

## Patients' priorities in PCD research

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### Why is it important?

To make the biggest impact on peoples' lives, we must focus our research on the most important issues for patients.

In rare diseases like primary ciliary dyskinesia (PCD), there are many things that we could research. We know patients often have different priorities from their healthcare professionals and we think it is important to consider their thoughts. This makes sure future research studies focus on the most important issues.

### How did we do this research?

We interviewed adults and teenagers with PCD, and those caring for children with PCD. We asked them how they felt about being in research and what the most important issues are to them. The answers helped us to make a survey on these topics. PCD patient support groups and the European Lung Foundation sent out this questionnaire. The survey was translated into 8 different languages.

### What did we find out?

399 people with PCD from 29 countries filled out the questionnaire. Nearly half of them had already taken part in PCD research. For many, the reason they did not take part in research was because no one had told them about it. Those involved in patient support groups often had more information about research and took part in more studies. Almost everyone wanted to have results from the studies they had joined.

The top three priorities were:

1. Finding a cure for PCD.
2. Creating better treatments to improve lung function, reduce infections, and reduce the amount of mucus.
3. Finding the best way to manage PCD by using existing medications.

Other priorities were: long-term effects of PCD and long-term medication use, involving more

doctors and people with PCD in research, knowing more about mental health, fertility, and ear/nose problems, understanding treatment burden as well as the impact of the environment and lifestyle.

### What does it mean?

We found those affected by PCD would like to join research. They also liked getting regular updates from these studies.

Researchers and support groups working together may help more people take part in research studies. This will also help patients find out more about research.

People with PCD and their families had many similar priorities to healthcare professionals such as PCD treatments. However, there were some topics that were raised by those affected by PCD, that healthcare professionals did not, such as effects of long-term medication use.

When research lines with the priorities of people living with a health issue, the research is more useful and more likely to make a real difference in their lives. Our work will help PCD researchers and healthcare professionals to work together to help decide which research is most important.

**Further information:** <https://beat-pcd.squarespace.com/>

**Full article reference:** Lam, Y. T., Behan, L., Dexter, K., Dixon, L., Kuehni, C. E., Schreck, L. D., Lucas, J. S., & Goutaki, M. Patients' research priorities and participation in primary ciliary dyskinesia research  
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You can find the full article in English [here](#).

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