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Social Participation of people with PCD

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Image source: canva.com

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

Living with primary ciliary dyskinesia (PCD) means managing treatments, symptoms, and medical appointments, which can make participation in social life difficult. However, most research on PCD so far has focused on physical health, and little is known about how PCD affects people's social lives. Understanding these experiences is important in order to find ways to support people with PCD so that they can fully participate in everyday life.

How did we do this research?

First, we had discussions with people with PCD and parents of children with PCD to understand how PCD shapes social life. Then, we used these insights to create a questionnaire that we sent to all participants of the *Living with PCD* study. The questionnaire asked about all parts of social life: relationships, responsibilities (work, school, caregiving), free time, how we see ourselves and how others see us, and more general support needs. 225 adults and adolescents with PCD, and 52 parents of children with PCD shared their experiences.

What did we find out?

Many people with PCD reported having active social lives and strong relationships with family, friends, and partners. Many also said how connecting with other people living with PCD helped them and they felt understood by them. However, taking part in everyday activities often needed extra planning, adapting activities, and deciding when to tell others about PCD. People generally felt comfortable talking about PCD with those close to them, but many found it much harder to discuss PCD at work or school, where support was often limited. Participants also highlighted areas where more support is needed, including more flexible workplaces and schools, better financial support, and healthcare professionals with better knowledge of PCD.

What does it mean?

Our findings show that living well with PCD depends not only on managing symptoms but also on having supportive relationships and environments. To improve social participation for people with PCD we need more support in healthcare, education, and work, as well as policies that make it easier for people with PCD to participate fully in all aspects of social life.

Further information: pcd.ispm.ch

Full article reference: Fernandez-Rodriguez A, Karavasiloglou N, Gkatzou V, Dexter K, Manion M, Silberschmidt H, Zambrano SZ, Pagnini, F, Living with PCD patient advisory group, Kuehni CE, Goutaki M. Social functioning in Primary Ciliary Dyskinesia (PCD) – a mixed-methods study of lived experience, relationships and support of patients and caregivers
medRxiv:
www.medrxiv.org/content/10.64898/2026.08.24.26360722v1
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You can find the full article in English here.

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