React19 Long-Haul Risk Factors Survey (Full Dataset)

Survey data from April 26 to May 6

REACT 19

RESEARCH • EDUCATION • ACTION • THERAPEUTICS

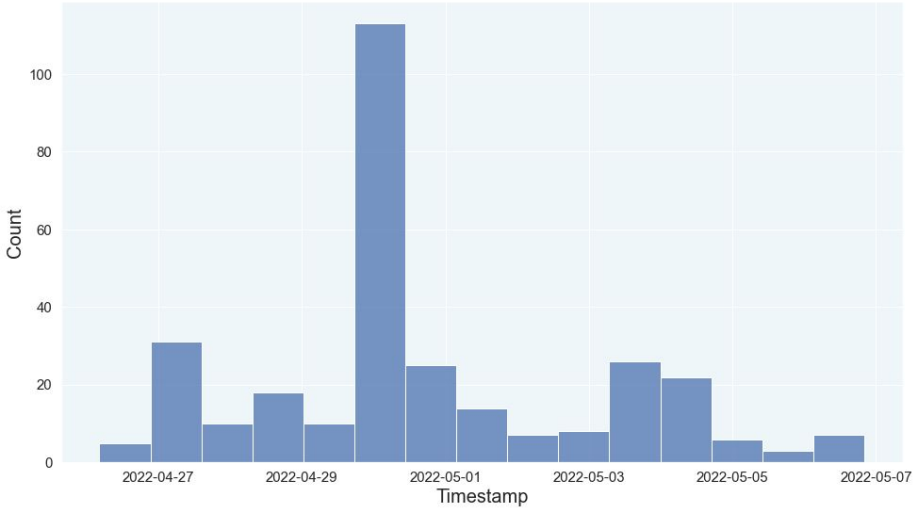
Key findings

1. **Both Long COVID and vaccine injury seem to share three risk factors:**
   - **Autoimmune conditions**
   - **Thyroid disorders**
   - **Certain types of foreign objects in the body**
2. **New autoimmunity, thyroid disorders, and small fiber neuropathy develop at high rates in both groups.**
   - **The composition of autoimmunity was not symmetrical. Celiac and Hashimoto's were far more common as a pre-existing condition while autoimmune Small Fiber Neuropathy appeared only as a new-onset condition.**
3. **Spike protein (re)exposure seems to flare autoimmunity, Long COVID, and vaccine injury.**
   - COVID vaccines in Long COVID patients may carry substantial risk.
4. **Each and every COVID vaccine shot seems to carry a risk of vaccine injury.**

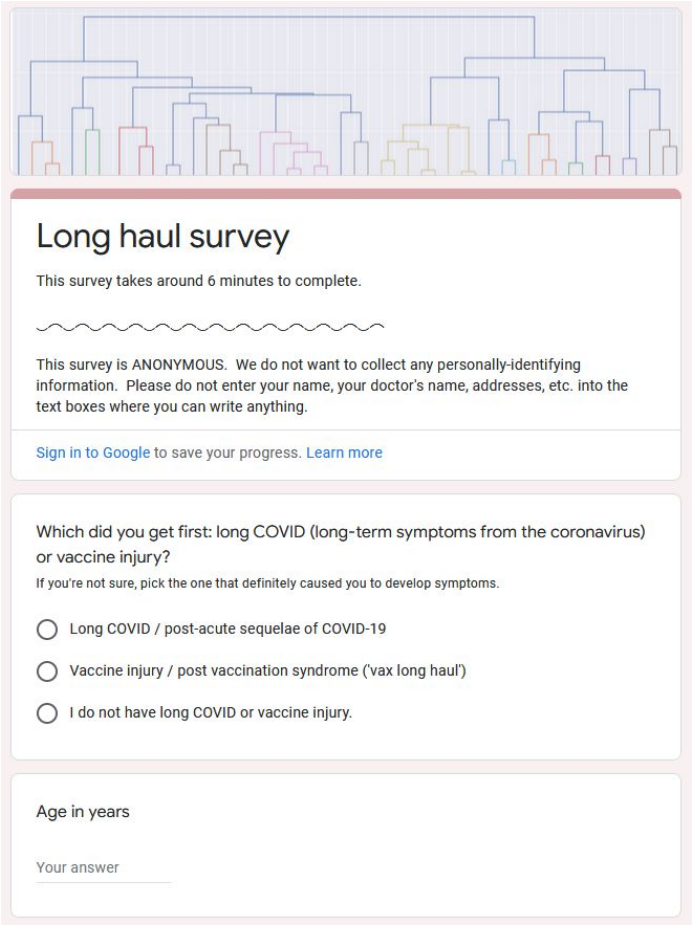
Methodology

Survey

A Google Form was used to collect responses. Survey questions are available via [this link](#).



Survey completion over time.

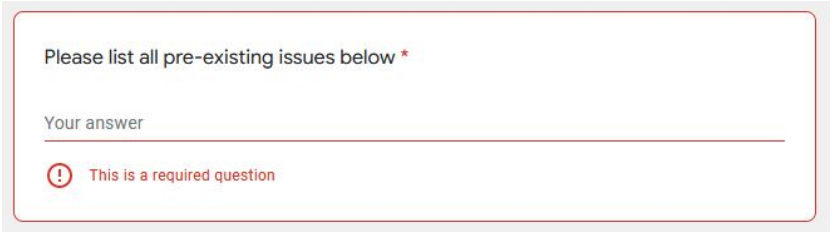


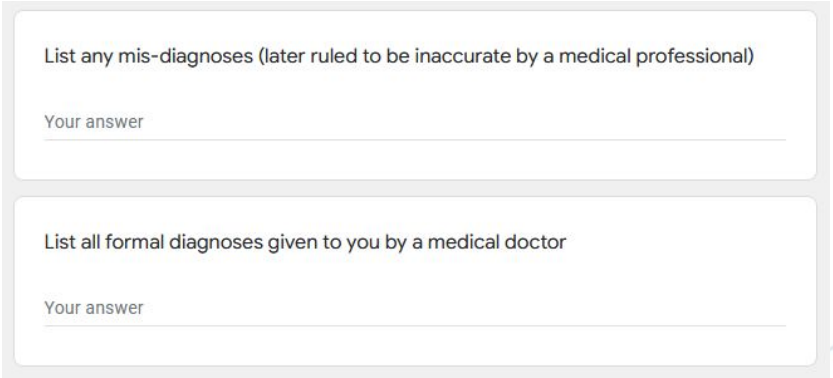
This survey follows up on previous autoimmunity findings

The previous survey asked about pre-existing autoimmune conditions and new diagnoses (questions shown on the right). One goal of this survey was to collect data that is more reliable and comprehensive.

The second goal was to gather data on both Long COVID sufferers and the vaccine injured. This survey explored whether the same phenomena actually exist in both groups of ‘Long-Haul’ patients.

*Long-Haul will refer to Long COVID and vaccine injury (Post COVID Vaccination Syndrome)





All free form responses were manually handled

The image on the right shows some free-form responses for the question about autoimmunity diagnoses after Long-Haul began. Most of the free-form answers were excluded as autoimmune diagnoses.

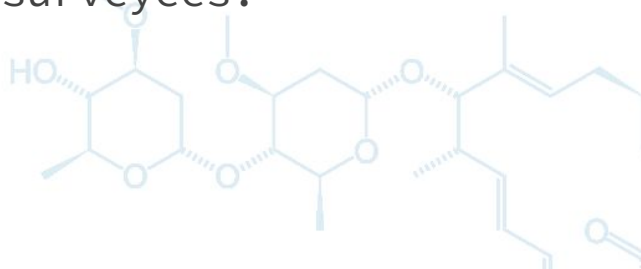
```
# Cleaning up the data for autoimmune conditions after illness/long haul has started
autoimmunity_after_bad_set = {
 ' tcell lymphoma ',
 'After v. Early Sjogren's panel 1 point positive',
 'Connecive tissue disorder',
 'Drs dx me with POTS and an underlying',
 'Dysautonomia (cluster of POTS',
 'Dysautonomia/POTS', # they answered maybe for something that's not autoimmune "Maybe - I have no formal diagnoses but I could
 'gastroperesis',
 'orthostatic hypotension)', #"Dysautonomia (cluster of POTS, gastroperesis, orthostatic hypotension)"
 'Elevated CRP & Sed rate',
 'but not an autoimmune diagnosis. Rather and autoimmune response to vax ', #
 'Endometriosis - formally diagnosed and linked to autoimmune diseases',  # not yet classified as autoimmune
 'FGFR3',
 'Fibromyalgia; ME/CFS',
 'Hashimoto's thyroiditis', # "Maybe - I have no formal diagnoses but I could have an autoimmune condition., Hashimoto's thyroi
 'I have an ANA marker for an immune disorder. My rheumatologist says it is similar to Shoguns',
 'Ibs',
 'mcas',
 'Mcas',
 'MCAS ',
 'MCAS',
 'Mast Cell Activation Syndrome diagnosed',
 'ME/CFS',
 'Positive on most of the celltrend ',
 'Positive to ACE2 and Mas1',
 'MGUS',  # Autoimmune disease is one potential cause of MGUS / (monoclonal gammopathy of unknown significance)
 'Neuropathy',
 'POTS/dysautonomia of post-viral autoimmune origin',  # HMMMM..... not on this list: https://www.autoimmuneregistry.org/the-li
 'Pericarditis',
 'Peripheral neuropathy  ',
 'Psoriasis',  # "Maybe - I have no formal diagnoses but I could have an autoimmune condition
 'Rosacea',
 'Same as before COVID ',
 'See previous question', # "No, I have hypermobile Ehlers Danlos syndrome (formal diagnosis), some research suggests it could

 'Small fibre neuropathy diagnosed after 2nd Pfizer. Symptoms began within 1 week and escalated. ', # HMMM didn't specify auto-
 'small fiber neuropathy',  # "small fiber neuropathy, acute onset"
 'Sfn',  # "Sfn, dysautonomy"
 'dysautonomy', # "Sfn, dysautonomy"

 'acute onset',
 'TS-HDS autoantibodies ', # HMMM they haven't received a diagnosis yet?
 'Visual Snow Syndrome',
 'but am only learning about them now. 2 years in and a doctor actually ran comprehensive labwork.', # "Maybe - I have no forma
 'but is not Shoguns. The marker has increased over the last 2 years.', # "I have an ANA marker for an immune disorder. My rheu
 'i have labwork consistent with autoimmune diseases',
```

Autoimmunity data

Key autoimmunity findings

There were very high rates of autoimmune diagnoses before and after Long-Haul.

1. Among Long COVID patients, **16.0%** had a formal diagnosis before Long COVID and **10.0%** had a new diagnosis after Long COVID.
2. Among the vaccine injured Long-Haulers, **21.8%** had a diagnosis pre-vax and **13.9%** had a new diagnosis post-vax.
3. Long-Haul syndromes (Long COVID and vaccine injury) caused pre-existing autoimmunity to flare in many surveyees.



Autoimmunity data

The columns of data on the right contain Long COVID data followed by vaccine injury data. While celiac and Hashimoto's made up **41%** (34/82) of pre-existing conditions , they made up **11%** (5/46) of new-onset conditions.

The cause of this asymmetry is unclear.

	Pre-existing Long COVID	New onset Long COVID	Pre-existing Vaccine injury	New onset Vaccine injury
Cohort size	100	100	202	202
Total with autoimmunity	16	10	44	28
% of cohort	16.00%	10.00%	21.78%	13.86%
Name of autoimmune condition				
Alopecia	0	0	3	1
Anti-MAG		1		0
Antiphospholipid syndrome		1		1
Autoimmune gastritis	0	0	1	1
Autoimmune hemolytic anemia		0		1
Autoimmune SFN		1		2
Celiac	4	1	10	1
Crohns	0	0	4	0
Glomerular Membranous Nephropathy	0		1	
Graves' disease	1	1	2	2
GBS AMAN variant		0		1
Hashimotos thyroiditis	5	0	15	3
IBD	2	0	7	1
Lympocytic colitis		0		0
Lupus	1	1	2	1
Multiple sclerosis	1		0	
Mixed Connective Tissue Disorder		0		2
Pernicious anemia	0	0	4	2
Neutropenia		0		1
Polymyalgia rheumatica	1	0	0	2
Psoriasis	2	1	2	0
Psoriatic arthritis	1	0	1	0
Rheumatoid arthritis	2	2	2	1
Scleroderma		1		1
Sjogrens	1	2	4	3
Transverse myelitis		0		1
Type 1 diabetes		0		1
Ulcerative colitis	0		1	
Undifferentiated Connective Tissue Disease		0		1
Uveitis		1		0
Ulcerative proctitis	0		1	
Vasculitis		1		2
Vitiligo	0		1	

Causes of non-overlapping autoimmunity

One possibility is that different forces lead to the develop of the new, different forms of autoimmunity. The joint replacement literature describes how invasive surgery leads to the development of very specific forms of autoimmunity: heparin-induced thrombocytopenia (HIT) and auto-antibodies against PF4.

Warkentin and Greinacher (doi:10.1016/j.thromres.2021.05.018) cites another study where knee replacement surgery (TKA) without heparin led to **26%** of patients developing anti-PF4. The type of surgery makes a difference, as THA (hip replacement) had roughly half the rate of TKA.

They also argue that knee replacement leads to a HIT syndrome that is very similar to a specific vaccine injury called VITT (vaccine-induced immune thrombotic thrombocytopenia).

Causes of non-overlapping autoimmunity (continued)

A prospective case-control study of 796 TKA patients found that **20.35%** (162/796) of the patients developed subclinical hypothyroidism with anti-TPO auto-antibodies. See Jing et al. (doi:10.1111/os.12934).

Perhaps more research would help us understand why specific forms of auto-immunity develop in patients who have never had surgery.

The survey data does suggest that spike protein exposure (from Long COVID and COVID vaccines) promotes the development of some autoimmune conditions more than others, perhaps similar to how invasive surgery promotes the development of very specific forms of autoimmunity.

Autoimmunity is a risk factor for future autoimmunity?

26.8% of surveyees with an autoimmune diagnosis before their illness began received a new autoimmune diagnosis post-illness.

9.7% of surveyees without an autoimmune diagnosis before their illness began received a new autoimmune diagnosis post-illness.

Baseline comparison

The rate of pre-existing autoimmunity was higher than baseline rates. Baseline data (the rightmost column in the table on the right) was taken from AutoimmuneRegistry.org.

Overall autoimmunity rate: A 2005 NIH report estimates that autoimmune diseases affect *up to* **8%** of the population (pg 8). Adjusted for sex*, the baseline rate of (up to) **10.8–12.8%** is lower than the rate in the Long-Haul groups surveyed- **16.0%** for Long COVID and **21.8%** for vaccine injury.

*At least **85.8%** of the surveyees were biologically female. The sex difference can be adjusted by multiplying 8% by ~1.35 to ~1.6.

	Pre-existing Long COVID	Pre-existing Vaccine injury	Baseline
Total	16	44	
% of cohort	16.00%	21.78%	
Name of autoimmune condition			
Alopecia		1.49%	0.21%
Autoimmune gastritis		0.50%	0.02%
Celiac	4.00%	4.95%	0.75%
Crohn's (excl. those who specified IBD)		1.98%	0.60%
Ulcerative proctitis		0.50%	
IBD	2.00%	3.47%	1.09% (Crohn's + UC)
Glomerular Membranous Nephropathy		0.50%	
Graves' disease	1.00%	0.99%	0.63%
Hashimotos thyroiditis	5.00%	7.43%	0.52%
Lupus	1.00%	0.99%	0.07%
Multiple sclerosis	1.00%		0.24%
Pernicious anemia		1.98%	0.49%
Polymyalgia rheumatica	1.00%		0.22%
Psoriasis	2.00%	0.99%	2.60%
Psoriatic arthritis	1.00%	0.50%	0.06%
Rheumatoid arthritis	2.00%	0.99%	0.33%
Sjogrens	1.00%	1.98%	0.15%
Ulcerative colitis		0.50%	0.49%
Vitiligo		0.50%	0.10%

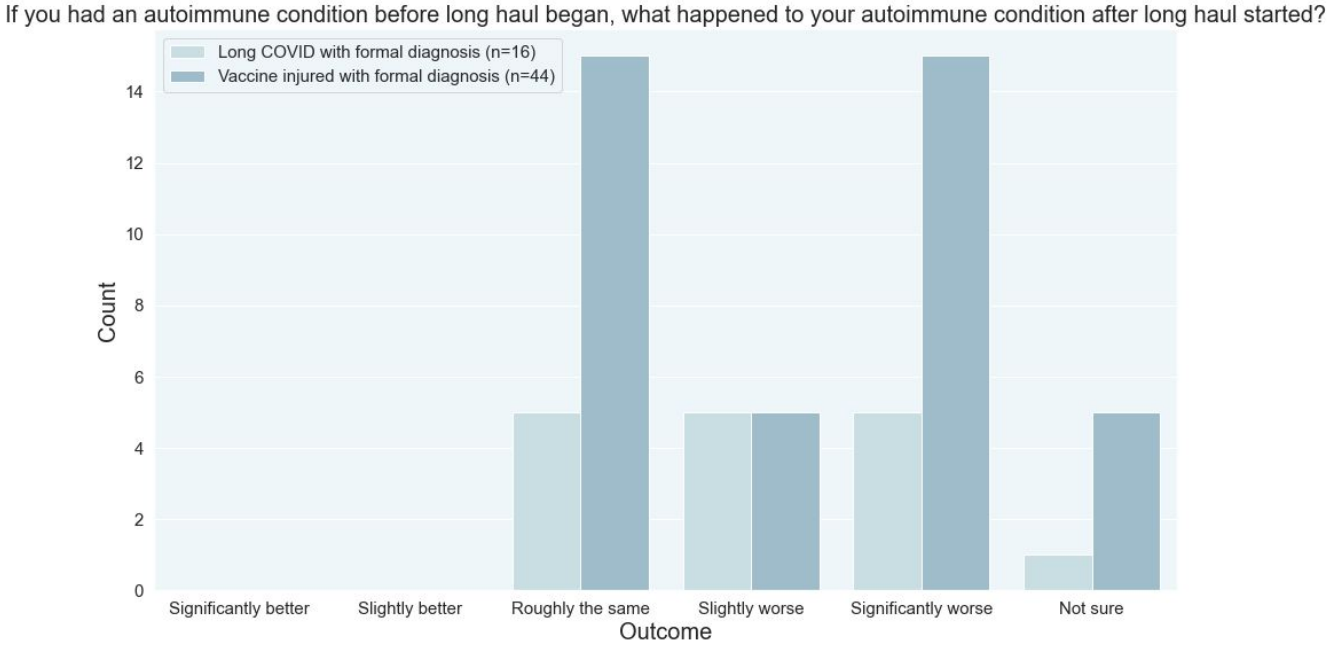
Caveats

It is very difficult to generate valid data regarding pre-existing autoimmunity as a risk factor. The appendices in this presentation contain a deeper look into those difficulties and why baseline rates of autoimmunity are difficult to determine. Please use some caution as baseline comparisons will have some reliability issues. As well, this survey may actually *under*state the rate of autoimmunity.

Flaring of autoimmunity following Long-Haul

53.4% (30/56) of the surveyees reported worsening of their autoimmunity symptoms following the onset of Long-Haul.

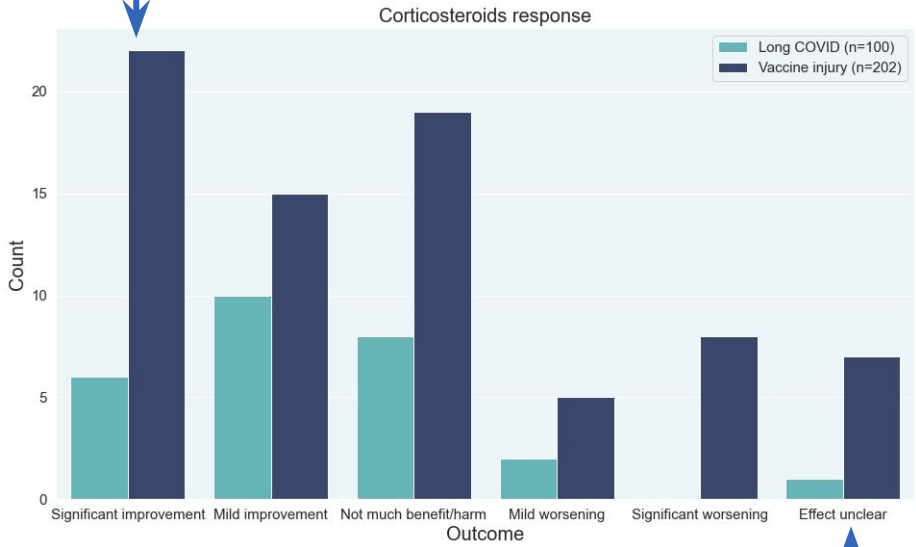
Treatment guidelines from the American College of Rheumatology have previously reported autoimmunity flaring and new-onset autoimmunity following COVID vaccination (DOI:10.1002/art.41877).



Treatment response and autoimmunity

Surveyees had the option of 6 checkboxes:

- “Tried this, effect was unclear.”
- 5 checkboxes ranging from “Significant improvement” to “Significant worsening”.

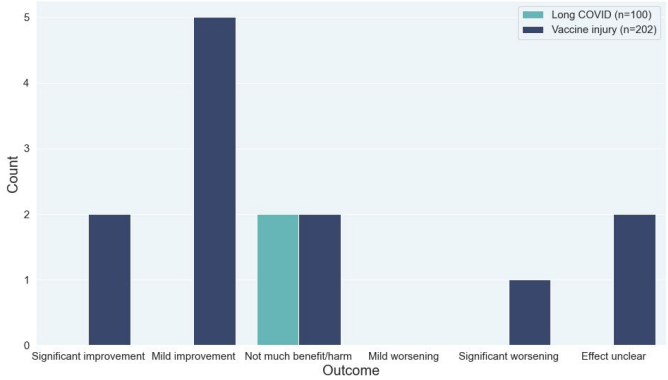


An important caveat

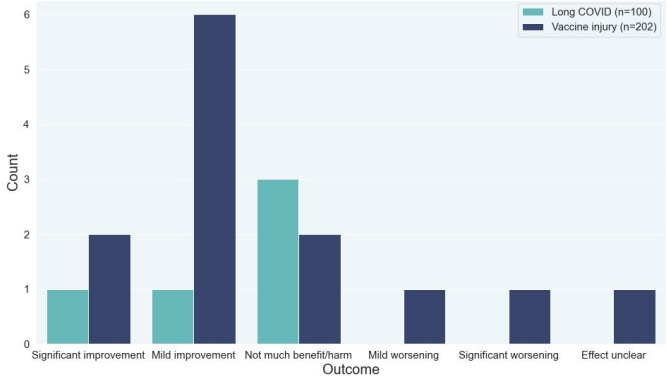
The survey data may not always be measuring health outcomes.

For example, surveyees reported positive results from *both* the carnivore and vegan diets. Because both diets may have opposite mechanisms (no plants versus all plants), it is possible that at least one diet does not work. If that is true, then the survey data is showing something other than health outcomes.

Carnivore or meat only diet



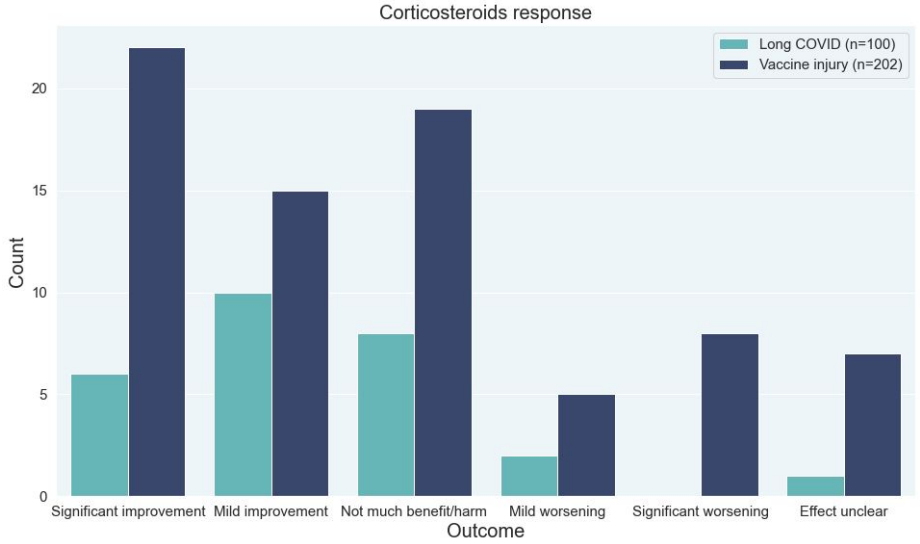
Vegan diet

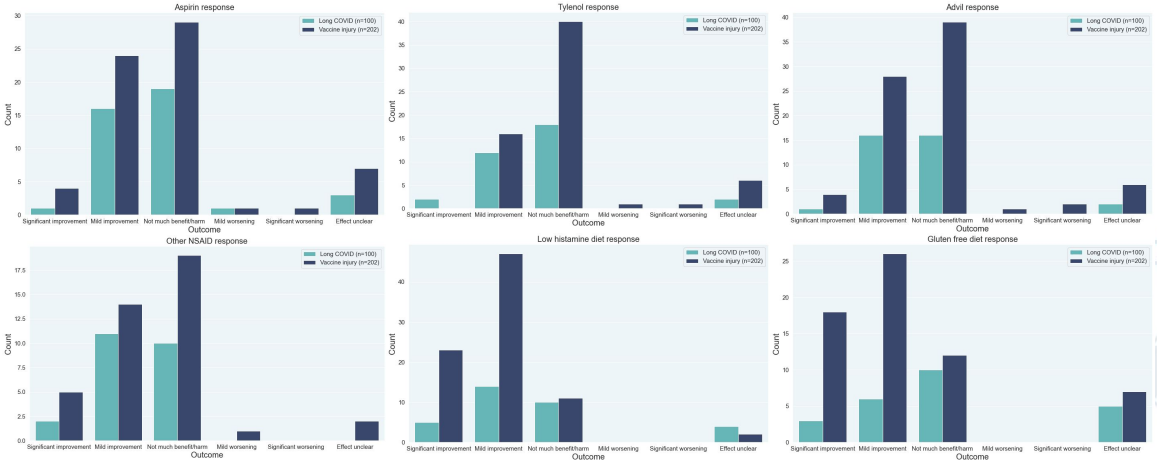


Response to corticosteroids was double-edged, unlike other treatments

Most treatments polled had very few surveyees reporting worsening of symptoms. Corticosteroids were the exception. There were more extreme results on both ends, with a greater proportion of patients reporting significant improvement and significant worsening of symptoms. Corticosteroids seem to be a double-edged sword.

*The survey did not differentiate between low-dose and high-dose steroids.

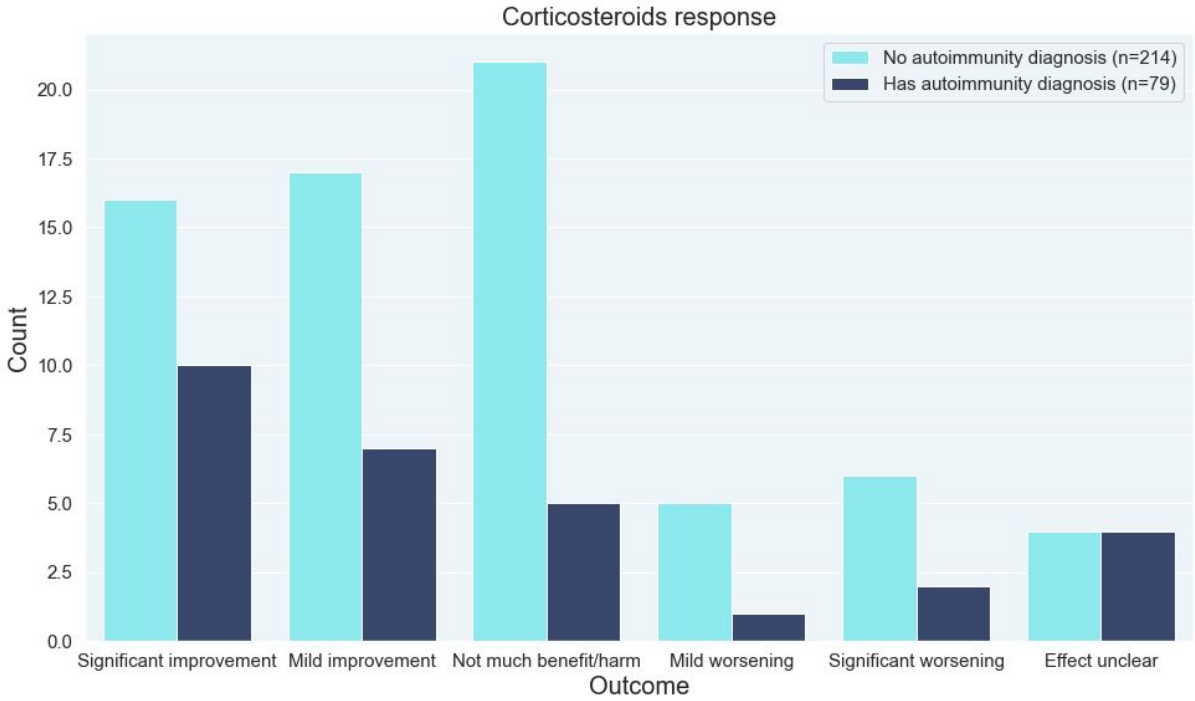




Corticosteroids and autoimmunity

Surveyees without a formal autoimmunity diagnosis also reported high rates of improvement on corticosteroids (though a minority reported significant worsening).

One possibility is that these surveyees have an unrecognized autoimmune condition. Other explanations are also possible.

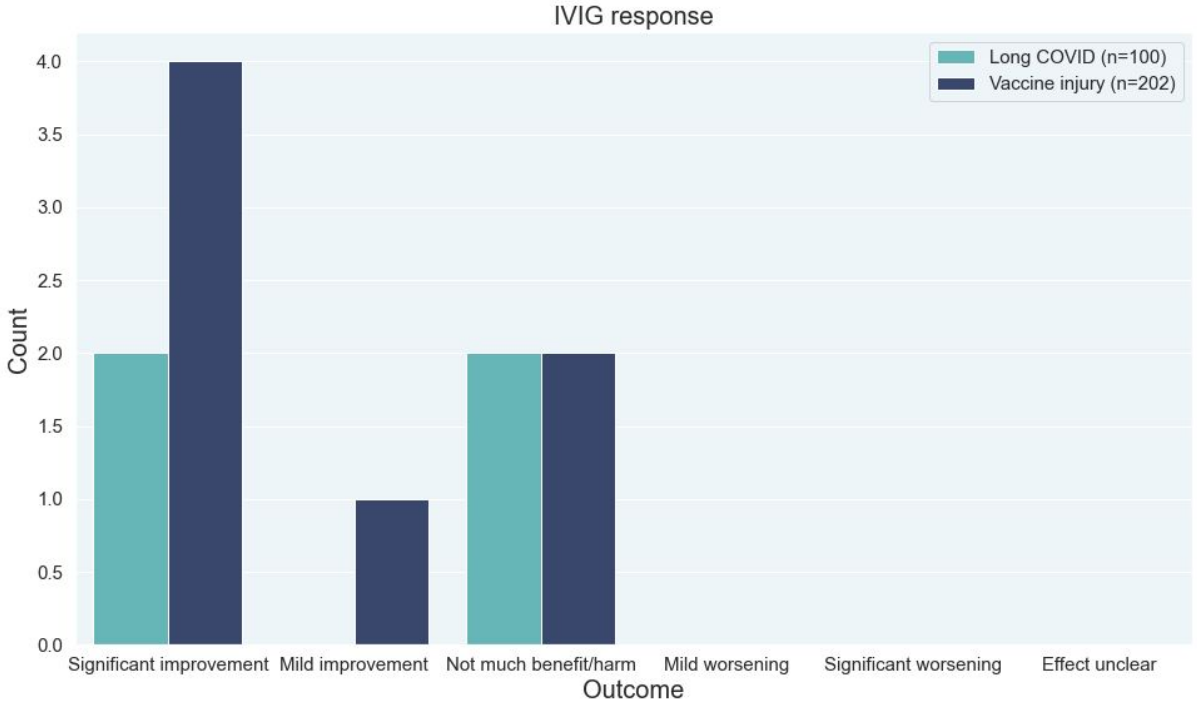


IVIG

Intravenous immunoglobulins are used to treat Guillain-Barre Syndrome and other autoimmune conditions.

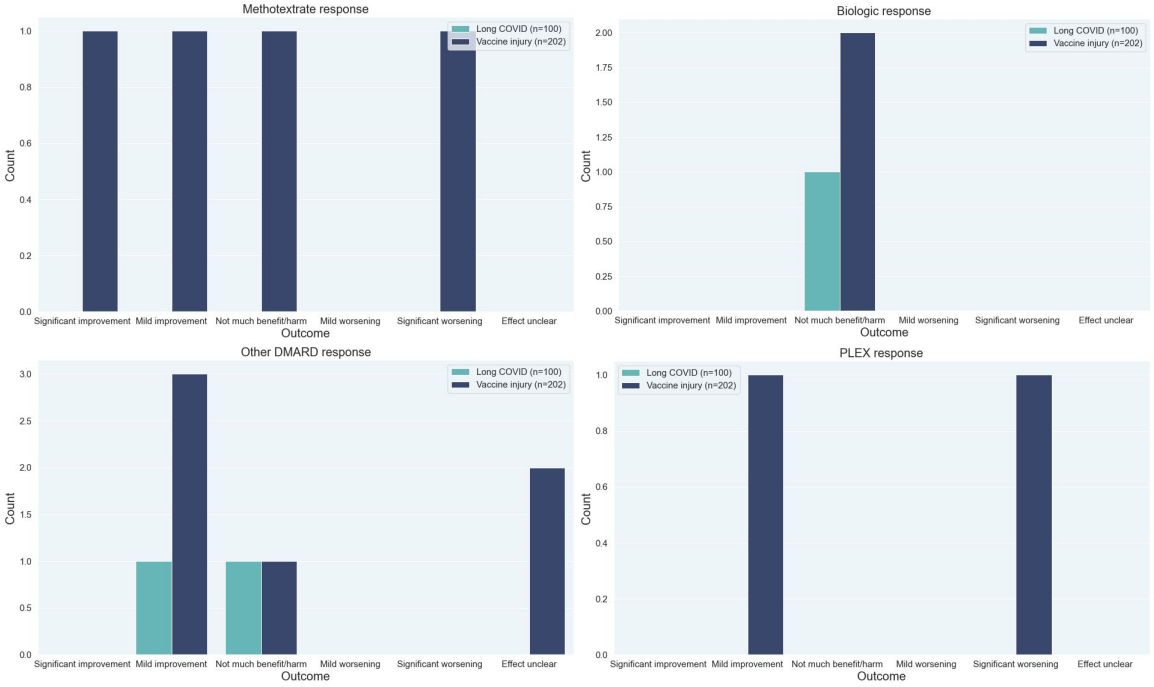
Its effectiveness on autoimmune conditions has been debated, with some arguing that randomized controlled trials have found IVIG ineffective for many conditions (e.g. this CADTH report).

Unfortunately, the sample size was low. It is difficult to draw meaningful conclusions from this data.



Other treatments for autoimmune conditions

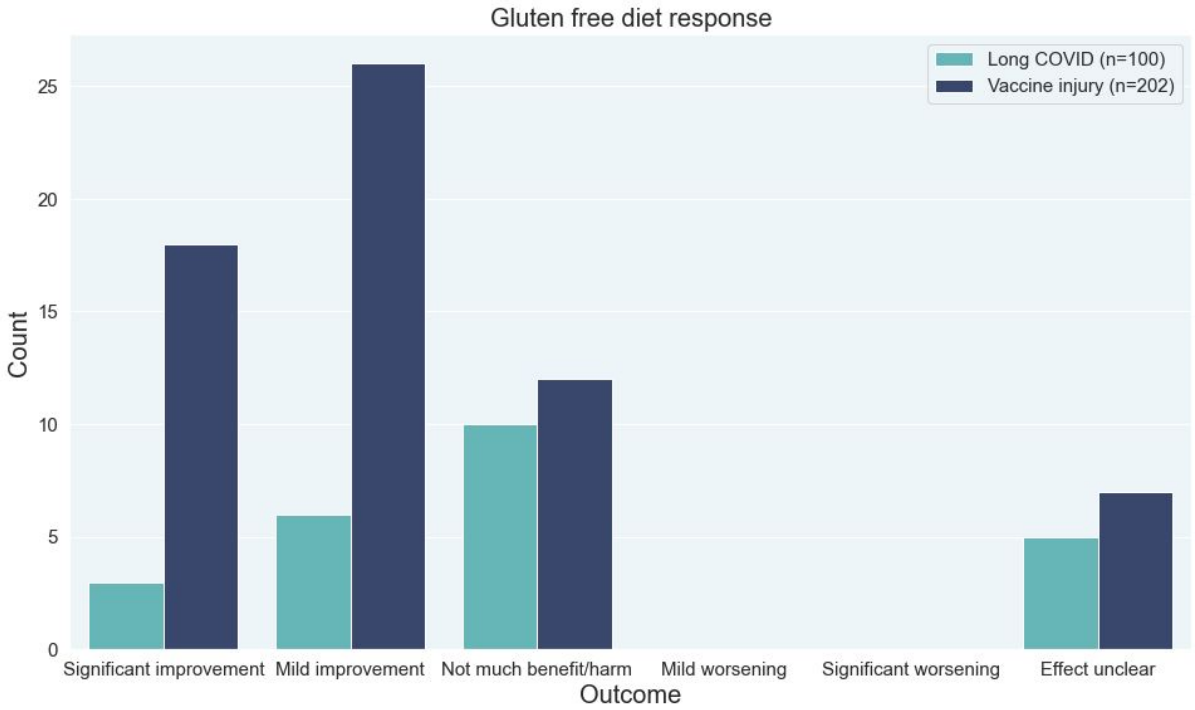
Unfortunately, the other therapies are not very popular. There is not much data to work with.



Gluten free diet

The gluten-free diet is the first-line therapy for celiac disease. Like most of the diets surveyed, some reported significant improvement while there were practically zero surveyees who reported negative effects.

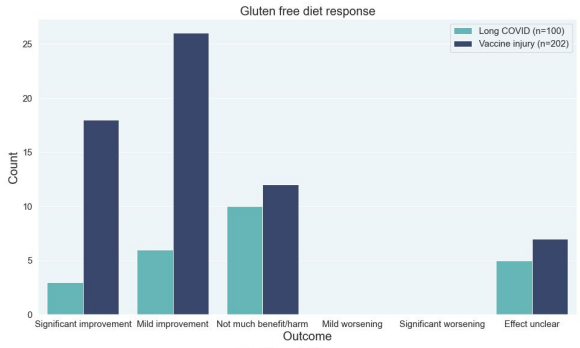
In this survey, there did not seem to be an obvious intersection between diet and autoimmunity. Diets used to treat autoimmunity, e.g. the ‘carnivore’ diet*, did not seem to fare much differently than other diets.

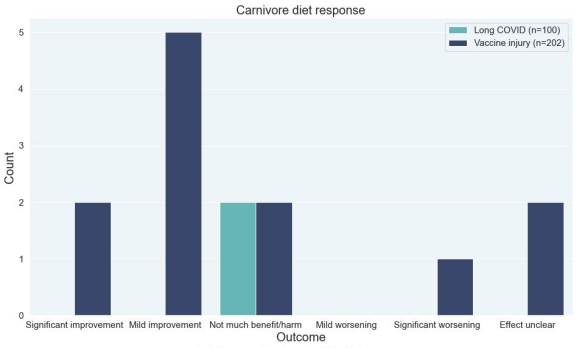


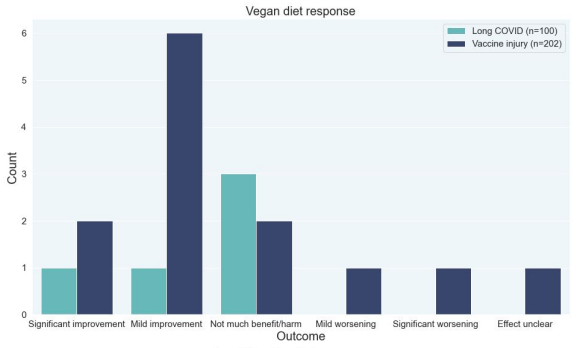
*A Harvard survey on the carnivore diet (DOI:10.1093/cdn/nzab133) found that some Type 1 Diabetes patients were able to go off insulin. 36% of long-term carnivores reported that their autoimmune condition resolved.

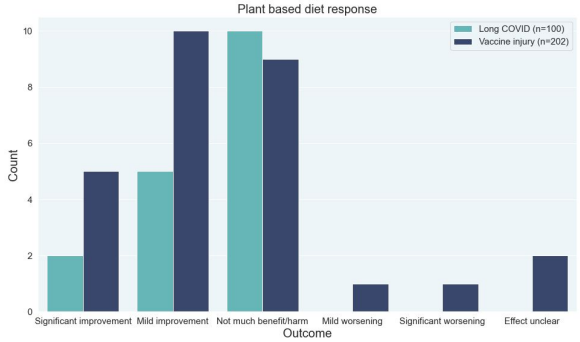
All of the diets surveyed had a favorable survey response

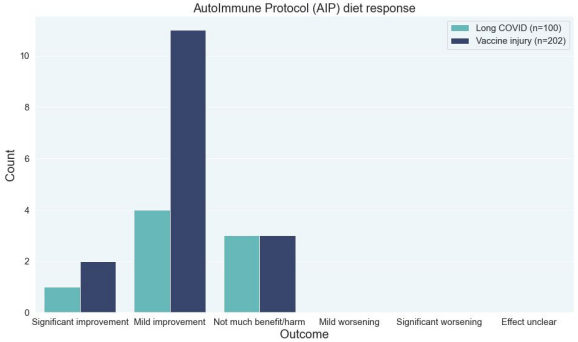
Larger charts follow this slide, including the Wahls protocol and other diet which were not shown below.

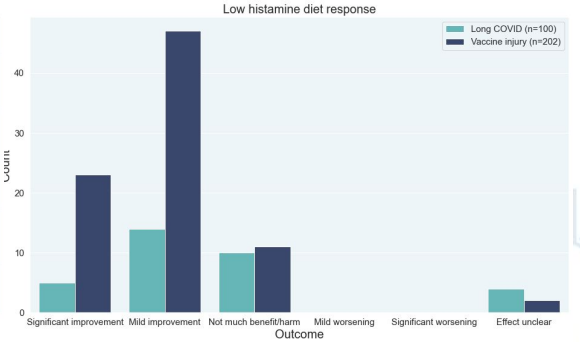


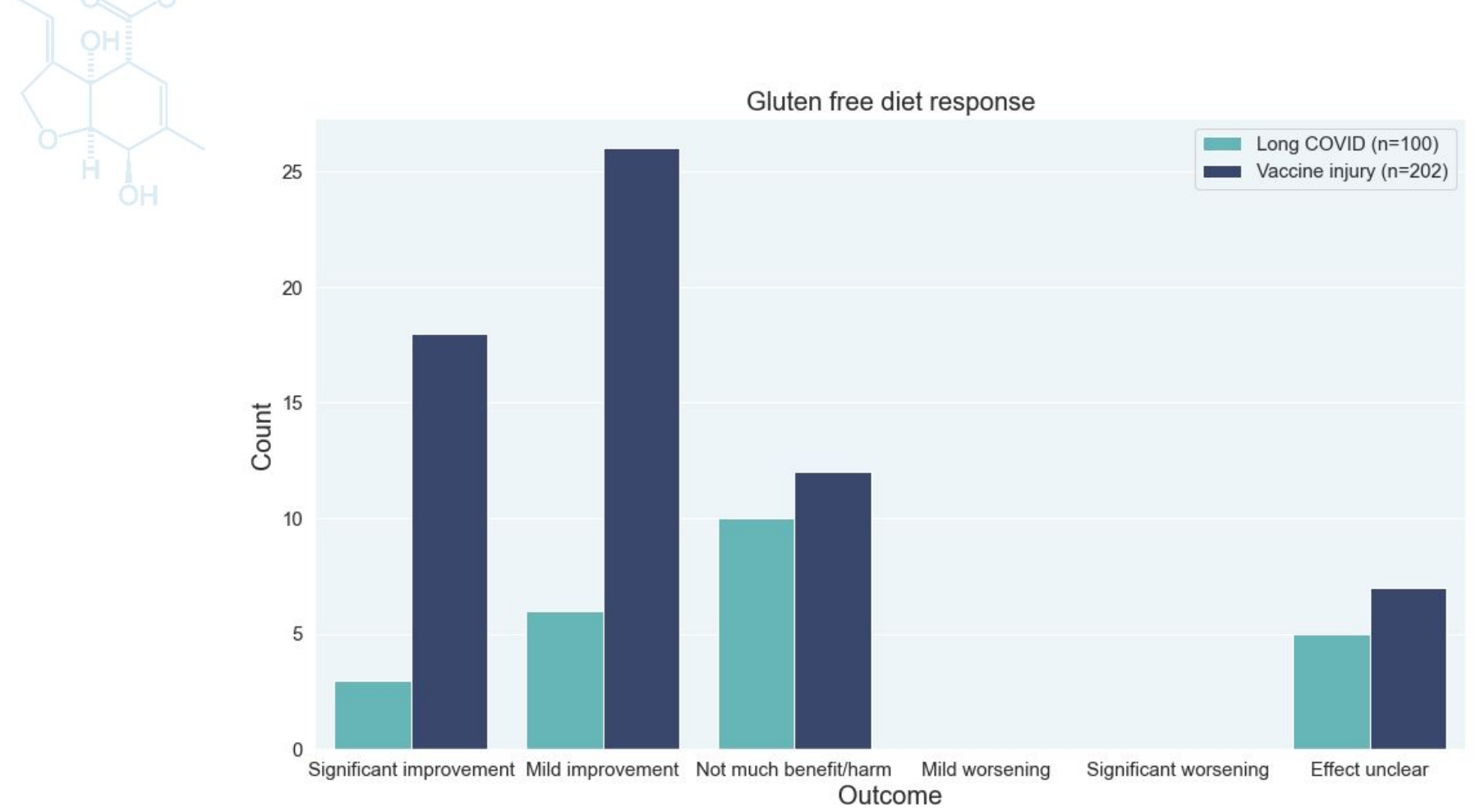


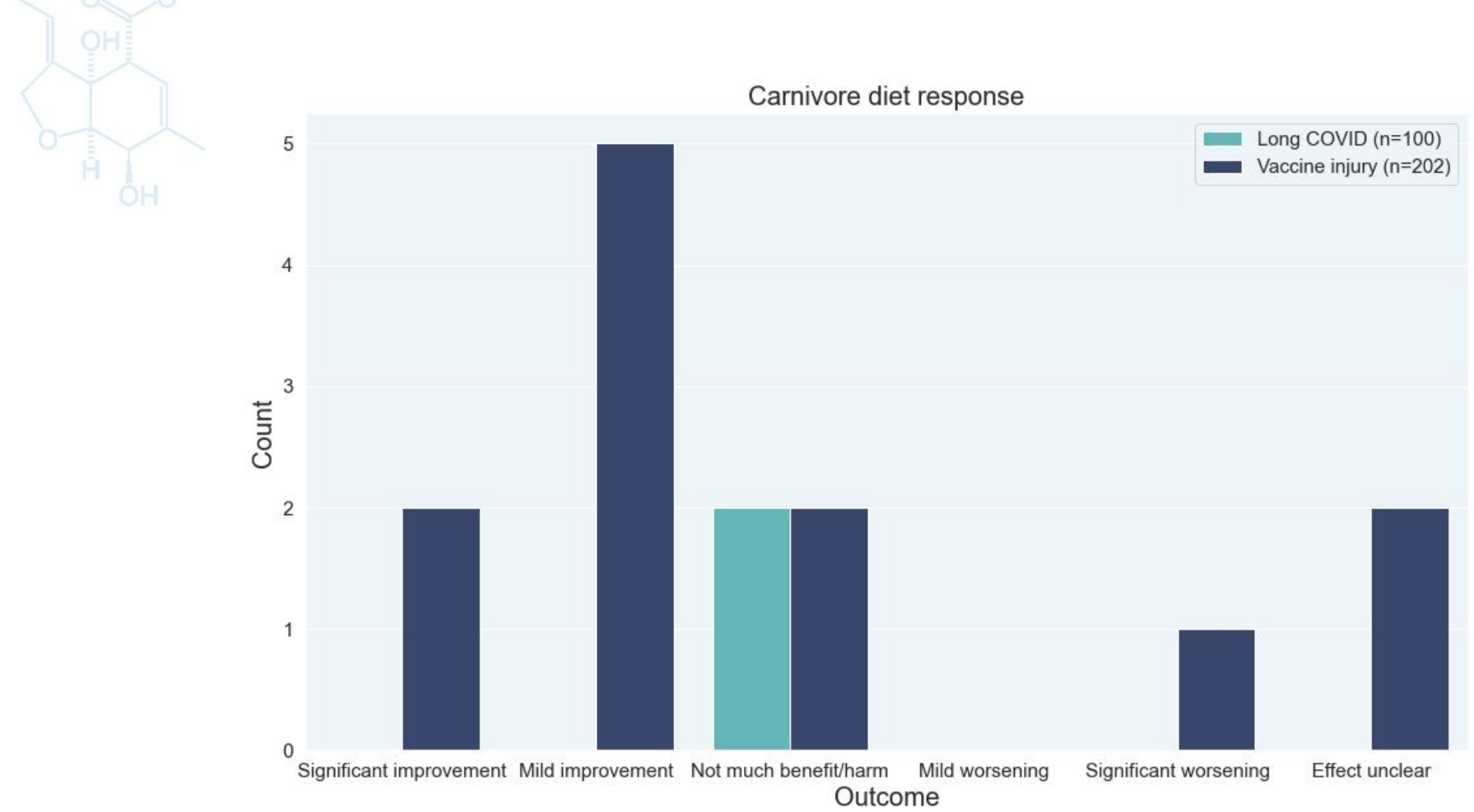


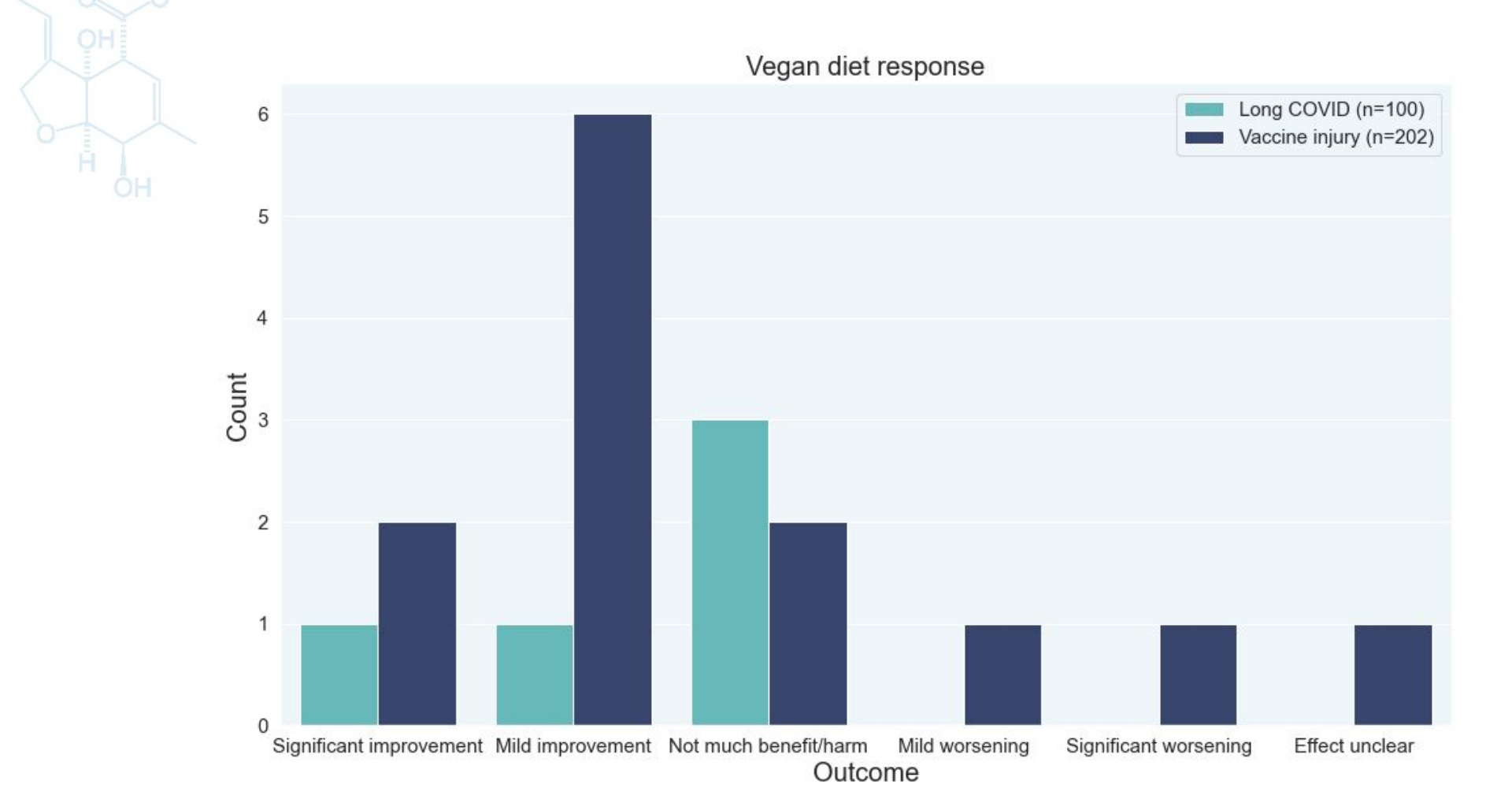


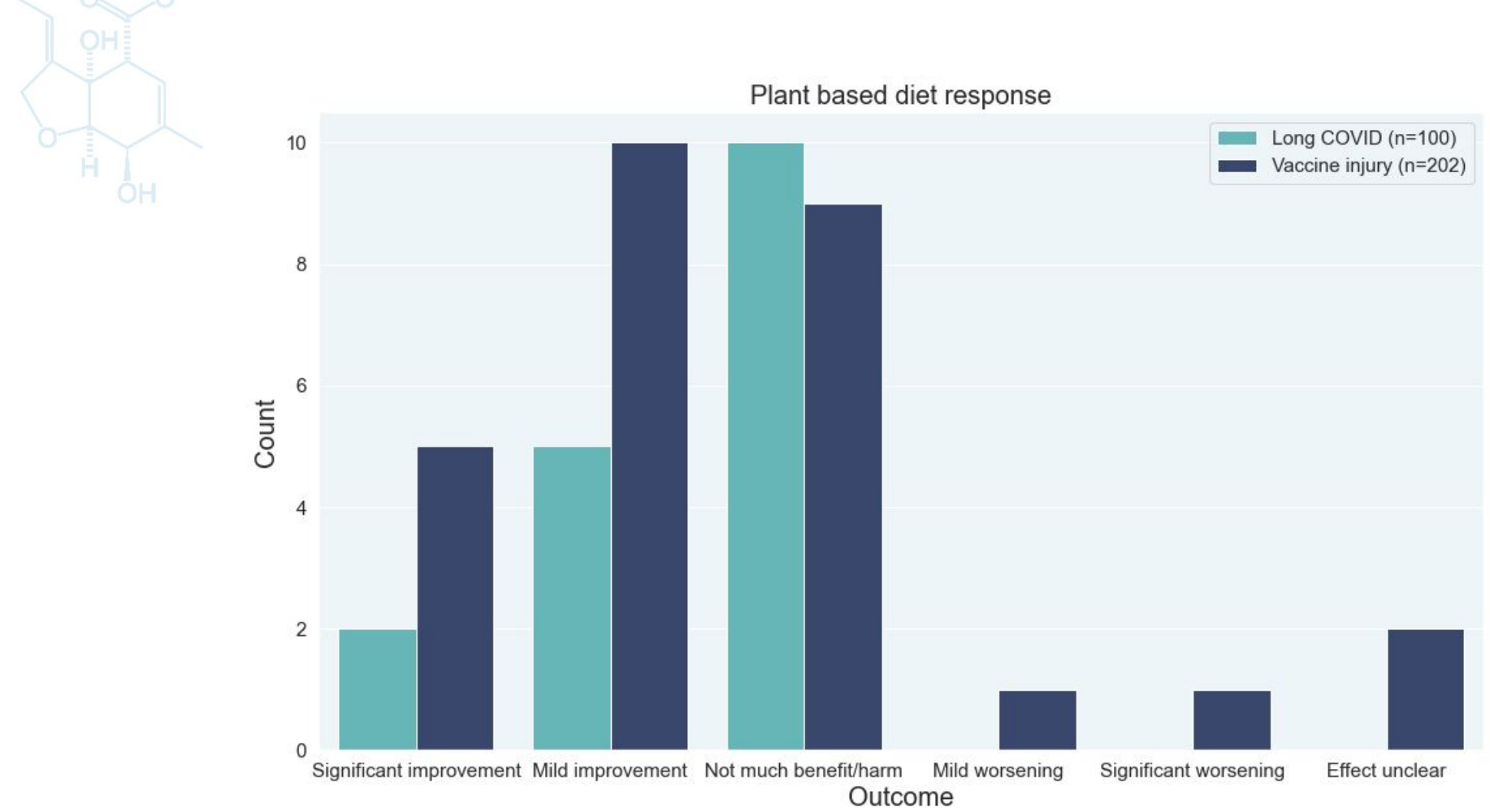


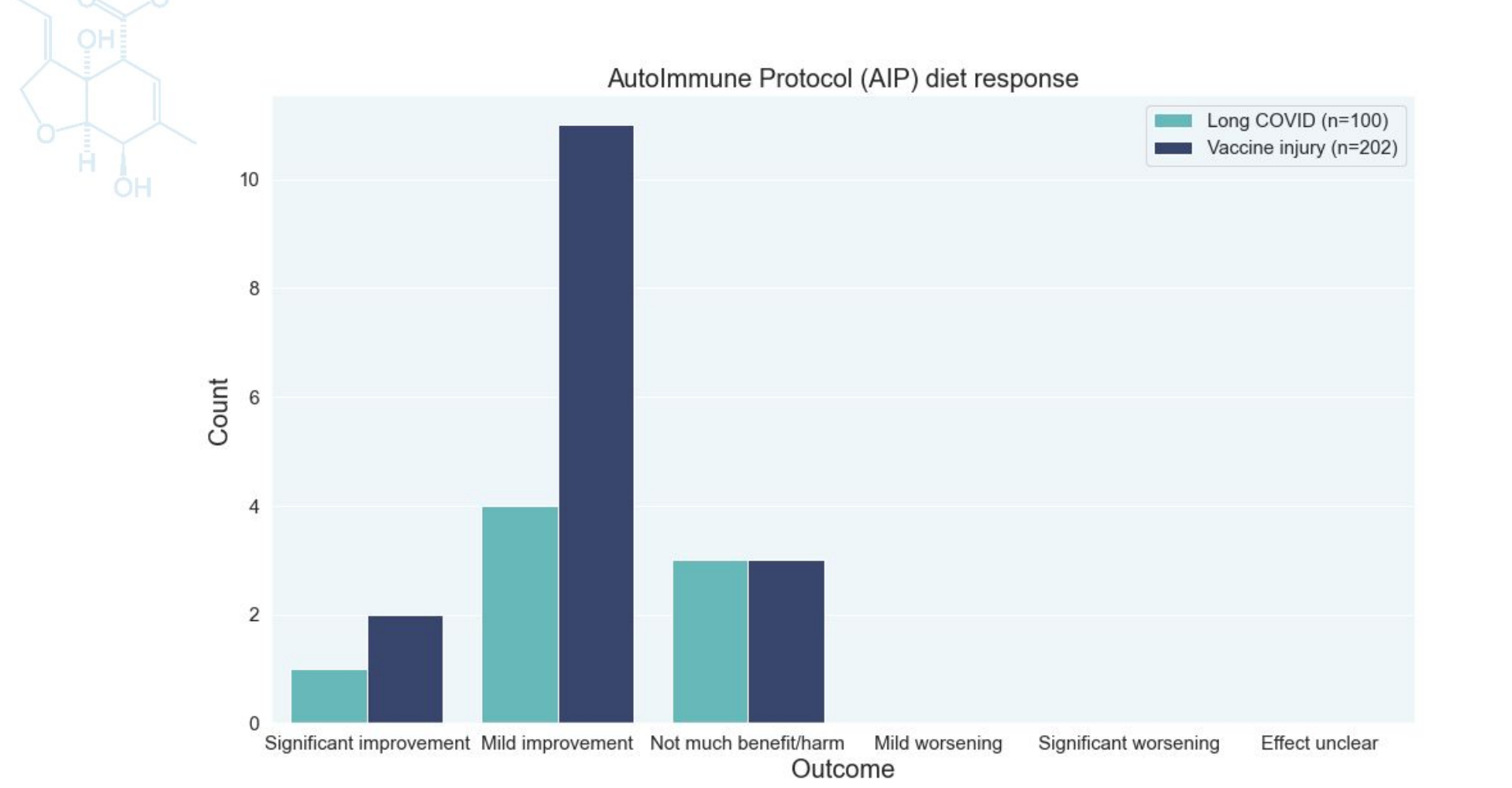


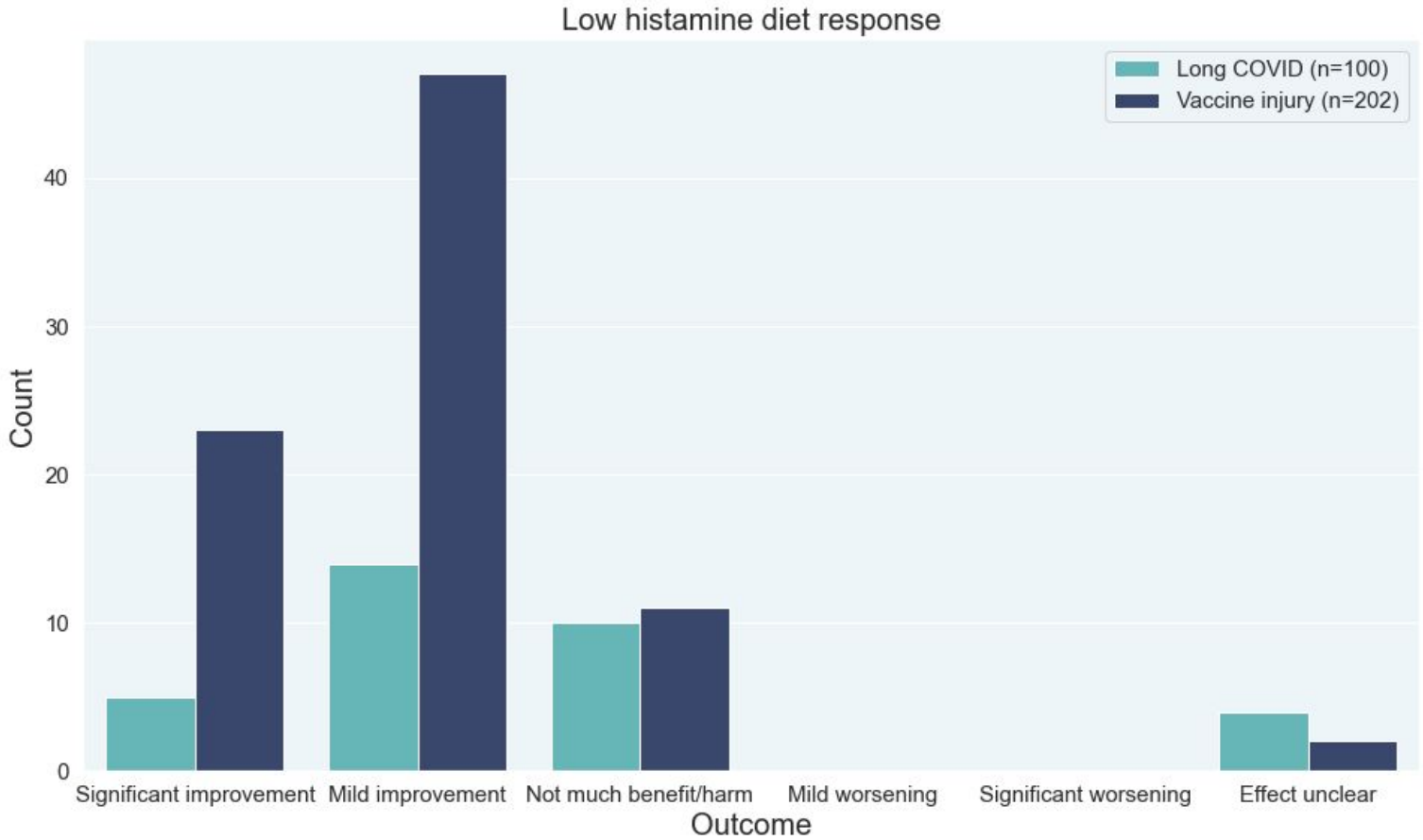

Gluten free diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
5
10
15
20
25
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

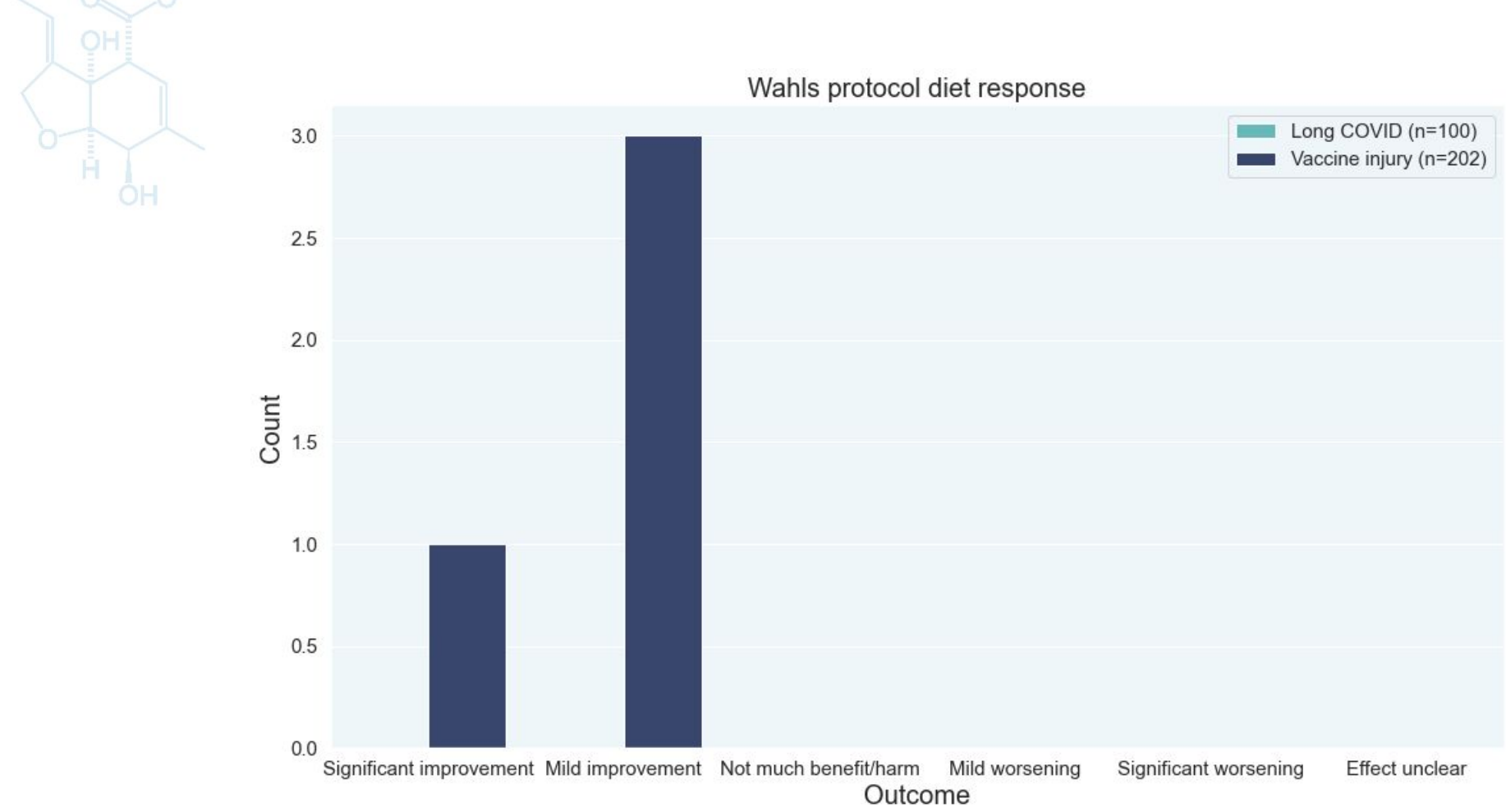

Carnivore diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
1
2
3
4
5
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

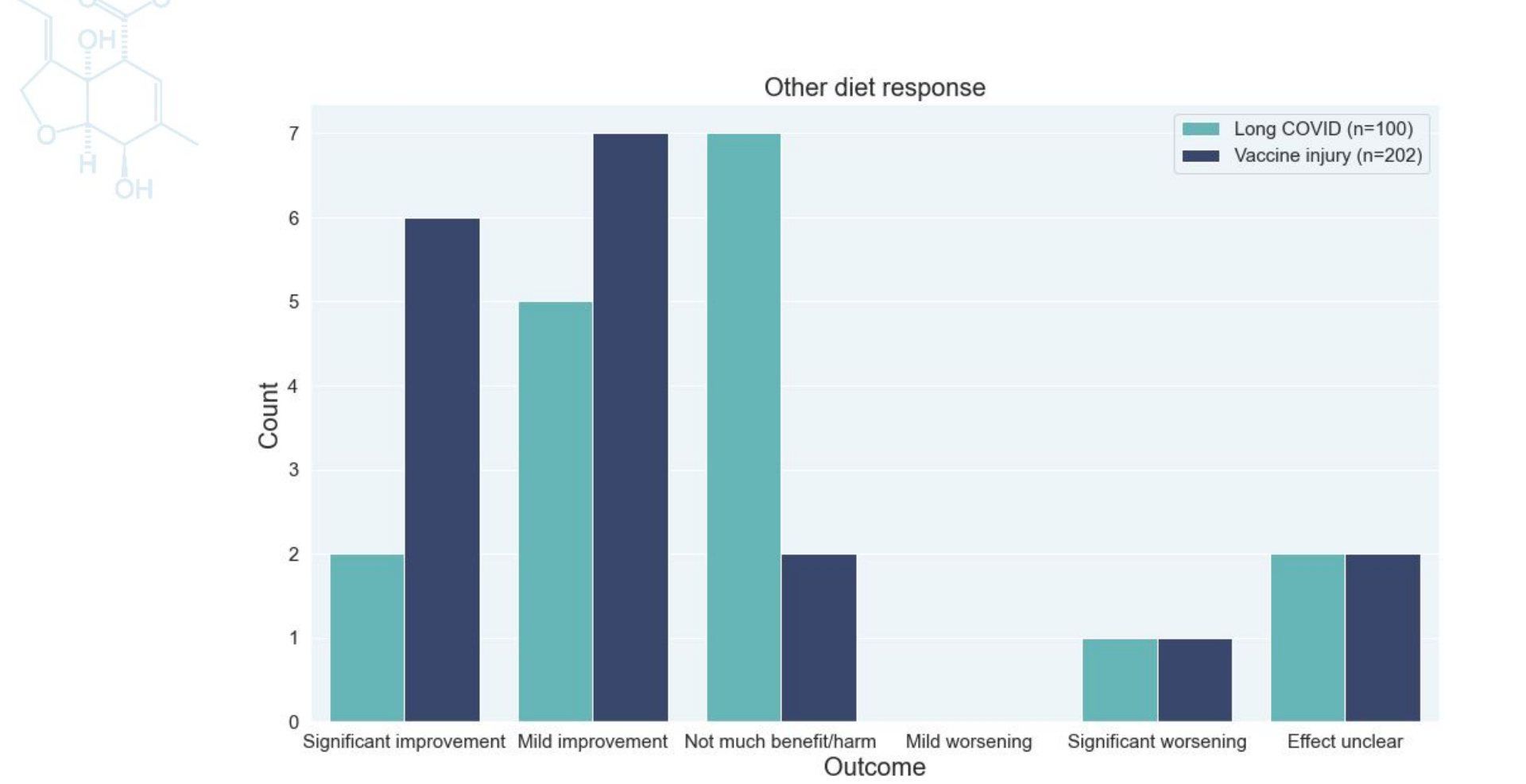

Vegan diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
1
2
3
4
5
6
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


Plant based diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
2
4
6
8
10
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


AutoImmune Protocol (AIP) diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
2
4
6
8
10
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


Low histamine diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
10
20
30
40
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


Wahls protocol diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
3.0
2.5
2.0
1.5
1.0
0.5
0.0
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

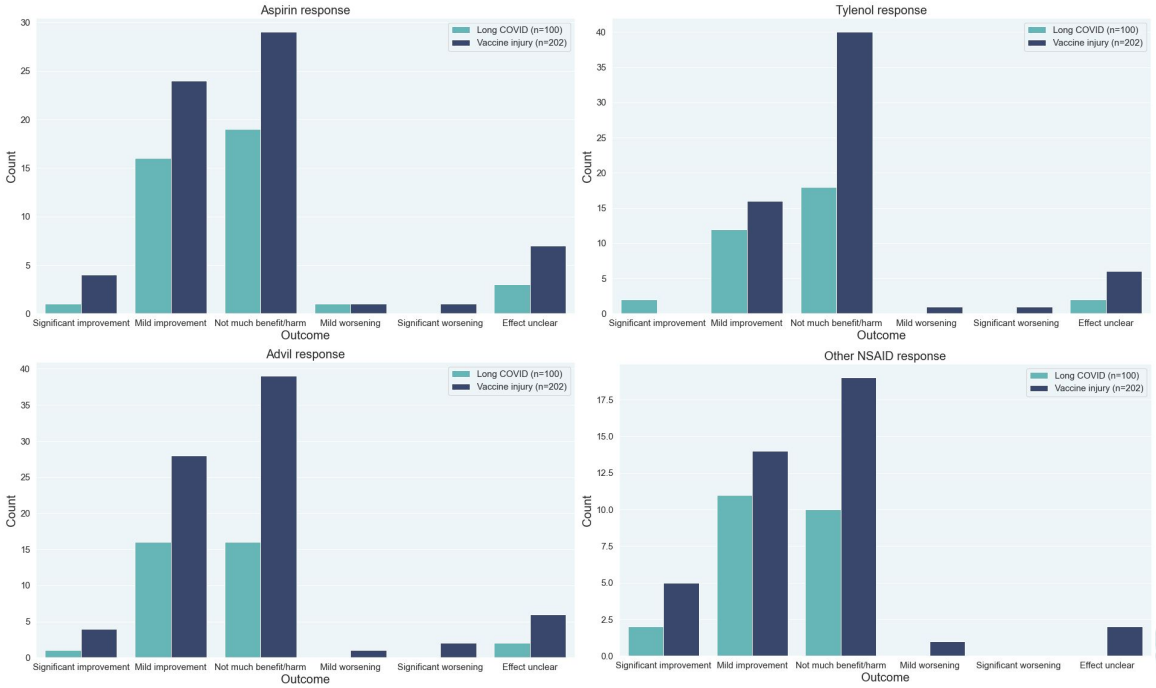

Other diet response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
1
2
3
4
5
6
7
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

NSAIDs

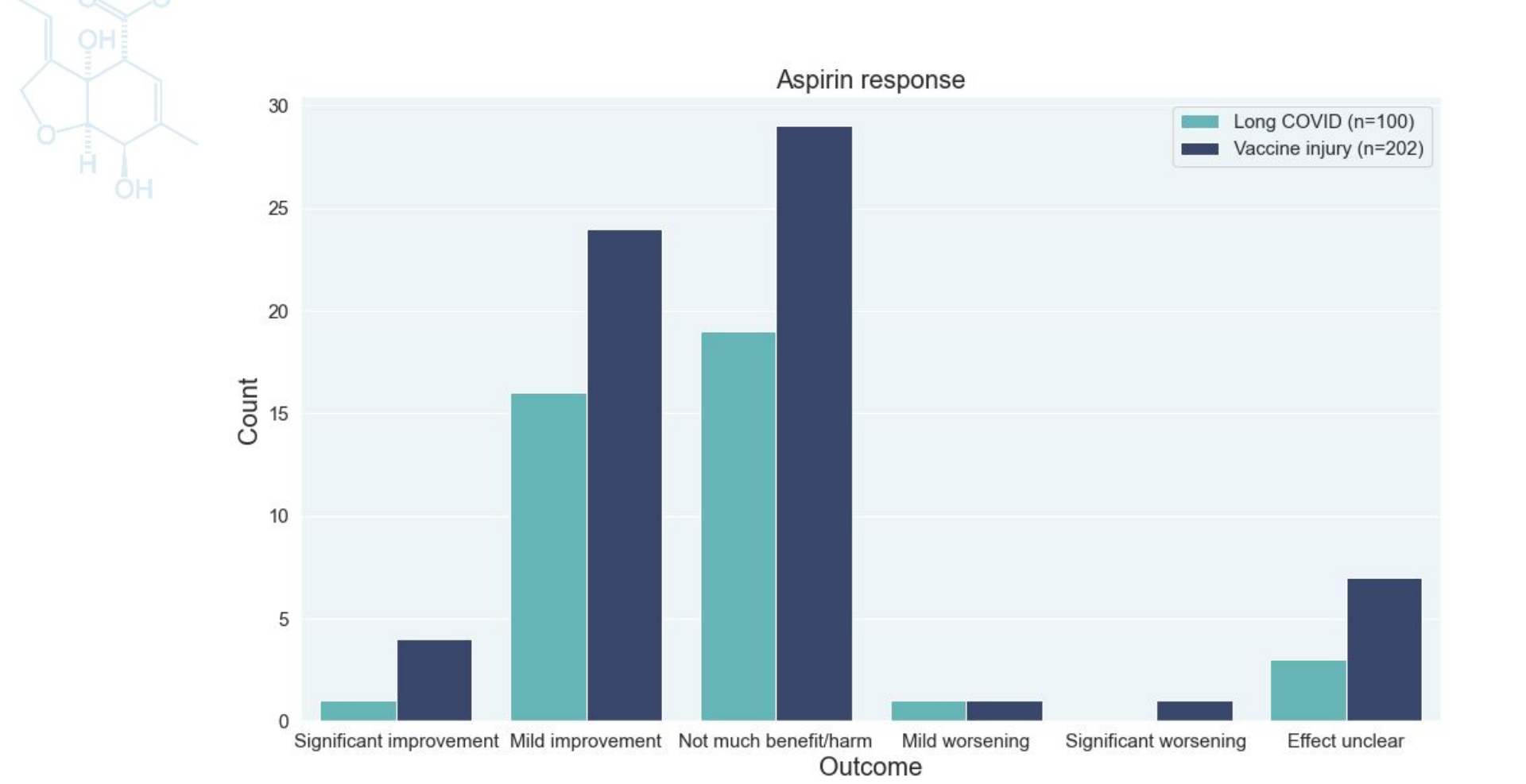
NSAIDs seemed similar to each other treatment-wise. Reported benefits were on the mild side compared to other treatments.

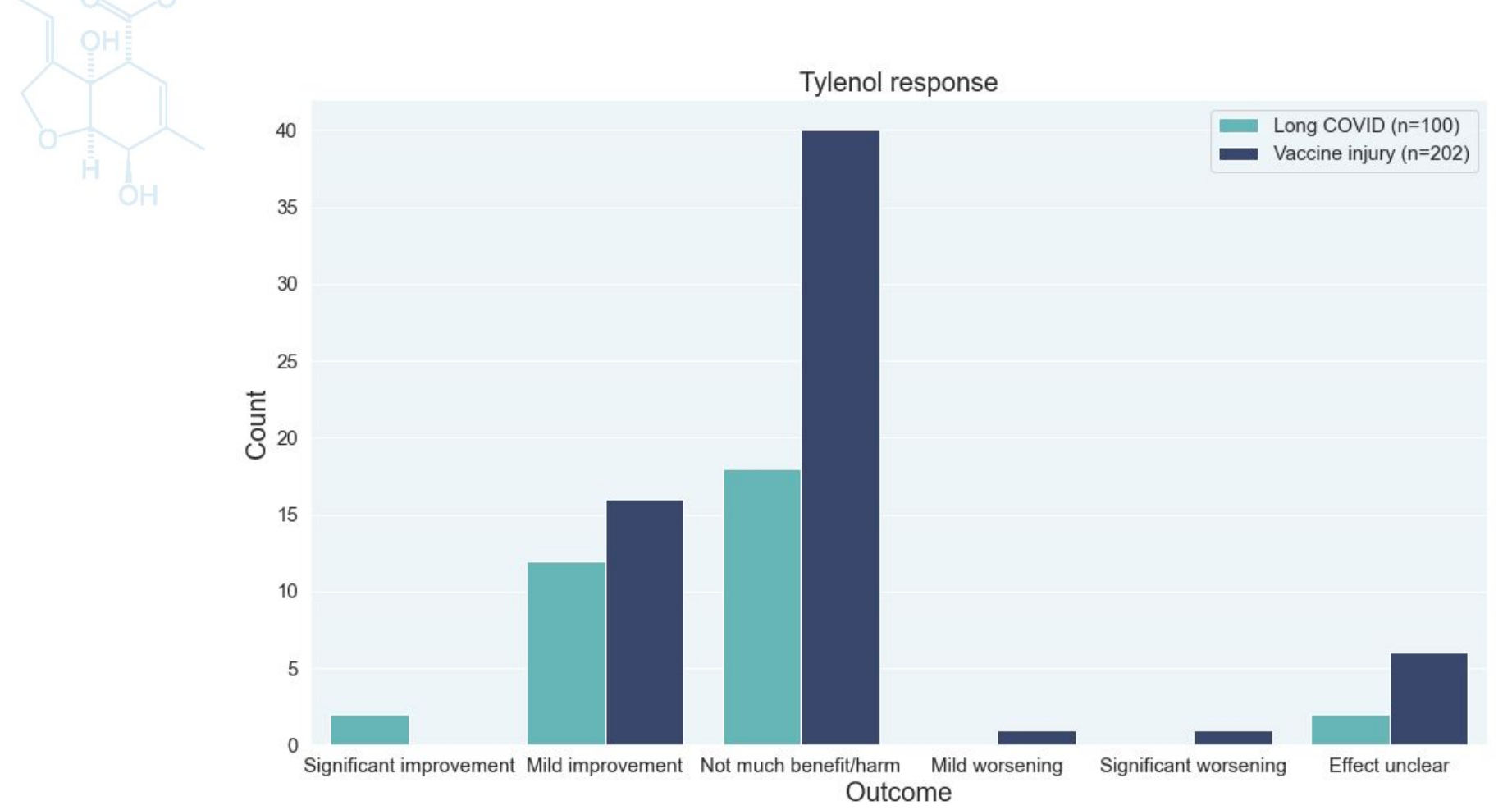
NSAIDs have a blood thinning effect, which could validate the ‘microclots’ theory of Long-Haul.

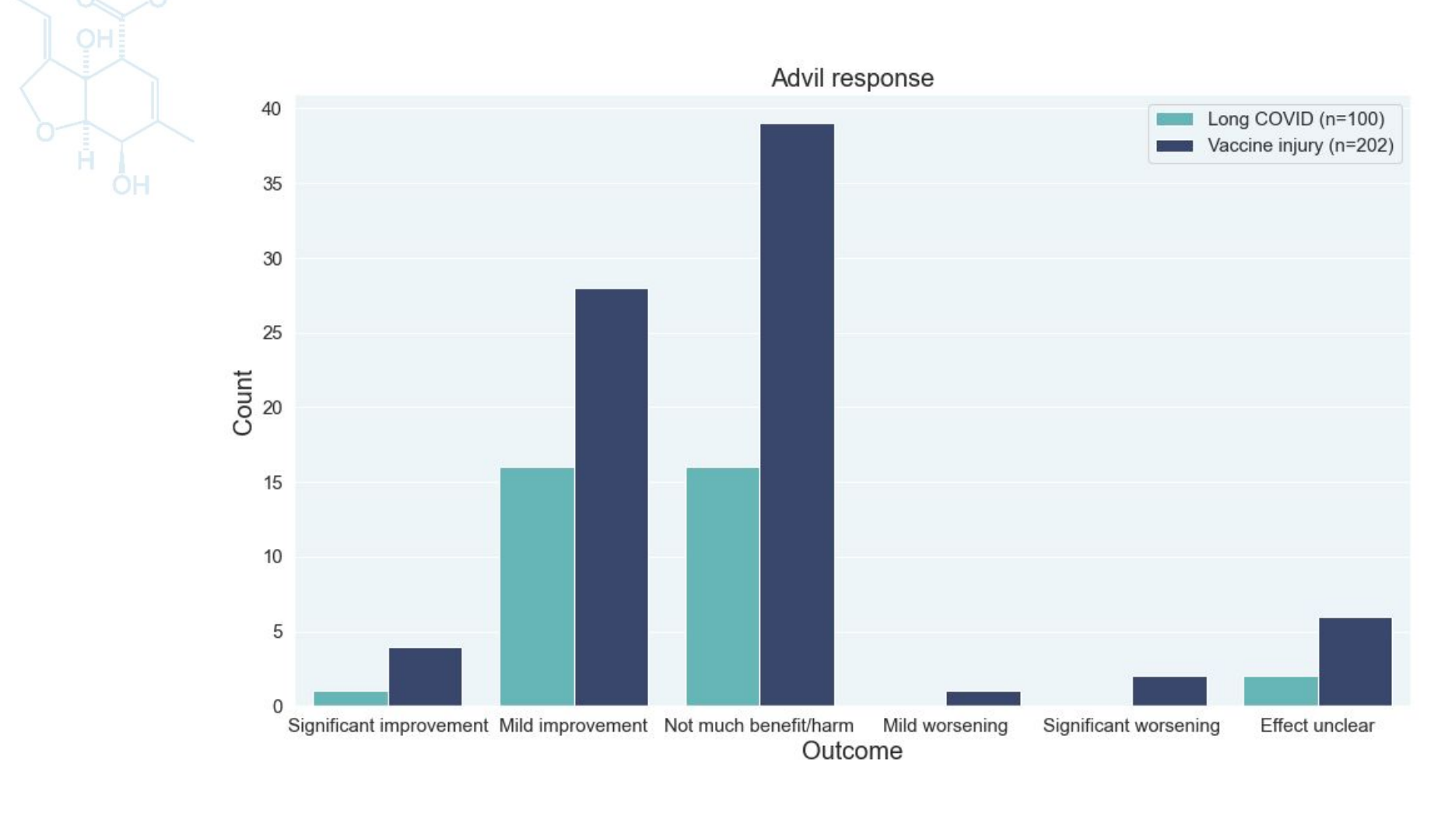
Pretorius et al. published a [pre-print] claiming that all 24 patients in their study responded to triple drug therapy.

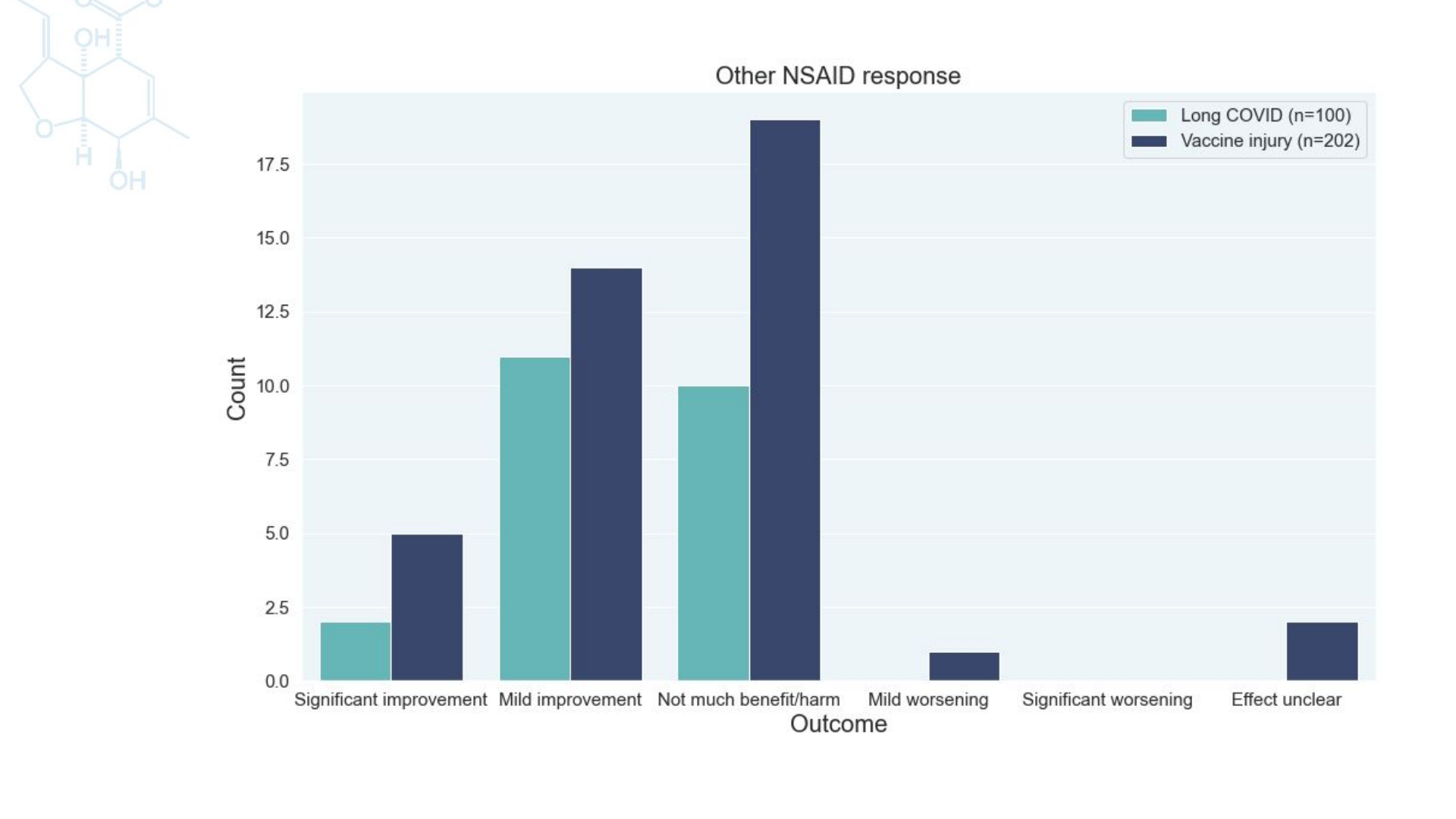


*Larger charts are in the next several slides.


Aspirin response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
5
10
15
20
25
30
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


Tylenol response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
5
10
15
20
25
30
35
40
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome


Advil response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0
5
10
15
20
25
30
35
40
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

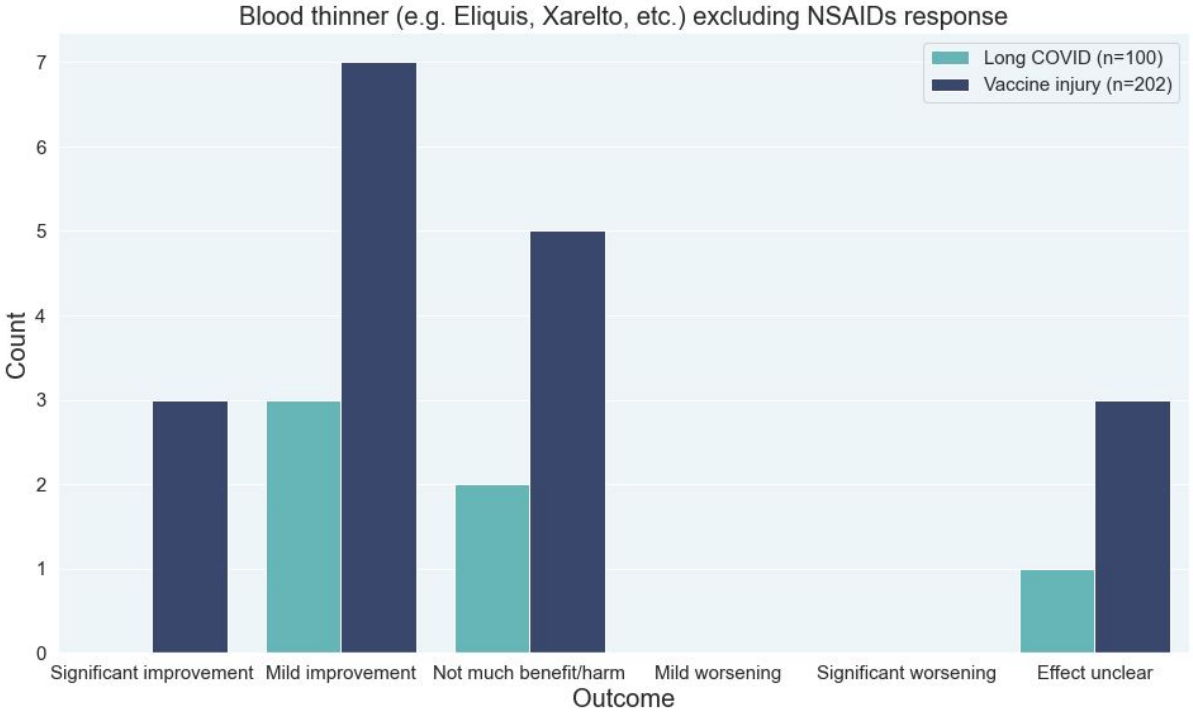

Other NSAID response
Long COVID (n=100)
Vaccine injury (n=202)
Count
0.0
2.5
5.0
7.5
10.0
12.5
15.0
17.5
Significant improvement
Mild improvement
Not much benefit/harm
Mild worsening
Significant worsening
Effect unclear
Outcome

Non-NSAID blood thinners

While the sample size was low, **29.2%** (7/24) of the respondents reported not much benefit or harm from blood thinners.

This is a different result than [Pretorius et al.](), where all 24 patients saw improvement when treated for microclots using a multi-drug combination.

Other microclot therapy: This survey collected only 1 response for HELP apheresis, a potential treatment for blood clotting-related pathology.



Thyroid data

High rates of pre-existing thyroid disorders

The rate of thyroid disorders was **15.2%** in people with Long COVID and **22.4%** in the vaccine injured. Hypothyroidism was the most common disorder.

Madariaga et al. (DOI:10.1210/jc.2013-2409) estimate the European prevalence of thyroid dysfunction to be **3.8%**.

Subclinical hypo/hyperthyroidism refers to ‘borderline’ cases. There is some debate as to whether or not subclinical hypo/hyperthyroidism should be considered a health condition.

	Long COVID (n=99)	Vaccine injury (n=201)
Pre-existing thyroid disorder	15	45
	15.15%	22.39%

Subclinical hyperthyroidism	0	1
Hyperthyroidism	3	3
Subclinical hypothyroidism	2	8
Hypothyroidism	9	23
Hashimoto's thyroiditis	5	15
"I don't know"	3	12
No thyroid issues	73	135

New thyroid disorders

The rate of new thyroid diagnoses was **3.0%** in people with Long COVID and **6.5%** in the vaccine injured. There seems to be an unusually high incidence of new thyroid conditions in both Long-Haul groups.

Others have reported somewhat similar findings. A single center in Milan (DOI:10.1530/endoabs.81.P200) found high rates of subacute thyroiditis and Grave's disease in the vaccinated.

	Long COVID (n=99)	Vaccine injury (n=200)
Thyroid new onset	3	13
	3.03%	6.50%

Hashimoto's thyroiditis	0	3
Hyperthyroidism	0	6
Hypothyroidism	3	4
Subclinical hypothyroidism	0	2

Foreign objects in the body

What types of foreign objects in the body matter?

The table on the right shows various objects found in human beings. Almost all of them are known to become infected or have been reported to react following Long-Haul.

The rows highlighted in light blue correspond to common objects that are probably harmless. While some Long-Haulers develop new allergies to jewelry and piercings, they are probably not a significant risk factor.

The next slides will focus mainly on the objects that do matter.

	Case reports - Long COVID	Case reports - Post COVID vax reaction	Surveyee reported reaction	VAERS	Known to become infected?
Fillings or crowns			y - root canal filling		
Earrings, jewelry, etc			y (3 reports)		
Tattoos etc			y (2 reports)		
Piercings etc			(see earrings)		
No foreign objects					
IUD					y* (contributes to infection)
Dental implants	y				y
Metal pins					?
Joint replacement, plates, discs, prosthetics			y	2107567	y
Surgical debris			y		
Mesh					y, has caused suicide
Temporary fillers		y			
Breast implants		y		multiple, e.g. 2041984	
Braces					*(contributes to infection)
Metal clip/marker					?
Essure and fallopian clips					y
Permanent implants					(see breast implants)
Dentures					y
Dissolvable stitches not dissolved					?
Pacemaker or medical device					y
Catheters etc					y
Cataract lenses					y
Other - AmnioFix Interceed					?
"Support group" objects in body					
Abiotic surfaces in body					
Old surgical sites			y		
Organ transplant, tissue graft		y			

Two groups of objects that matter the most

“Support group” objects include those with patient support groups and those that are known to lead to serious infection:

- Breast implants
- Other permanent implants
- Pacemaker or similar medical devices
- Joint replacements (plus anchors for prosthetics, any prosthetics attached to bone, and metal plates [excluding pins])
- Mesh
- Essure
- Fallopian tube clips

Abiotic surfaces include “support group” objects plus:

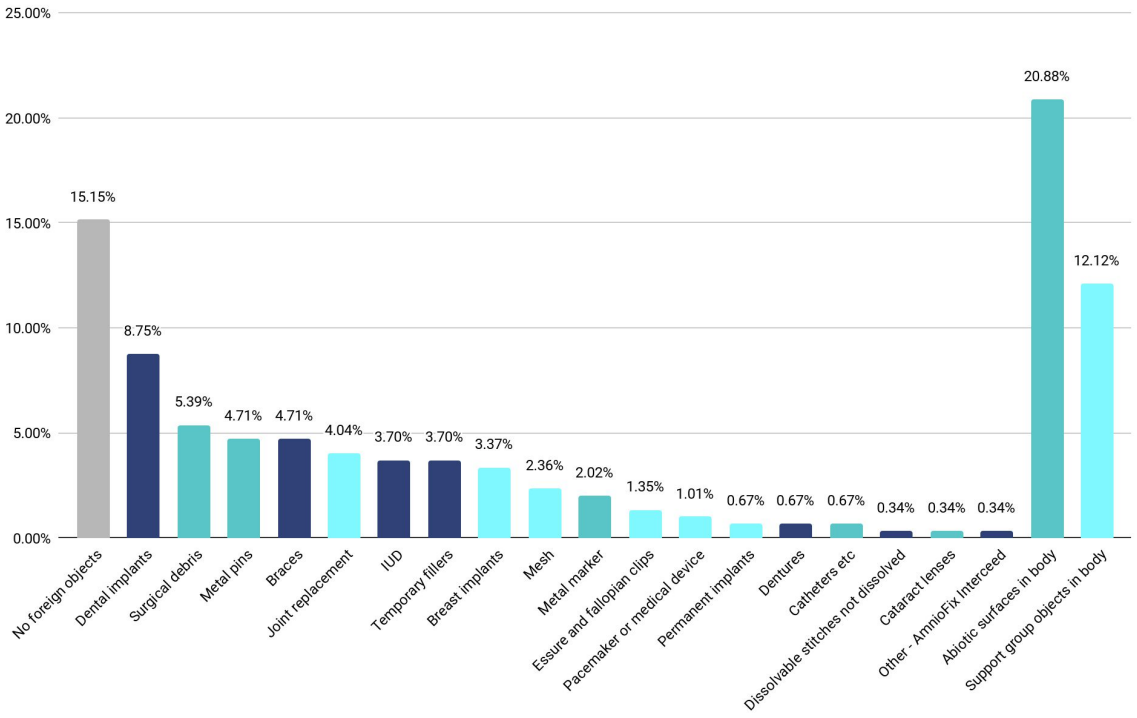
- Metal markers/clips (often placed after a breast biopsy)
- Surgical debris
- Catheters
- Metal pins
- Cataract lenses

There is less information about infections associated with these objects*. (*It is well known that catheters frequently become infected but are easily replaced or removed.)

The data shows above-average rates of breast implants

Of the biological females in the survey who answered the question about foreign objects, **3.9%** (10/256) reported breast implants before Long-Haul.

Cook et al. estimate breast implant prevalence at **0.8%** for American women (DOI: 10.1007/978-3-642-85226-8_45), which is well below the **3.9%** in this survey.



Joint replacements

Kremers et. al (doi:10.2106/JBJS.N.01141) found that the prevalence of hip and knee replacements was:

- **0.1%** in women under 50
- **2.54%** in women 50+

In this survey:

- **2.9%** of females and males under 50 had joint replacements (and other prosthetics)
- **7.1%** of males and females aged 50+ had joint replacements (and other prosthetics)

It seems that joint replacements are overrepresented in the Long-Haul population, especially in younger people. However, this survey did not ask about hip/knee replacements versus other joint replacements, prosthetics, discs, metal plates, etc. The numbers may not necessarily be directly comparable.

How foreign objects in the body can lead to chronic illness

For joint replacements and periprosthetic joint infection (PJI), the consensus is clear: bacteria and fungi/yeast form biofilm colonies on the abiotic surface of the prosthetic. This can result in non-specific symptoms that are sometimes difficult to diagnose.

Lee et al. (DOI: 10.1097/GOX.0000000000002755) found evidence of biofilms in Breast Implant Illness (BII) patients. The authors noted that patients often complained of new autoimmune conditions following implantation. 14/15 of those patients reported improvements in their autoimmunity following explantation. However, the existence of BII remains controversial in that area of the scientific literature while the PJI literature simply accepts the idea that infection causes health problems. And while the FDA website presents data on breast implants being associated with autoimmune disease, it still notes that BII “is not recognized as a formal medical diagnosis”.

Autoimmunity may develop because many microbes change their surface antigens to mimic the host’s antigens (molecular mimicry). See Proal et al. Re-framing the Theory of Autoimmunity in the Era of the Microbiome: Persistent Pathogens, Autoantibodies, and Molecular Mimicry. The ASIA syndrome literature (DOI:10.1016/j.jaut.2010.07.003) also notes a connection between breast implants, vaccines (from a pre-COVID era), and autoimmunity. However, the ASIA syndrome literature generally does not consider microbes to be an ‘adjuvant’ that leads to autoimmunity.

Treatment for foreign objects in the body

Explantation (removal of the object) leads to fairly good patient outcomes for Breast Implant Illness; data is provided on the next slide. However, explantation is not always possible. Many foreign objects in the body (e.g. surgical mesh, pacemaker leads) were not designed to be removed and often cannot be safely removed.

Where explantation fails or is not viable, treatment can be difficult. Bacteria and fungi growing in biofilm colonies are incredibly resistant to most antimicrobial drugs. The Lyme disease-causing bacteria *Borrelia Burgdorferi* is one microbe whose persistent behavior is well studied. The review paper by Bobe et al. (DOI:10.3389/fmed.2021.666554) describes how B. Burgorferi biofilms (consisting of ‘persisters’ / stationary cells) are highly resistant against the standard treatment for Lyme (doxycycline).

Explantation outcome data

Breast implants:

- **FDA MDR database:** 279 noted improvement (**96%**) and 11 noted either no improvement or worsening of symptoms. https://www.fda.gov/medical-devices/breast-implants/medical-device-reports-systemic-symptoms-women-breast-implants
- **Magno-Padron et al.: 23%** of patients reported complete resolution of symptoms following explantation, with **74%** reporting partial resolution. Only 3% reported no improvement. https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC8342259/
- **Lee et al.: 84%** of patients reported partial or complete resolution of BII symptoms on Patient-Reported Outcome Questionnaire. https://dx.doi.org/10.1097%2FGOX.0000000000002755

Essure and mesh have less favorable outcomes:

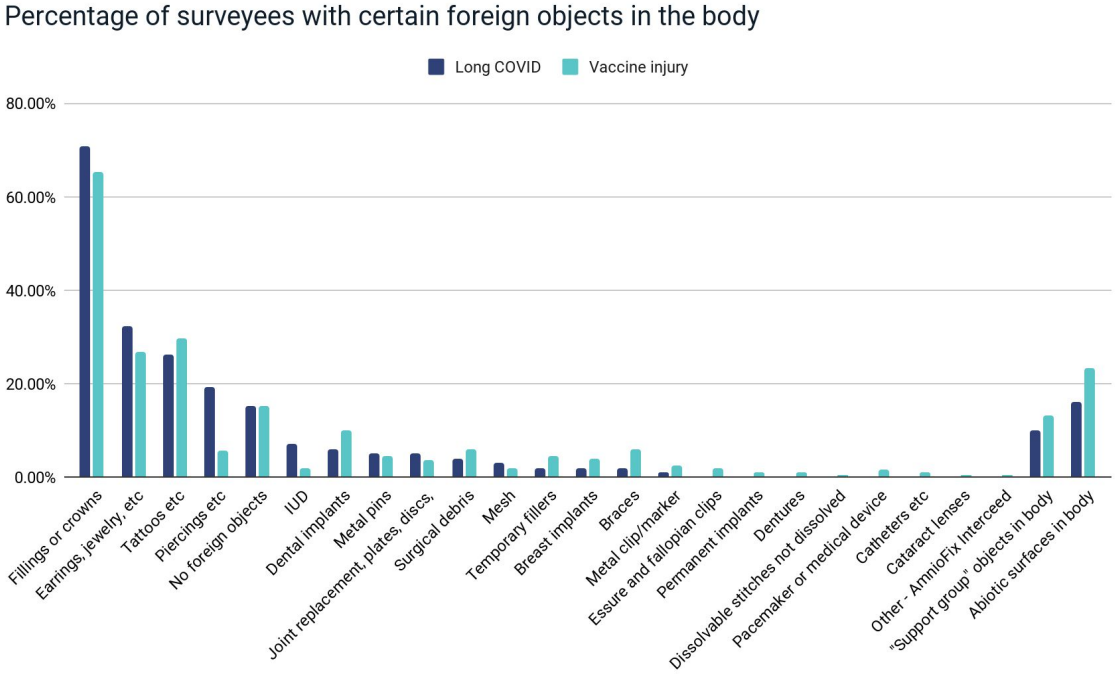
- **Essure:** Roughly **31% failure rate**- almost a third of patients had ongoing or worse symptoms after Essure removal. https://doi.org/10.1016/j.jmig.2017.05.015
- **Mesh:** Of patients who underwent surgery, complete removal was only possible in **6/19** patients. doi:10.1016/j.berh.2019.01.003

Differences between Long COVID and vaccine injury?

The prevalence of foreign objects in the body is somewhat similar between Long COVID and vaccine injury.

There are some large differences with piercings, IUDs, and braces. There are also small overall differences in the prevalence of “support group” objects and abiotic surfaces.

It would be premature to assume that the vaccine injured are more likely to have abiotic surfaces in their body. Survey cohort composition and survey recruitment could be responsible for the difference.



“Support group” objects include breast implants, other permanent implants, pacemaker or medical devices, joint replacements, mesh, Essure, and fallopian clips.

“Abiotic surfaces” are the support group objects plus metal markers/clips, surgical debris, catheters, metal pins, and cataract lenses.

Foreign objects data

(See table on the right.)

	Long COVID	Vaccine injury
Fillings or crowns	70.71%	65.15%
Earrings, jewelry, etc	32.32%	26.77%
Tattoos etc	26.26%	29.80%
Piercings etc	19.19%	5.56%
No foreign objects	15.15%	15.15%
IUD	7.07%	2.02%
Dental implants	6.06%	10.10%
Metal pins	5.05%	4.55%
Joint replacement, plates, discs, prosthetics	5.05%	3.54%
Surgical debris	4.04%	6.06%
Mesh	3.03%	2.02%
Temporary fillers	2.02%	4.55%
Breast implants	2.02%	4.04%
Braces	2.02%	6.06%
Metal clip/marker	1.01%	2.53%
Essure and fallopian clips	0.00%	2.02%
Permanent implants	0.00%	1.01%
Dentures	0.00%	1.01%
Dissolvable stitches not dissolved	0.00%	0.51%
Pacemaker or medical device	0.00%	1.52%
Catheters etc	0.00%	1.01%
Cataract lenses	0.00%	0.51%
Other - AmnioFix Interceed	0.00%	0.51%
"Support group" objects in body	10.10%	13.13%
Abiotic surfaces in body	16.16%	23.23%

Abiotic surfaces in the body did not correlate with autoimmunity

Surprisingly, there did not seem to be a correlation between abiotic surfaces in the body and autoimmunity diagnoses. Presumably, there are autoimmunity-generating forces other than abiotic surfaces in the body. It could be the case that multiple factors are needed for autoimmunity to develop.

Abiotic surfaces in body?	Autoimmunity diagnosis before illness	Autoimmunity diagnosis after illness	New autoimmunity diagnosis after onset of illness
no	20.3%	27.6%	13.2%
yes	21.3%	26.7%	13.3%

Small fiber neuropathy occurs at very high rates

Small Fiber Neuropathy (SFN) Data

The rate of new SFN (**2.3%** or 7/298) seems extremely high in Long-Haulers. The *new-onset* rate is **77 times** the 52.95 per 100,000 population rate reported by Chan and Smith (DOI:10.1002/mus.25082). Note: the survey did not specifically ask about SFN and what type of SFN; this likely led to under-reporting.

Vaccine injured (5 cases):

- Immune mediated small fiber neuropathy (**2** with and 1 without a formal diagnosis)
- Autoimmune SFN (**1**)
- Small fiber neuropathy (**2** cases; type unknown, surveyee may have meant autoimmune)

Long COVID (**2** cases)

- Autoimmune small fiber neuropathy with positive TS-HDS auto-antibodies and POTS auto-antibodies
- Small fiber neuropathy (type unknown, surveyee may have meant autoimmune)

In the previous React19 survey, **2.0%** (18/913) reported a formal SFN diagnosis.

SFN may be more common than the survey data suggests

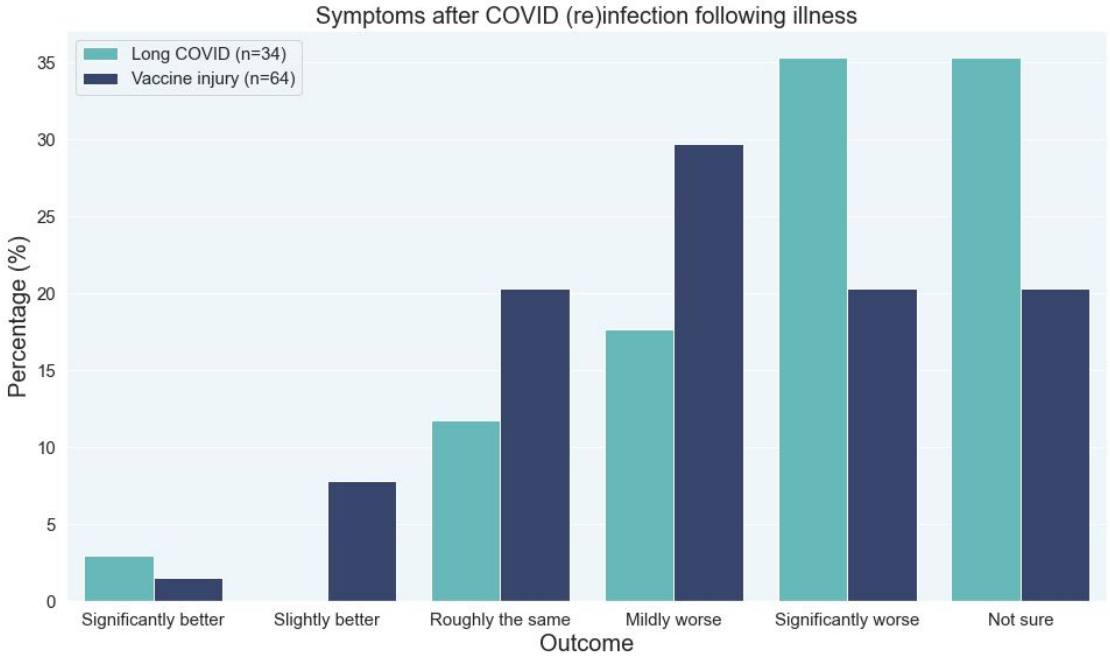
The NIH/NINDS studied vaccine-injured patients *with* neuropathic symptoms (DOI:10.1101/2022.05.16.22274439). They found that **12/23 (52%)** of these patients had objective evidence of small-fiber peripheral neuropathy.

Should Long-Haulers be concerned about COVID reinfection and COVID vaccines?

Symptoms following COVID (re)infection

Responses skewed very heavily towards worsening of symptoms. **The data suggests that COVID infection is a serious concern in both patient groups.** However, there are a few reports of symptoms becoming significantly better (!).

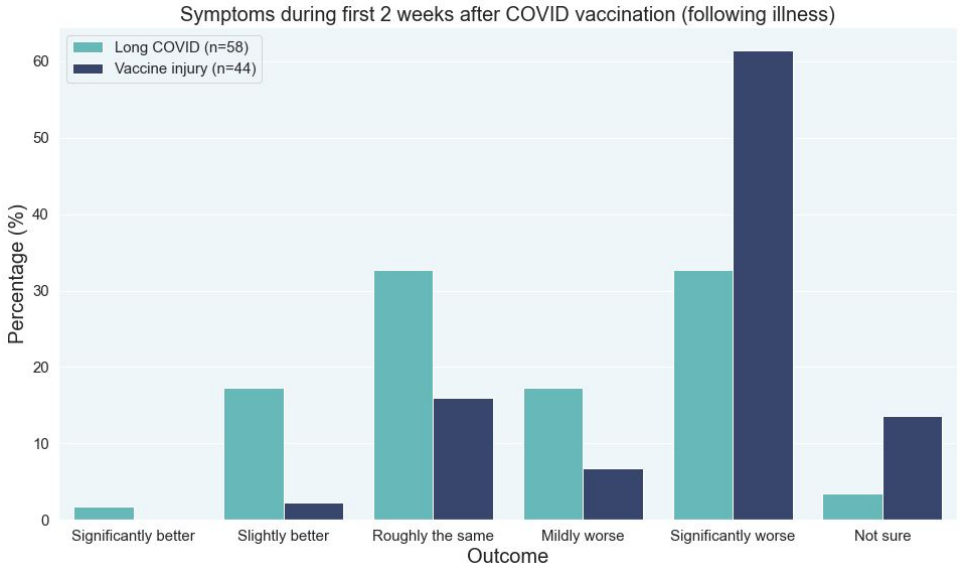
20-35% of surveyees weren't sure about their reaction to their COVID (re)infection.



Symptoms following COVID (re)vaccination

The response to COVID vaccination was quite different between Long COVID and vaccine injury. The vaccine injured were far more negative in their assessment of vaccines. Various non-medical factors may have affected the reporting of outcomes such as social politics, being mandated/coerced into getting vaccinated, the hope that Long COVID can be treated with vaccines (e.g. viral persistence theory), etc. This survey did not attempt to measure such reporting biases.

Compared to COVID infection, fewer surveyees reported “Not sure”.

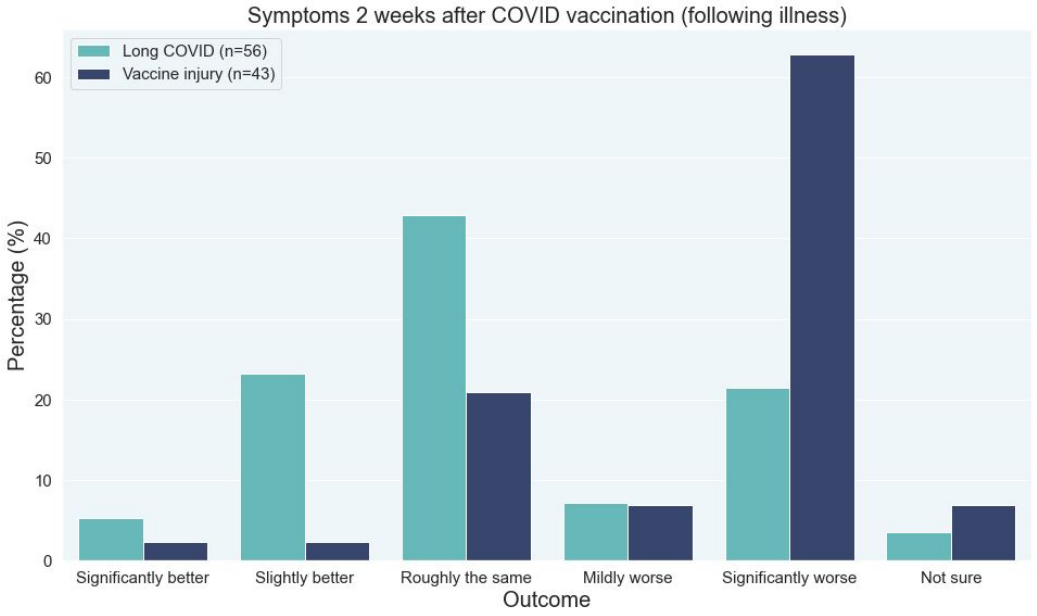


One limitation is that several surveyees may have misinterpreted the survey question, which used the word “illness” instead of “Long-Haul”. Several surveyees likely reported their symptoms after an initial (non-Long-Haul) illness such as chronic Lyme or an autoimmune disease.

Symptoms following COVID (re)vaccination

Overall, there does not seem to be major differences between symptoms during the first 2 weeks and symptoms after the first 2 weeks. However, Long COVID surveyees reported more favourable long-term reactions compared to short-term reactions.

45.5% (45/99) of the surveyees provided different answers for the 2 questions about post-vaccination symptoms. It may be a coincidence that the data balances out to give the impression of similar outcomes.



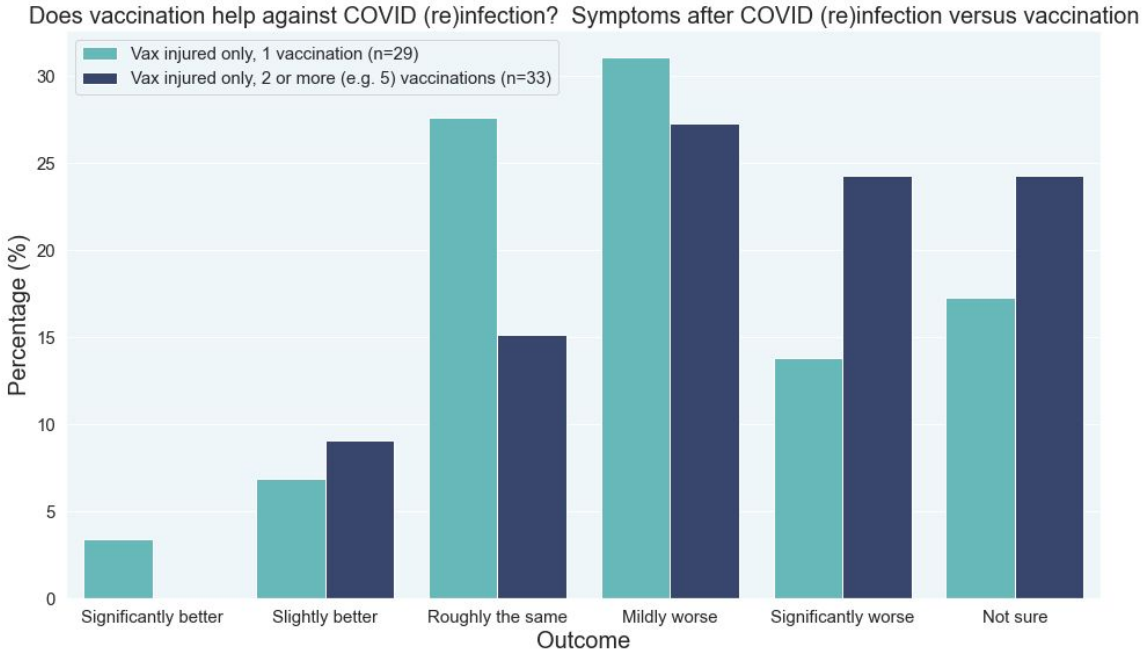
At least one Long COVID sufferer has committed suicide following vaccination. This survey may not necessarily capture the full severity of symptom worsening.

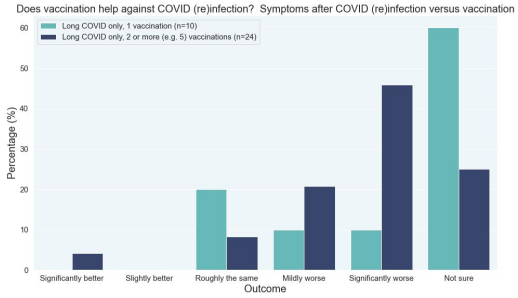
Vaccination may not protect against Long COVID?

In the minority that reported a COVID infection, the data trended towards showing better outcomes for surveyees with the *fewest* vaccinations.

The difference was *not* statistically significant.
X^2 (1, N = 62) = 1.08, p = .30. The comparison was between 'Significantly worse' versus all 5 other categories combined.

A larger sample size would be more reliable in detecting any potential safety signal. It is possible that vaccines may *increase* the risk of Long COVID. More research is needed.





*Long COVID surveyees are shown separately on the left as they tend tend to be more vaccinated and tend to report worse outcomes following reinfection.

Limitations of our vaccination data

1. The survey did not ask about the number of vaccinations *before* COVID (re)infection. Any miscategorization caused by this would dilute the results and make the difference between the two categories smaller than it actually is.
2. **The survey was *not* designed to determine whether or not vaccines help prevent Long COVID.**
3. The survey question may have been misinterpreted because it asked about 'illness'. Illness could refer to autoimmune disease, which was mentioned earlier in the survey.
4. Those with more than 1 vaccination were less likely to answer the question about COVID (re)infection; this suggests that those with more vaccinations had a slightly lower rate of infection.
5. There are demographic and vaccination differences between the two groups (see the table on the right).
6. Correlation does not prove causation. Nonetheless, experimental vaccinations should not be deployed unless the preponderance of evidence leans towards likely benefit.

1 vaccination, vaccine injured only		
Brands that caused injury (excludes non-injuring shots)		Average age (mean)
Pfizer	20	40.4
Johnson and Johnson	4	
Moderna	3	
AstraZeneca	1	
Astrazeneca (Covishield)	1	

More than 1 vaccination, vaccine injured only		
Brands that caused injury (excludes non-injuring shots)		Average age (mean)
Pfizer	18	42.8
Moderna	11	
AstraZeneca	2	
Pfizer, AstraZeneca	1	
Pfizer, Moderna	1	

The risk/benefit of COVID vaccines in the chronically ill

Overall, the data suggests that exposure to COVID vaccination risks significant worsening of long-term symptoms in both Long COVID (**21.4%**) and COVID vaccine injury patients (**62.8%**). More rigorous research could quantify the risk/benefit of COVID vaccination in these cohorts, particularly in the Long COVID cohort where the risk/benefit margin is smaller.

It is very interesting that the two groups differed dramatically in their survey responses regarding possible vaccine harms. Aside from vaccination, the two groups have otherwise behaved similarly.

Risk of COVID vaccines in the chronically ill (continued)

ME/CFS patients also seem to see their symptoms flare after vaccination. The New Zealand advocacy group ANZMES published preliminary survey findings on a cohort of mostly ME/CFS patients. **19.8%** were reported as “worsened and not returned to baseline - relapsed”. (The survey did not seem to ask for positive effects following vaccination.)

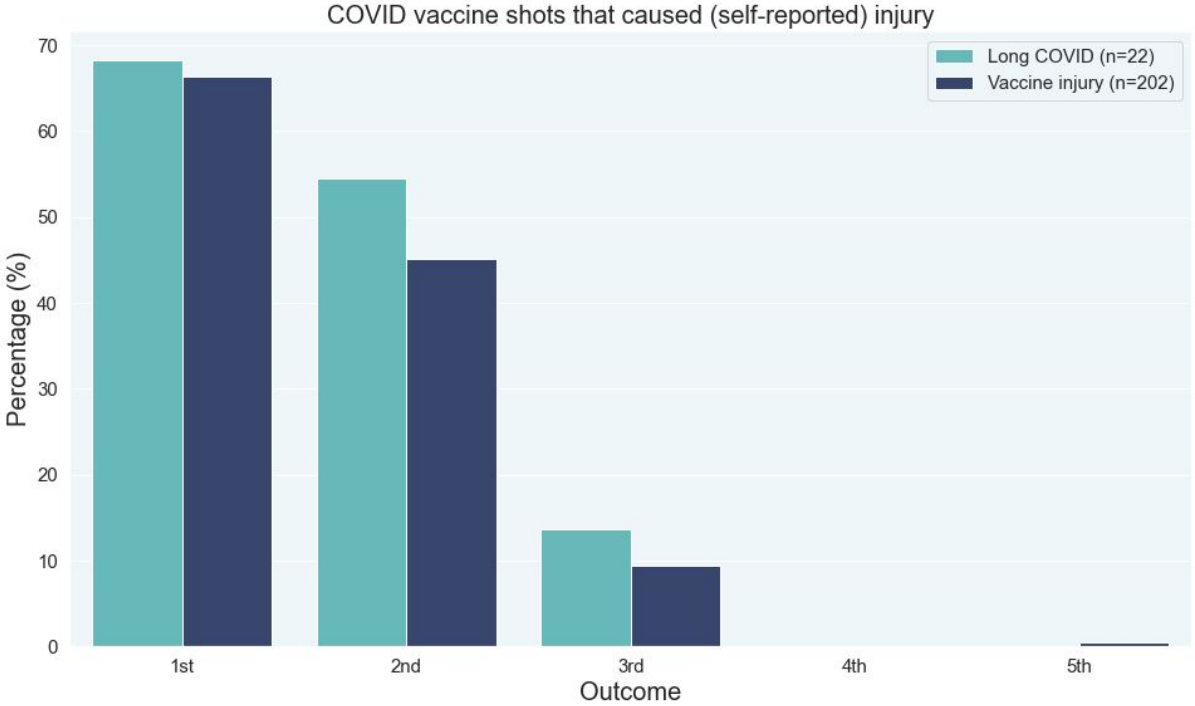
We believe that it is important for doctors and researchers to find safe and effective strategies for Long COVID treatment and prevention in the chronically ill, who seem to be especially vulnerable.

Every shot carries a risk of vaccine injury

The survey asked which shots led to vaccine injury. **22%** (22/100) of the long COVID surveyees answered this question.

It seems that injury can occur even if the person had no reaction to the 1st or 2nd shot.

One surveyee reported injury on the 5th shot.



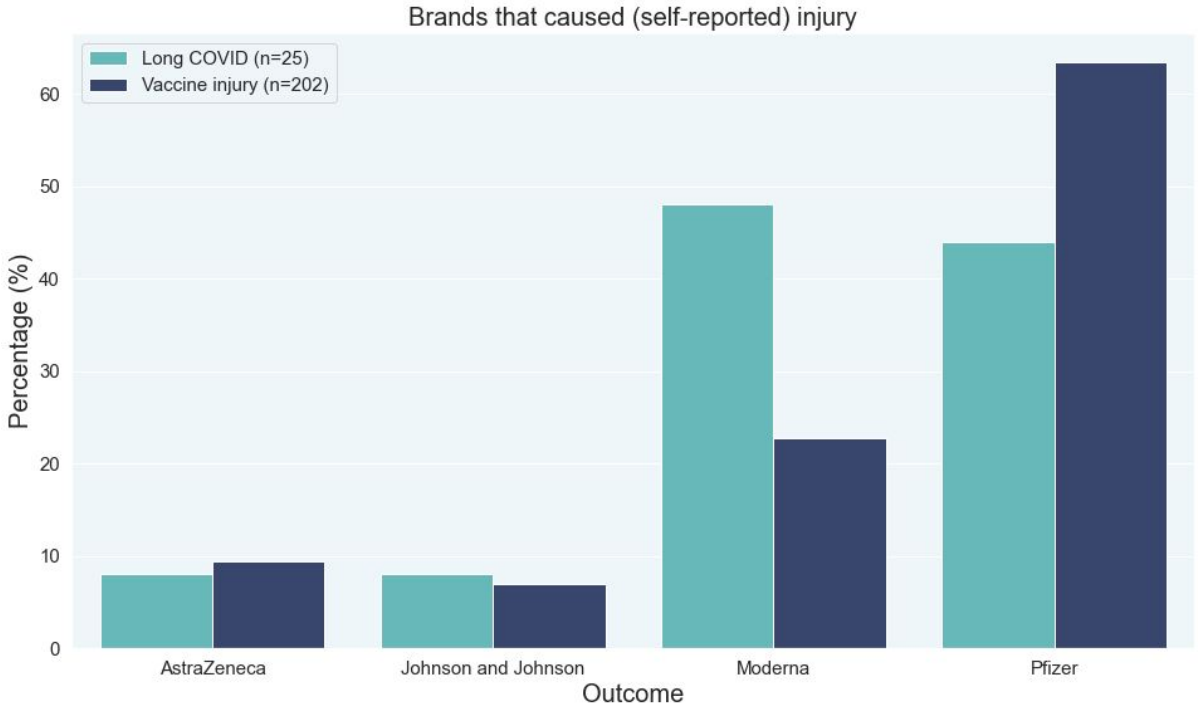
*Some jurisdictions will vaccinate without checking for identification or prior vaccination history (e.g. to accommodate the homeless). This allows individuals to receive multiple boosters.
Other jurisdictions are already on their 5th booster.
**The percentages total over 100% because surveyees could say that they were injured by multiple shots.

All the major vaccine brands seem to cause injury

Surveyees reported injury from both mRNA and adenovirus vector vaccines.

While the vaccine injury support groups in the Western world have rare reports of Sinovac and Novavax injuries, no such injuries were reported in this survey.

Moderna and Pfizer branded vaccines have more than one version with different ingredients and dosages. This survey did not identify the exact vaccine used.



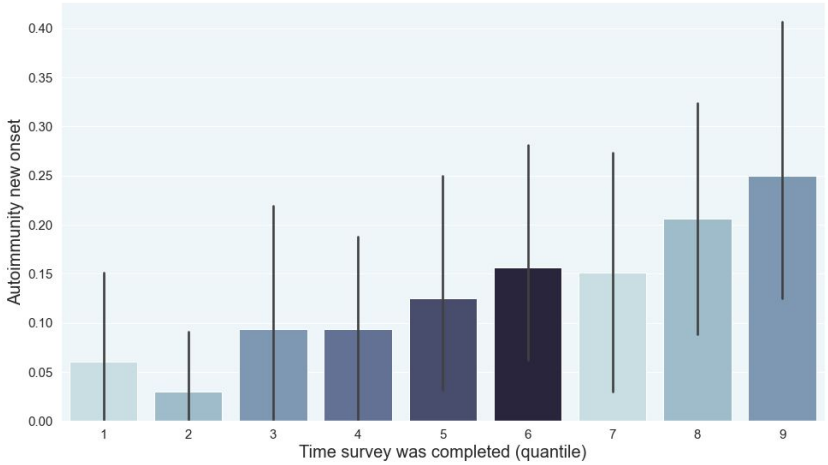
*The first React19 survey reported injury from the Sinovac vaccine.

Demographics

Unusual demographics

The survey cohort was unusual. **85.8%** were biologically female, **13.6%** male, **0.3%** intersex/other, and **0.3%** preferred not to say. The proportion of females was high compared to most other surveys and data sources*. We have not analyzed other sources of data to see if Long-Hauler demographics are shifting over time, e.g. due to lower recovery in females.

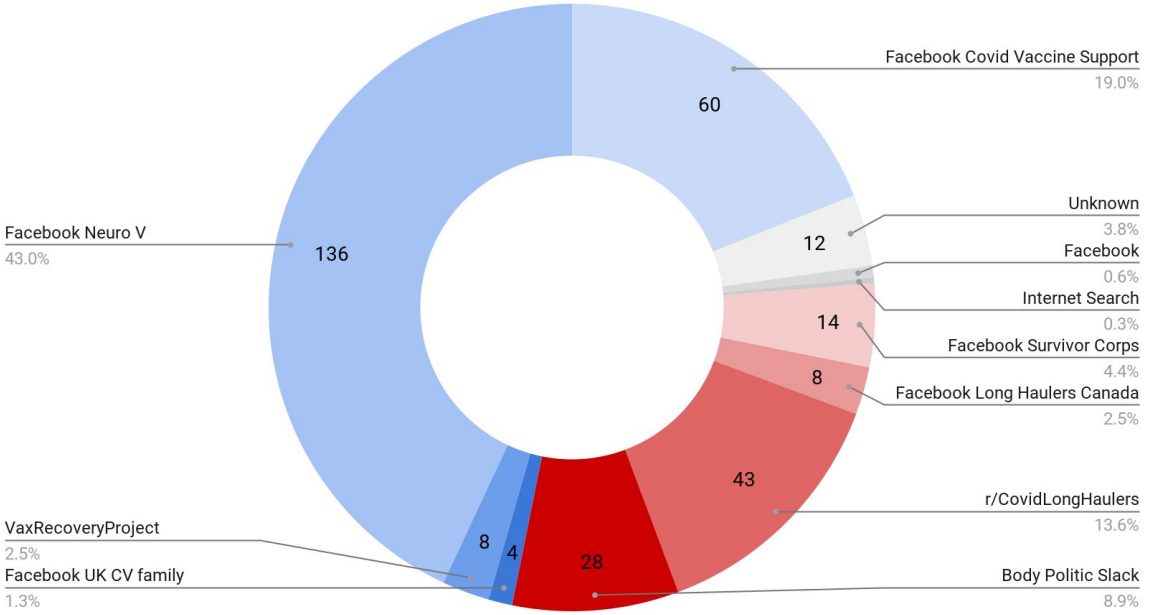
The prevalence of autoimmunity trended higher for surveyees who responded later (shown on the right). The rate may be highly sensitive to the demographics of the surveyees recruited.



*First React19 survey: 81% female
Pfizer's safety data Dec10-Feb28: 76.5%
PLRC survey published May 2020 (LC): >76.6%?
PLRC survey published July 2021 (LC): >78.9%?
Lambert et al. published March 2021 (LC): >85.7%
Japanese Twitter poll (vax): 82.2%

Where surveyees came from

200 surveyees came from vaccine injury support groups, **93** from Long COVID support groups, with **12** unknown or other.

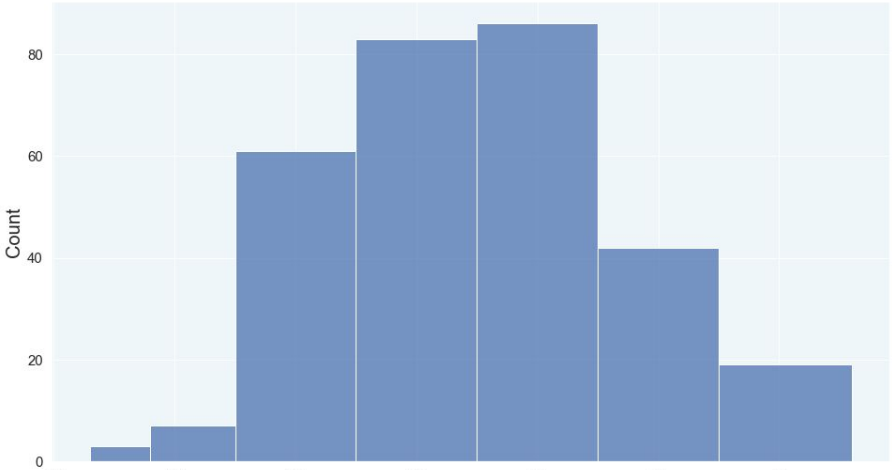


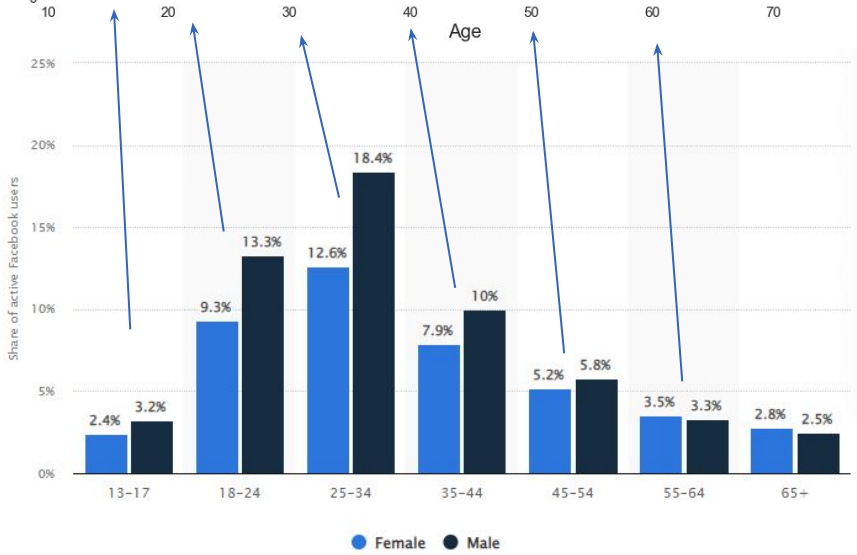
Age distribution

Surveyee age is shown in the top right. Facebook demographics from Statista are show in the bottom right.

Compared to Facebook: The surveyee demographic peaked in the 45-54 demographic rather than 25-34. 18-24 year olds were quite under-represented in this survey compared to the Facebook demographic.

Compared to the general population: Elderly individuals are under-represented despite receiving vaccines and boosters first, possibly because they are less likely to use the Internet and are therefore less likely to use online support groups.





Where do we go from here?

Possible future research

There are two threads that should be worth exploring:

1. Collecting data on patients who undergo **explantation surgeries** (e.g. breast implants, mesh, etc.). This would provide evidence as to whether or not antimicrobial treatments might be useful in treating Long-Haul syndromes.
2. Tracking patient outcomes from **drugs or supplements with antimicrobial properties**: nigella sativa (contains carvacrol, thymoquinone), antibiotics, antifungals (e.g. fluconazole), tilorone, interferons, etc. Some of these drugs are currently in widespread use so there may be reasonably high rates of incidental use in Long-Haul patients.
   One limitation is that most antimicrobial molecules are highly ineffective against bacterial and fungal biofilms. There is a limited amount of research being performed on antimicrobials that are effective against biofilms in humans. Goc et al. (DOI:10.1177/2040622320922005) have demonstrated some success in treating possible *Borrelia burgdorferi* (Lyme) in humans.

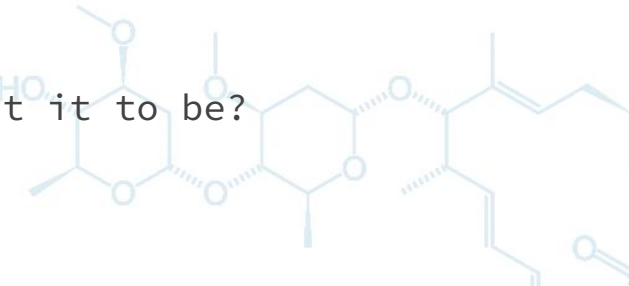
A call to action

Patients deserve the right research

The world currently has a shortage of 2 things:

1. **Courage**. Pushing science forward requires researchers to objectively examine the data because politics will not heal patients. Those suffering need open-minded researchers who are willing to follow the evidence wherever it leads.
2. **Compassion**. Those who signed up for the fight against the pandemic put their bodies on the line. Now the injured need your help. So do the people suffering from ME/CFS, Long COVID, MCAS, Breast Implant Illness, surgical mesh, etc.

Will you join us in shaping the world into what we want it to be?



Thank you for listening!

Appendices in the upcoming slides contain information on:

- Twins and possible genetic links.
- Discussions about the unreliability of autoimmunity data.

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

Appendix - twins and possible genetic causes

Very limited data

In this survey, there were 2 surveyees with identical twins. Both surveyees reported that Long COVID developed in both twins. For vaccine injury, one surveyee reported that both twins were vaccine injured. The other surveyee reported that neither twin was vaccine injured.

In a Facebook poll conducted in a vaccine injury support group, 2 unrelated individuals with identical twins responded. **Interestingly, one reported that both twins were vaccine injured while the other respondent said that only 1 twin was vaccine injured. This suggests that there are environmental factors that drive vaccine injury**. This is not a surprising finding given the high rates of breast implants and joint replacements.

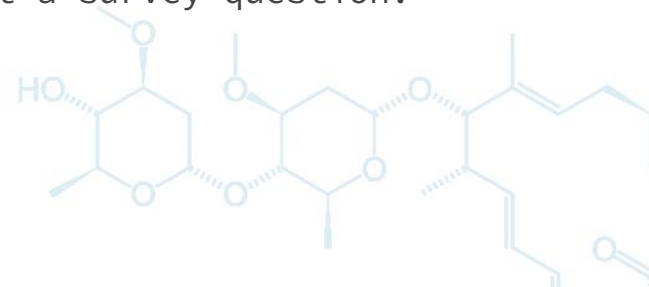
Appendix - difficulties of collecting data on autoimmunity

Collecting reliable data on autoimmunity is hard

- **Many patients are undiagnosed** because symptoms aren't specific to a particular condition. Doctors often miss the diagnosis. It may take years for a patient to receive a formal diagnosis.
  - A 2003 study by Fasano et al. (doi.org/10.1001/archinte.163.3.286) strongly suggests that celiac disease is significantly underdiagnosed in the US.
  - The study notes that "a recently published survey of 1612 patients with CD in the United States revealed that the average gap between the onset of symptoms and the time CD diagnosis was confirmed was 11 years". doi.org/10.1016/S0002-9270(00)02255-3
- There is debate as to whether or not particular syndromes are autoimmunity-driven. **Scientific opinion is constantly in flux.**
  - Long COVID patients have high levels of auto-antibodies compared to healthy controls (e.g. Wallakut et al. doi.org/10.1016/j.jtauto.2021.100100). It is possible that Long COVID is an autoimmune condition.
- The chronically ill are often **denied access to healthcare**, being told that it's all in their head. This contributes to underdiagnosis.
  - A 2020 commentary (doi.org/10.1089/aid.2020.0095) discusses ME/CFS activists and expresses the point of view that ME/CFS is "all in their head".

Other challenges

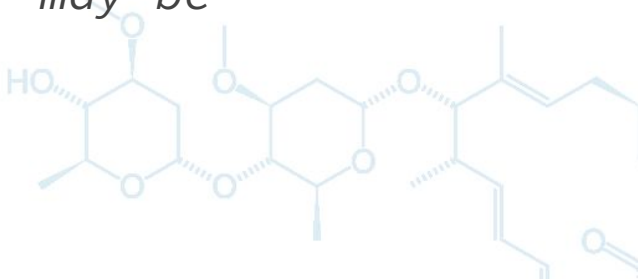
- **A few people have biomarkers** of autoimmunity (auto-antibodies, multiple sclerosis-like lesions) **without symptoms**.
  - Wang et al. (2021) profiled COVID and non-COVID patients for auto-antibodies for a wide range of auto-antibodies. Both patients groups had auto-antibodies, though the COVID patients had more types of auto-antibodies (on average). doi.org/10.1038/s41586-021-03631-y
  - Aksel Siva (2013) describes the phenomenon of asymptomatic Multiple Sclerosis. doi.org/10.1016/j.clineuro.2013.09.012
- **Doctors have discretion** in diagnosing autoimmunity. The diagnosis is often based on biomarkers, symptoms, and the exclusion of other causes. Interest in IVIG may drive the diagnosis of autoimmune-mediated conditions so that the patient's insurance will approve IVIG.
- Some patients experience **long-lasting remission** of their autoimmune condition. 3 surveyees reported remission, even though it was not a survey question.



Data on baseline rates of autoimmunity may be unreliable

Many sources of baseline data do not discuss the role of lasting remission, the rate of undiagnosed autoimmunity, or factors that influence a doctor’s discretion in testing for and diagnosing autoimmune conditions.

This survey is limited by the many difficulties of generating reliable statistics on autoimmunity. The data on pre-existing autoimmunity as a risk factor *may be unreliable*.



This survey aimed for comparability

Autoimmunity was conservatively interpreted so that the data would align with published rates of autoimmunity. **This may dramatically understate autoimmunity prevalence before and after Long-Haul.**

Pilot surveys found that some surveyees would report self-diagnosed conditions. Because the inclusion of self-diagnosis would affect comparability, this survey asked surveyees to differentiate between formal diagnoses and other types of diagnoses. Many other decisions bias the survey results towards under-reporting autoimmunity.

This survey aimed for comparability (continued)

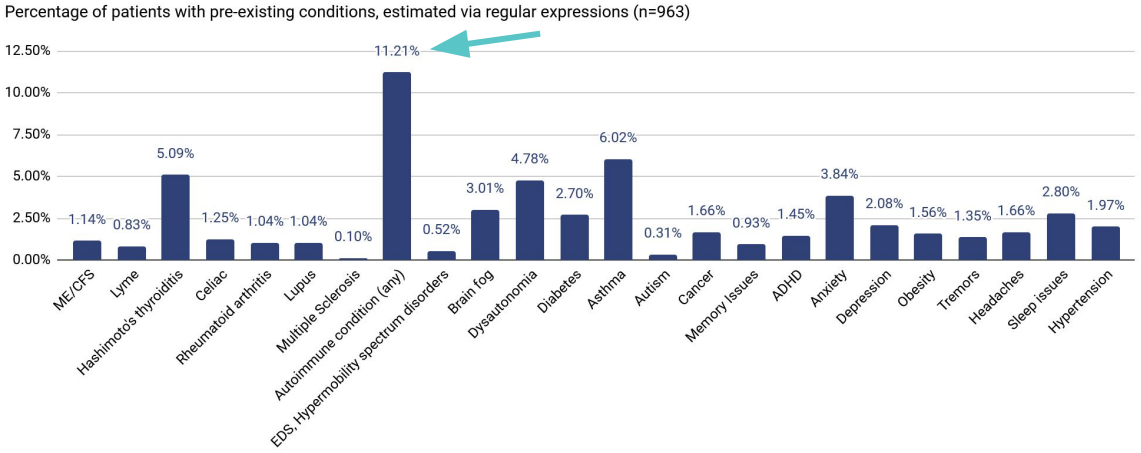
- If the surveyee selected the ‘maybe’ option *and* a formally diagnosed autoimmune condition, their response was ambiguous. These ambiguous answers were excluded. (We will try to improve our survey questions in the future.)
- Test results showing auto-antibodies were not considered to be a formal autoimmunity diagnosis.
- Surveyees commonly reported non-consensus conditions as being a (possible) autoimmune condition: ME/CFS, IBS, asthma, dysautonomia, POTS, MCAS, etc. They were not considered to be formal autoimmunity diagnoses.
- ‘Grey area’ conditions were also excluded: hEDS, EDS, eczema, endometriosis, fibromyalgia, hemochromatosis, interstitial cystitius, and lymphocytic colitis.
- Formal diagnosis of unknown and unspecified autoimmune condition were excluded (3 cases).
- Small fibre neuropathy diagnoses were excluded unless the surveyee specified that it was the autoimmune type. (With the benefit of 20/20 hindsight, we should have asked about the type of SFN.)
- 3 surveyees reported that their autoimmune condition was in remission prior to Long-Haul. 2 surveyees reported that their autoimmune condition came back; their prior diagnosis was included. The third surveyee reported that their autoimmune condition stayed in remission, so their formal diagnosis was arbitrarily excluded.

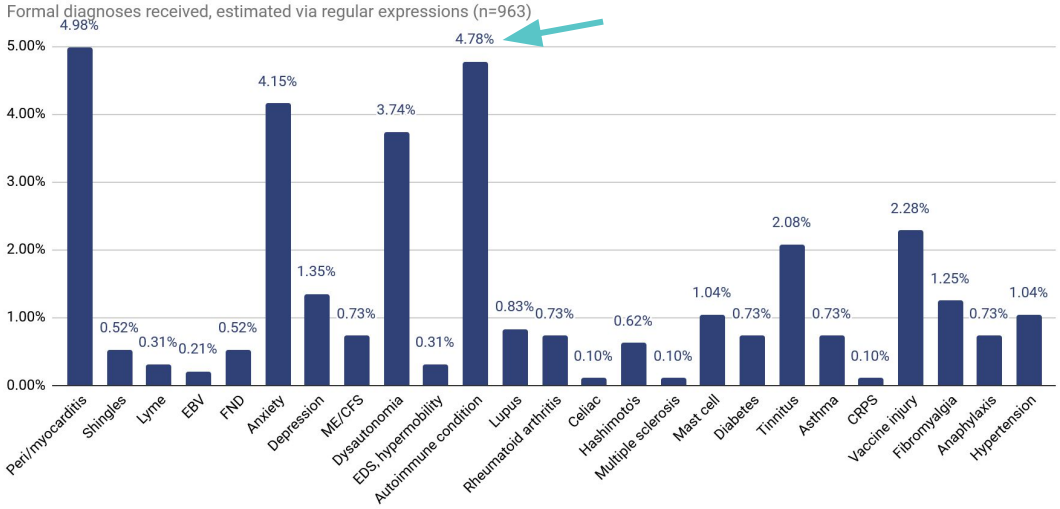
Appendix - the large gap in autoimmunity rates between this survey and the previous React19 survey

The gap

The [previous React19 survey] estimated pre-existing autoimmunity in the vaccine injured at **11.2%** versus **21.8%** in this survey.

Newly diagnosed autoimmunity was estimated at **4.8%** versus **13.9%** in this survey.





Possible factors

Factors that may have overstated the actual gap:

- The estimation tool (regular expressions) used in the previous survey missed some obscure autoimmune conditions.
- It takes time for patients to receive an autoimmunity diagnosis. The wait times for specialists are typically many months.
- There are demographic differences between the two surveys.
- The previous survey did not require surveyees to list all formal diagnoses given to them.
- The previous survey may have had a higher rate of people who didn't report their autoimmune condition, e.g. because they didn't think that it was important or because they had many conditions and forgot to list them all.

Factors that may have understated the actual gap:

- The previous survey allowed non-formal diagnoses for its pre-existing conditions question. The non-formal diagnosis rate could be quite high. In the previous survey, an estimated **5%** had a formal diagnosis of peri/myocarditis while **13.3%** reported myocarditis as a symptom.
- There are demographic differences between the two surveys.

It is not clear why the current survey's autoimmunity rates are so much higher than the previous survey. However, other sources of data also suggest high rates of autoimmunity.

PLRC (Patient-Led Research COVID19) surveys

Surveys on *Long COVID* by the PLRC group found high rates of pre-existing auto-immunity: **10.5%** and **6.9%**. These numbers are somewhat comparable to the **16.0%** rate from this survey.

One caveat is that the PLRC surveys had some inter-survey differences. The rate of pre-existing obesity was **0.63%** in one survey and **10.8%** in the later survey.

	Report: What Does COVID-19 Recovery Actually Look Like?	Characterizing long COVID in an international cohort: 7 months of symptoms and their impact (C.2 in the supplementary material)
URL	https://patientresearchcovid19.com/research/report-1/	https://doi.org/10.1016/j.eclinm.2021.101019
Survey copy		https://figshare.com/articles/online_resource/Questionnaire_to_Characterize_Long_COVID_200_symptoms_over_7_months/13642553/2
Obesity	0.63%	10.8%
Cancer	1.72%	2.7%
Auto-immune / Rheumatologic Conditions	**10.47%**	**6.9%**
Asthma	16.88%	17.20%