

Summary of COVID-19 Data Collected by AlphaNet

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Introduction

The pandemic of disease caused by the corona virus SARS-CoV-2 and its variants has shaken the world and the Alpha-1 community since late 2019. Infection caused by this virus, called COVID-19, which stands for Corona Virus Infectious Disease from 2019, can be without symptoms at one extreme and lead to hospitalization, organ failure, and death at the other. Most people who develop symptoms of infection from this virus don't require hospitalization and recover at home. In the general adult population, between 9% and 18% of those who are infected wind up in the hospital or ICU, depending on which study you read. A significant percentage of those admitted to the ICU die. According to one study, about one third of people admitted to the ICU with COVID in 2020 died (citation: Rate of Intensive Care Unit admission and outcomes among patients with coronavirus: A systematic review and Meta-analysis. Semagn Mekonnen Abate, Siraj Ahmed Ali, Bahiru Mantfardo, Bivash Basu; Published: July 10, 2020 in PlosOne; <https://doi.org/10.1371/journal.pone.0235653>). In addition, the hospitalization rates and death rates for those with underlying medical conditions are much higher than those in the general population.

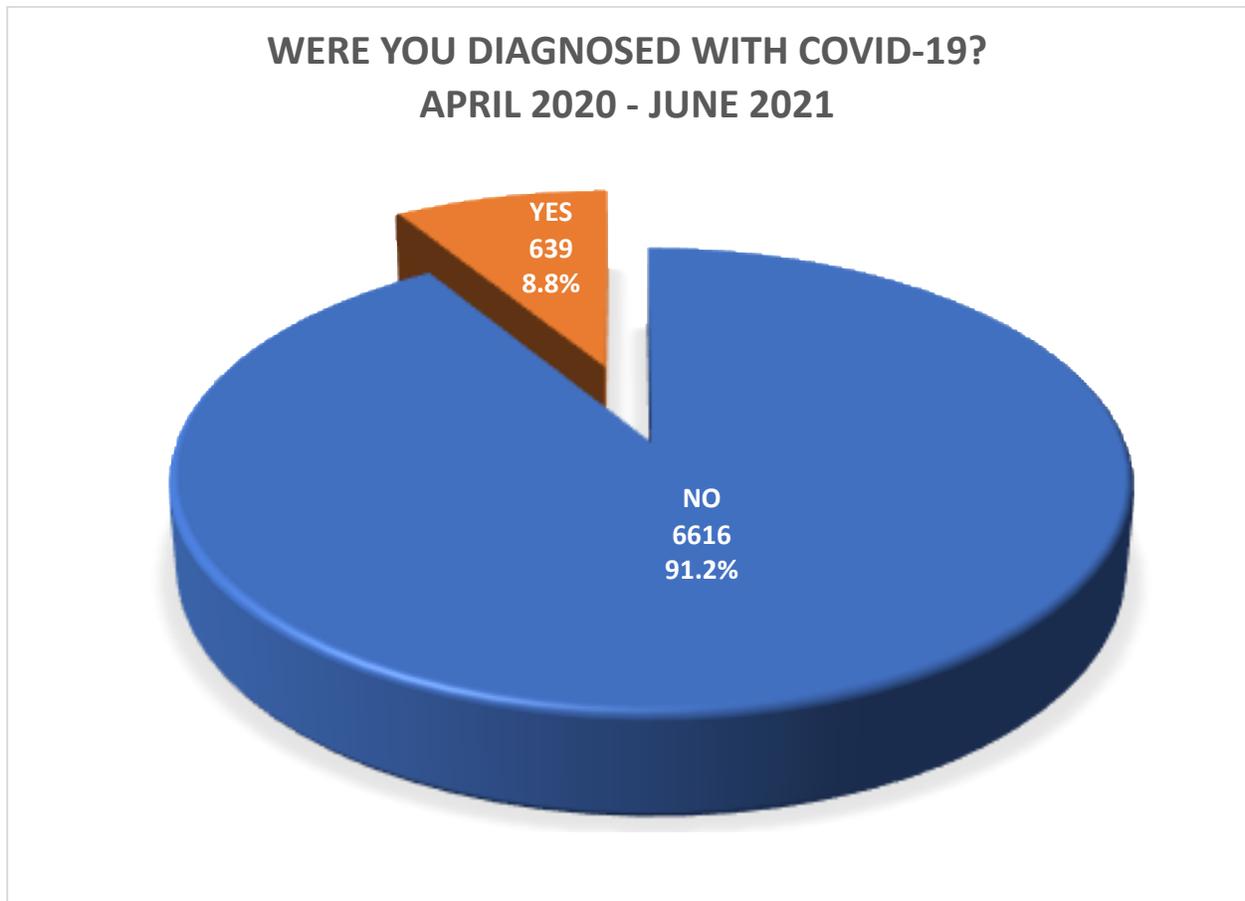
On top of these statistics, there has been growing concern about mutations and variants of the virus and some of these like the Delta variant have increased the infection rate for COVID-19. Long symptom duration and slow recovery following even mild infections have presented ongoing issues for those who recovered from infection. And finally, with the development of several highly effective vaccines that can prevent serious illness, we are confronted with hesitancy of some people to accept vaccination and other preventative measures to increase the safety of individuals and the people around them.

In view of the above and questions about whether Alpha-1 Antitrypsin Deficiency (Alpha-1, for short) might increase the risks of COVID-19, AlphaNet and AlphaNet Canada began collecting data regarding COVID-19 every month from its more than 7,000 subscribers starting in the first week of April 2020. This article summarizes some of the results we found through the end of June 2021. It's important to know that most of the individuals who join AlphaNet's health improvement program have lung disease due to Alpha-1, in part because most people with Alpha-1 are diagnosed because they have lung disease. Therefore, this information may not reflect the answers of someone who has Alpha-1 but is entirely healthy or is liver affected. The heroes of this story are the AlphaNet subscribers who provided this information and the more than 65 AlphaNet Coordinators who collected it.

COVID-19 Diagnosis

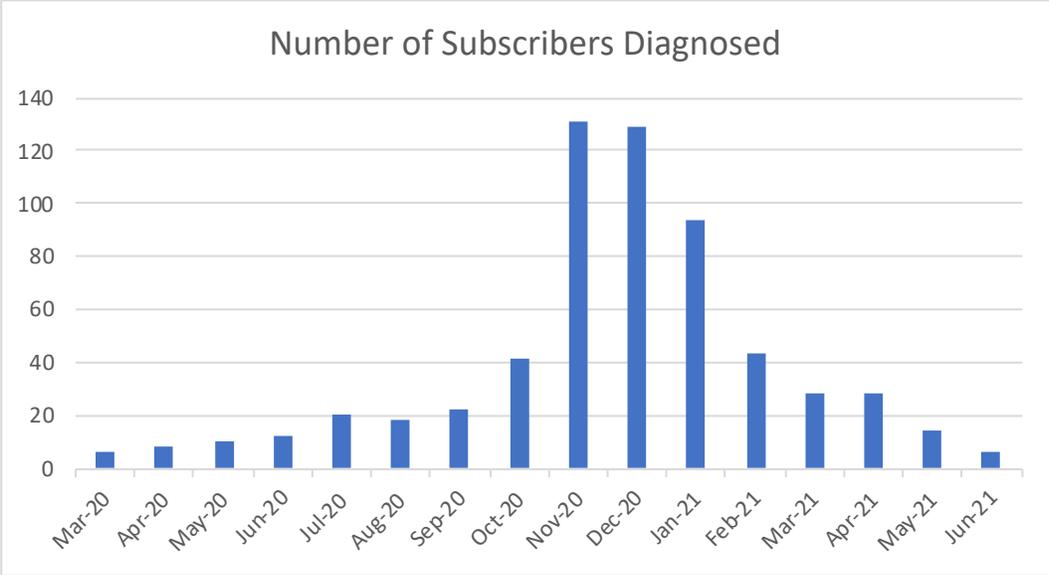
We started by collecting information about how many of our subscribers and the people living in their households were diagnosed with COVID-19. Over the 14 months we've collected this

information about 11% reported that they or someone living in their household had been diagnosed with COVID. If we just concentrate on the AlphaNet subscribers themselves, this is what the data look like:



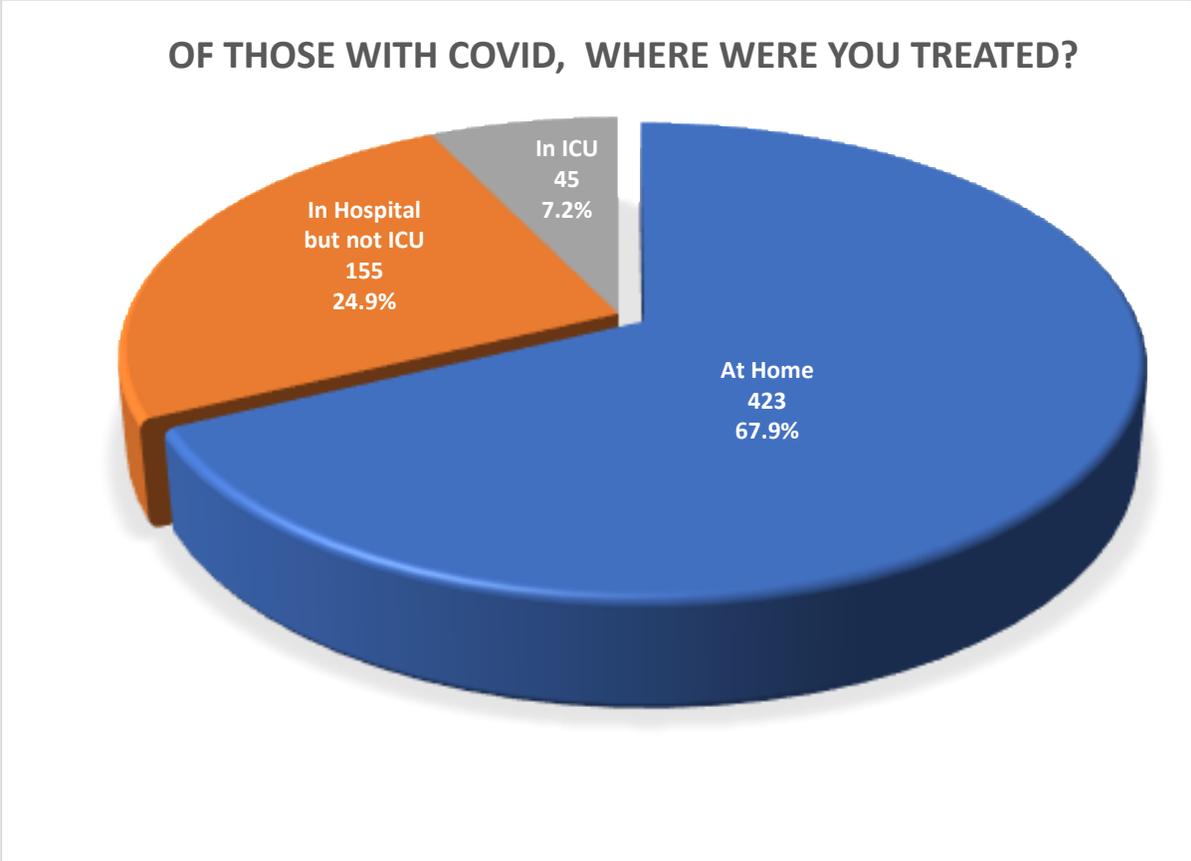
When you consider that in the general population about 17% of adults have been reported to be diagnosed with COVID-19, this suggests that those with Alpha-1 are doing a better job than the general population of keeping themselves safe from COVID-19, whether that mean abiding by changing recommendations to wear masks, social distance, avoid crowds, and/or get vaccinated. The number of people who are diagnosed in any given month varies based on the number of people in the general population who are infected. The next graph demonstrates how many people each month reported they had been diagnosed. It is likely that when we look at our data beyond the end of June 2021, we'll see an rise in the number of people who report a COVID-19 infection based on the growing role of the more-infectious Delta variant.

When we look at the diagnosis of COVID-19 in AlphaNet participants on a month by month basis we see that diagnosis numbers each month follow a similar pattern to the general U.S. and Canadian population.

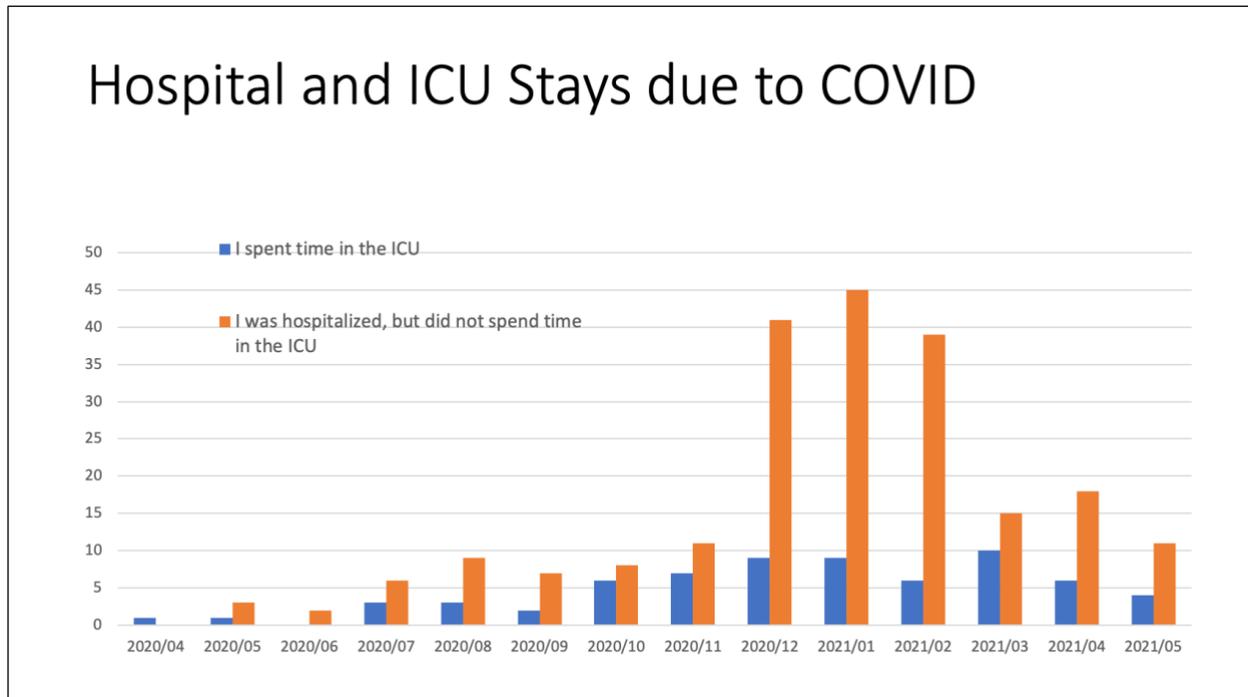


Treatment

We asked Alphas who were diagnosed with COVID-19 whether they were treated and recovered at home, whether they were admitted to the hospital and then went home, or whether they needed a stay in the ICU. Here is what we learned.



We can also see that the monthly totals of hospitalizations and ICU stays reported to AlphaNet seem to follow the spikes of infection in the general population.

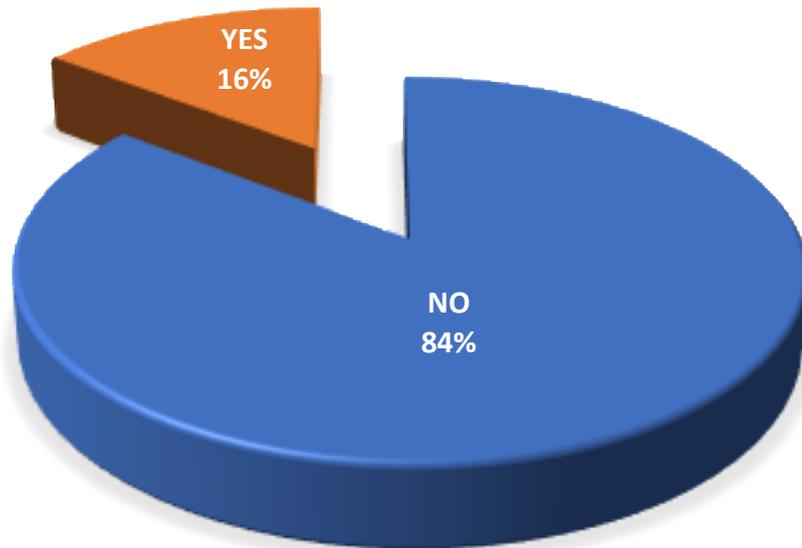


As mentioned at the start, we know that between 9% and 18% of the general population with COVID-19 wind up in the hospital or ICU. In those with Alpha-1 followed by AlphaNet, more than 32% were treated in the hospital or ICU. This suggests that having a diagnosis of Alpha-1, especially in those with Alpha-1-related lung disease, approximately doubles your chances of winding up the hospital or ICU. This is why it is so important the individuals with Alpha-1 follow all guidance regarding protecting themselves from COVID-19 infection. If you have questions about COVID-19 guidance for Alphas please refer to the Alpha-1 Foundation website (www.alpha1.org) where you will find extensive information about COVID-19 and steps to take to reduce infection risks. It is especially important for all individuals with Alpha-1 and their household members to be vaccinated.

Recovery

Most patients who survive COVID-19 recover completely and have no residual symptoms. There has been a growing appreciation that this is not the case for 10-30% of those infected. Symptoms lasting more than three weeks and often for many months after the virus is no longer detected have been call “long COVID” or “long-haul COVID.” The causes of such long COVID symptoms and their treatment are not well understood at this time. It has been reported that COVID-19 vaccination has reduced or eliminated long COVID symptoms in some.

Long COVID

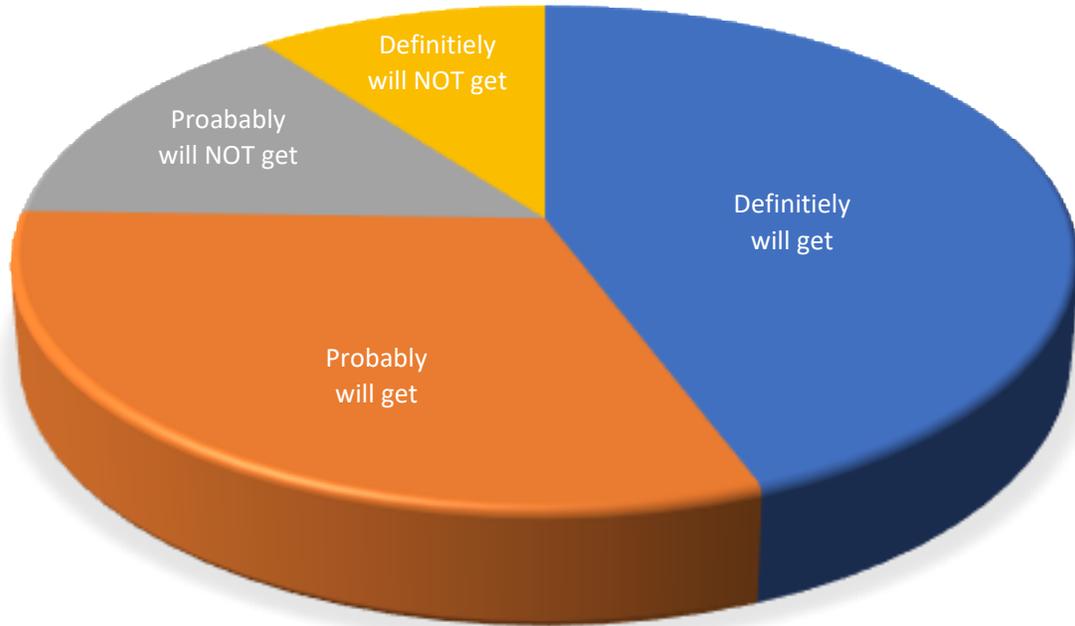


In the AlphaNet questions, we asked subscribers who had COVID-19 infection whether they had symptoms lasting more than three weeks after recovery. 102 of the more than 600 Alphas with COVID-19 said they had, or about 15%.

Vaccination

Soon after the first vaccines were given an emergency approval by the U.S. FDA, we added a question which we asked only once: How likely are you to get the COVID vaccine? The next chart shows the responses we received.

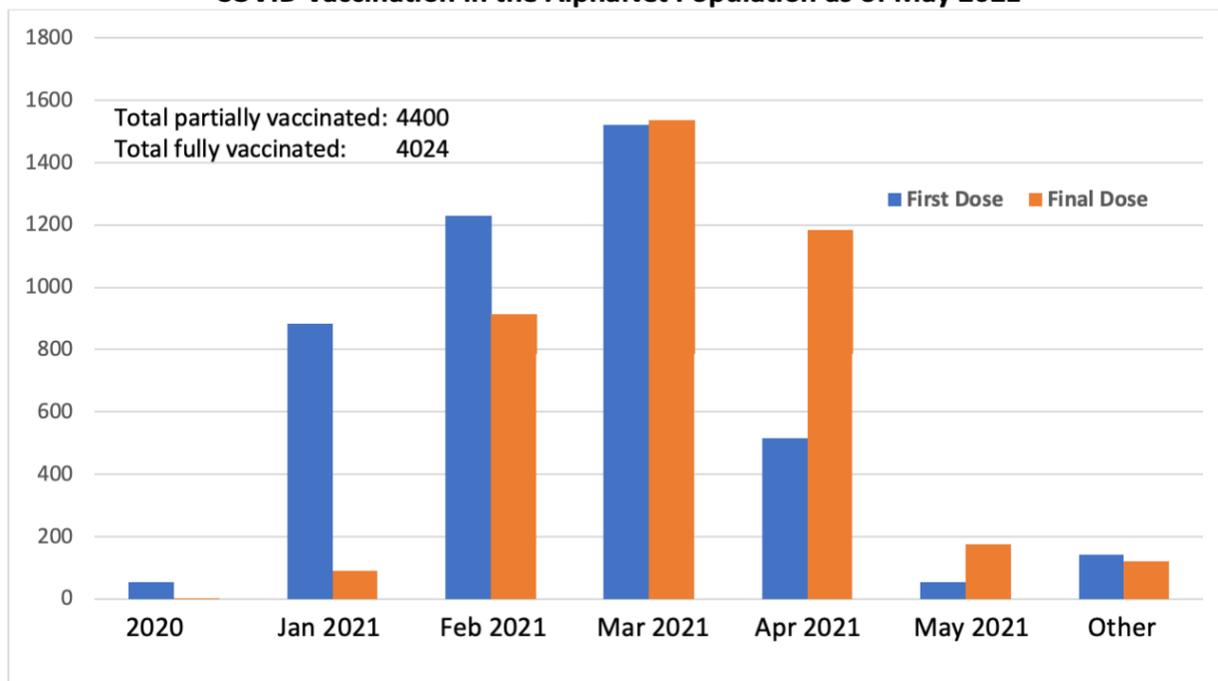
**HOW LIKELY ARE YOU TO GET THE VACCINE?
(ASKED WHEN VACCINES STARTED TO BECOME AVAILABLE)**



Definitely or probably will get = 75%
Definitely or probably will NOT get = 25%

AlphaNet Coordinators also ask their subscribers what vaccines they've received from time to time. COVID-19 vaccine was added to the vaccine list in January 2021. Our last evaluation of those data was at the end of May 2021. This chart shows the results at that time.

COVID Vaccination in the AlphaNet Population as of May 2021

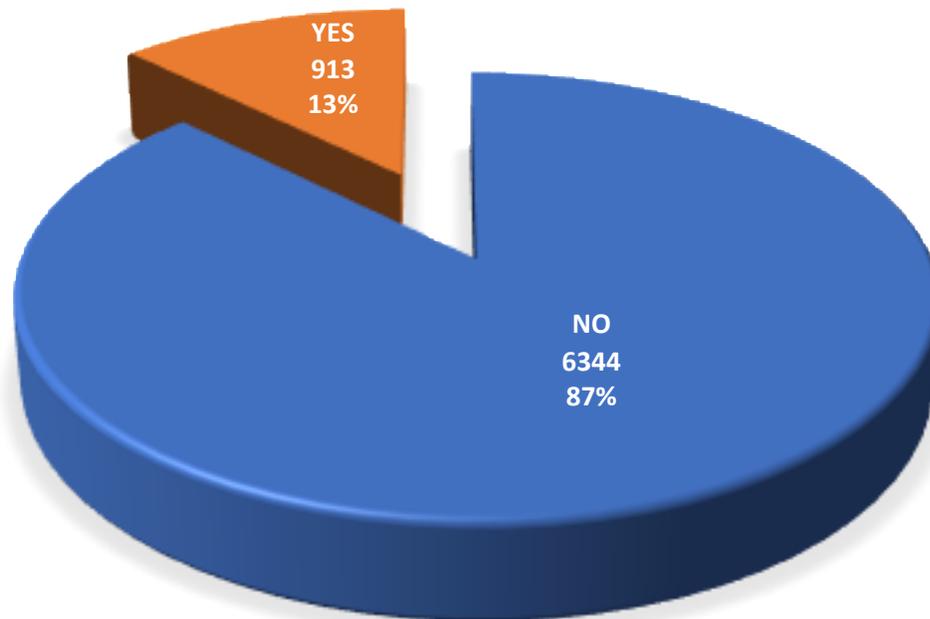


Because the Coordinators do not ask vaccination questions on a regular basis, the numbers shown above may under-count to total number of vaccinated Alphas being followed by AlphaNet.

Augmentation therapy during COVID-19

Early in the pandemic, we found that many individuals with Alpha-1 who were receiving infusions of augmentation therapy had to change where they received their infusions or even miss infusions for a variety of reasons. People who were receiving home infusions using a nursing service worried that nurses who had been visiting multiple patients' homes might bring infection risk into the Alpha's home. People who were receiving infusions in the hospital or infusion center setting worried that going to such a facility where COVID-19 patients were being treated would increase their risk of infection. Some infusion centers closed because of these potential risks. This led to people with Alpha-1 missing or postponing infusions or changing to alternated infusion regimens. The next chart shows the results of asking if AlphaNet participants had missed infusion one or more infusions because of COVID-19.

**DID YOU MISS AT LEAST ONE SCHEDULED INFUSION
DUE TO COVID-19?
APRIL 2020 - JUNE 2021**



There were various reasons reported for these missed infusions including concern that it would increase their health risk (64%), they were switched to infusions longer than 1 week apart (9%), their nursing and/or supplies were unavailable (27%), and their augmentation therapy was unavailable (13%). There were a small number of other reasons listed as well. Most of the changes in augmentation administration occurred early in the pandemic and have since moved back to more regular infusions.

Deaths among Alpha-1 patients

One might ask how many of our AlphaNet community have died from COVID-19. We are certainly aware that we have lost members of our community to this virus. But AlphaNet doesn't collect this information for several reasons. First, since all our COVID-19 data is collected by calling our participants on the phone, when a subscriber doesn't answer the phone, we usually don't really know the reason there was no response. There are methods for accessing what is known as the National Death Index or NDI which is a searchable repository of all U.S. death certificates, but such a search requires the social security number of the individuals you are inquiring about. Due to our commitment to confidentiality, AlphaNet does not collect social security numbers from our subscriber.

Summary

Thanks to the data AlphaNet has collected, we know that people with Alpha-1 have done a good job of protecting themselves from COVID-19 compared with the general population. Just the same, a significant number of Alphas have become infected, and it appears that Alpha-1 Antitrypsin Deficiency makes severe disease more likely than in the general population. Contributing to this risk of more severe disease may be the fact that the majority of the AlphaNet population already has significant lung disease. In addition, the role of alpha-1 antitrypsin protein in moderating inflammation is well known and lower levels of this protein, even in those receiving augmentation therapy, might lead to worse COVID-19 symptoms.

On the other hand, the two major issues that remain are vaccine hesitancy and the shadow of COVID-19 symptoms lasting well beyond the resolution of the actual COVID-19 infection, known as long COVID. The burden of long COVID symptoms among those with COVID-19 is yet to be known or well understood. Many researchers are looking for the causes of these prolonged symptoms with the hope of finding treatments that can halt them.

With the growing threat of current and future infectious variants increasing the spread COVID-19 and the vast majority of those with severe disease and death from these variants occurring in those who have not been vaccinated, it is ever more important that Alphas be vaccinated. The effectiveness of the vaccines currently available is well documented and the risk of side effects from the vaccines is infinitesimally smaller than the risk of severe disease or death from COVID-19 if unvaccinated.

We hope the information presented here will encourage the Alpha-1 community to continue to do the work of protecting themselves, their loved ones, and their neighbors from this pandemic. Current predictions are that we will be living with COVID-19 in the world for a long time to come. Hopefully, there will come a day when COVID-19 will be conquered, just as modern medicine has conquered many infectious diseases that ravaged the world.

This project was carried out as part of AlphaNet's quality assurance (QA) activities and does not meet the definition of human research per DHHS regulations.