Share your experiences of PCD diagnostic testing

We want to find out about the experiences of people who have been tested for PCD. If you or a child that you care for has undergone testing, please complete this survey. We are interested in opinions from patients who were found not to have PCD as well as those with the disease.

It can be difficult to diagnose PCD and many people have bad, as well as good experiences in the lead up to a positive or negative diagnosis. We would like to learn more about peoples' experience of PCD diagnosis so that we can improve how people with PCD are diagnosed. The European Respiratory Society has funded a working group to form guidelines for the diagnosis of patients with primary ciliary dyskinesia (PCD) and we wish to ensure that the opinions of patients are reflected in the guideline. This survey will take no longer than 10 minutes to complete.

Please mark the answer that best describes you:

1. Are you…?
    - A person who has been tested (or waiting for tests) for PCD?
    - A parent or carer of a child tested (or waiting for tests) for PCD?

2. How old is the person who has been tested for PCD? :
    - Under 5 years
    - 5-12 years
    - 13-17 years
    - 18-35 years
    - 36-50 years
    - 51-65 years
    - Over 65 years

3. Is the person male or female?
    - Male
    - Female

4. Where do you live?
    - Town/ city (free text)
    - Country (drop down of all countries, world-wide)

5. Which best describes you/ your child? Mark one answer only
    - tested and found to have PCD
    - tested and were found **not** to have PCD
    - tested and the results are uncertain

- waiting for test results
- A doctor has said 'you probably have PCD' but I/ my child have not been tested
- Previously given a diagnosis of PCD but further testing found this to be incorrect.
- Other, please specify (free text for explanation)

6. Approximately how old were you/ your child when first tested for PCD?
   - Never tested (SKIP TO 9)
   - If under 1 year XX months
   - If over 1 year XX years

7. Approximately how long did it take to get the results?
   - Immediately
   - Less than 6 months
   - 6-12 months
   - More than 1 year XX years XX months
   - Not sure

8. What diagnostic tests have you had for PCD? (tick all that apply)
   - Nasal nitric oxide (measuring a gas from the nose)
   - Nose brushing (a scrape from the nose to obtain cilia and cells)
   - Brushing or biopsy during bronchoscopy (a camera in the lung)
   - Genetics testing (a blood test or mouth swab)
   - Saccharine test (how long it takes to taste sugar placed in the nose)
   - Nuclear medicine scan
   - Other (free text)

9. Please rate the following statements. Please add any comments in the box at the end of the survey.
   (scale: Strongly agree, agree, neither agree or disagree, disagree, strongly disagree PLUS Don't know option).

- Understanding the cause of my symptoms is important to me.
- Seeing a doctor who is an expert in diagnosing PCD is important to me.
- Having a diagnosis of PCD so that I can receive the correct treatment is important.
- I should not be told that I probably have PCD, without the proper diagnostic tests being done
- I should be able to see a doctor with specialist knowledge of treating PCD.
- Tests should not be repeated if the results are inconclusive.
- I should be able to have tests done locally to my home, even if it is less accurate than the tests possible in a specialist centre.

- Being able to see a doctor who is an expert in PCD is important, even if you have to travel a long distance to see them.
- The doctor should give me good information about how PCD is tested for
- I would rather have a greater number of tests if it ensures the result is more accurate.
- I would welcome the opportunity to participate in research to improve diagnostic testing.

10. The following should be given priority to improve diagnostic testing (scale: Strongly agree, agree, neither agree or disagree, disagree, strongly disagree PLUS Don't know option).

- A database of European PCD diagnostic centres.
- Improving the speed that test results are available.
- Improving the accuracy of diagnostic tests.
- Patient organisations in all countries to support patients.
- Improved information for patients about diagnostic testing.
- Improved information for patients about PCD once they have been diagnosed.
- Increased understanding of the genes that cause PCD to enable reliable genetic testing in all cases.

11. Tell us which of the statements you agree with. You can select more than one. (only for participants who have indicated a positive diagnosis 5a) … Since diagnosis (scale: Strongly agree, agree, neither agree or disagree, disagree, strongly disagree PLUS Don't know option).

- I feel my health/my child's health has improved.
- Treatment from my family doctor has improved.
- Treatment from hospital specialists has improved.
- it has improved non-medical support (e.g. greater understanding from teachers or employers, access to financial support to help manage PCD, support from PCD patient organisation)

12. Please share any further comments or experiences with us in the box below

Free text box

Thank you for completing our survey

If you would like to receive updates about this project or would be willing to take part in an interview about you opinions of PCD diagnosis please enter your email address.

I would like to receive further information about this project Y/N
I am happy to be contacted to arrange an interview about my experiences of PCD Diagnosis Y/N

Email (free text)