

## OIF COVID-19 Survey Results

In July, the OI Foundation sent a survey to members of the OI Registry to help us better understand how the COVID-19 pandemic is affecting families and individuals living with OI. Thank you to the 199 community members who filled out the survey! We are excited to share the responses!

The impact of the pandemic is changing daily. We will be sending a second survey out in early 2021, so, if you missed the first survey, please be sure to enroll for the next one! To complete the survey, you must be a member of the OI Registry.

To sign up for the OI Registry, go to [www.oif.org/OIregistry](http://www.oif.org/OIregistry). Participants receive information about upcoming studies and online surveys about OI. Sign up today to help move OI research forward! For questions, contact the OIF via email: [bonelink@oif.org](mailto:bonelink@oif.org) or telephone: 301-947-0083.

### Overview

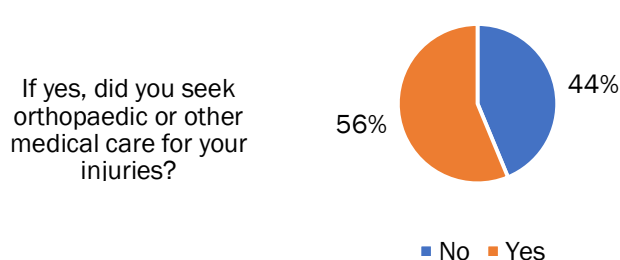
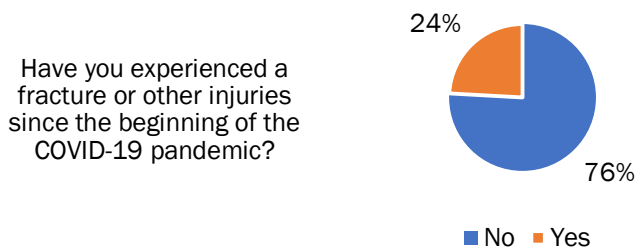
Of the survey respondents, 145/199 (73%) were **women** and 182/198 (92%) were **white**. The average **age** of respondents was **39.4** (range 0-84), and 159/199 (80%) of respondents were the individual with OI. For race, 7/198 (3.5%) responded Asian, 3/198 (1.5%) responded Black or African American, 2/198 (1.0%) responded American Indian or Alaskan Native, and 4/198 (2.0%) responded Other. 20/199 (10%) respondents self-identified as **Hispanic, Latino or Spanish Origin**, while 5 (3%) preferred not to say. For self-reported OI type, 100/199 (50%) of respondents said they had **Type I** OI, while 48/199 (24%) reported **Type III**, 25/199 (13%) **Type IV**, 6/199 (3%) **Type V**. Of the 19 respondents who said Other, 14 (7%) **did not know their type**. Of the 4/199 (2%) of respondents who believed they had COVID-19, none responded that they needed to go to the hospital.

### Day-to-Day Activities

While some respondents faced work and school changes due to the pandemic, most were able to transition to online or remote employment/school. **Many respondents** have been **able to stay completely at home** during the pandemic by switching to delivery services or having friends/family bring over food and other supplies. While **most respondents** said they had **no difficulties in obtaining supplies**, challenges faced included grocery shortages, delivery delays, local food access, mobility/pain, going to store less frequently, and fear of sanitation of purchased goods. Most respondents 170/194 (88%) said they were able to stay home and typically work remotely, however 24/194 (12%) continued working in person.

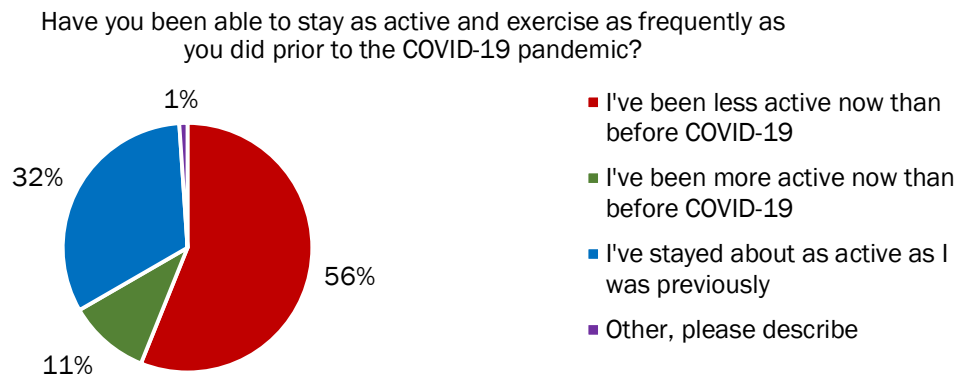
### Access to Care

Initially, stay-at-home orders may have impacted the OI community's ability to access care, the majority of respondents were still able to communicate with their healthcare provider, either in-person or via telemedicine/telephone. Only 10/199 (5%) noted their **care was interrupted** or they **could not communicate with their healthcare provider**, and 49/199 (25%) did not attempt or need to communicate with their clinician. **Fracture or other injury** were reported by 48/199 (24%) of respondents after March of 2020, but of those, little more than half of respondents 27/48 (56%) sought care for their injuries.



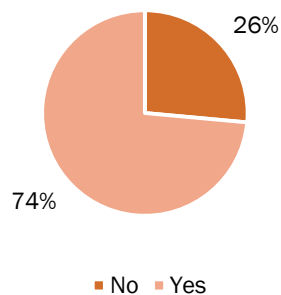
## Healthy Habits

**Exercise:** 106/199 (56%) people said they **were less active** than before the pandemic started, while **only 20/199 (11%)** said they were **more active**. For the OI community, decrease in activity is a source of concern as it can lead to muscle loss and reduced bone density.

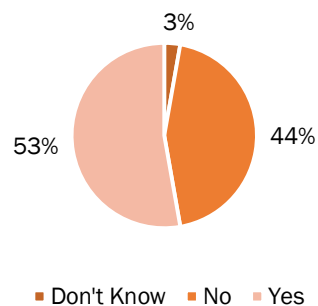


**Vaccines:** There were 50/189 (26%) respondents who **did not get the influenza (flu) vaccine in 2019**, and **only 53% of adults older than 50 have ever gotten the Pneumovax vaccine**. Additionally, 32/189 (17%) said they would be a) not very willing or b) not at all willing to get a COVID-19 vaccine. Research demonstrates that **the flu vaccine reduces the risk of having to go to the doctor for the flu by 40-60%**. Similarly, **flu vaccination** has been shown to **reduce flu associated hospitalizations**, and reduces the severity of illness in individuals who do get sick ([CDC](#)). For seniors 65 and older, the pneumococcal vaccine has been shown to prevent pneumococcal pneumonia in 9 of 20 individuals (45%) ([CDC](#)).

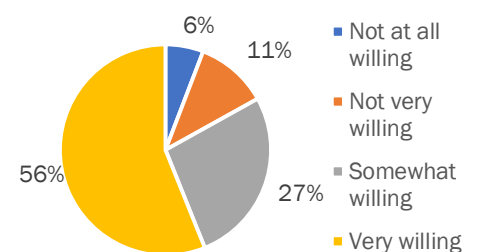
Did you get the influenza vaccine in 2019?



If you are age 50 or older, have you ever received the pneumococcal pneumonia vaccine (Pneumovax)?

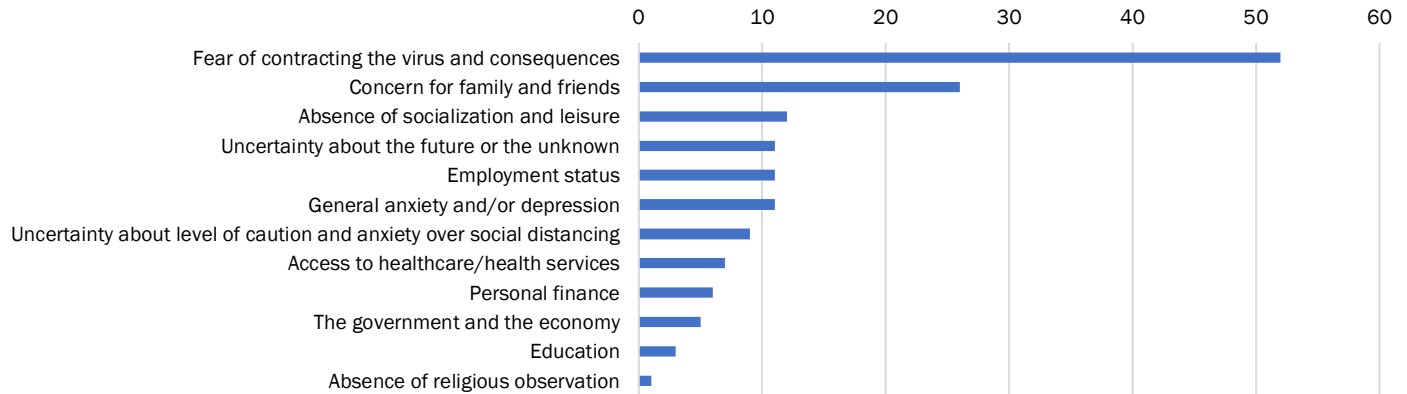


If a COVID-19 vaccine is developed, how willing are you to get the vaccine?



**Mental Health:** The COVID-19 pandemic and related consequences have been a major cause of worry for the OI community. When asked about **how stay-at-home orders and isolation have affected mood and behavior**, **10% reported very much**, **19% quite a bit**, **56% somewhat**, and **15% not at all**.

Have you experienced anxiety, fear, stress, or depression related to the current COVID-19 pandemic and OI?



### Important Findings

- A large portion of the OI community has become less active. Health advocates believe that “movement is life.” Therefore, the OIF will provide new opportunities to encourage OI-appropriate exercises and activities.
- The OIF recommends that community members take the flu and Pneumovax vaccines in order to maintain the best possible pulmonary health. Of note, many pharmacies are offering drive-thru vaccine stations. To view locations where you can receive a flu shot in your area, use the Vaccine Finder at [www.vaccinefinder.org](http://www.vaccinefinder.org).
- Anxiety and/or depression have been a challenge for many individuals during the COVID-19 pandemic. The OI Foundation has held two community calls on this topic, focusing on resiliency and self-care (available at [www.oif.org/podcast](http://www.oif.org/podcast)) as well as sharing numerous resources for addressing the pandemic, and will continue to offer similar events in the future.

**Next Steps:** Please enroll in the [OI Registry](#) and plan to participate in the next OI COVID-19 survey in January 2021!