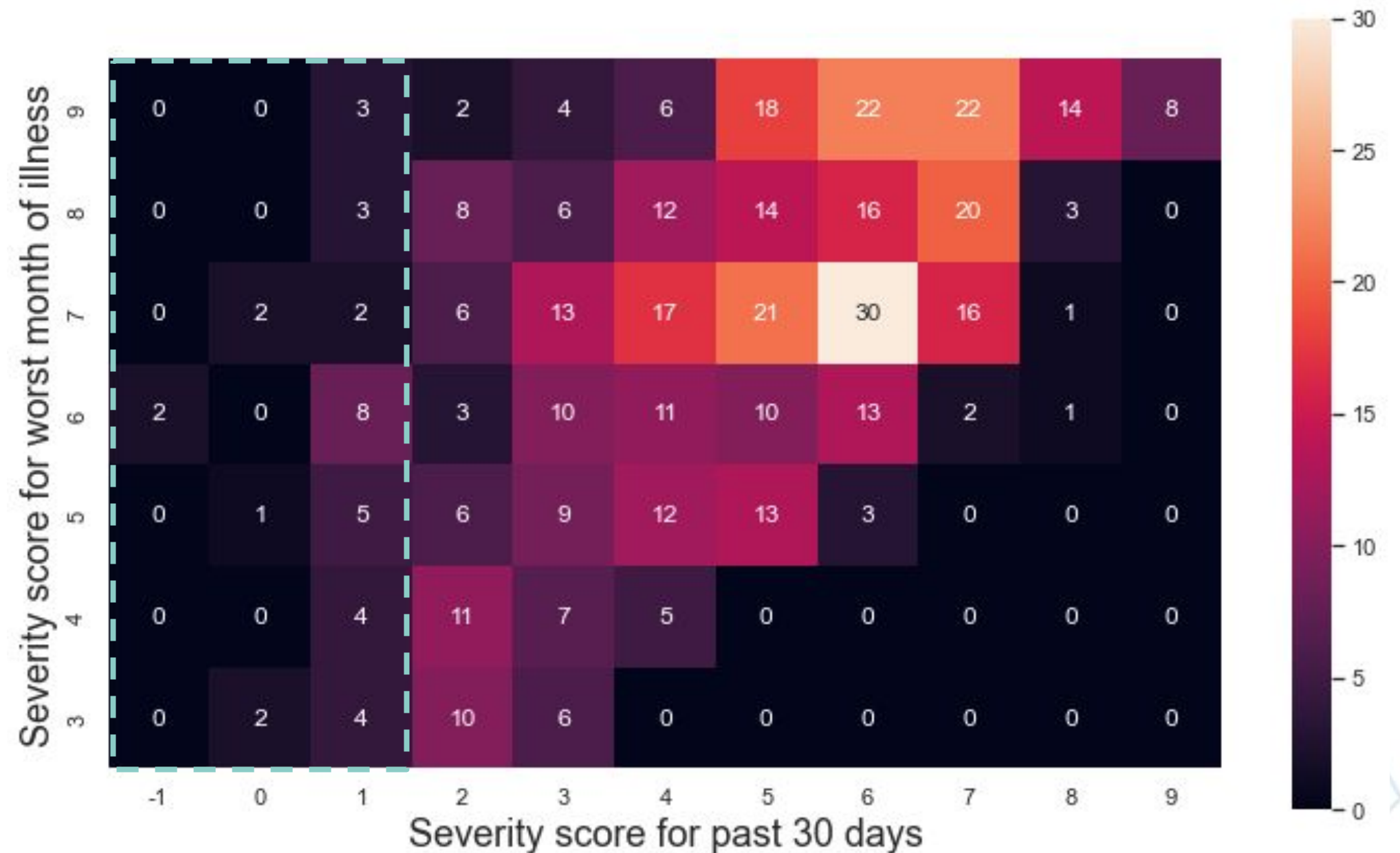


Data is from the Patient Experiences Survey ([Dec 26](#)). The mostly recovered (in the **turquoise** box) could:

- Work their last job full-time.
- Walk more than 5 minutes without causing symptoms to worsen.
- Report that their suffering was 1 or less on a scale of 0-4, where 4 is the worst suffering imaginable.

About **8% (36/459)** of the surveyees were mostly recovered.

*A lengthier description of the severity score can be found [in a previous presentation's](#) slides.





Data from the mostly recovered may be more reliable



Somebody who has seen little actual improvement from treatment may still rate treatments as leading to “significant improvement”. Their perspective on the world is different than somebody who has gotten their life back. *Both perspectives are valid* but the mostly recovered perspective should be a better indicator of actual medical outcomes.

Everything works?!



The **red** dots on the right show people who are mostly (or fully) recovered.

Those in the **dark blue** area reported that almost every treatment led to ‘significant improvement’. Data from those patients may not necessarily reflect treatment outcomes; these surveyees have a different perspective on the world.

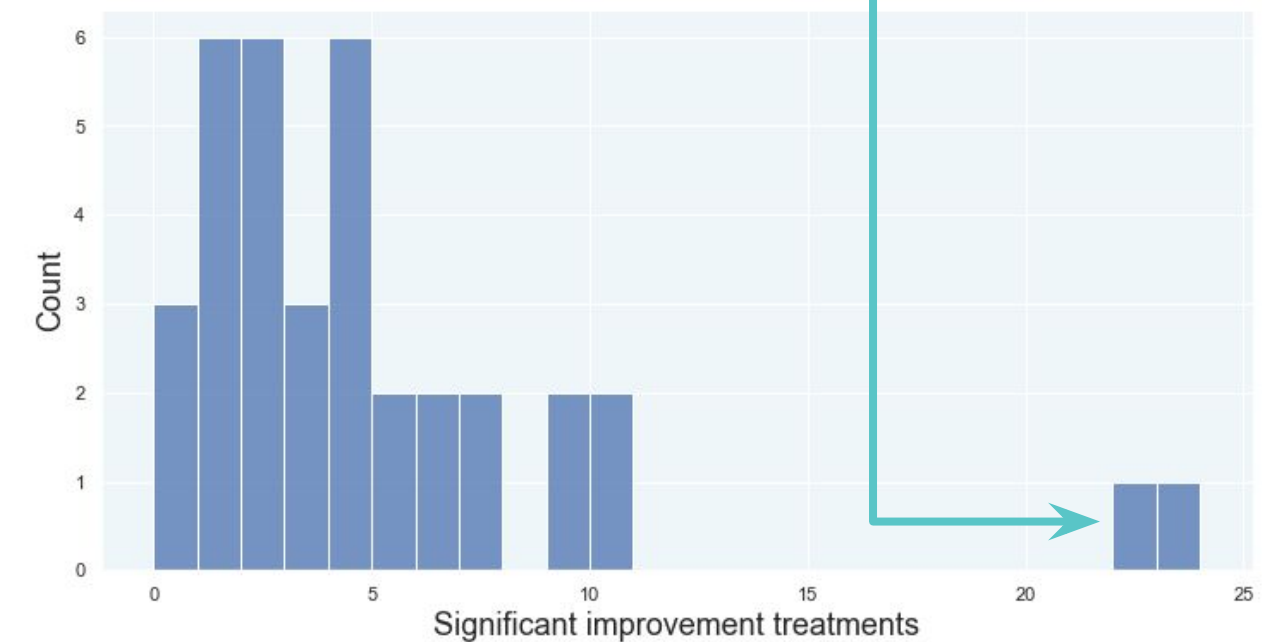


Why a free-form question was used for treatment outcomes



If we simply look at the treatments rated highly among the recovered, the results can be skewed by the pair of participants rating **23 and 22 treatments** highly. Their data is likely of lower confidence.

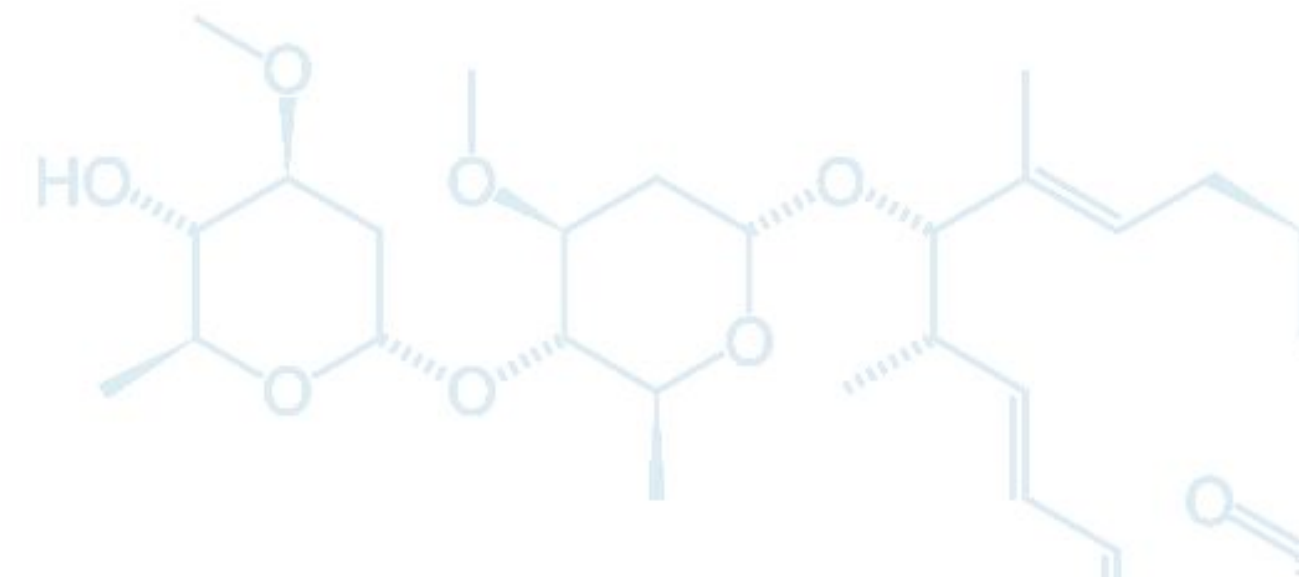
The free-form question shown below restricts the resulting data to only the top treatment(s), allowing us to know what treatments surveyees think the most highly of.



What was the one treatment (or combination of treatments) that helped you the most?

If no treatment helped, then please answer "no treatment helped".

Your answer





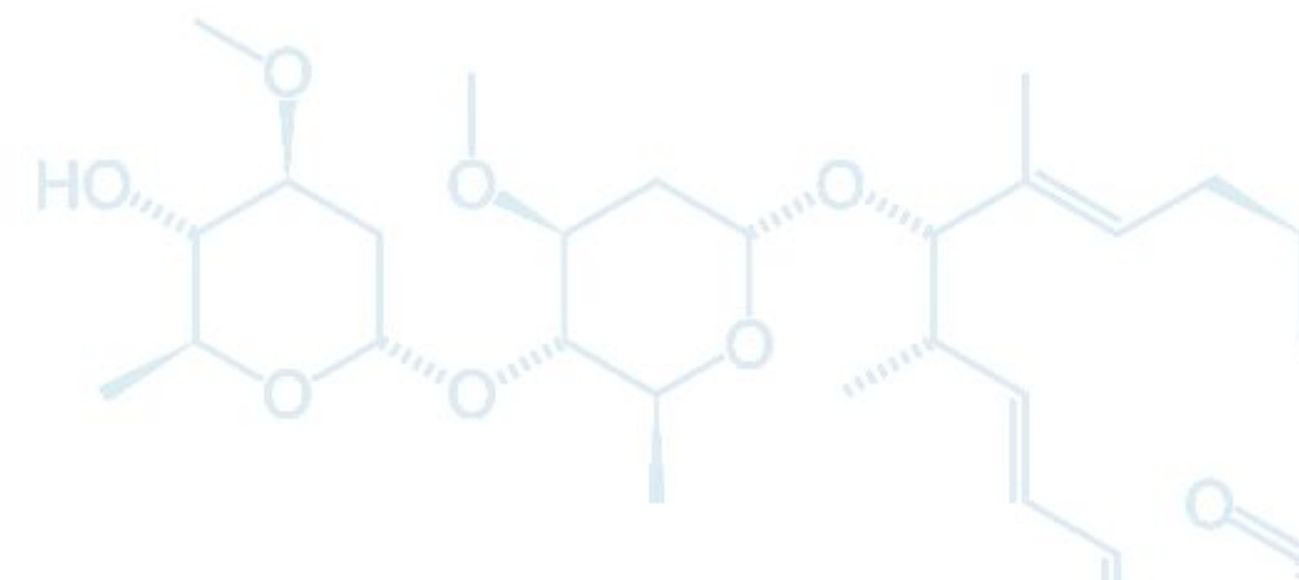
Treatments Favoured By The Recovered



The most frequently cited treatments in the free-form answers



- Fasting (different forms) - 6
- Ivermectin - 3
- NAC - 3
 - Note that about half of the people on the survey tried NAC. After adjusting for popularity, it may not be as good as it first appears (e.g. 1% success rate).
- Exercise - 2
 - Exercise was even more popular than NAC, so interpret with caution. Most people respond negatively to exercise, even if it is light.
- Nattokinase - 3
- LDN (low dose naltrexone) - 2
- HBOT (high ATA above 1.5) - 2
- Time - 4, no answer/treatment - 5



What treatments helped the most? - Long COVID

- 18 day water only fast
- Antivirals and anti-inflammatory meds
 - This person reported results for Valtrex plus diet, LDN, Zyrtec, other NSAID, an unspecified antibiotic, B vitamins
- Consistent gentle exercise and supplements.
- Exercise and time
- HBOT (above 1.5 ATA), LDN, physical therapy
- Hope Biosciences stem cells + vision rehab therapy (concussion protocol)
- Magnesium, black seed oil
- Rest
- Somatic Experiencing, somatic touch work, Electrolytes
- [Time] X 2
- Triple anti-coagulant therapy, HELP apheresis
- [No answer] X 4

What treatments helped the most? - Vaccine Injured

- ASEA redox, ivermectin.
- Aviv HBoT 3-month protocol. **Aviv likely refers to [this chain of clinics](#).*
- Chlorella **Type of algae that grows in fresh water.*
- Dry fasting 72 hrs
- Fasting **This person rated 24-48 hour fasting and Multiday juice fasting as mild improvement. Did not try multiday wet/dry fasting.*
- Fasting in combination with a well sourced (local farm) carnivore diet.
- Getting covid for the first time (year after vaccine doses)
- Guaifenesin (OTC cough medicine), nattokinase, Resveratrol
- Drug protocol of Maraviroc, Statin and Plavix
- Ivermectin
- Ivermectin, NAC, nattokinase, cardio miracle
- LDN, methylene blue and chlorine dioxide
- NAC and Bromelain together
- Nattokinase and Serrapeptase
- Nicotine, [Augmented/Quantum] NAC and fasting
- Paleo/keto diet.
- Rest, custom liquid herbal tinctures/supplements and low histamine diet.
- Time and fasting (1 meal a day or eating less)
- Vitamin b1
- No treatment (helped the most)

Raw counts of **significant improvement** treatments among the recovered

Treatment	Count
Serrapeptase	5
Ivermectin	5
LDN	5
Nattokinase	5
Corticosteroids	4
Low histamine diet	4
Avoiding exercise	4
B vitamins	4
Magnesium	4
OMAD	3
Graded exercise therapy	3
Prayer	3
Other NSAID	3
Glutenfree diet	3
Intermittent fasting	3
Pacing strategies	3
Zinc	3

Treatment	Count
Meditation	3
Intense exercise	3
Light exercise	3
Vitamin D	3
Stem cells	2
Cat's claw	2
HBOT >1.5 ATA	2
Colchicine	2
Statins	2
Other brain retraining	2
VNS	2
Aspirin	2
NAC	2
Water and salt	2
Probiotics prebiotics	2
Vitamin C	2

Exactly 1 person reported significant improvement from these treatments:

- | | |
|----------------------|-------------------------|
| Famciclovir | EMDR |
| Cardio Miracle | Nigella sativa capsules |
| HELP apheresis | Lexapro |
| Tollovid | Nigella sativa oil |
| ASEA Redox | Keto diet |
| Maraviroc | Diazepam |
| Multiday dry fasting | Augmented NAC |
| Pamelor | Chiropractic |
| Eliquis | Anti inflammatory diet |
| Clopidogrel | Lion's mane |
| TRT | Dandelion |
| Paleo diet | Gabapentin |
| Aciclovir | Resveratrol |
| St. John's Wort | Ashwagandha |
| Methylene blue | K vitamins |
| Doxepin | Benzodiazepines |
| Carnivore diet | Acupuncture |
| Wim Hof without cold | Claritin |
| AIP diet | Drinking water |
| Plaquenil | Massage |
| Multiday wet fasting | Quercetin |
| Other TCM | CoQ10 |
| Valtrex | Curcumin |
| Tetracyclines | Advil |
| Patches | |

Significant improvement data



This analysis looked at the percentage who **recovered AND reported significant improvement** from a treatment.

Treatments with count ≤ 1 were removed to reduce the size of the table on the right.

The complete Dec 26 data is available at docs.google.com/spreadsheets/d/1CqKM53QWFjZHICx95vDzYyhq0jYlFZ7oMa5DEADm514/edit?usp=sharing. Go to File → Make a Copy. **The filter feature in Google Sheets can help sift through the data.**

	# that tried this treatment	% of surveyees (with recovery data) who tried this	Count	% who mostly recovered AND reported significant improvement
Stem cells	4	0.9	2	50
Cat's claw	20	4.4	2	10
HBOT >1.5 ATA	23	5	2	8.7
Colchicine	27	5.9	2	7.4
Time	411	89.5	21	5.1
Serrapeptase	101	22	5	5
Ivermectin	109	23.7	5	4.6
Statins	46	10	2	4.3
Other brain retraining	48	10.5	2	4.2
LDN	124	27	5	4
Corticosteroids	123	26.8	4	3.3
OMAD	113	24.6	3	2.7
Nattokinase	194	42.3	5	2.6
Graded exercise therapy	114	24.8	3	2.6
Low histamine diet	186	40.5	4	2.2
Prayer	137	29.8	3	2.2
Other NSAID	146	31.8	3	2.1
VNS	98	21.4	2	2
Glutenfree diet	169	36.8	3	1.8
Intermittent fasting	188	41	3	1.6
Avoiding exercise	279	60.8	4	1.4
Pacing strategies	215	46.8	3	1.4
B vitamins	313	68.2	4	1.3
Zinc	236	51.4	3	1.3
Meditation	226	49.2	3	1.3
Intense exercise	226	49.2	3	1.3
Magnesium	323	70.4	4	1.2
Light exercise	302	65.8	3	1
Aspirin	201	43.8	2	1
Vitamin D	343	74.7	3	0.9
NAC	217	47.3	2	0.9
Water and salt	242	52.7	2	0.8
Probiotics prebiotics	237	51.6	2	0.8
Vitamin C	282	61.4	2	0.7

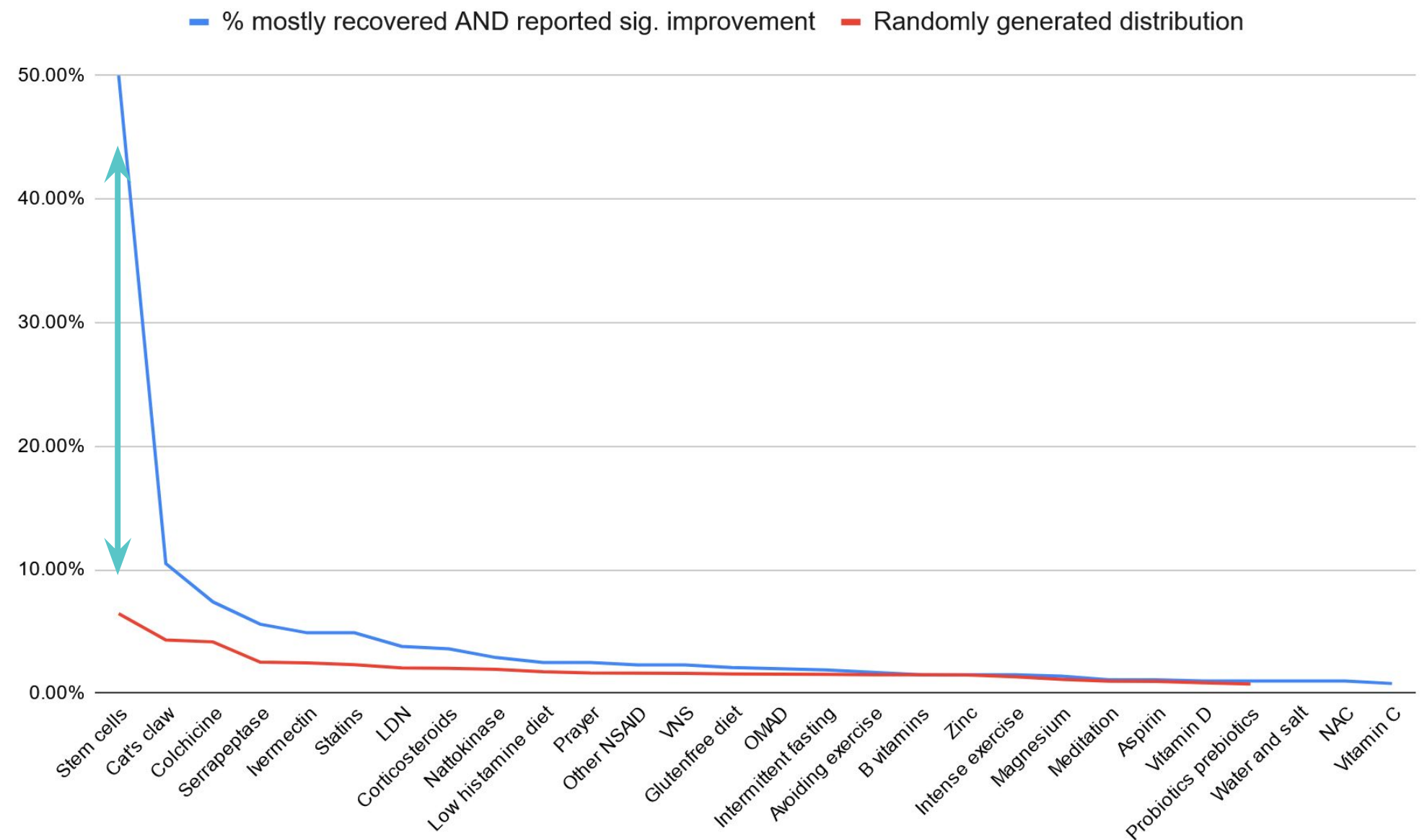
Is the data due to chance, effective treatment, or survey bias?



The **red** line on the right shows a randomly generated distribution. The **blue** line on the right shows the actual data (with its treatments labelled correctly).

A large **spread** between the blue and red line suggests that the difference is due to effective treatment and/or a bias in how people answer surveys.

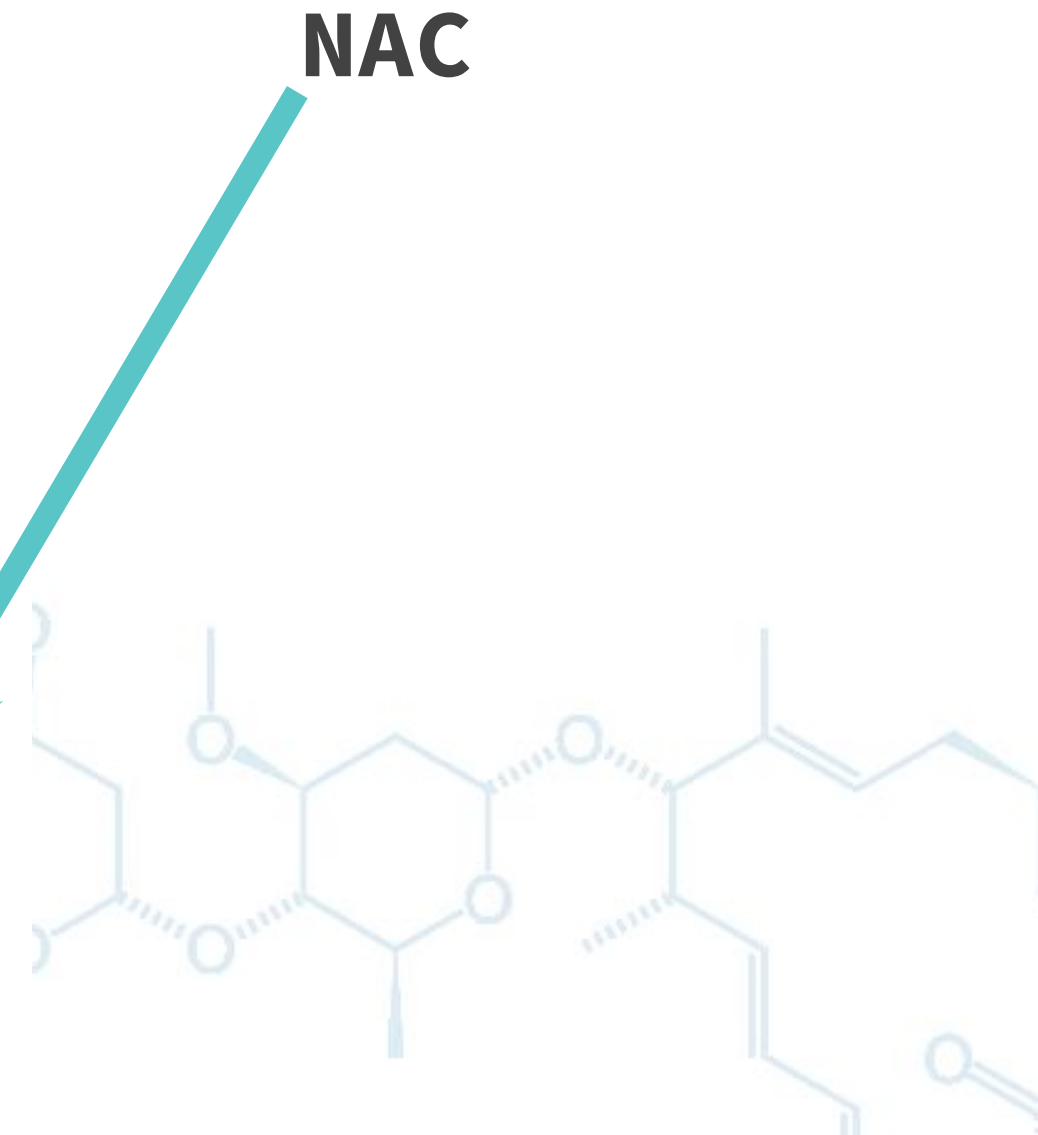
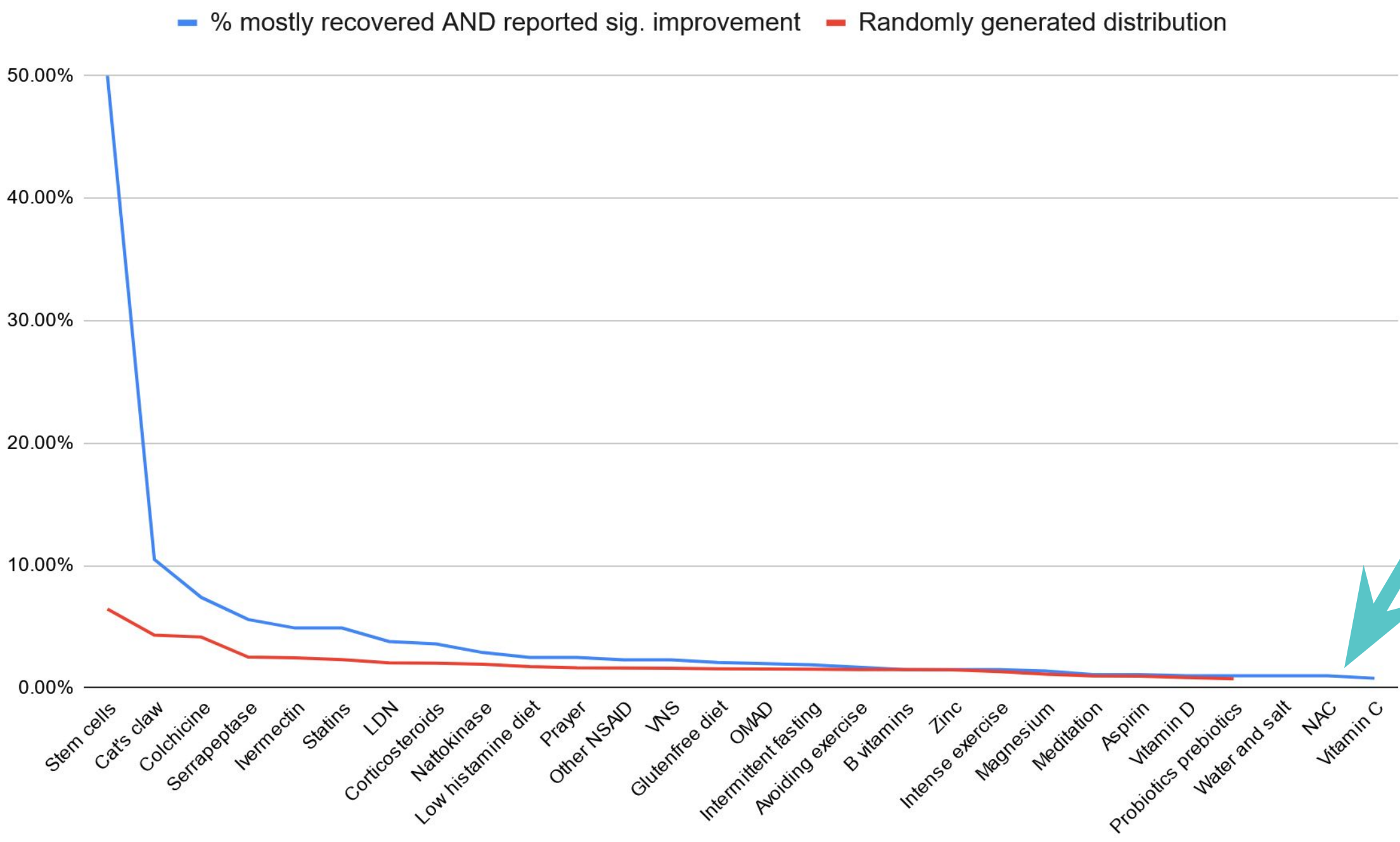
The data can be biased if some people think highly of prayer and therefore rate prayer highly, independent of prayer's medical effect.



Conflicting results for NAC (N-Acetyl Cysteine)



While the free-form answers may seem to suggest that NAC leads to recovery, the other method does not as it adjusts for how often a treatment was tried.

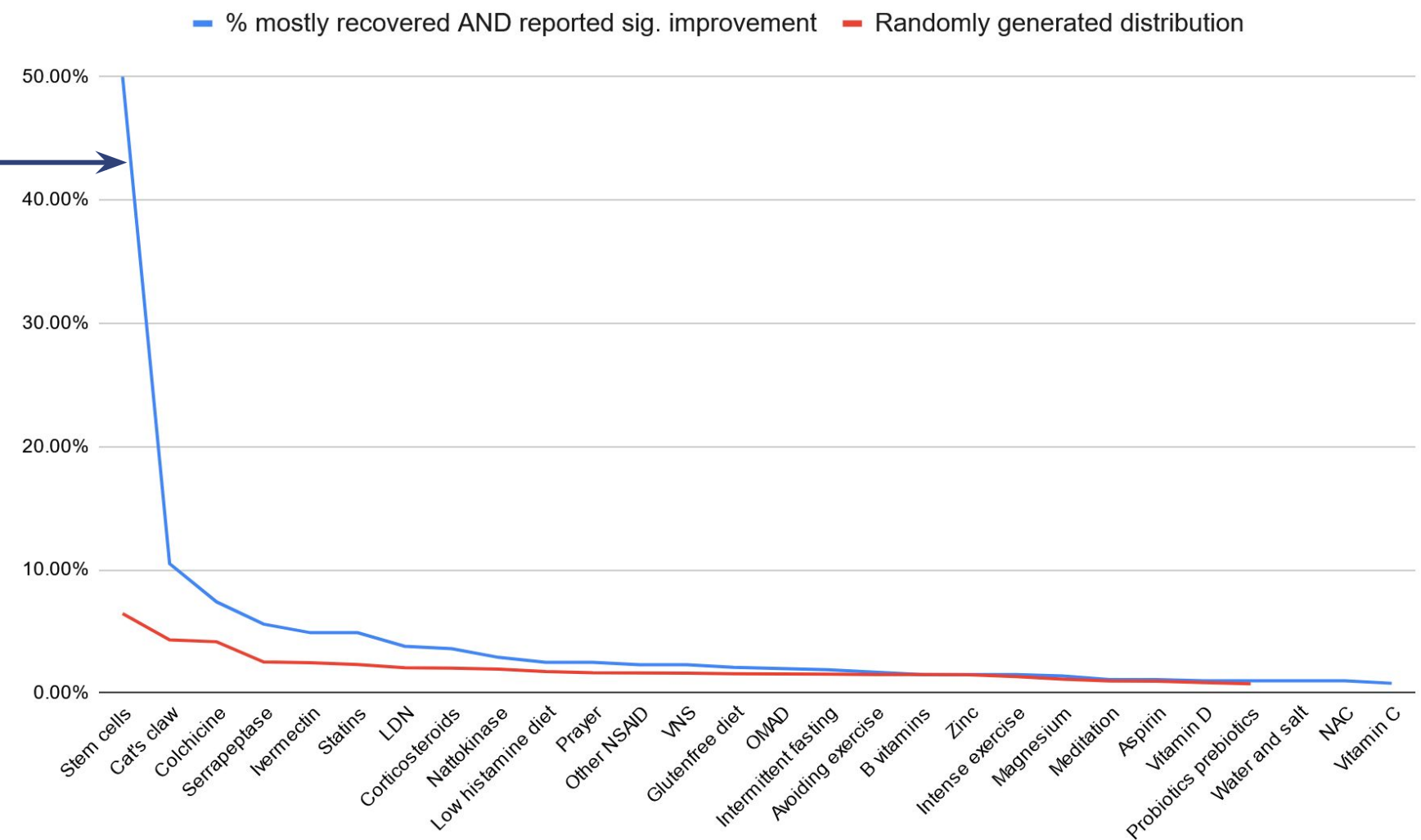
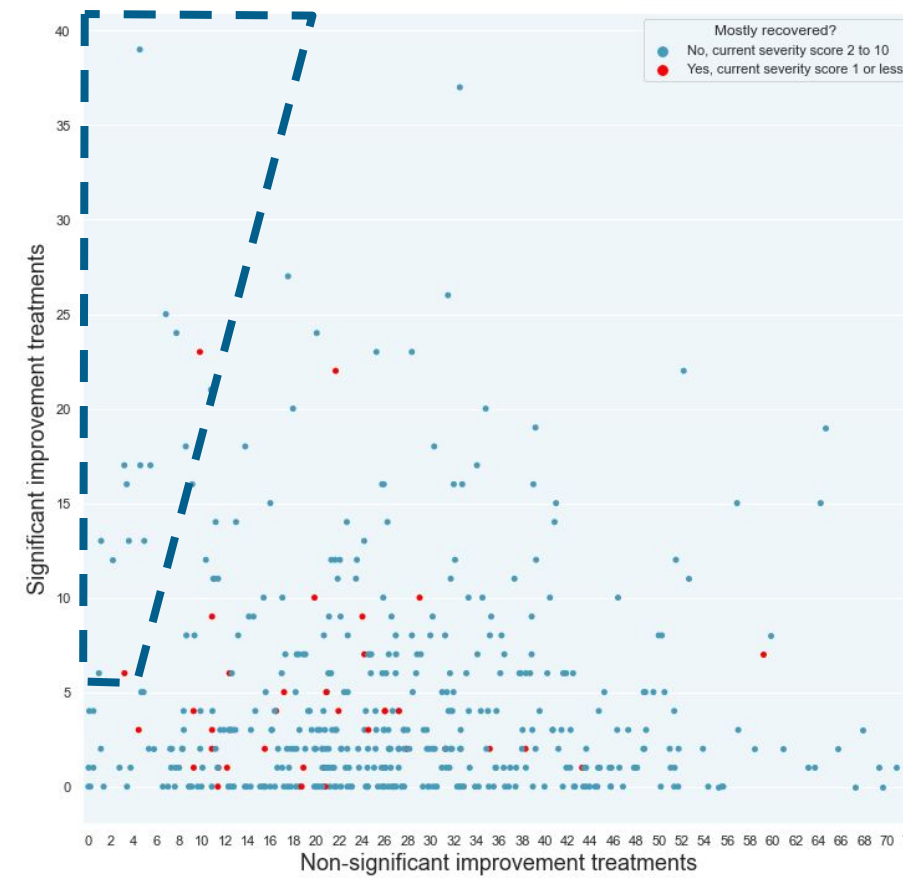


The 80/20 rule (or Pareto Principle)



The 80/20 rule states that 80% of outcomes results from 20% of causes. This rule of thumb is a rough approximation of probability distributions that frequently occur in life, where a small minority accounts for the majority of impact.

The **blue** line on the right shows an 80/20 style probability distribution. **The distribution suggests that most treatments do not have a meaningful impact- only a few treatments work.** This suggests that the data from ‘everything works’ surveyees includes survey biases and does not fully reflect their medical outcomes.



Medical practitioners need to question if patients are accurately reporting treatment outcomes!



Chronic illness is largely based on self-reporting by patients as there are few biomarkers and objective measures (e.g. employment) that track the patient's well-being.

The survey data strongly suggests that patients have reporting biases. Furthermore, some of their reported outcomes are indistinguishable from random noise.

Conversely, patients can ask the same questions about medical professionals- are *they* accurately reporting their patients' medical outcomes? Do they have biases driven by financial pressures or social factors?



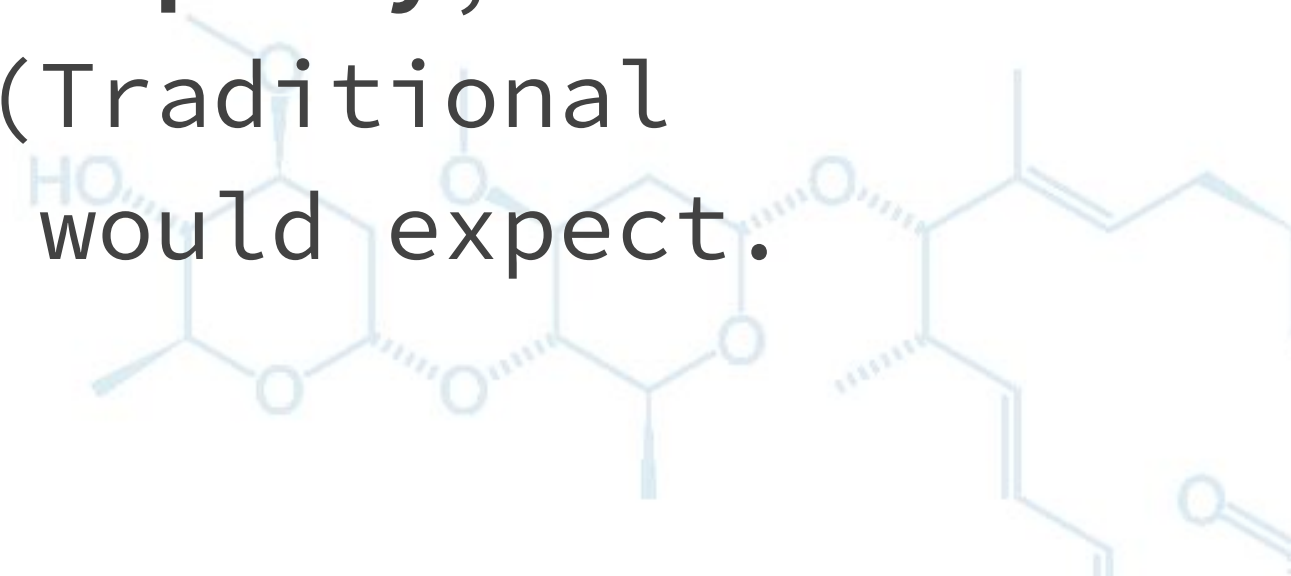
Applications of the PES dataset



The data can be used to identify promising treatments *as well as treatments that may not be worth trying.*

- The full data dump is available at LongHaulWiki.com/pes/.
- [This post](#) explains how you can search through the data dump (which is 200+ pages if printed).

Certain treatments such as **homeopathy**, **osteopathy**, **chiropractic**, **acupuncture**, and **other TCM** (Traditional Chinese Medicine) may be riskier than one would expect.





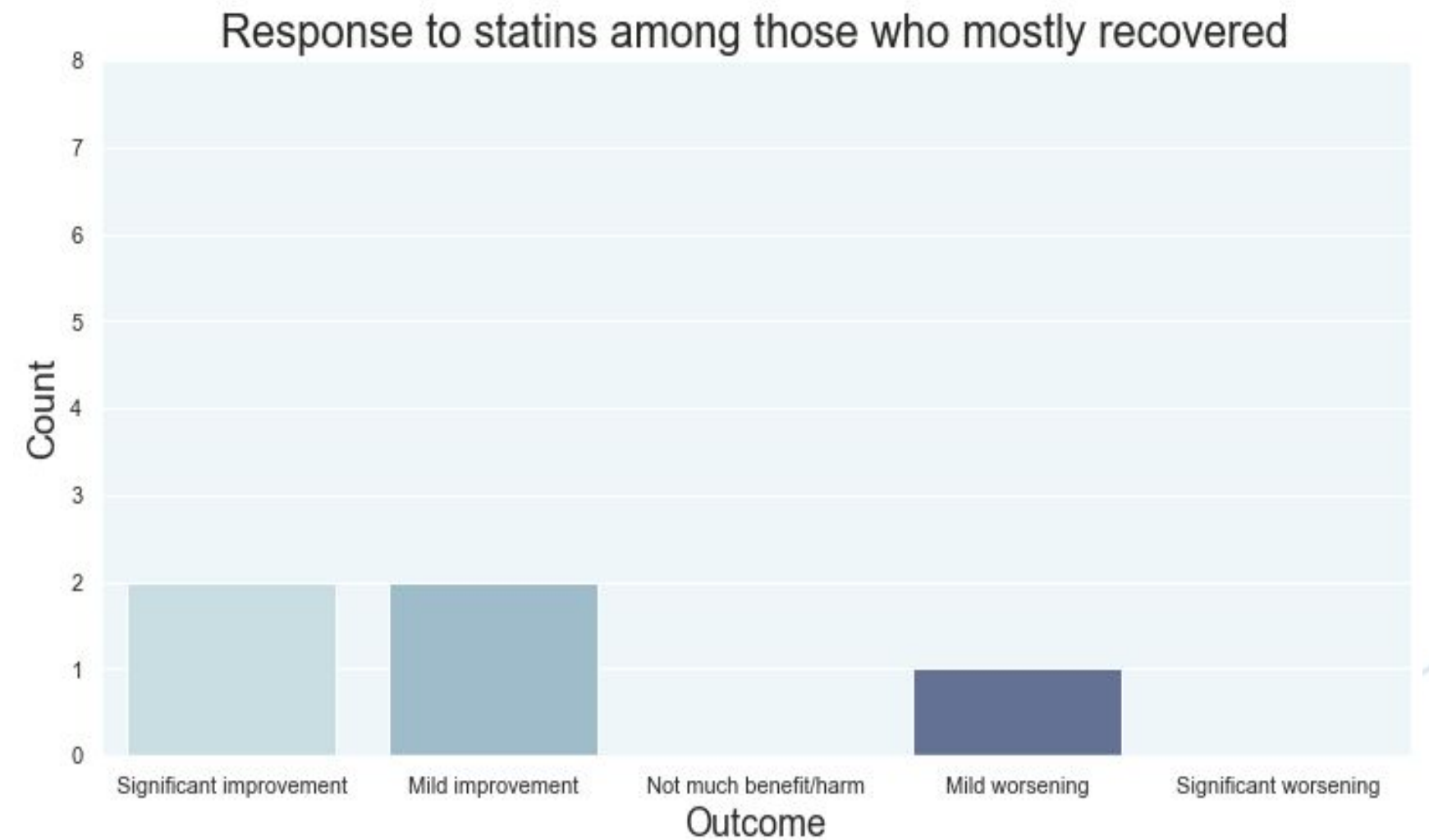
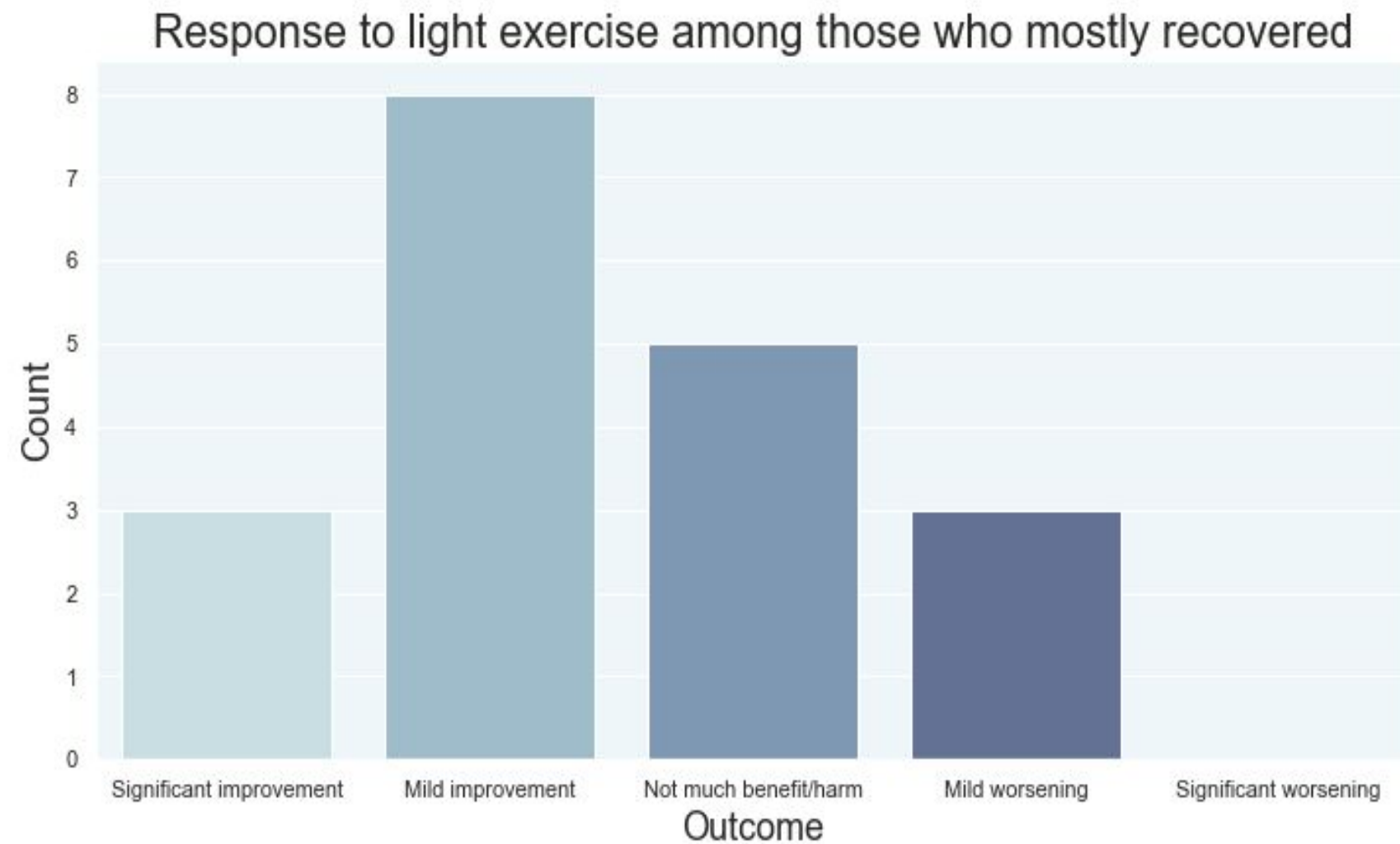
Other Findings



Different paths to recovery



Among those who recovered, there were mixed results for light exercise and statins.



Did higher doses perform better?



- Black seed oil in *oil* form (e.g. oil poured out of a bottle) and capsule form was rather higher than the seed form.
- Higher pressure HBOT above 1.5ATA outperformed cheaper, lower pressure HBOT.
- There were mixed results for fasting, though intermittent fasting generally underperformed relative to other fasting methods.



Treatment	% (of those who tried this) who mostly recovered AND reported significant improvement from this treatment	% of surveyees (with recovery data) who tried this	Count	Number who tried this treatment
Multiday dry fasting	7.7	2.8	1	13
OMAD	2.7	24.6	3	113
Multiday wet fasting	2.8	7.8	1	36
Intermittent fasting	1.6	41	3	188
Multiday juice fasting	0	3.9	0	18

Are higher doses riskier?



Unlike the previous Treatment Outcomes survey, the Patient Experiences Survey did not show clear correlations between higher doses and risk:

- Mixed results for nigella sativa. Presumably, the oil form is taken at higher dosages than capsules which are taken at a higher dose than the seeds.
- Higher pressure HBOT somehow had lower risk than lower pressure HBOT (!).
- Fasting did show a relationship between dose and risk (see next slide).

Anti-microbials

Chronic Lyme treatments such as HBOT, methylene blue, IV ozone, and monolaurin are included. Amphotericin, Canesten, Econazole, etc. are anti-fungals.

	Treatments with more than 0 data points	Score	Risk score	# of data points (out of 525 surveyees)
1	[HBOT >1.5 ATA]	1.52	-0.16	25
2	[Rapamycin]	1.33	0.00	3
3	[Alinia]	1.20	0.00	5
4	[Monoclonals]	1.00	0.00	11
5	[Ivermectin]	1.00	-0.14	129
6	[Plaquenil]	0.74	-0.29	42
7	[Oil of oregano]	0.70	-0.05	56
8	[Methylene blue]	0.70	-0.07	27
9	[Nigella sativa oil]	0.67	-0.05	66
10	[IV ozone]	0.65	-0.17	23
11	[Cat's claw]	0.61	-0.13	23
12	[Molnupiravir]	0.60	0.00	5
13	[Aciclovir, Famciclovir, Valtrex, Valcyte]	0.59	-0.09	75
14	[Amphotericin, Canesten, Econazole, Fluconazol...]	0.51	-0.27	101
15	[HBOT <=1.5 ATA]	0.50	-0.27	26
16	[Favipiravir]	0.50	0.00	2
17	[Lion's mane]	0.49	-0.16	106
18	[Nigella sativa capsules]	0.48	0.00	62
19	[Lavender]	0.48	-0.08	52
20	[Monolaurin]	0.32	-0.08	37
21	[Paxlovid]	0.29	-0.38	34
22	[Tetracyclines, Fluoroquinolones, Penicillins,...]	0.21	-0.55	220
23	[Nigella sativa seed]	0.00	-0.10	10
24	[Biocidin]	-0.38	-0.50	8

Are higher doses riskier? - fasting



The least intense forms of fasting, intermittent fasting and one-meal-a-day (OMAD), had the lowest risk compared to other forms of fasting.

Fasting and autophagy

Hydroxychloroquine/Plaquenil inhibits autophagy rather than promotes it.

	Treatments with more than 0 data points	Score	Risk score	# of data points (out of 525 surveyees)
1	[Multiday wet fasting]	0.82	-0.26	38
2	[Intermittent fasting]	0.77	-0.08	212
3	[Plaquenil]	0.74	-0.29	42
4	[Resveratrol]	0.52	-0.03	126
5	[Multiday juice fasting]	0.45	-0.35	20
6	[OMAD]	0.44	-0.24	124
7	[24-48 hour fasting]	0.43	-0.42	89
8	[Multiday dry fasting]	0.21	-0.79	14
9	[Spermidine]	0.09	-0.09	32





Many Treatments Helped Some, Worsened Others

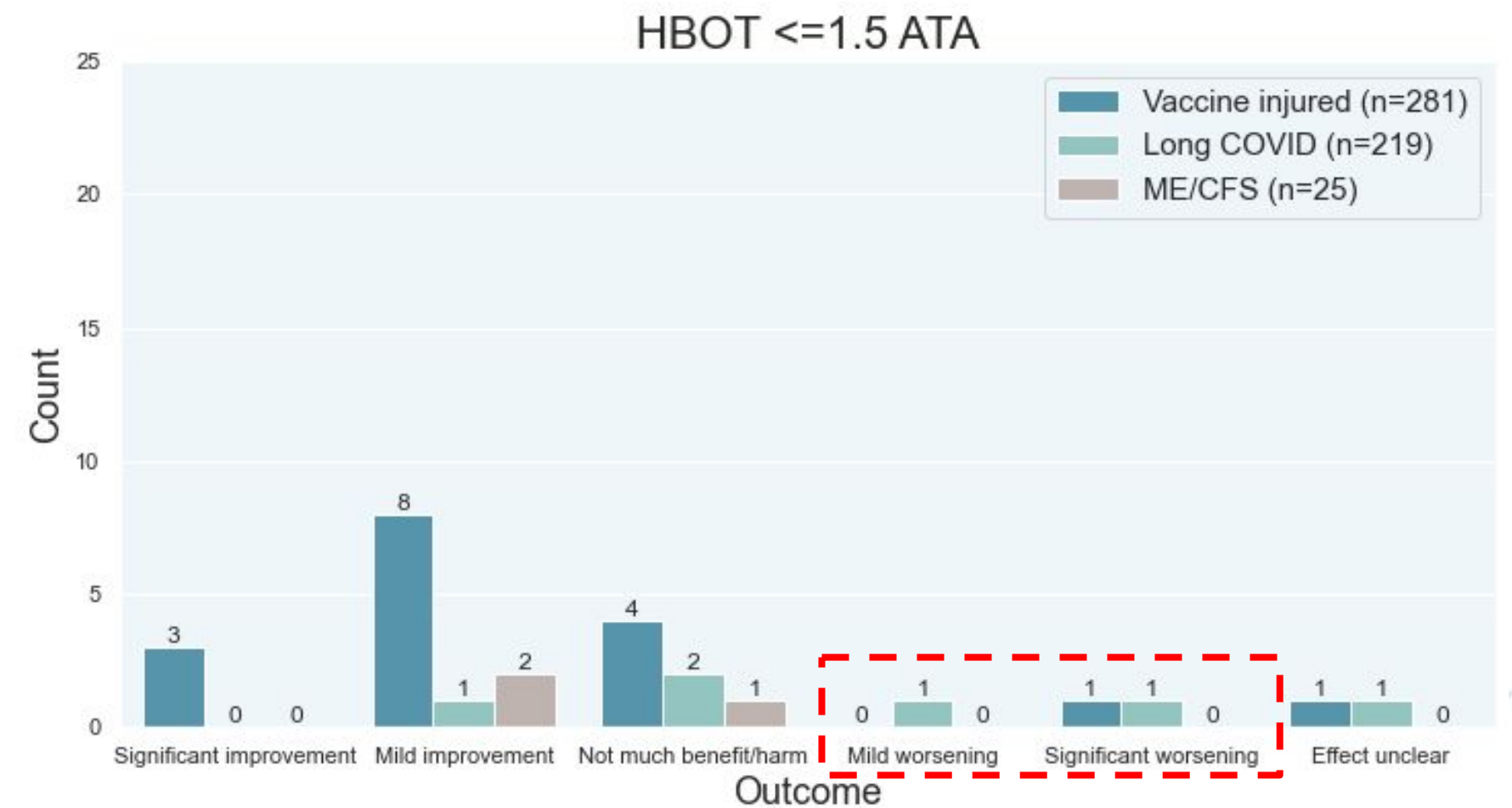
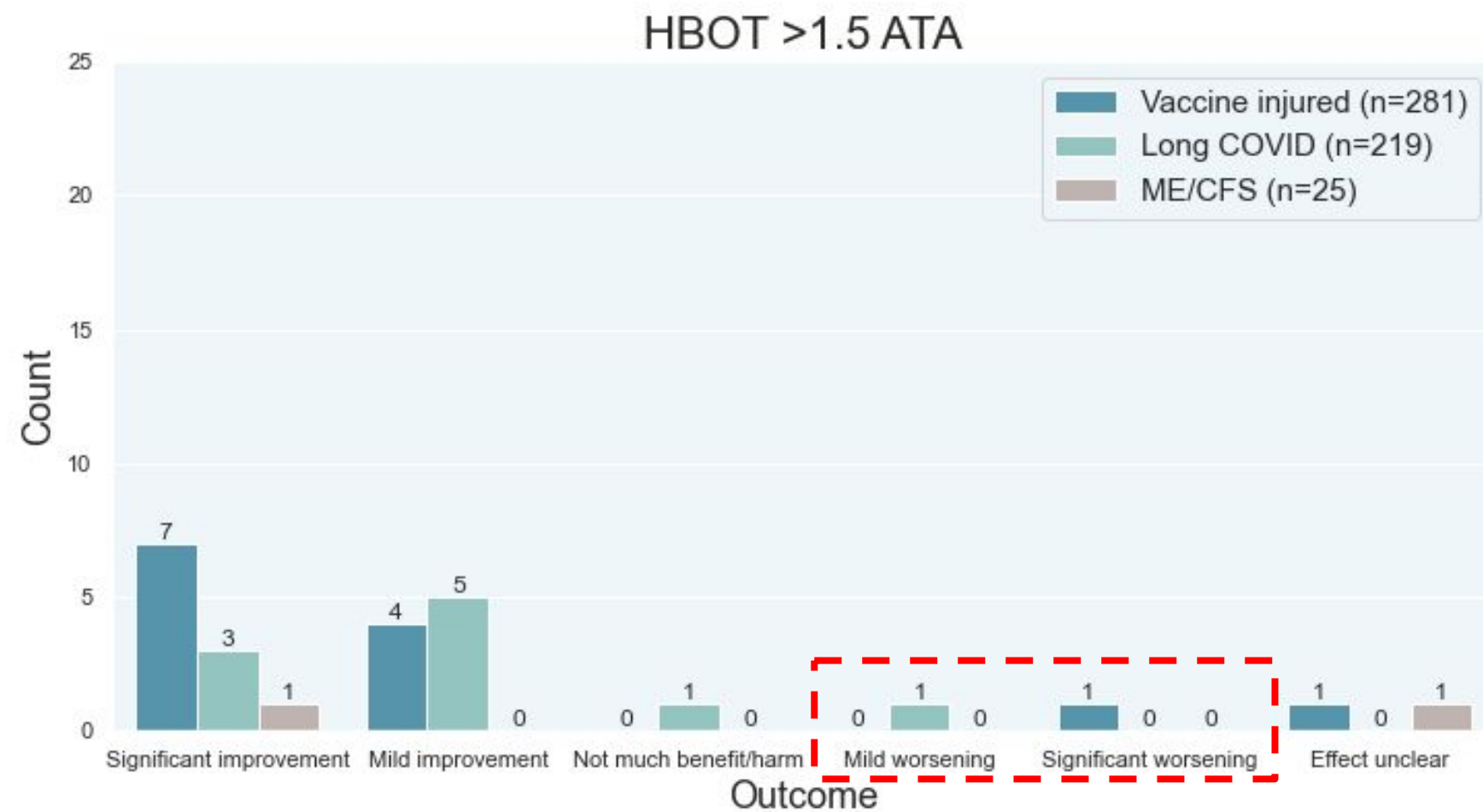
3 Examples



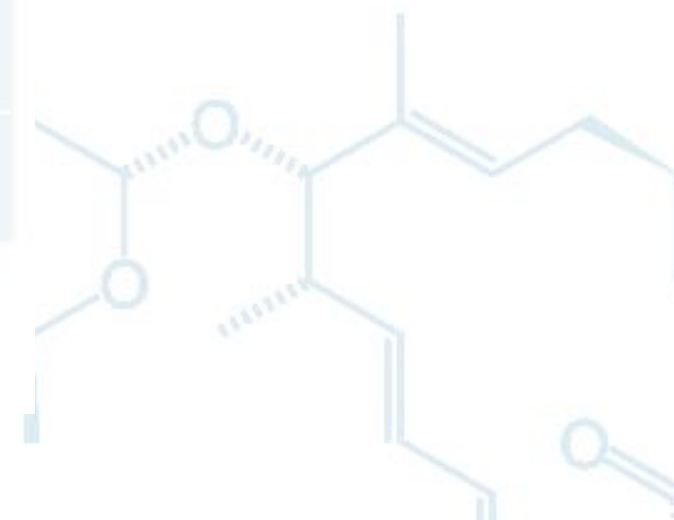
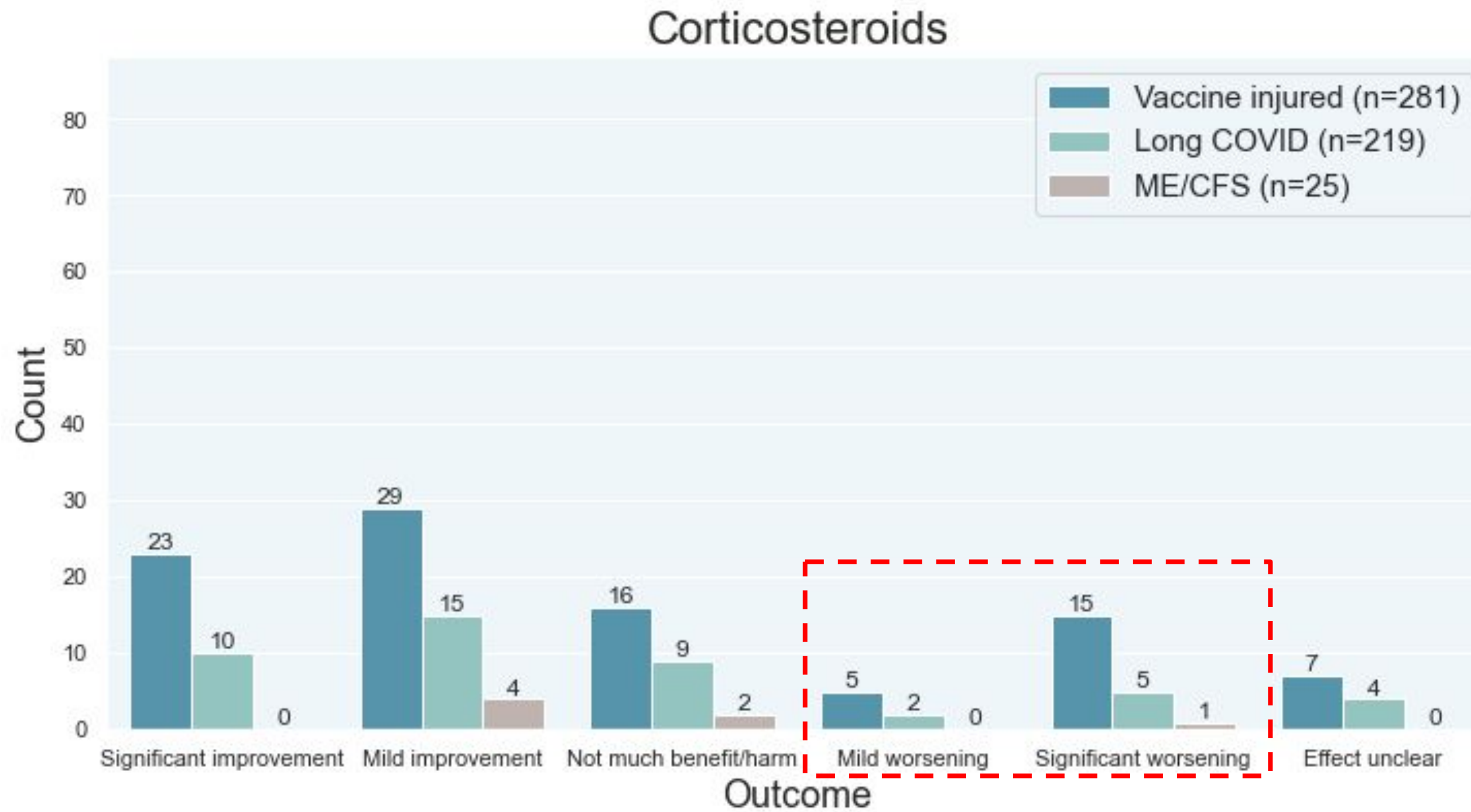
Different responses to HBOT



There were multiple people reporting **negative** experiences with HBOT (both high and low ATA). The data below includes the non-recovered.



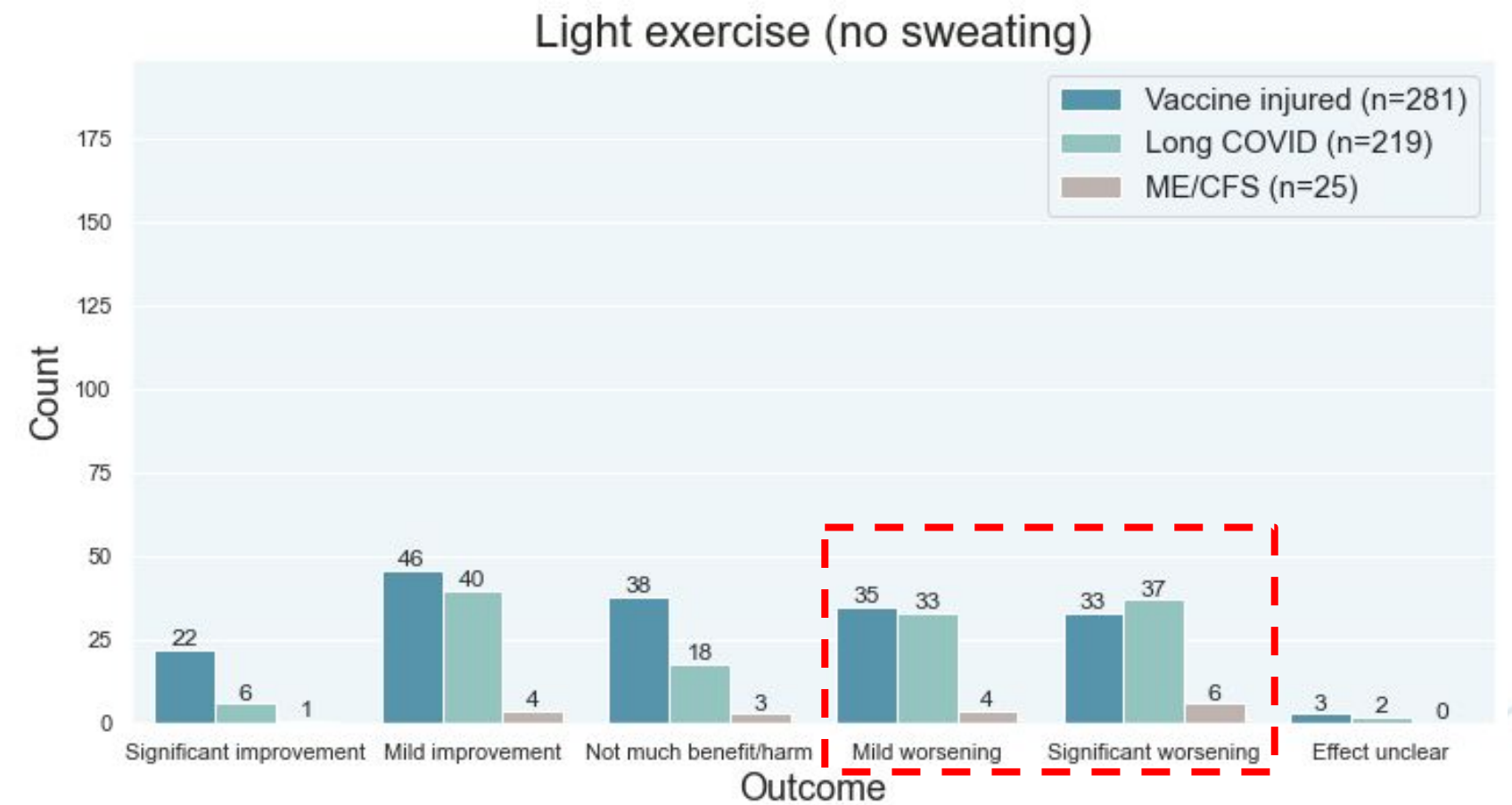
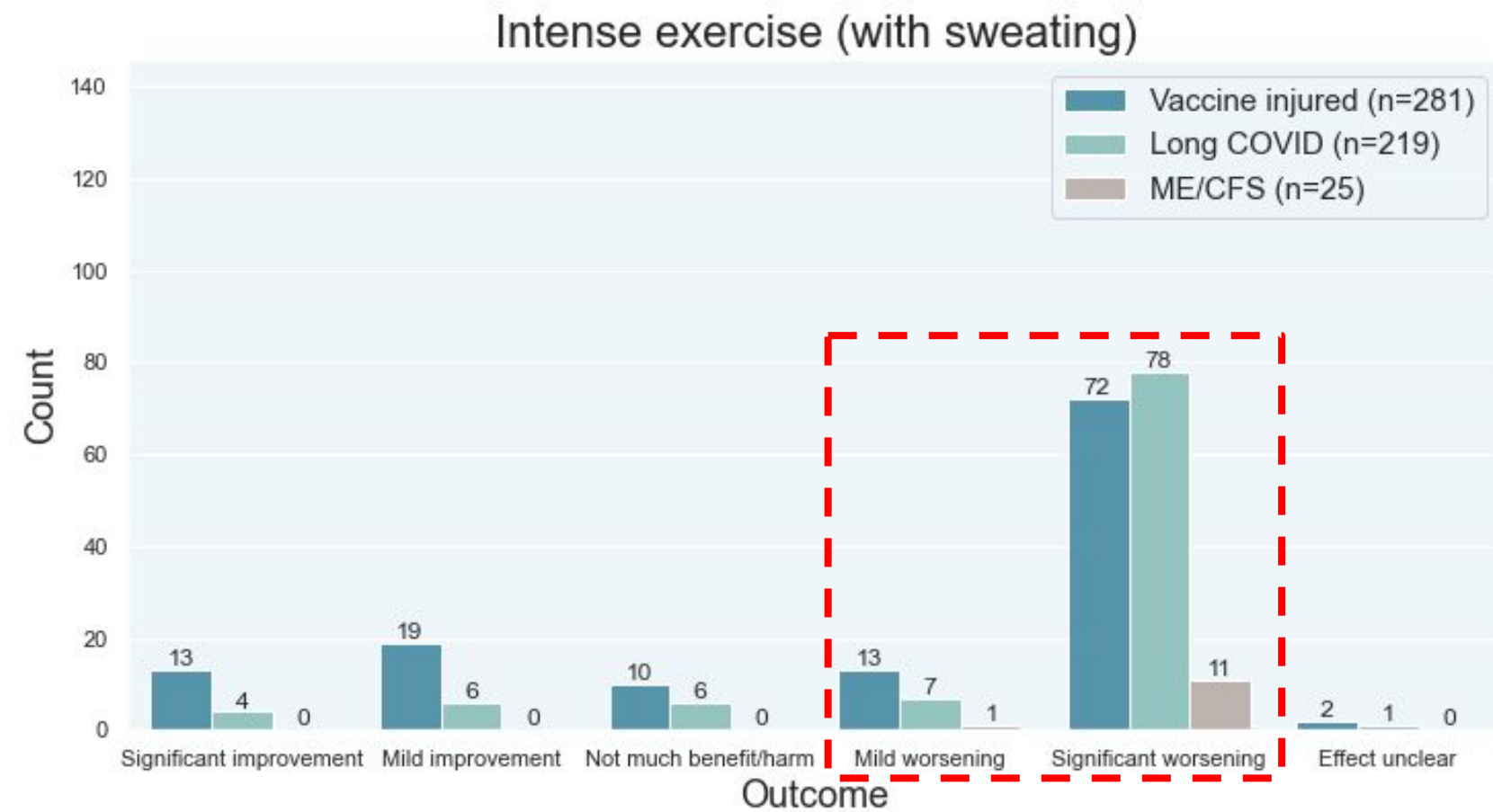
Different responses to corticosteroids



Different responses to intense and light exercise



While exercise is generally presumed to be beneficial, most chronic illness patients react very poorly to it (even if it is light exercise). Other treatments such as acupuncture also seem to be much riskier in chronic illness patients (not shown).



Double-edged swords

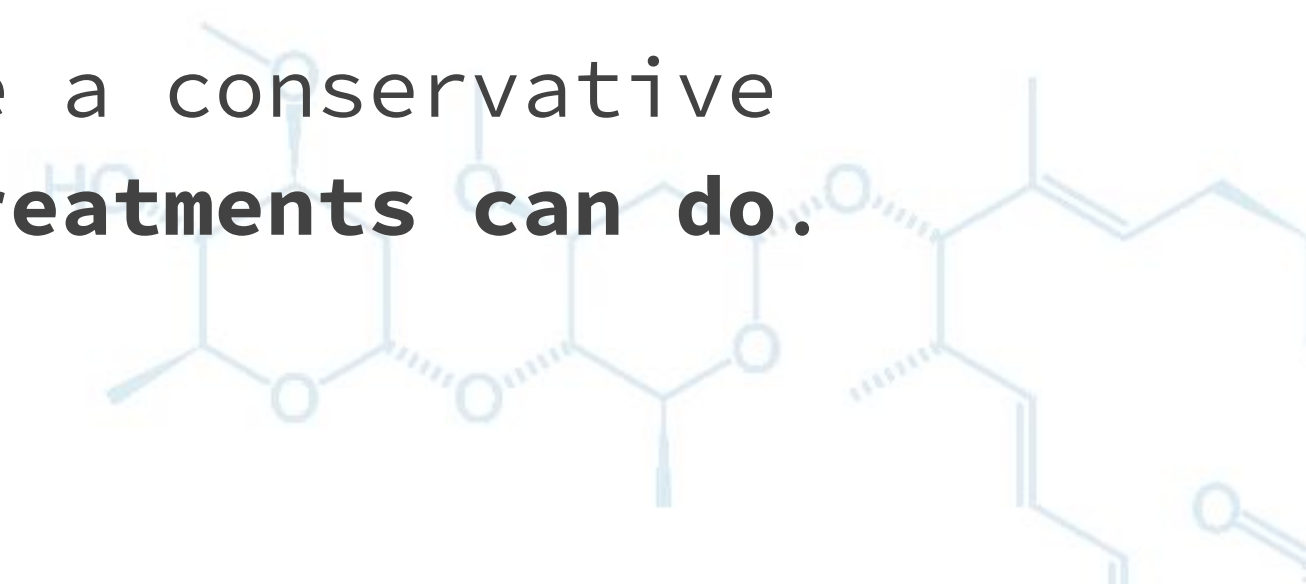


Treatments that were rated highly by those who recovered usually had a medium or high rate of symptom worsening.

There are very few treatments that do not carry the risk of reported worsening *and* show some potential for facilitating recovery.

Exceptions include pacing strategies, prayer, low histamine diet, nattokinase and serrapeptase.

There is currently no test or methodology that would allow one to predict the outcome of treatment beforehand. Due to the riskiness of most treatments, it would be prudent to take a conservative approach **that recognizes the harm that these treatments can do.**

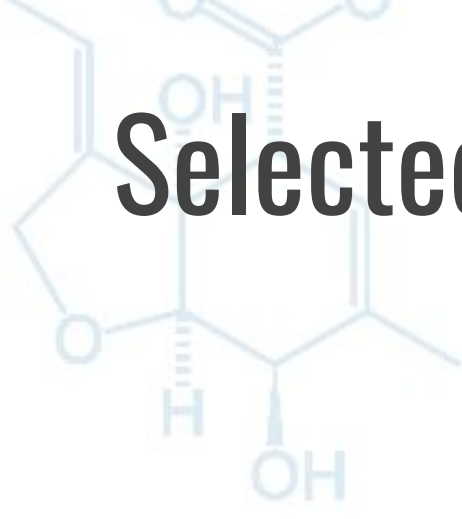




Promising Treatments



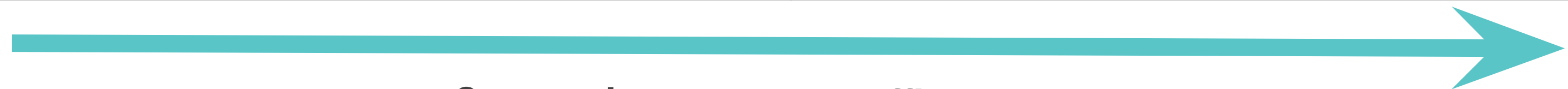
Selected treatments grouped based on safety and efficacy



Lower risk
(but typically
still risky)



Prayer Cat's claw NAC Low histamine diet	Nattokinase Serrapeptase Ivermectin* Statins* *Can be considered high risk.
Corticosteroids Exercise	LDN HBOT Fasting Colchicine Stem cells?



Survey data suggests efficacy

Risky treatments with lower evidence of efficacy



Corticosteroids and **exercise** have a high rate of surveyees reporting worsening. Exercise was the riskiest treatment by far, exceeding all prescription drugs.

While it is possible that these treatments helped a few people recover, it is also possible that they cause more harm than good. Without more reliable data, it would not be prudent to recommend these treatments.

Risk rankings

Treatments sorted from highest risk score to lowest risk score. May be limited to the 60 riskiest treatments.

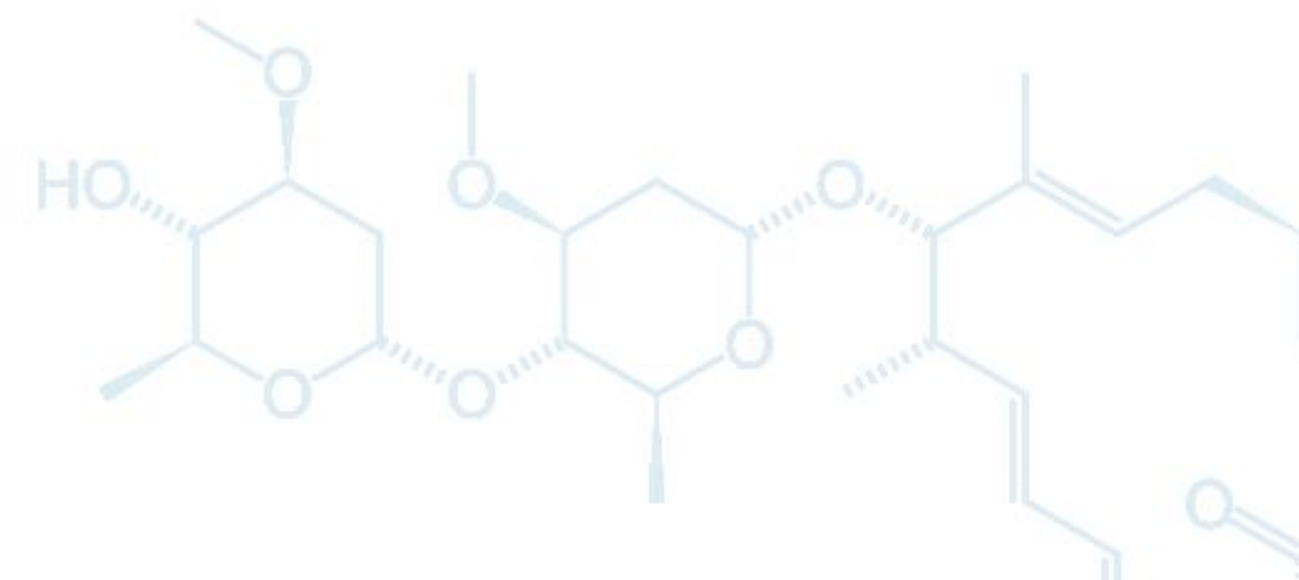
	Treatments with more than 90 data points	Score	Risk score	# of data points (out of 525 surveyees)
1	[Intense exercise]	-1.76	-2.07	243
2	[Graded exercise therapy]	-0.71	-1.19	118
3	[Light exercise]	-0.37	-0.91	331
4	[Remeron, Seroquel, Wellbutrin]	-0.31	-0.72	126
5	[Celexa, Lexapro, Fluvoxamine, Prozac, Paxil, ...]	-0.17	-0.70	264
6	[Tetracyclines, Fluoroquinolones, Penicillins, ...]	0.21	-0.35	220
7	[Corticosteroids]	0.52	-0.48	147
8	[Beta blockers]	0.66	-0.37	136
9	[CBD with THC]	0.48	-0.36	159
10	[Time]	0.83	-0.35	465
11	[Amphotericin, Canesten, Econazole, Fluconazol...]	0.51	-0.27	101
12	[LDN]	0.91	-0.26	140
13	[Benadryl]	0.35	-0.25	112
14	[Pepcid]	0.46	-0.24	157
15	[OMAD]	0.44	-0.24	124
16	[Other NSAID]	0.43	-0.22	171
17	[Acupuncture]	0.66	-0.21	165
18	[Ashwagandha]	0.34	-0.19	139
19	[Melatonin]	0.53	-0.18	236
20	[Advil]	0.31	-0.17	254

Low risk treatments with the most evidence of efficacy



There is low downside for patients to try these treatments.
(Note that ivermectin and statins have risk.)

However, please be aware that the data for efficacy may be unreliable. There is a good chance that at least some of the treatments identified as promising have no benefit.



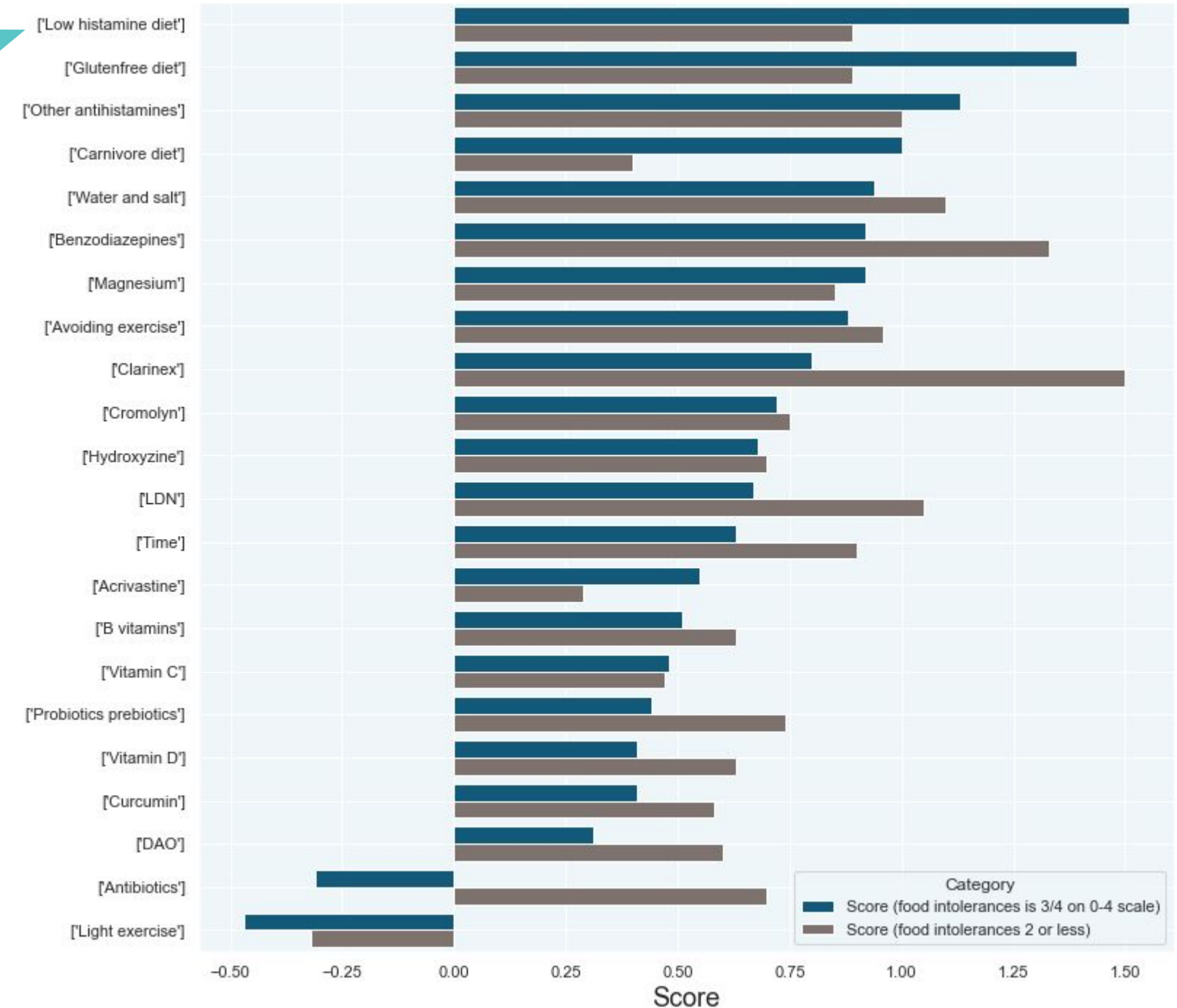
Low risk treatments with low evidence of efficacy



These treatments can be worth trying due to their low downside.

Prayer may not work for those who are not religious. There is no data as to its effects on the non-religious.

Diets such as the **low histamine diet** may offer rapid symptom relief, especially in those with severe food intolerances. However, such treatments may not necessarily have a meaningful impact on recovery.

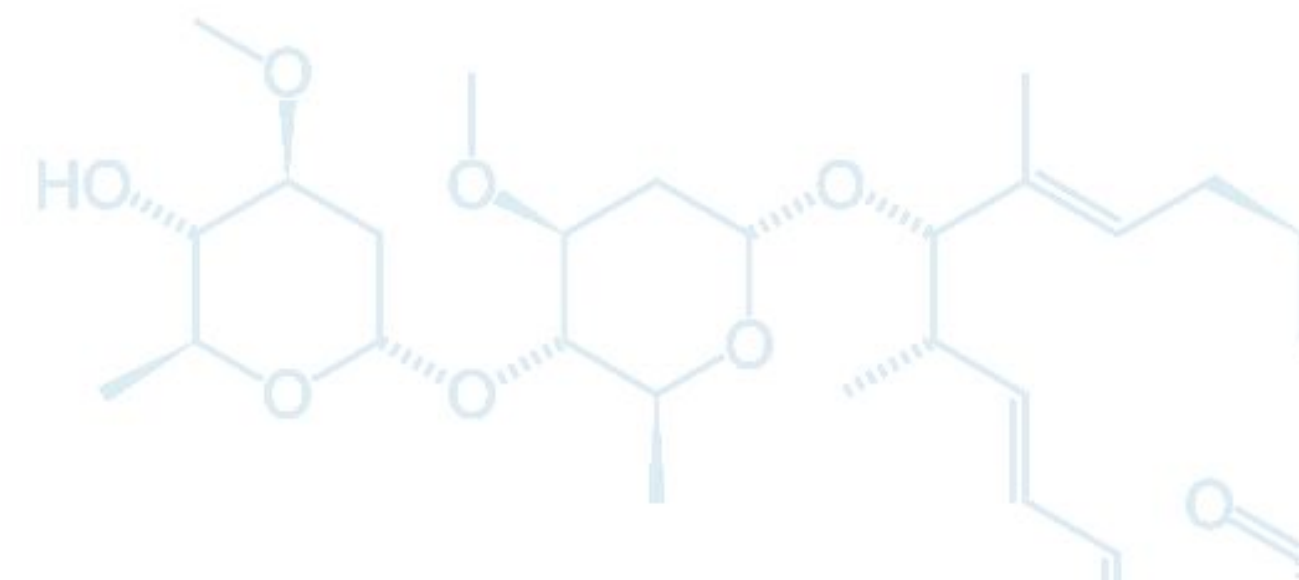


High risk treatments with the most evidence of efficacy



Ivermectin and statins could be included in this category as they are prescription drugs and do have risk.

It is possible that the *only* effective treatments are the double-edged swords. Most of the potentially effective treatments identified so far exhibit some level of risk, with the exception of nattokinase and serrapeptase.





Chronic Illness May Have Multiple Underlying Factors



The 'double edged sword' phenomenon



Chronic illness is full of paradoxes. The treatments with the strongest indications of efficacy have also been reported to cause worsening in some. HBOT, [which has strong empirical support from RCT data](#), leads to negative symptoms in some.

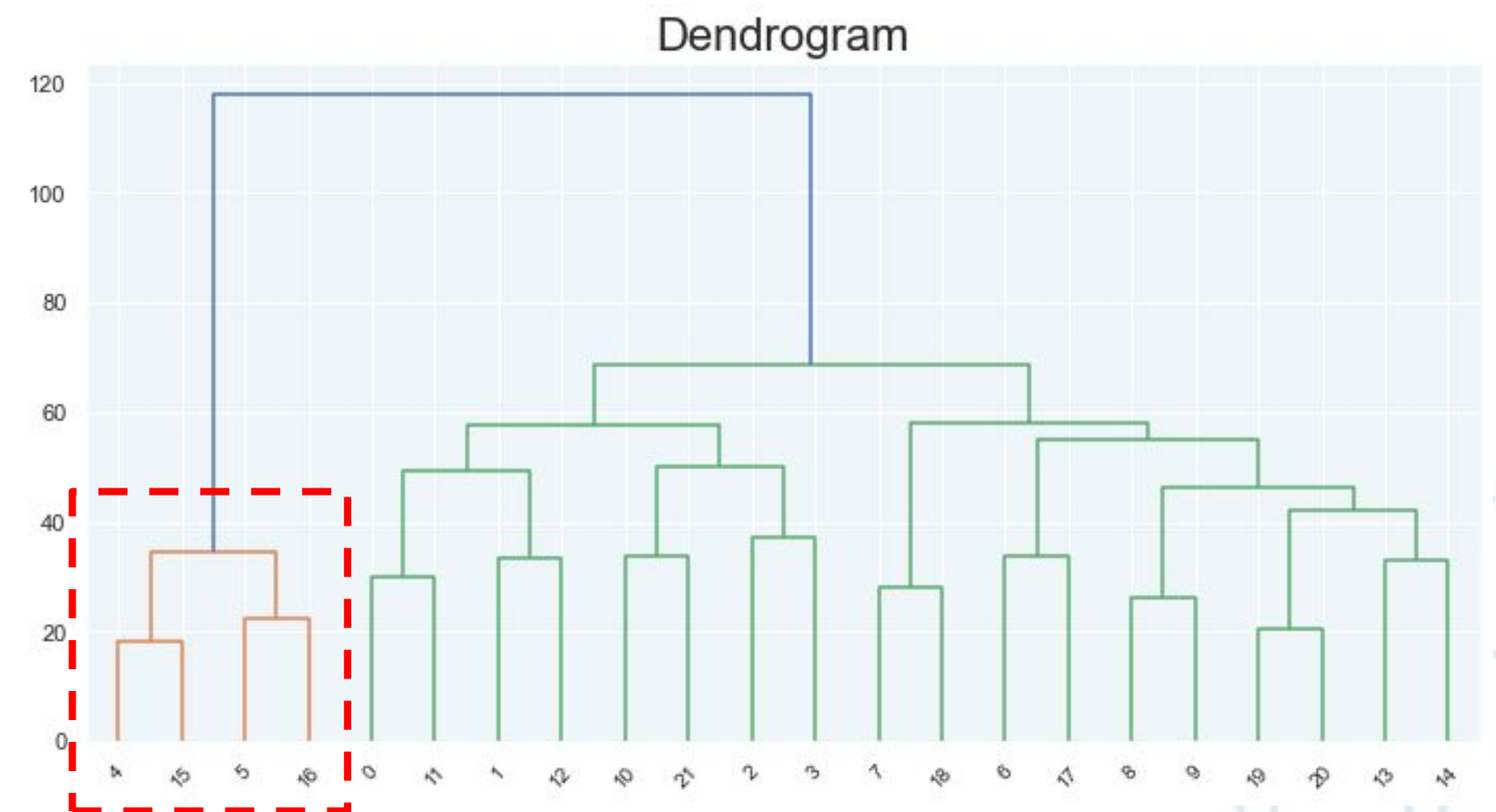
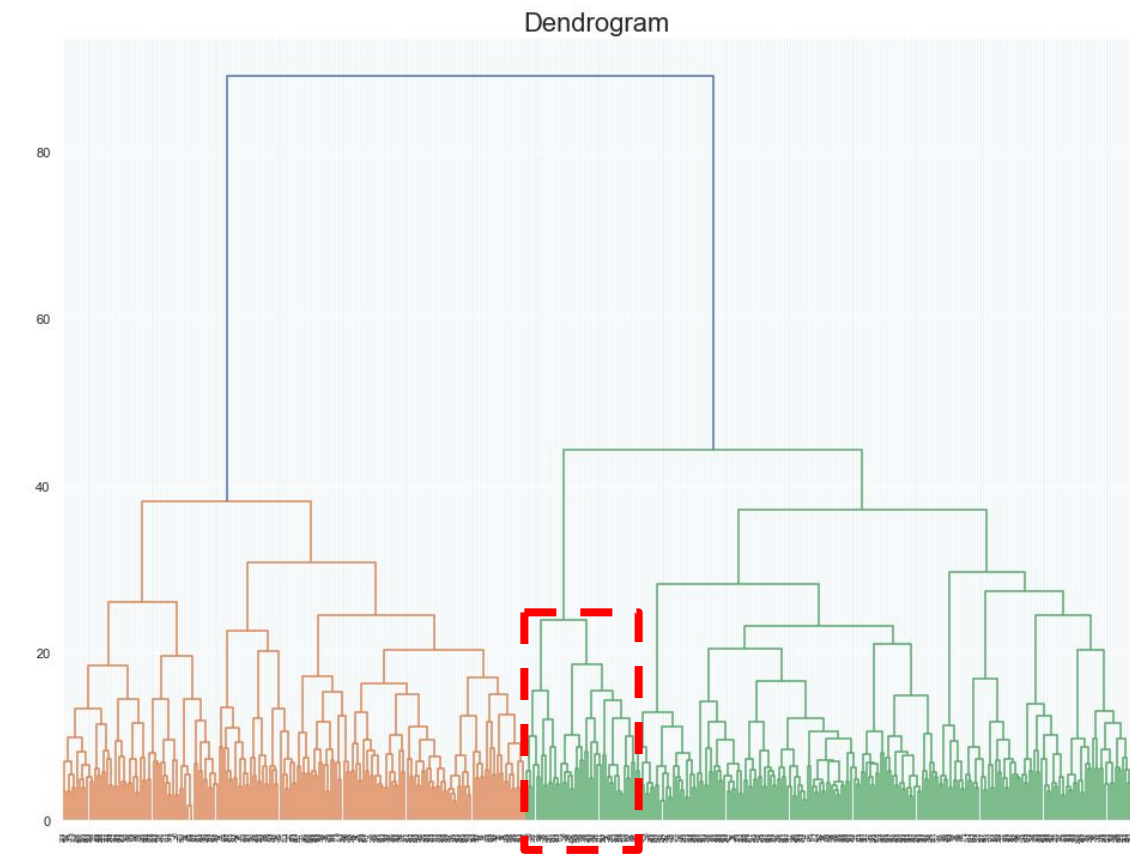
This could be explained by multiple underlying factors that **interact with** and **oppose** one another. For example, microbes/pathobionts living in human tissue affect the fitness of other microbes through competition and symbiosis.

Symptoms do not exhibit obvious phenotypes



Hierarchical clustering can be used to detect patterns and phenotypes based on patients' reported symptoms. In practice, it tends to find groups of people who answer surveys differently (rather than medical differences).

In the PES data set, there is a distinct cluster of 45 people. Most of this cluster reported *both* severe blood clots and bleeding issues, which is medically unlikely given the prevalence of the combination and the low rates of prescription blood thinners being tried.

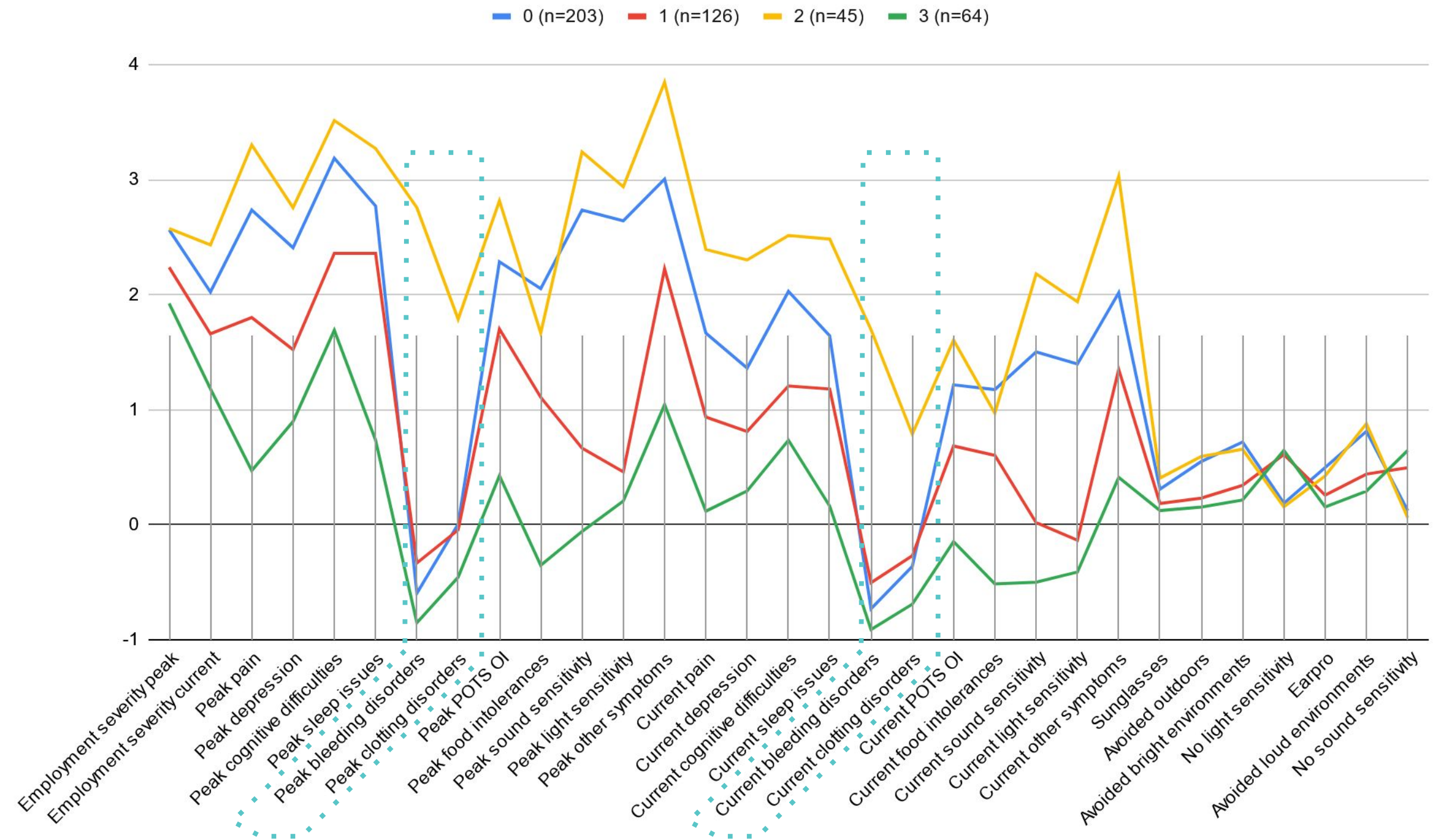


Cluster 2



Cluster 2 **in yellow** is the one reporting both blood clots and bleeding.

That is the most striking difference between it and cluster 0 **in blue**, which is the most similar.

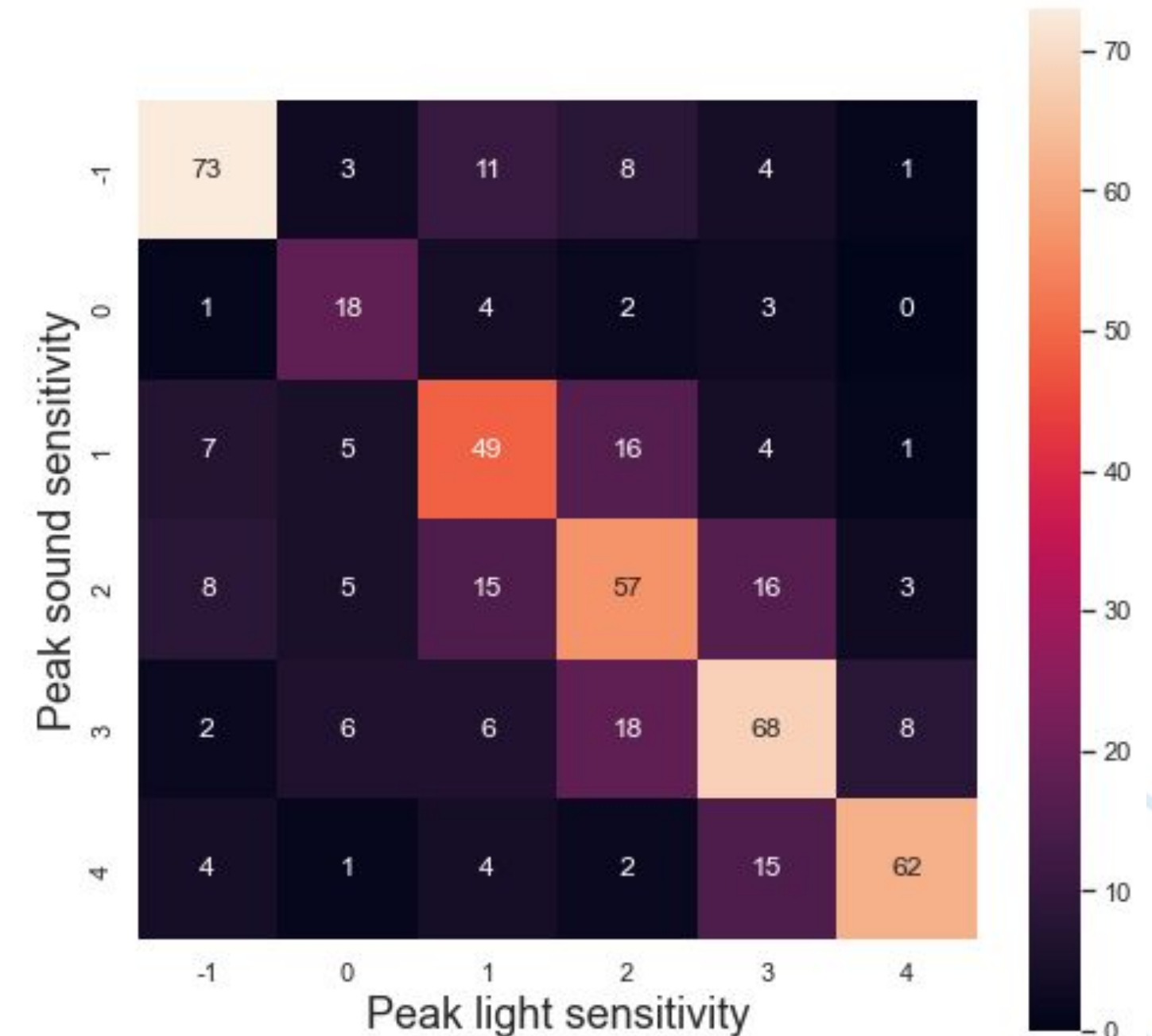


No obvious phenotypes discovered so far



Clustering analysis of data from [other surveys](#) (e.g. see [pages 33-34](#)) seems to show that there are no obvious phenotypes. Patients seem to draw from a shared pool of common symptoms but there are no clear patterns.

Certain symptoms such as sound and light sensitivity with each other, perhaps due to a shared underlying cause (e.g. meningitis) that can cause both symptoms.



We lack the missing pieces



Multiple underlying causes would explain why effective treatment is so elusive for most while a lucky few stumble into recovery. The answers seem to be different for each patient.

Without any testing or intuition that can predict treatment outcomes (e.g. based on underlying cause), chronic illnesses can currently only be treated in a blind fashion.





The Future Of Treating Chronic Illness





Data will show us the way



Gathering reliable data is hard, making it easy to develop misconceptions about medical outcomes.

Whereas little progress will be made with unreliable anecdotes from patients or clinicians, **big data** (large datasets) and **careful data collection** will move us forward.



Data will inform clinical care



- The double-edged nature of many treatment needs recognition to reduce harm.
- **HBOT** should be considered as a first-line treatment, where feasible. It is the most proven Long COVID treatment so far.
- We should avoid treatments where it is known that the risk/reward is poor.



Data points towards recovery



While the efficacy signals are subtle, data points towards promising treatments such as **fasting**. Patterns among popular treatments (such as antimicrobial effects) can be extrapolated to identify other potential treatments such as anti-parasitics (e.g. Plaquenil). Continued research and/or patient experimentation will inevitably move us forward.



Thank you



If you have questions, please
feel free to ask them at
forum.SickAndAbandoned.com.

Or email:

glennchan /at/ gmail [dot] com



Appendix - Should Long COVID, Vaccine Injury, And ME/CFS Be Considered Inter-related?

Similar symptoms



The chronic illnesses Long COVID, ME/CFS, and vaccine injury (Post COVID Vaccination Syndrome) all had similar symptom profiles as self-reported by participants (see next slide).

Participants were recruited from online support groups, where most people suffer from a long list of symptoms and severity is high. This syndrome is likely different than the so-called “Long COVID” or PASC that is far more common in the general population following COVID.



Symptom profile comparison between illnesses

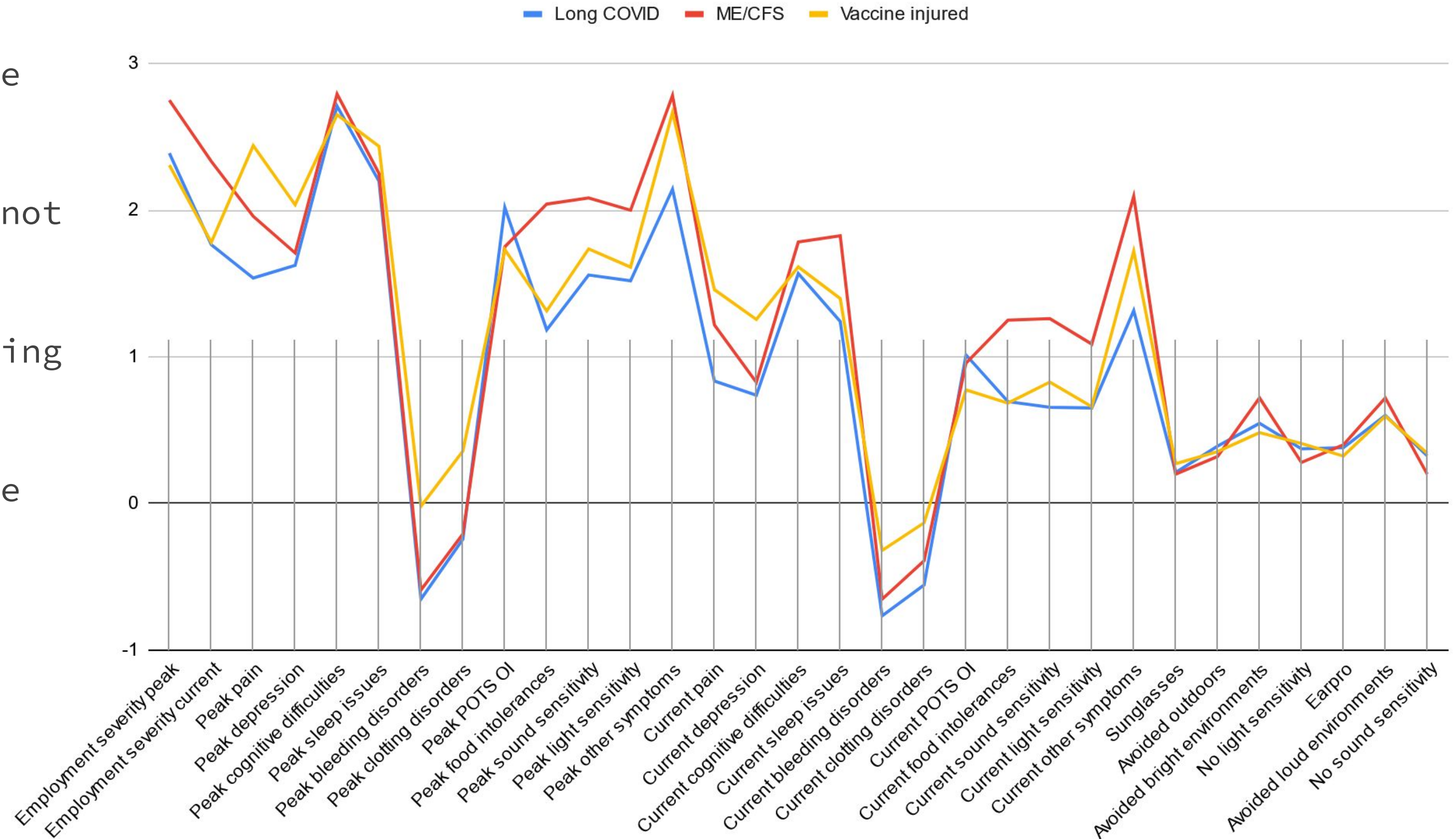


-1 = “Did not have these symptoms”

0 = “Symptoms do not bother me”

4 = “Worst suffering imaginable”

Average values are shown.

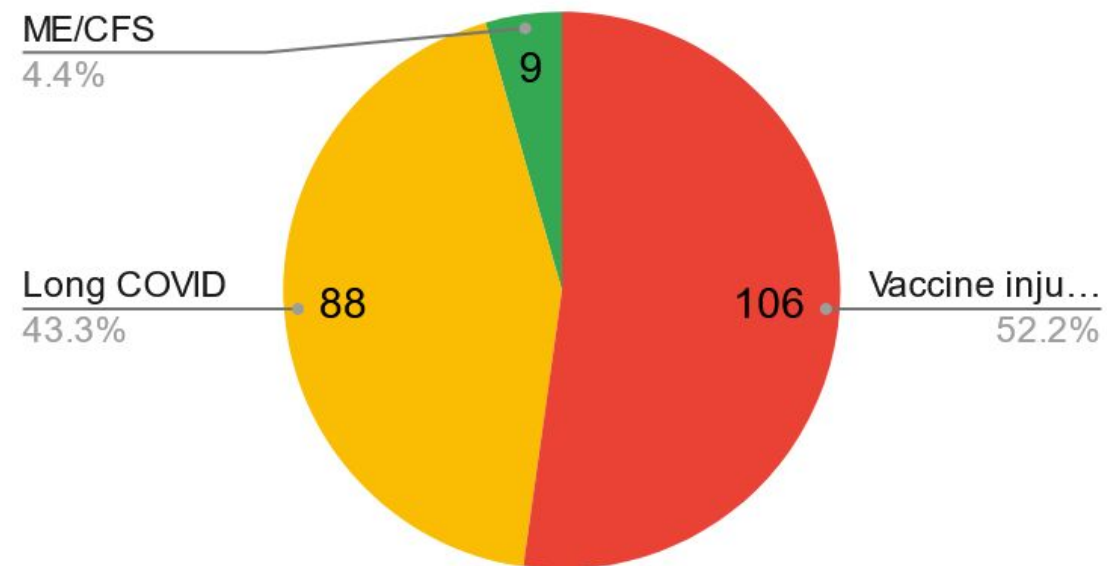


Cluster analysis

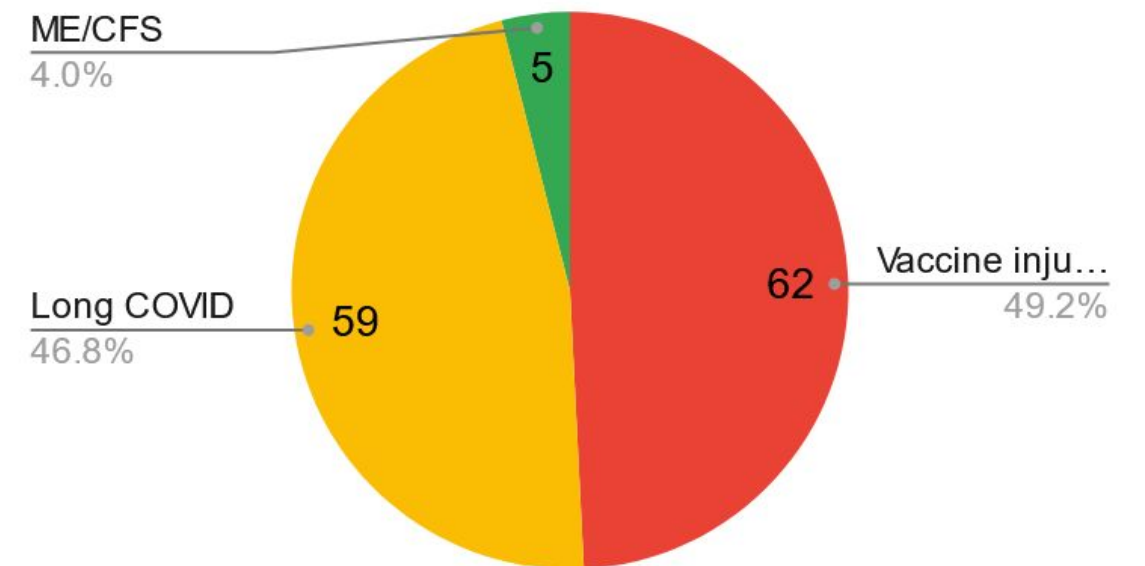


The PES data can be arbitrarily split into 4 clusters. Cluster 2 consists mainly of the vaccine injured. This small cluster of 45 people (10.3% of all participants) often reported severe suffering from *both* blood clots *and* bleeding. It is likely not medically driven (see earlier slides).

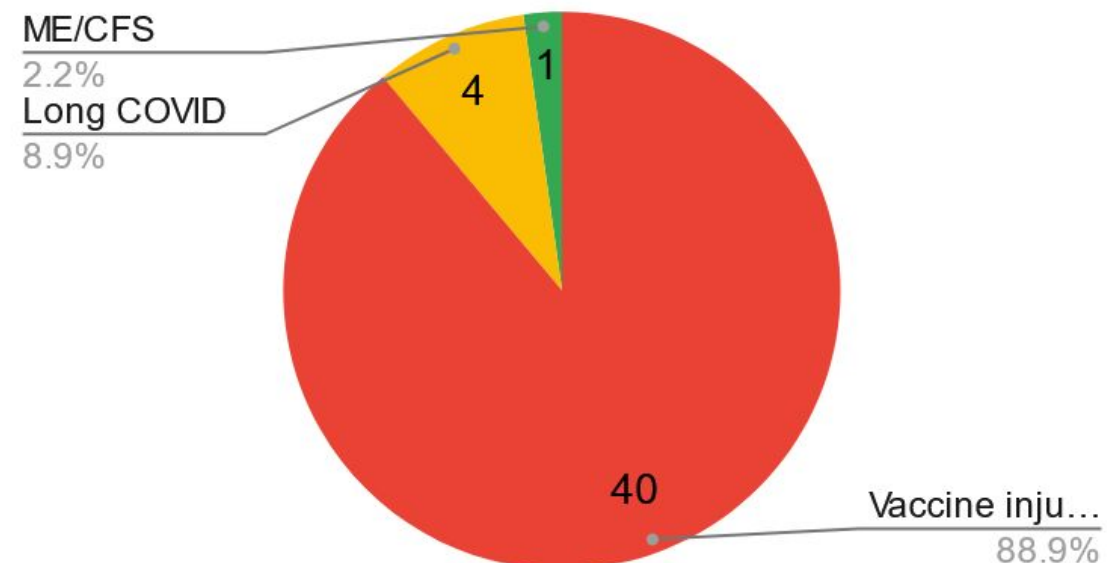
Cluster 0



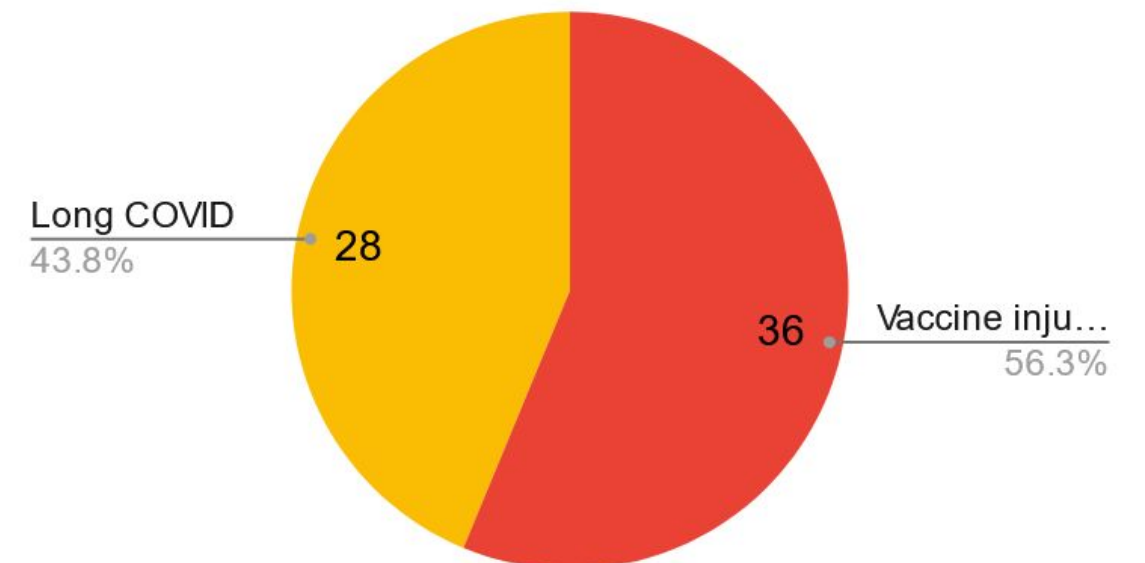
Cluster 1



Cluster 2 (bleeding and blood clots)



Cluster 3



Limitations



The Patient Experiences Survey was **not** designed to carefully compare the chronic illnesses. It did not ask about potentially distinctive symptoms such as loss of taste or smell. It did not ask about most symptoms (there may be over 200 symptoms).

The survey was not iterated repeatedly to reduce erroneous data from questions being misinterpreted, such as the bleeding/clotting cluster identified in the PES dataset.

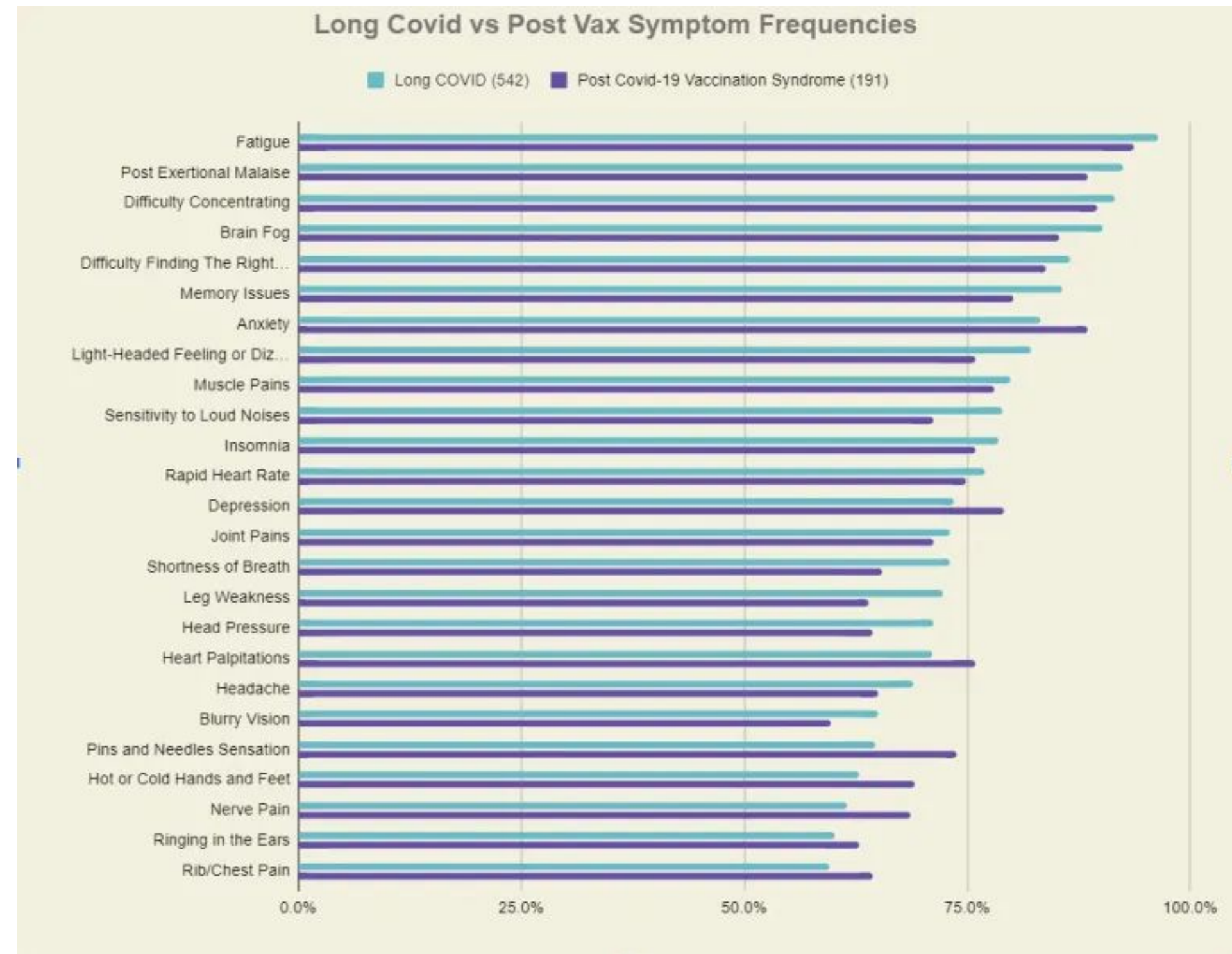


Other datasets- Tom Bunker



A patient-led survey that recruited both Long COVID and the vaccine injured shows a high level of similarity between the 2 chronic illnesses.

RecoverFromLongCovid.com/vaccine-injured-long-covid/



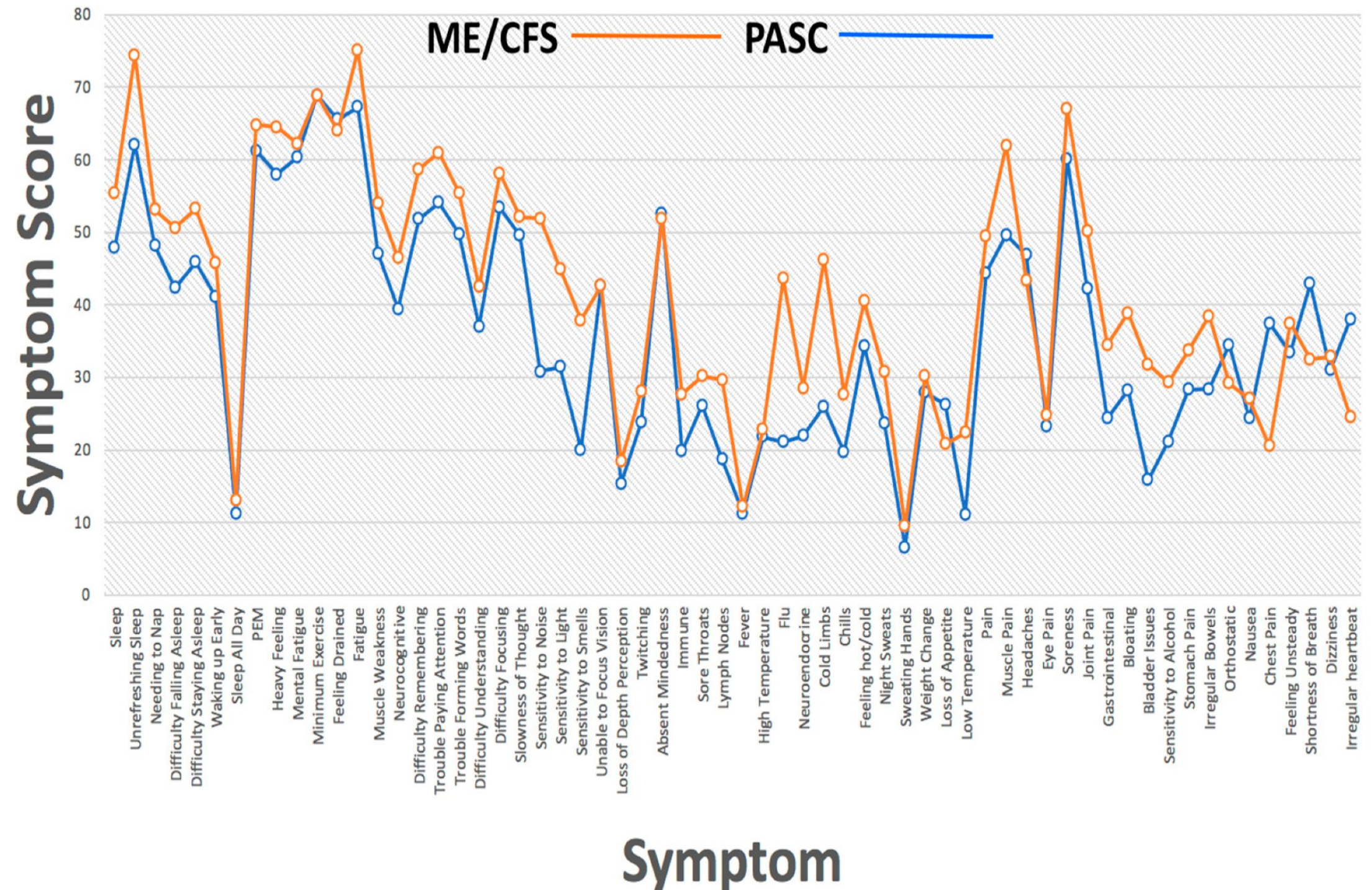
Other datasets- David Marks



A paper by David Marks argues that there is a high degree of similarity between ME/CFS and PASC (Long COVID).

doi.org/10.3390/biomedicines11010180

Symptom Profiles for ME/CFS and PASC





Appendix - Demographics

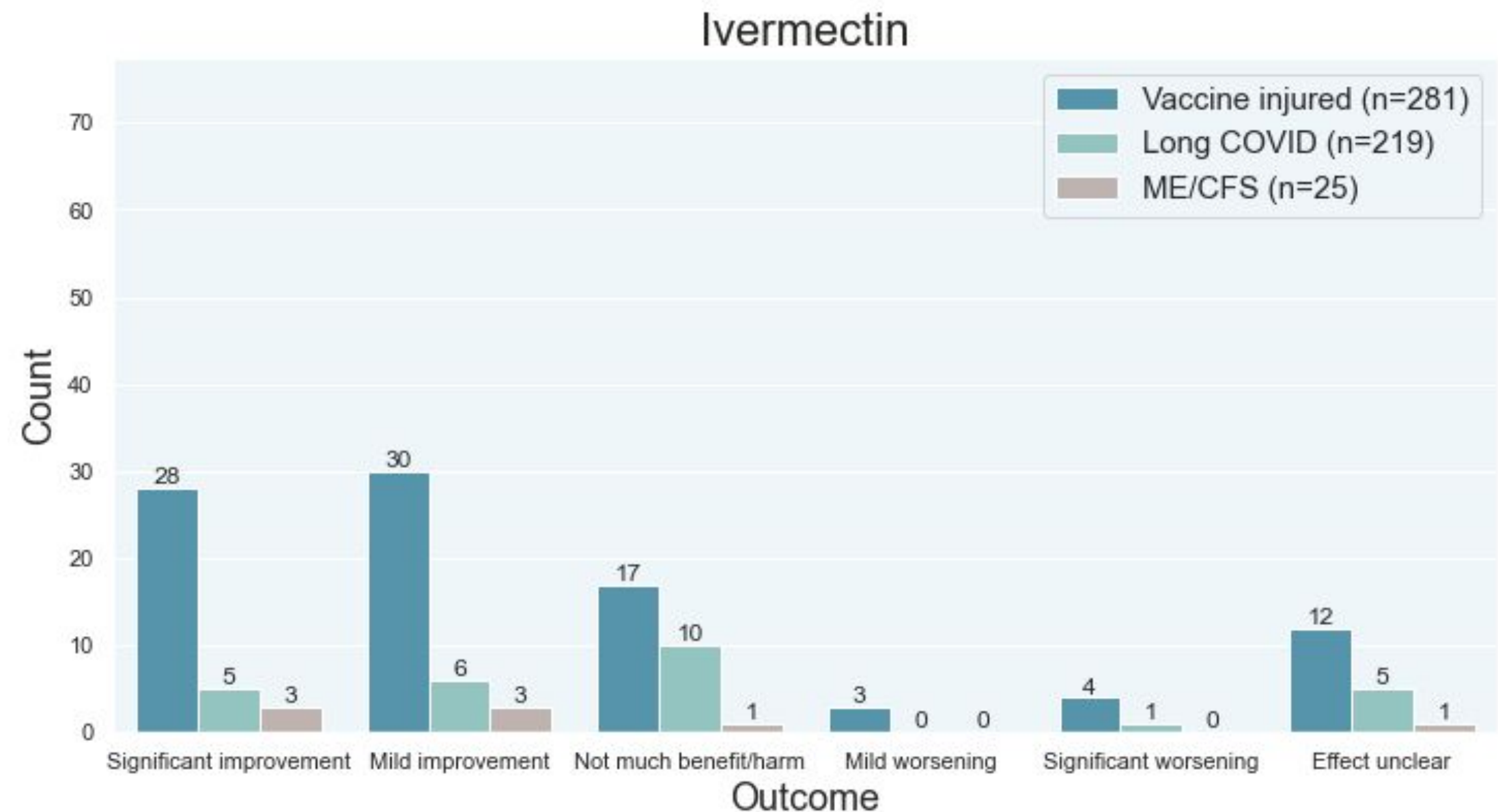


Demographics heavily influenced views on ivermectin



Long COVID participants rated ivermectin worse than other chronic illness groups. As they were recruited mainly from [r/COVIDLongHaulers](#), the political tendencies of that subreddit (e.g. no misinformation, no anti-vaccine content) may have influenced reported outcomes.

Only **12.3%** of LC participants tried ivermectin, lower than the [Treatment Outcomes Survey](#) (**31.0%**). That survey recruited LC participants mainly from certain Facebook groups.

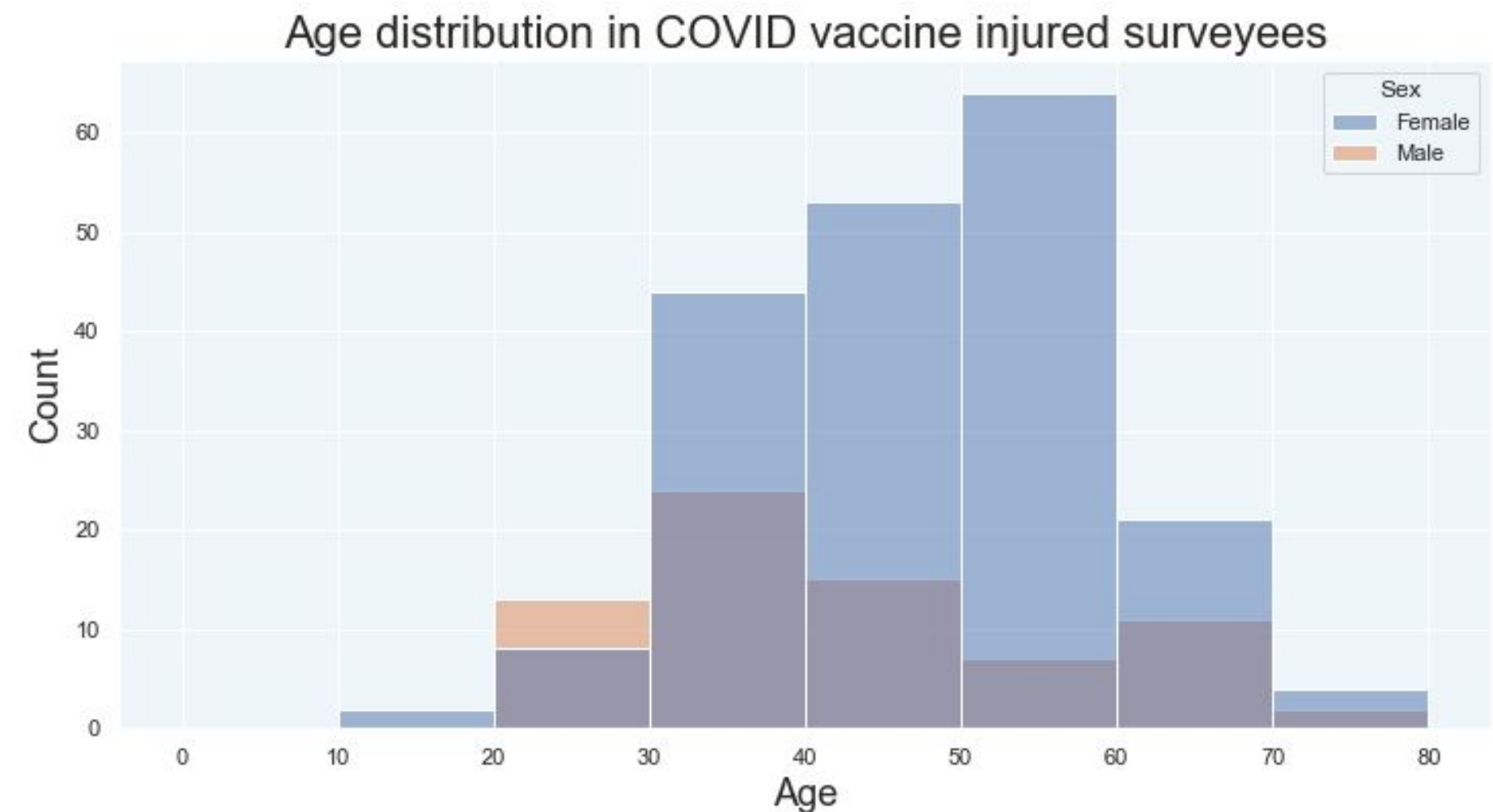
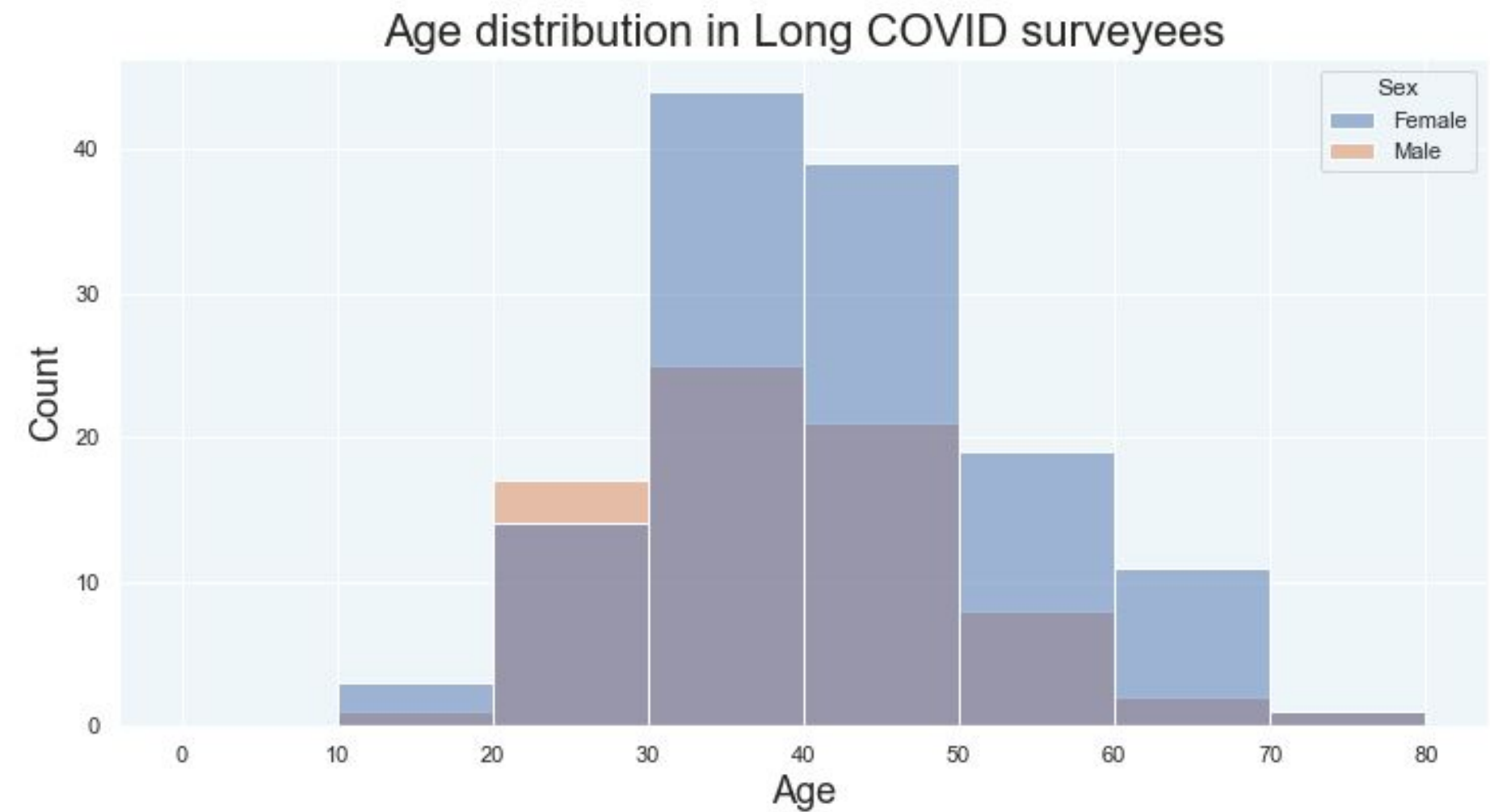


Demographics of Long COVID



In the PES dataset, it appears that Long COVID skews younger in males than it does in females, similar to vaccine injury.

- Blue = biological female
- Orange = biological male





Appendix - Survey Design Issues



Known issues with the dataset



- Some participants did not answer the question for treatments that they tried- a few free-form answers mentioned treatments such as LDN but the surveyee did not answer elsewhere for LDN. (Trying to fix this issue could cause more issues than it would solve.)
- There are likely memory recall issues for treatments tried years ago.
- Increased intake of 'Water and salt' was tried at much higher rates than other POTS treatments. This perhaps suggests that people without POTS interpreted it as a dietary change that they have tried.

