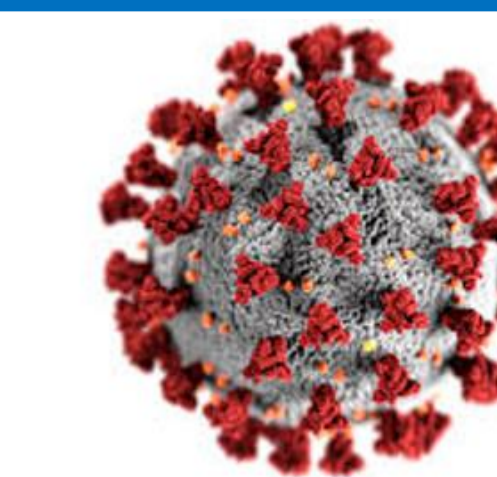


# SARS-CoV-2 infections in people with primary ciliary dyskinesia

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COVID-19 and PCD



## Background

People with chronic health conditions are at high risk of severe COVID-19 if infected with SARS-CoV-2. Primary ciliary dyskinesia (PCD) is a multisystem, genetic disease which leads to chronic upper and lower airway disease. It was unclear if PCD predisposed for frequent and severe SARS-CoV-2 infections.

## Aim

To study risk and severity of SARS-CoV-2 infections among people with PCD and study changes in social contact behaviour during the COVID-19 pandemic.

## Methods

### Study design

**COVID-PCD** is an international participatory study set up in collaboration with PCD patient support groups worldwide ([www.covid19pcd.ispm.ch](http://www.covid19pcd.ispm.ch)). It includes persons of any age worldwide with a confirmed or suspected diagnosis of PCD. Recruitment started on May 31, 2020.

### Data collection

Participants complete questionnaires anonymously online: a baseline questionnaire at registration and a short follow-up questionnaire every week.

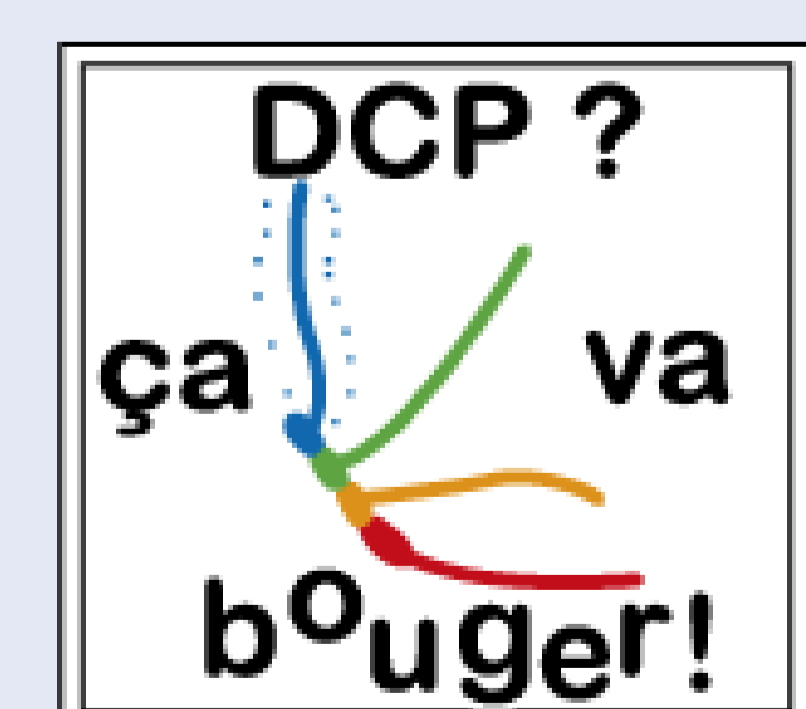
### Definitions

- A SARS-CoV-2 infection reported in the baseline or follow-up questionnaire was counted if a patient reported a positive PCR, antibody, or antigen test.
- Severity of illness was grouped into asymptomatic disease, mild disease (e.g. mild fever or cough), moderate disease (e.g. high fever, cough, headache), or severe disease (treated in the ICU).
- Social contact behaviour was reported in the weekly questionnaire.

### Statistical methods

Incidence rate was calculated as number of incident infections (SARS-CoV-2 infections reported in the weekly questionnaires at least two weeks after study registration) per 100 person years.

Collaborating PCD patient support groups



## Results

### Participants

694 people from 47 countries participated by August 1, 2021. Median age was 27 years (range 1-85) and 416 (60%) were female.

### SARS-CoV-2 infections

34 (5%) reported a SARS-CoV-2 infection. Most infections were reported between October 2020 and April 2021 (figure 1).

### Incidence rate

18 of the 34 SARS-CoV-2 infections were reported during follow-up (417 person years). The incidence rate was 4.3 infections per 100 person years (95% CI: 4.3-4.4).

### Severity of illness

- 7 (21%) participants were asymptomatic,
- 17 (50%) had mild disease, and
- 10 (29%) had moderate disease.

4 were treated in a hospital, but none were treated in the ICU or died. The longest hospital stay was 9 days.

### Social contact behaviour

Participants carefully protected themselves. During Dec. '20 and Feb. '21, 15% reported not to have left the house in the past 7 days, 18% went to their workplace, and less than 40% saw family and friends (figure 2).

Figure 1: Number of people who were infected with SARS-CoV-2 per month between February 2020 and July 2021 (total cases: n=34)

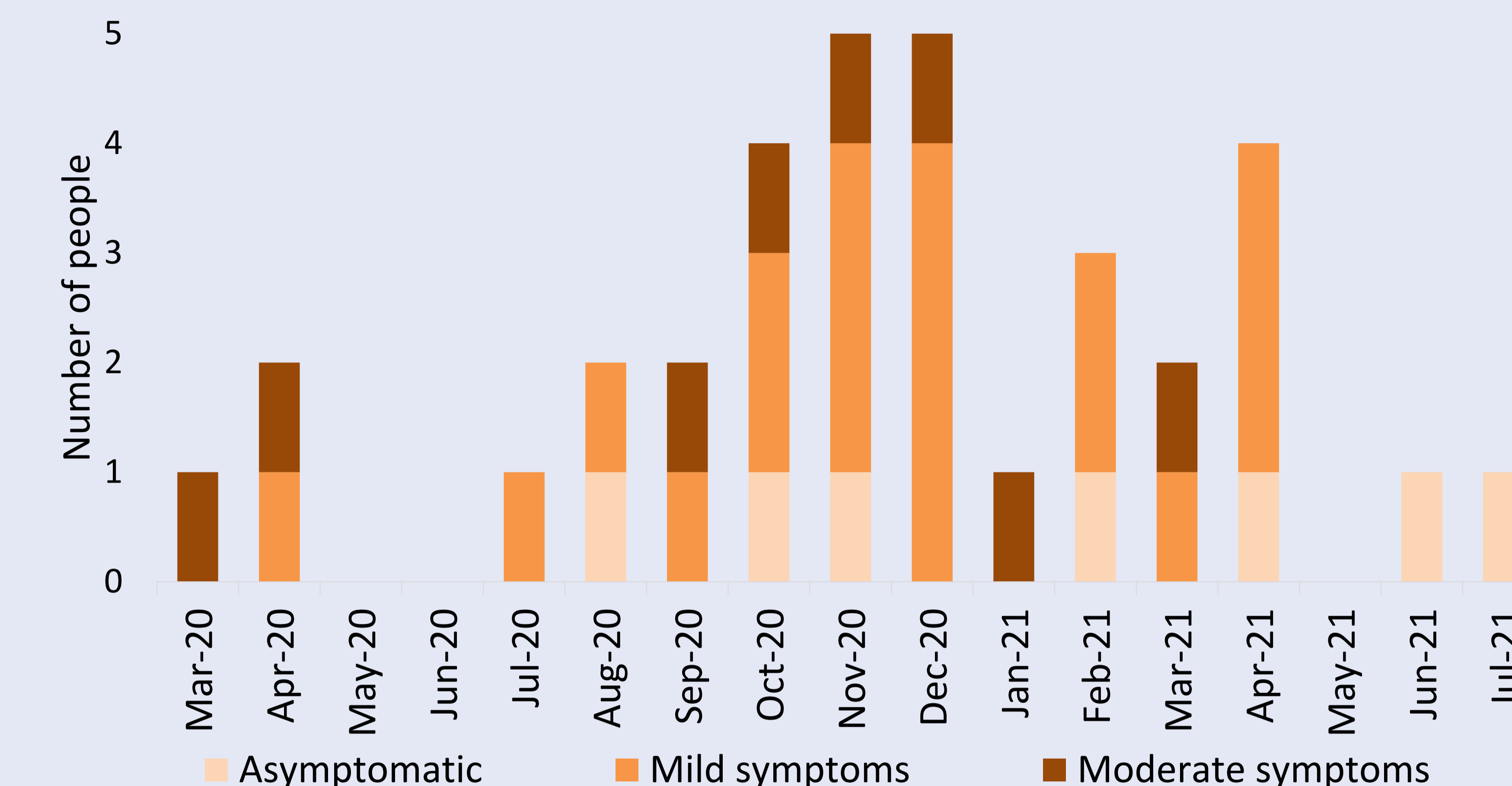
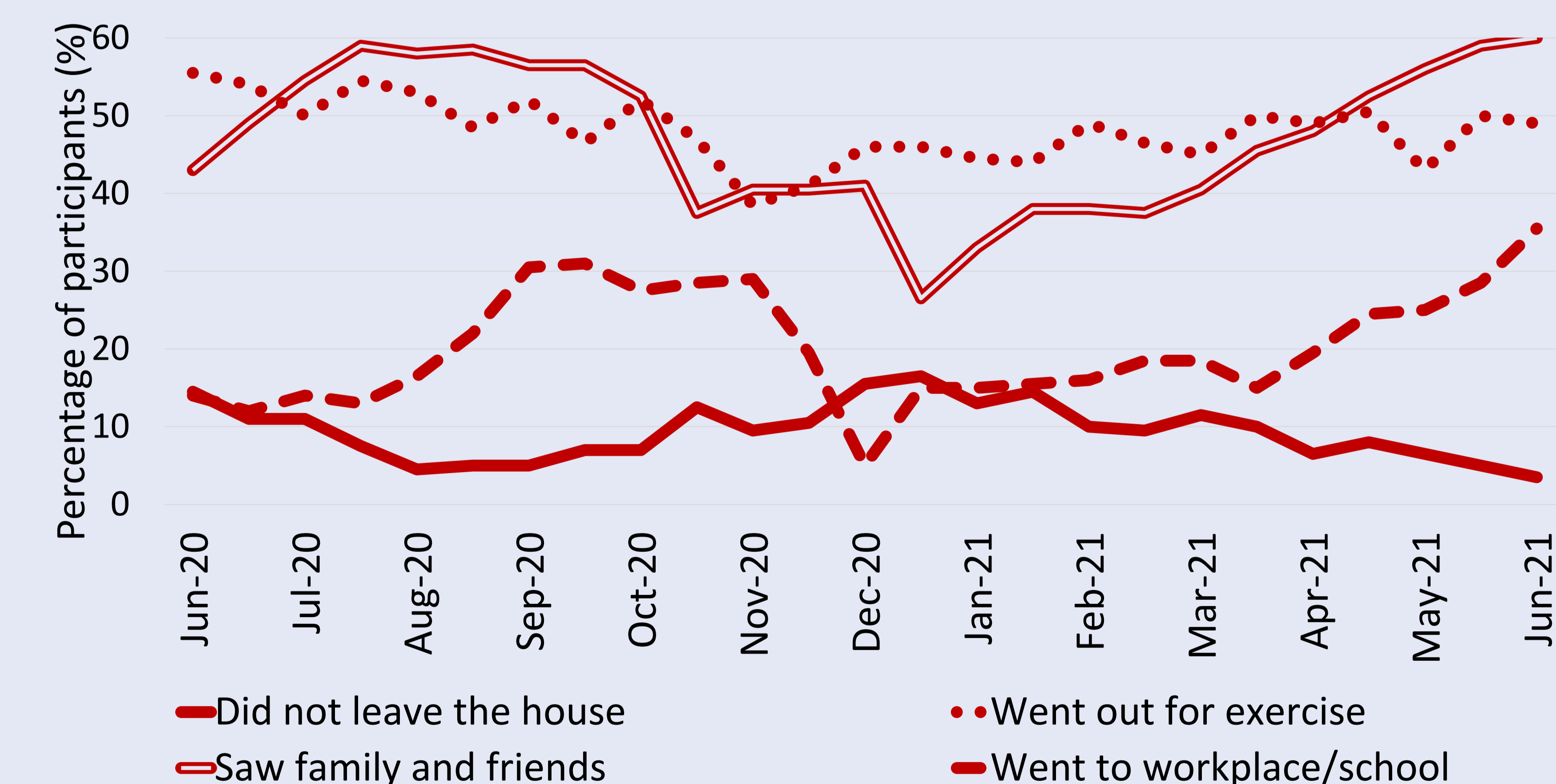


Figure 2: Social behaviour reported weekly between June 2020 and June 2021 (mean number of completed questionnaires per week = 223)



## Conclusions

This study suggests that with careful personal protective measures there was no evidence that people with PCD had an increased risk of infection with SARS-COV-2 or an especially severe disease course.

QR to published paper:

