

COVID-19 SURVEY III KEY FINDINGS

Tremendous thanks to everyone who completed our third COVID-19 Survey. Our goal is to keep you up-to-date on the ever-changing landscape of COVID-19 and how it is impacting the OI Community.



31% of respondents report they have had COVID-19 at least once.

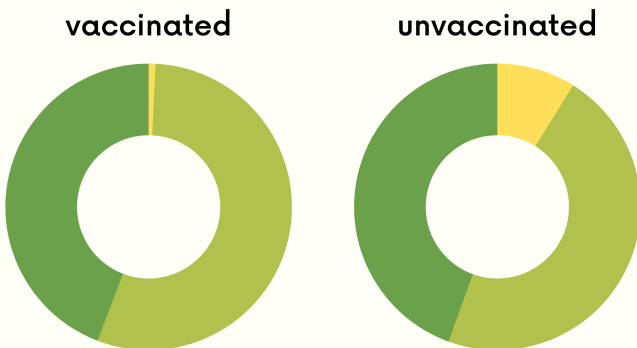


report they **are fully vaccinated** against COVID-19.



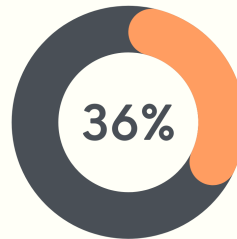
report that they **have received a booster shot.**

Unvaccinated individuals reported higher rates of severe COVID-19 infections requiring hospitalization.



- hospitalized
- moderate symptoms
- none or minor symptoms

The OIF continues to recommend COVID-19 vaccines and boosters as safe and effective methods of lowering your risk for serious illness or death from COVID-19.



of respondents were **less physically active now than before the pandemic started.** Exercise is essential to maintaining muscle mass and bone density, and supports mental health and mood.

Many respondents reported positive outcomes from the pandemic including:

- more time spent with family
- working from home
- new and different social interactions
- ability to exercise and meditate
- new hobbies



For a full report and for more COVID-19 resources, please visit www.oif.org

OIF COVID-19 Survey 3 Results

Thanks to all of the 577 community members who took the time to fill out the survey, we were pleased to see such a wide response in a short amount of time. Our goal in gathering the community's input is that we can provide feedback during the changing landscape of COVID-19 and direct the OIF's resources where most needed.

It is our goal to keep the OI community informed about how COVID-19 impacts individuals with OI. If you missed the first three surveys, keep an eye out for the next one! To complete future surveys about OI, we highly encourage you to sign up for the OI Registry at www.oif.org/OIregistry to be the first to hear about these opportunities.

For questions, contact the OIF via email: bonelink@oif.org or telephone: 301-947-0083.

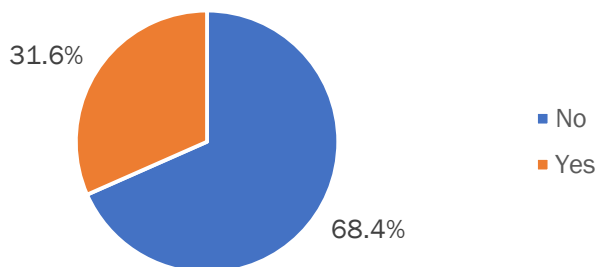
Overview

In total, **577 individuals** responded to the survey, the average **age** of respondents was **40.4** [Survey 1 **39.4**, Survey 2 **46.5**]. For demographics, **70.7%** respondents identified as **female** [compared to 75% in Survey 2], and **85.1% white**, compared to 87% and 92% previously. **8.8%** respondents identified as **Hispanic/Latino**, **3.8% Asian**, and **4.5 % African American**, which represented a more diverse group of respondents than the first two surveys.

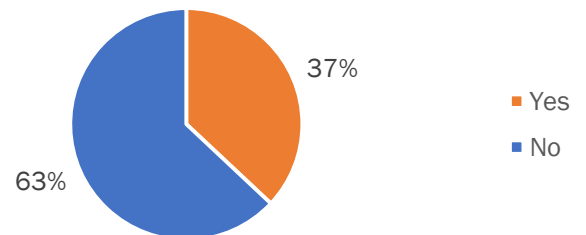
COVID-19

The number of respondents reporting that they had COVID increased significantly from **14.1%** to **31.6%**, but this remains less than the CDC estimate of 43% nationwide (CDC link). Of these, **120 (68%)** reported a **positive test** while **38 (22%)** were **self-diagnosis** and **18 (10%)** were **physician diagnosis**.

Do you believe you have had COVID-19?

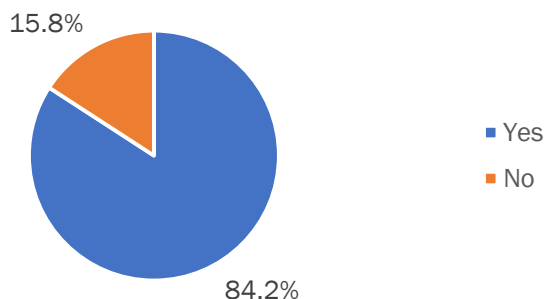


Did you still experience symptoms 4 weeks after your initial infection?

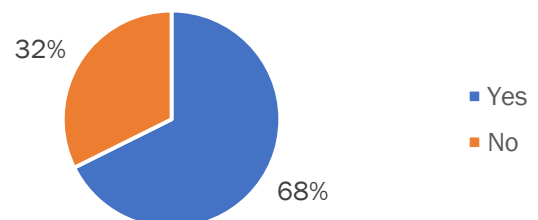


The percentage of individuals who reported symptoms 4 weeks after initial infection **fell from 50% to 37%**. After over a year of vaccine availability, **462 (84.2%)** respondents **had received the COVID-19 vaccine**, which is **significantly up** from **222 (34%)** a year ago. This is also better than US data where only 76.4% of eligible people have gotten at least one dose (per CDC data https://covid.cdc.gov/covid-data-tracker/#vaccinations_vacc-total-admin-rate-total). Similar results were seen regarding **COVID-19 Booster** doses: **68% of respondents** had received a booster. To date, only **44% of those eligible in the US** have received a booster.

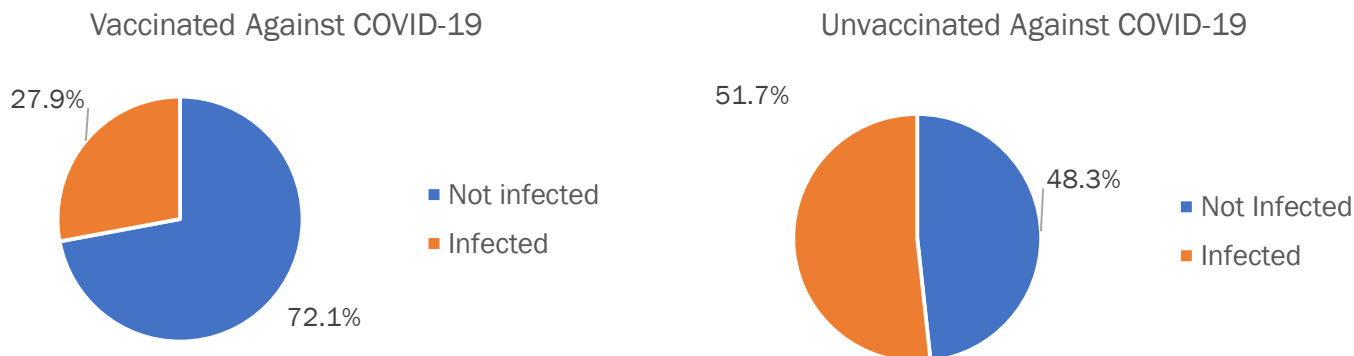
Have you received the COVID-19 vaccine?



Have you received a COVID-19 vaccine booster?



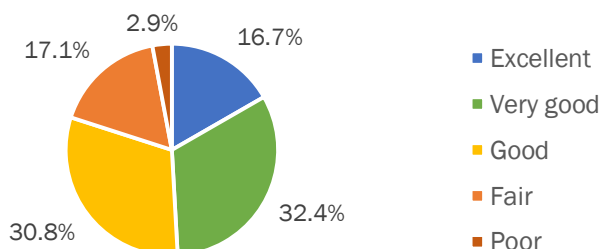
Of those surveyed, a **smaller portion (27.9%) of those vaccinated** against COVID-19 reported **having COVID** versus those who were **unvaccinated (51.7%)**. This appears to match CDC data which demonstrates a 3-fold increased risk for testing positive for COVID-19 in unvaccinated adults (<https://covid.cdc.gov/covid-data-tracker/#rates-by-vaccine-status>). Most importantly, a larger percentage of those **unvaccinated who contracted COVID had severe illness requiring hospitalization (9%), versus 1% in those who were vaccinated.**



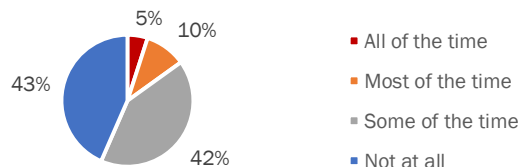
Impact of COVID-19 on OI Community (Resiliency)

Most respondents reported having **Good, Very Good, or Excellent mental health (80%)** including mood and ability to think. In addition, only a small number of respondents felt depressed or isolated most or all of the time, demonstrating the resiliency of the OI community in the face of a prolonged global pandemic.

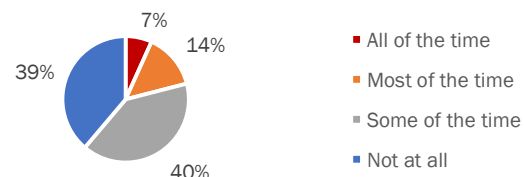
In general, how would you currently rate your mental health, including your mood and your ability to think?



You feel depressed.

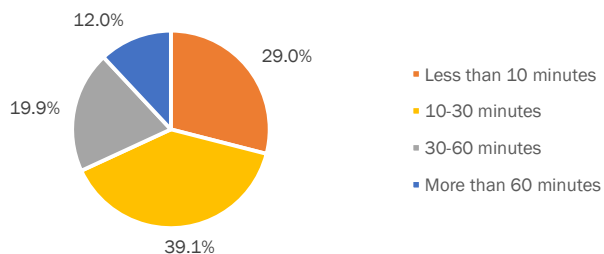


You feel isolated.

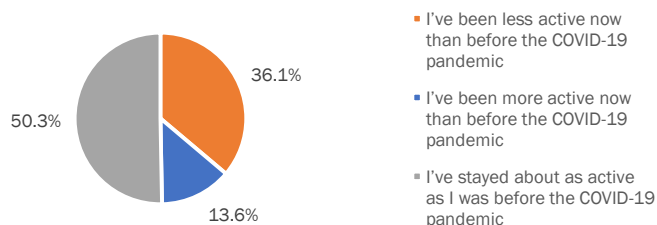


Healthy Habits - 50% of respondents have been about as active as before COVID-19, while **36% are less active** and **14% are more active** compared to 30% the same, 62% less, and 8% more active in Survey 2. For the OI community, decrease in activity is a source of concern as it can lead to muscle loss and reduced bone density. Physical activity is also a major component of mental health and mood. Please visit www.oif.org for resources on how to stay active during the COVID-19 pandemic, applicable for all ages and levels of ability.

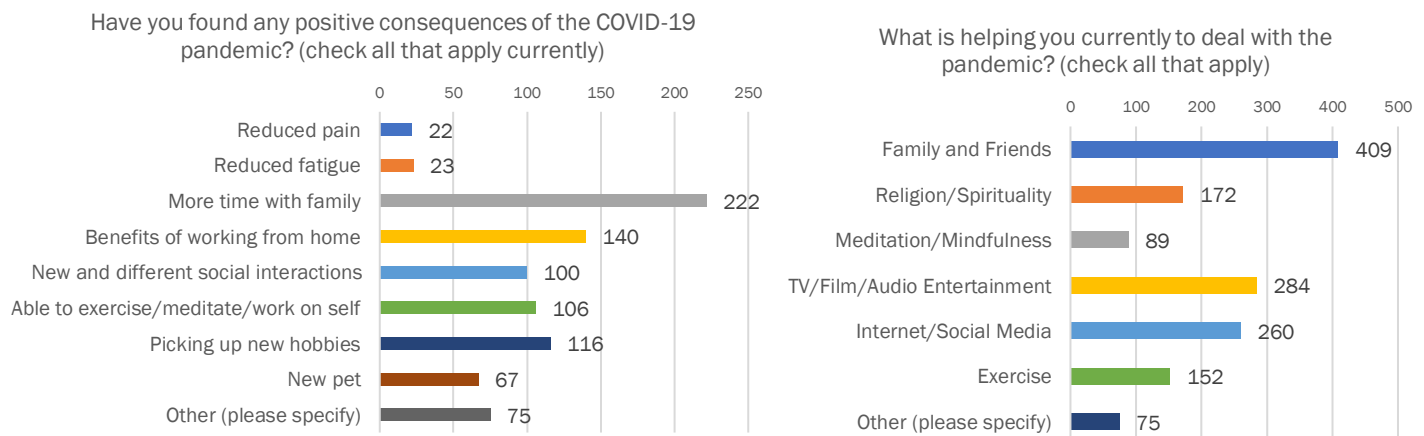
Typical Day Amount of Time Exercising



Activity Level Compared to Before the COVID-19 Pandemic



Individuals also reported a number of positive aspects of the pandemic, and listed things that helped them deal with the challenges of COVID-19. Respondents said more time with family (222), benefits of working from home (140), and picking up new hobbies (116) were common benefits, while friends and family (409), entertainment (284), and the internet (260) were commonly cited as helping people deal with the pandemic.



Important Findings

- While COVID-19 vaccination and boosters were higher among OI respondents than in the United States overall, a significant percentage of unvaccinated OI respondents had COVID and, moreover, had severe COVID requiring hospitalization. Please visit <https://oif.org/category/covid19/> for more information about COVID vaccines, boosters and how to receive one.
- A portion of the OI community has become less active, and this negatively impacts bone and overall health. We encourage all community members to utilize the following resources to maintain active and healthy lifestyles! Click the link or type in the URLs below.
 - National Conference 2021 Fitness and OI Presentation- YouTube Recording <https://youtu.be/oJ-PeOc13pA>
 - Exercise and Activity: Key Elements in the Management of OI- OIF Factsheet https://oif.org/wp-content/uploads/2019/08/Exercise_Activity.pdf
 - Wheelchair-Based Exercises for People with Osteogenesis Imperfecta- HSS four-part video series https://www.hss.edu/conditions_wheelchair-based-exercises-osteogenesis-imperfecta.asp
 - How to Be Physically Active While Social Distancing- CDC recommendations <https://www.cdc.gov/physicalactivity/how-to-be-physically-active-while-social-distancing.html>
- Despite the many challenges of the COVID-19 pandemic, the OI community has proven itself to be incredibly resilient!!! Community members have particularly found family and friends to be critical to coping with these difficult times.

Next Steps: Please enroll in the [OIF Registry](#) and plan to participate in future OI surveys!

In Case You Missed It- The OIF COVID-19 Toolkit provides a wide range of content which is all available for free on the OIF website, which can be found here: www.oif.org/category/covid19/

COVID-19 Community Calls (recordings)

- [COVID-19 Q&A - Dr. Sandhaus, Dr. Glorieux](#)
- [Mental Health and Self-Care](#)
- [Orthopedic Perspectives on COVID-19](#)
- [Eating Healthy during the COVID-19 Pandemic](#)
- [COVID-19 Q&A - Dr. Sandhaus, Dr. Nagamani](#)
- [Preparing for Your TeleHealth Appointment](#)
- [Mental Health during COVID-19](#)
- [Employment Accommodations and COVID-19](#)

COVID-19 Surveys

- [COVID-19 Survey I Results](#)
- [COVID-19 Survey II Results](#)

COVID-19 Vaccine Resources

- [COVID-19 Vaccine Q&A - Dr. Bottazzi, Dr. Sandhaus, Dr. Lee](#)
- [COVID-19 Vaccine State Distribution Information](#)
- [Resources on COVID-19 Vaccinations](#)
- [COVID-19 Vaccine Statement from the OIF Medical Advisory Council](#)
- [CDC Vaccine Finder](#)
- [COVID-19 Vaccine Q&A - Dr. Sandhaus](#)
- [COVID-19 Vaccine Update](#)