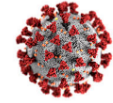


## COVID-PCD: a participatory research study to follow people with PCD during the COVID-19 pandemic



COVID-PCD

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### Why did we set up the COVID-PCD study?

People with chronic diseases are at higher risk of severe COVID-19 disease. Primary ciliary dyskinesia (PCD) is a chronic disease, but we do not know if people with PCD are at higher risk of severe COVID-19. To find this out, we set up the COVID-PCD study together with PCD support groups worldwide. We want to find out how many people with PCD get COVID-19 and how sick they become.

### Who can participate in COVID-PCD?

People with PCD of any age from anywhere in the world can participate in COVID-PCD. Participants register anonymously via the study website [www.covid19pcd.ispm.ch](http://www.covid19pcd.ispm.ch). The study website also includes information about the study, and we show the latest results from COVID-PCD.

### How and what data was collected?

COVID-PCD data is collected via online questionnaires that are sent via email. Study participants complete a baseline questionnaire at registration. This questionnaire includes questions about COVID-19 infections, questions about PCD diagnosis and usual symptoms, and questions about environment and lifestyle. Every week after study registration, participants receive a short follow-up questionnaire about new COVID-19 infections, symptoms, and lifestyle. From time to time, we send extra questionnaires on a special topic.

### What is a participatory study?

A participatory study is a study where patients and their families are involved in setting up and running the study. In COVID-PCD, people with

PCD have an important role in all stages of the study. They help decide which question should go into the questionnaires and how often questionnaires can be sent out. They also help to invite participants for the study, and they help decide how results from the study can best be communicated. Study participants may also propose topics for questionnaires.

### What is the status of COVID-PCD?

The study started in May 2020 and by November 2020, 556 people with PCD from 36 countries had joined. The COVID-PCD study is an important study to learn more about PCD and to find out how people with PCD are affected by the COVID-19 pandemic.

### Further information [www.covid19pcd.ispm.ch](http://www.covid19pcd.ispm.ch)

**Full article reference:** Pedersen ESL, Collaud ENR, Mozun R, Ardura-Garcia C, Lam YT, Harris A, Lucas JS, Copeland F, Manion M, Rindlisbacher B, Silberschmidt H, Goutaki M, Kuehni CE. COVID-PCD: a participatory research study on the impact of COVID-19 in people with primary ciliary dyskinesia. ERJ Open Res. 2021 Mar 22;7(1):00843-2020. doi: 10.1183/23120541.00843-2020. PMID: 33778058; PMCID: PMC7983255.

You can find the full article in English [here](#).

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