

COVID-PCD: By and for people with PCD

Updates and plans

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The COVID-PCD Study

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 set up the COVID-PCD study.

The COVID-PCD study uses anonymous questionnaires to understand COVID-19 in people with PCD as well as other questions relevant for people with PCD. Participants receive a detailed questionnaire when they start the study and thereafter extra questionnaires on special topics 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

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

COVID-PCD: two years into the COVID-19 pandemic

Thank you for taking part in the COVID-PCD study. 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 read about the research questions we investigated last year, you can read about study results and publications, and about the future plans for COVID-PCD.

In spring 2022, we saw that less and less people completed the weekly COVID-PCD questionnaires. We therefore decided to stop sending out the weekly questionnaires. In total, the COVID-PCD study participants have completed 18,009 weekly questionnaires during a period of two years. This is an amazing number of questionnaires, and the data is incredibly valuable to understand how people with PCD are affected by the COVID-19 pandemic. We are currently analyzing this data.

There are many questions unrelated to COVID-19 that we would like to answer with data from the COVID-PCD study. In July 2022, we sent out an extra questionnaire about fertility counseling and fertility problems in people with PCD. In fall 2022, we will send out a questionnaire with detailed questions about the lung, ears, and nose. This will help us to find out how symptoms change over time.

You are very welcome to contact us if you have questions or suggestions about the study or you have an idea for a questionnaire. Please send us an email: covid19pcd@ispm.unibe.ch. We look forward to your suggestions and input!

With thanks,



The PCD study team from the Institute of Social and Preventive Medicine at the University of Bern in Switzerland: (from left) **Leonie Schreck** (PhD student), **Helena Koppe** (research assistant), **Eva Pedersen** (postdoc researcher), **Claudia Kuehni** (group leader, professor), **Yin Ting Lam** (PhD student), **Myrofora Goutaki** (senior researcher). Not in the picture: **Lara Pissini** (research assistant)

Results:

How many people have participated in the COVID-PCD study?

By August 2022, 751 people with PCD from 49 countries have participated in the COVID-PCD study. Most participants come from Europe and North America.

Figure 1: Countries represented in the COVID-PCD Study



How many people reported a SARS-CoV-2 infection and how ill did they get?

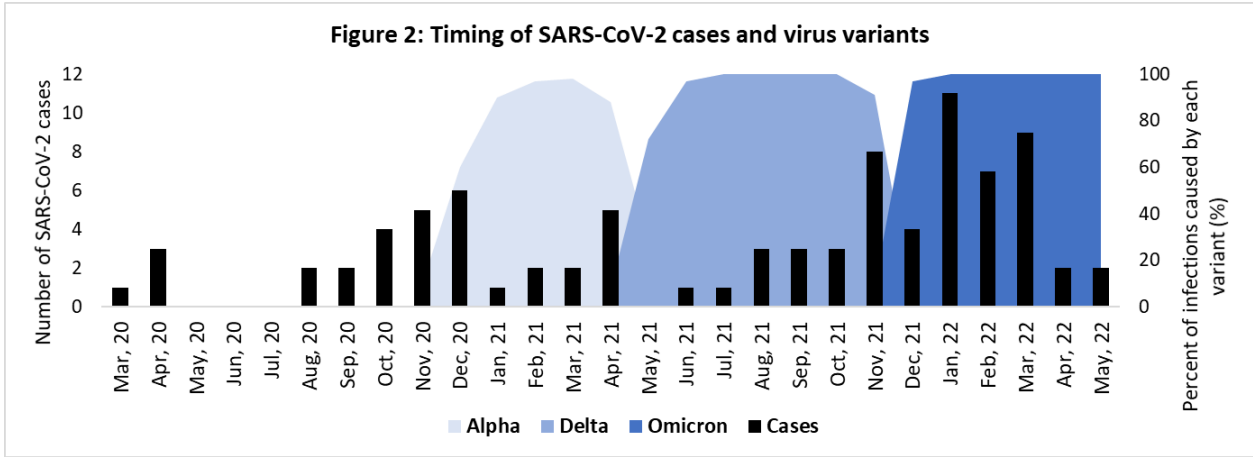
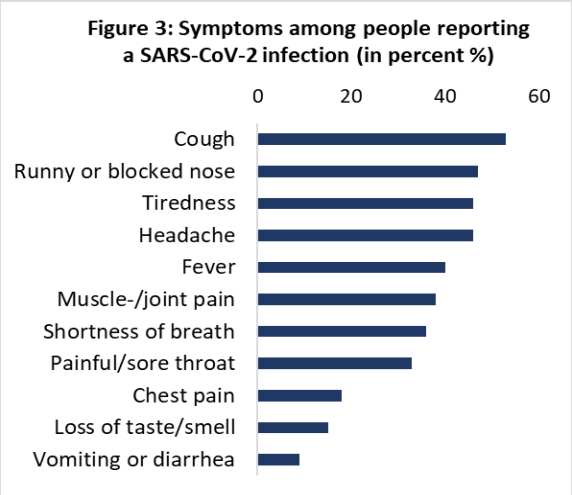
By May 2022, 87 of 728 people (12%) had reported a SARS-CoV-2 infection. Most infections were reported in autumn 2021 and winter 2022 when the Delta and Omicron virus variants were dominant (figure 2). On average during the two years, SARS-CoV-2 infections were reported twice as often in children as in adults.

Most people with PCD reported no symptoms or mild symptoms. 29% reported moderate symptoms which could include high fever, headache, and cough. Only 4 people were treated in hospital, but none had to be treated in the intensive care unit and nobody died.

What research questions did we want to answer during the past year?

Our two main research questions to answer during the past year focused on SARS-CoV-2, and diagnosis of PCD. We asked the following questions:

- How many people reported a SARS-CoV-2 infection and how ill did they get?
- Which diagnostic tests were used to diagnose PCD around the world?



The most common symptom was cough, which was reported by 53% of those with a SARS-CoV-2 infection. Other common symptoms were runny or blocked nose, tiredness, headache, and fever (figure 3).

Which diagnostic tests were used to diagnose PCD around the world?

PCD can be difficult to diagnose, and usually several diagnostic tests are needed to make a definite diagnosis. We wanted to find out which tests have been used to diagnose people with PCD, how this differs between countries, and how it changed over the years. We used data from the COVID-PCD baseline questionnaire where we asked each participant to describe diagnostic tests performed.

673 of 728 participants (92%) had had diagnostic tests for PCD. The most common diagnostic test was the biopsy that was analysed by video microscopy and/or electron microscopy (TEM). Biopsy had been done in 81% of all cases. Genetic tests had been

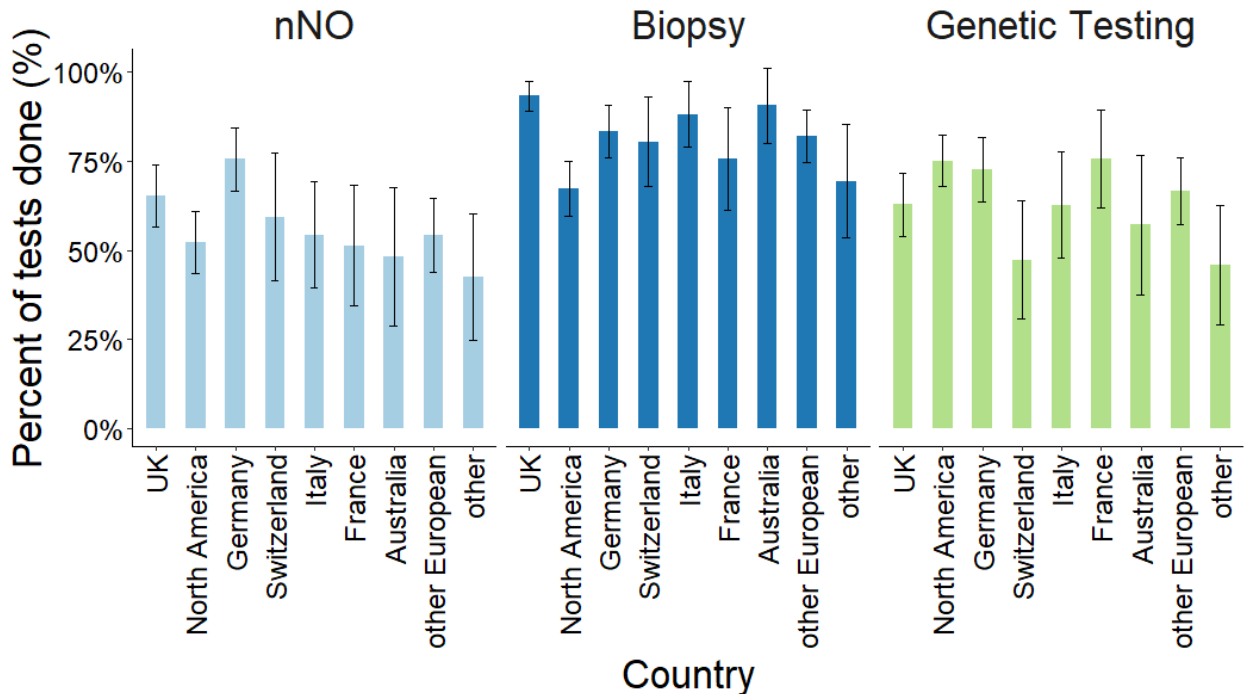
performed in 67% and nasal nitric oxide (nNO) had been measured in 58%.



Nasal nitric oxide testing (shown in the picture) requires specialized equipment and an experienced technician. This is also true for other diagnostic tests such as video microscopy, electron microscopy, and genetic analysis.

Diagnostic testing differed between countries. nNO was most often done in Germany, biopsy most often in the United Kingdom, and genetic testing most often in North America (figure 4).

Figure 4: Diagnostic tests in different countries



Special questionnaire on fertility in people with PCD



In July 2022, we sent a special questionnaire about fertility counseling and fertility problems in people with PCD.

Already 378 people have completed the questionnaire. We have started with the analysis, but further responses to the questionnaire are still welcome. The project is led by Leonie Schreck.

Plans:

Which research projects are planned for next year?

Next year, we plan to work on several projects.

Project 1: Phenotypes: how does PCD vary between people

The first project will look at subtypes of PCD, so called phenotypes. We will use information from the baseline 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 understand how PCD varies between people and will eventually help doctors improve follow-up care and treatments. We already started working on this project. This project is led by Eva Pedersen.

Project 2: Physical activity in people with PCD

For the second project, we want to study how physically active people with PCD are and how physical activity patterns differ between people of different ages and in



different countries. In people with PCD, physical activity is important for a healthy life, as it helps to improve airway clearance. This project is led by Eva Pedersen.

Will the COVID-PCD study continue?

Yes, there are still many questions about PCD that can only be answered with data directly from people who have PCD. We therefore continue the COVID-PCD study.

Next questionnaires

At the moment, there are no weekly questionnaires. Rather we will send you special questionnaires that cover a specific subject or topic (such as fertility or exercise). You are welcome to suggest topics for questionnaires.

Participation:

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

We appreciate a lot your participation in the COVID-PCD study, and we hope you want to continue. If you would like to influence and shape the COVID-PCD study, this is possible in several ways:

- Send us your feedback about how it is to participate in the study.
- Send any suggestions you have for new questionnaires or for research questions that you think could be answered with the data that was already collected.
- Send ideas for the next newsletter.
- Tell us if you want to participate in a group that meets every few months to discuss new ideas

You are also welcome to ask any question you may have about the study. Our email address is: covid19pcd@ispm.unibe.ch.

We look forward to hearing from you!

Publications and communication:

Publications

We already published 4 articles from the COVID-PCD study. You can read the articles by pushing the links (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"](#)

["COVID-19 Vaccinations: Perceptions and Behaviours in People with Primary Ciliary Dyskinesia"](#)

We are currently writing short summaries of these articles in the different languages and will publish them on our website soon.

Communication

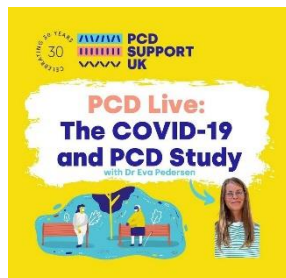
During the past year, we presented results from the COVID-PCD study at several congresses including the European Respiratory Society congress, the BEAT-PCD annual meeting, and the German patient congress in Berlin.

We also presented results from the COVID-PCD study at events organised by PCD support organisations. You can watch the presentations and following discussions through these links:

English, PCD support UK, PCD live: [Link](#)

German, Kartagener Syndrom und Primäre Ciliäre Dyskinesie e. V., Zoom Lounge: [Link](#)

Spanish, Asociación Española de Pacientes con Discinesia Ciliar Primaria: [Link](#)



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](#)

