

COVID-PCD: By and for people with PCD

updates and plans

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The COVID-PCD Study

Because Primary Ciliary Dyskinesia (PCD) support groups from all over the world wanted to know how COVID-19 affected people with PCD, a research team from the Institute of Social and Preventive Medicine (ISPM) at the University of Bern in Switzerland helped to set up this study.

The COVID-PCD study uses anonymous questionnaires to understand COVID-19 in people with PCD. Participants receive a detailed questionnaire when they start the study, and thereafter short weekly questionnaires. Extra questionnaires on special topics are sent from time to time.

We still invite new participants. Participate via www.covid19pcd.ispm.ch

Partners

University of Bern, Switzerland; University of Southampton, UK. Selbsthilfegruppe Kartagener Syndrom und Primäre Ciliäre Dyskinesie, Switzerland; PCD Support UK; Verein Kartagener Syndrom und PCD, Germany; PCD Australia; PCD Foundation, USA; Asociación Española de Pacientes con Discinesia Ciliar Primaria, Spain; Associazione A.I.D. Kartagener Onlus, Italy; and Association ADCP, France.

Study Funding from

- the Swiss National Science Foundation (320030B_192804/1)
- the Swiss Lung Association
- the PCD Foundation, USA
- the Verein Kartagener Syndrom und Primäre Ciliäre Dyskinesie, Germany
- PCD support UK
- PCD Australia

Thank you!

On behalf of the study team and partners, thank you for taking part in the COVID-PCD study. We know that people with PCD are the experts when it comes to PCD.

We truly appreciate the time you have given and continue to give completing the questionnaires and we hope you will continue to take part.

In this newsletter, you can find out about the results from the study. You can also read about future plans for the study, how you can participate, and where we have published the study results.

The pandemic is not over but with more people getting vaccinated every day, the number of new infections goes down. However, we think the COVID-PCD study should continue because it is a unique opportunity to answer emerging questions about PCD.

For now, we continue to send out the weekly questionnaires in case of another wave of COVID-19. However, we intend to stop the weekly questionnaires at a later date and will thereafter send only short special questionnaires.

You are welcome to contact us if you have questions or suggestions about the study. If you have an idea for a special questionnaire about a PCD-related issue or an idea about what we should look into using the questionnaires that you have already completed, please send us an email: covid19pcd@ispm.unibe.ch. We look forward to your suggestions and input!

With thanks,



The study team from the Institute of Social and Preventive Medicine at the University of Bern in Switzerland: (from left) **Myrofora Goutaki, Eva Pedersen, and Claudia Kuehni**

Results:

How many people participated in the COVID-PCD study?

By July 2021, 701 people with PCD from 47 countries have participated in the COVID-PCD study. Participants are from 6 continents, and most participated from Europe and North America.

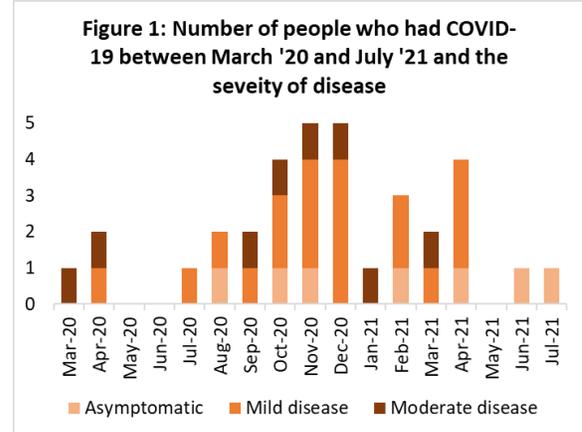
Continent	Number of participants
Europe	509
North America	147
Australia	27
Asia	8
Africa	7
South America	3

What were the COVID-PCD study goals?

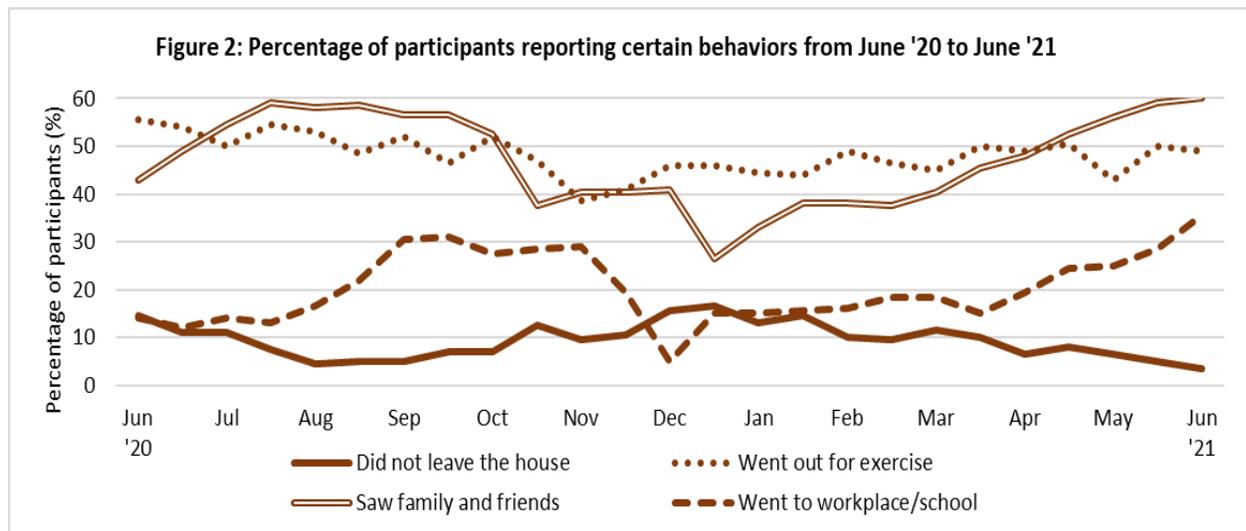
We wanted to learn about the health of people living with PCD during the coronavirus pandemic. We asked these questions:

- how many people with PCD become ill with COVID-19?
- how sick do they get?
- how does COVID-19 affect the daily lives of people with PCD?

How many people with PCD had COVID-19 and how sick did they get?



34 people (5% of all study participants) reported that they tested positive for SARS-CoV-2, the virus that causes COVID-19. You can see in figure 1 that most were infected in the fall of 2020 or the winter of 2021. Participants who were infected with SARS-CoV-2 reported that they only had mild or moderate symptoms that were treated at home. Only 4 needed treatments at the hospital. Of these, no one needed intensive care, and no one died from COVID-19.



How did COVID-19 affect the daily lives of people with PCD?

Figure 2 shows how the pandemic affected people’s daily lives and behaviors during the past year. You can see how often people with PCD did not leave the house, saw family and friends, went out for exercise, and went to school or work.

During December 2020 and January 2021, 1 out of 6 participants reported that they did not leave their home in the previous week (solid line). About 60% of participants saw family and friends during the summer periods, but in the winter 2020/2021 this went down to 30% (double line). During the winter months, only about 15% reported regularly going to their school or workplace (dashed line). Fortunately, outdoor sports and exercise, which is so important for our health, was not much reduced. On average, half of participants reported that they exercised outdoors at least every week (dotted line).

Two special questionnaires:

Facemasks:

In October 2020, we sent a special questionnaire about facemasks.

People with PCD carefully protected themselves by wearing facemasks almost everywhere in public.



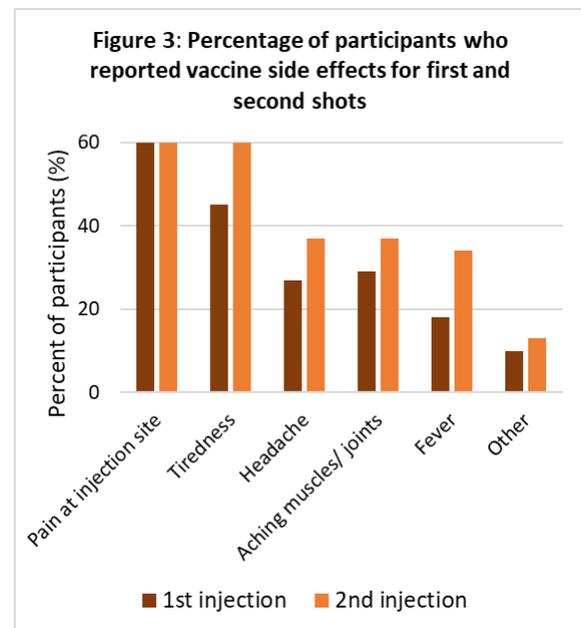
Half of the respondents told us that facemasks were uncomfortable because of runny nose, coughing, headache, or breathing difficulty. Also, 41% reported that their cough

worsened when they wore a mask.

Vaccinations:

In June 2021, we sent another special questionnaire about vaccinations. We learned that 92% of 286 adults who completed the questionnaire had already been vaccinated.

We also learned that 17 of 41 adolescents with PCD (aged 12 to 17-years old) had been vaccinated. And 2 children under the age of 12 had been vaccinated.



Side effects of the vaccination were common but mild and reflected what has been seen in the general population. Most common side effects were pain or swelling around the injection site, reported by 60%.

Tiredness was also frequently reported, followed by headaches and aching muscles or joints. Other side effects that were reported included dizziness, nausea, vomiting, and coughing. These other side effects were rare.

Overall, participants reported more side effects after the second shot than after the first one.

Plans for the future:

What PCD research projects are planned for the next year?

Thanks to participants, we gathered a large amount of information during the past year. We are still in the process of analyzing it. Based on the remaining questionnaire responses, we are currently working on two projects which will be reported to you in upcoming newsletters.

Project 1: Phenotypes: how does PCD vary between people

The first project will look at subtypes or PCD. We will use information from the initial questionnaire and try to understand if there are groups of people with PCD who have similar symptoms. For example, some might have more issues with their sinuses or ears while others might have more problems with their lungs. This will help us to understand how PCD varies between people and will eventually help doctors improve follow-up care and treatments.

Project 2: Diagnosis of PCD in different continents

For the second project, we want to understand differences in the way PCD is diagnosed around the world. This might help to speed up and improve PCD diagnosis in the future.



Will the COVID-PCD study continue?

Yes, since this is a unique opportunity to better understand PCD, we plan to continue the

COVID-PCD study to answer emerging questions about PCD.

Weekly questionnaire

The weekly questionnaire provides important information about how PCD-related problems and how symptoms change from week to week. We appreciate the responses to the weekly questionnaires. However, we understand if you need to skip a weekly questionnaire from time to time.

Special questionnaires

During the next year, we plan to send 2-3 shorter questionnaires that focus on special topics.

The next planned special questionnaire will ask about your experiences with health care during the pandemic. For example, we want to find out if you had online consultations and if these were helpful.

Other special questionnaires might ask about physiotherapy, nutrition, mental health, and school and work.



Participation: How can you be involved in the COVID-PCD study?

We appreciate your participation in the COVID-PCD study! Without you, we cannot continue to learn more about PCD. We hope you will continue to participate by answering the questionnaires.

Develop new questionnaires

If you have an idea for a special questionnaire on a PCD-related issue, we welcome your

input. You can also ask us to investigate a topic using your replies to previous questionnaires. Please let us know.

Participate in the next newsletter

If you would like to offer an idea for a topic we address in the newsletter, we invite your suggestions. And if you would like to share your experiences with PCD and COVID-19 for an upcoming newsletter, please contact the study team (covid19pcd@ispm.unibe.ch).

We look forward to hearing from you!

Publications: Where have we published the results from your COVID-PCD questionnaires?

It is important to communicate study results to doctors and researchers by publishing articles in medical journals. We have already written 3 articles:

(Articles currently only available in English)

["COVID-PCD – A Participatory Research Study on the Impact of COVID-19 in People with Primary Ciliary Dyskinesia"](#)

["SARS-CoV-2 Infections in People with PCD: Neither Frequent nor Particularly Severe"](#)

["Facemask Usage during the COVID-19 Pandemic among People with Primary Ciliary Dyskinesia: A Participatory Project"](#)

Partners: Who are the partner institutions and groups for the COVID-PCD study?

France: [Association ADCP](#)



Italy: [Associazione A.I.D. Kartagener Onlus](#)



Spain: [Asociación Española de Pacientes con Discinesia Ciliar Primaria](#)



Australia: [PCD Australia](#)



United Kingdom: [PCD support UK](#)



USA: [PCD Foundation](#)



Switzerland: [University of Bern](#)



United Kingdom: [University of Southampton](#)



Germany: [Verein Kartagener Syndrom und PCD](#)



Switzerland: [Selbsthilfegruppe Kartagener Syndrom und PCD](#)