



Fertility care among people with primary ciliary dyskinesia

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Why did we do this research and why is it important?

People with primary ciliary dyskinesia (PCD) can have problems having children. It is important that they are informed about these problems before trying to have children and that they receive information about family planning options if needed. This is also referred to as fertility care. It is unclear how many people with PCD have received fertility care. We therefore wanted to know how many people with PCD had ever visited a doctor who specializes in fertility, and at which point in their life. We also wanted to know how many had received information about fertility and if they were satisfied with the information.

How did we do this research?

To answer these questions, we sent a questionnaire to all participants in the COVID-PCD study in July 2022. This questionnaire asked about fertility care.

What did we find out?

384 study participants completed the questionnaire. 266 were adults, 16 adolescents, and 102 parents of children with PCD. Half of the adult participants (128; 48%) said that they had visited a doctor who specializes in fertility. At the time of the visit, they were on average 30 years old. The visit typically took place 10 years after their PCD diagnosis (or age 18 for people diagnosed during childhood). Adults who had

already tried becoming pregnant and who said that their fertility was important to them had seen fertility doctors more often. Females had seen fertility doctors less often than males. Only 56% of participants were satisfied with information about fertility they received from their PCD care team. They said they would like more and better understandable information about fertility.

What does it mean?

People with PCD are not always sent to fertility doctors. We recommend that people with PCD visit a fertility doctor as part of their standard care. PCD doctors should already inform about fertility at PCD diagnosis or latest when patients transition to the adult service.

Further information: covid19pcd.ispm.ch

Full article reference: Schreck LD, Goutaki M, Jörgen P, Dexter K, Manion M, Christin-Maitre S, Maitre B, COVID-PCD patient advisory group, Kuehni CE, Pedersen ESL. Fertility care among people with primary ciliary dyskinesia.

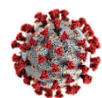
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You can find the full article in English [here](#).

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COVID-PCD