

What Does COVID-19 Recovery Actually Look Like?

An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team

Executive Summary

Public discourse on COVID-19 has largely centered around patients with severe or fatal illness. While this focus is critical and urgent, it has become clear that a growing number of patients will experience mild to moderate symptoms for a prolonged period of time. These patients currently have little guidance and their experiences are often downplayed. However, their insights can be extremely valuable in learning more about the long-term impacts of the virus, as well as the lived experiences of those who have contracted and will contract COVID-19.

In order to highlight these experiences, patients and survivors of COVID-19 from the [Body Politic COVID-19 Support Group](#) created and analyzed a survey targeted at patients experiencing symptoms for over two weeks. Responses from 640 patients were collected between April 21 and May 2, 2020. While we acknowledge that this analysis pertains to a biased sample of patients with higher recovery times than typically reported, we hope the report will inform public health professionals, inspire future research, and give family, friends, employers, and the general public deeper insight into the range of experiences of people living with COVID-19.

[Read the full report](https://bit.ly/bp-covid-survey-analysis) at <https://bit.ly/bp-covid-survey-analysis>

Key Findings

- **Symptoms are not limited to cough, fever, and shortness of breath:** Other widely reported symptoms span neurological, gastrointestinal, cardiovascular, and other systems and include fatigue (reported by 81.3% of respondents), chills/sweats (75.9%), body aches (73.9%), headache (72.2%), brain fog and concentration issues (68.6%), gastrointestinal issues (66.9%), trouble sleeping (66.1%), and dizziness (60.6%). An elevated temperature under 100.1°F was reported by 72.2% of respondents while a fever over 100.1°F was reported by only 47.8% of respondents.
- **Recovery is volatile, includes relapses, and can take six or more weeks:** At the time respondents took the survey, 90.6% reported not being recovered and were, on average, on day 40 of experiencing symptoms. 89% of respondents said that their symptoms fluctuated in intensity and frequency, and 70% reported new symptoms appearing at different stages of their illness. Based on textual responses and anecdotes from the support group, patients may feel better for days or weeks only to relapse into old or new symptoms soon after.
- **Early testing is crucial, and questions remain around test accuracy:** Despite all respondents showing COVID-19 symptoms, 47.8% were either denied testing or not tested for another reason. The main difference between respondents who tested positive and those who tested negative was *how early in their illness they were tested* (on average day 10 for those testing positive, and day 16 for those testing negative). Furthermore, the only difference in symptoms between these groups is that those who tested positive reported loss of smell and loss of taste more often, even when controlling for testing time. *This could indicate that current tests are not picking up on a subset of COVID-19 patients*, and further investigation into whether tests are accurately capturing the presence of the virus is encouraged.
- **Stigma and lack of understanding compromise access to healthcare and quality of support:** 50% of respondents felt only somewhat supported by medical staff, and many respondents reported receiving conflicting advice from different healthcare professionals on testing eligibility, symptom severity, and when to cease self-isolation. Furthermore, patients experienced a wide range of social stigmas. Both systemic and internalized stigma impact patients' ability and willingness to seek care, self-isolate, and recover with adequate medical and social support.

For in-depth analyses on the above findings and many more, including data on medical treatments, pre-existing conditions, and week-by-week symptoms, please read the [full report](#).