

Physical activity for young people with cystic fibrosis

Start of Block: Basic information

Hello and Welcome,

Thank you very much for your interest in our study. This survey has been developed by researchers at the Universities of Exeter, La Trobe, Swansea, UCL, and Hospital for Sick Children in collaboration with the Cystic Fibrosis Trust. The aim is to increase our understanding of physical activity and cystic fibrosis. The survey contains approximately 20 questions and should take about 10 minutes to complete. You may skip any question you do not wish to answer. Please indicate whether you are a healthcare provider, a person with cystic fibrosis or a parent or caregiver for someone with cystic fibrosis:

- Healthcare provider for individuals with Cystic Fibrosis (1)
- Person with Cystic Fibrosis (2)
- Parent / care provider of someone with Cystic Fibrosis (3)

End of Block: Basic information

Start of Block: Healthcare providers



Consent to take part Thank you very much for agreeing to take part in our study. Before you begin, please read our [participant information sheet](#) and tick the boxes to indicate that you are happy to take part.

I confirm that I have read and understood the participant information sheet (1)

I understand that my participation is voluntary and that I am free to withdraw at any time (2)

I understand that any information given by me may appear in research reports, articles or presentations by the research team (3)

I understand that my name will not appear in any reports, articles or presentations (4)

I consent to take part in the study (5)

Q1 Country of clinic

Q2 What is your position in the clinic?

- Doctor (1)
 - Nurse (2)
 - Dietician (3)
 - Physiotherapist (4)
 - Psychologist (6)
 - Pharmacist (7)
 - Manager (8)
 - Technician (9)
 - Other (please describe) (5) _____
-

Q3 Is the clinic

- Adult only (1)
- Paediatric only (2)
- Combined (3)

End of Block: Healthcare providers

Start of Block: Physical activity and exercise

Q4 Using the scale below, indicate the importance that you personally attach to the topic of physical activity and exercise in the healthcare of the patient.

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q4.1 Using the scale below, indicate how important you think the rest of the CF team attach to the topic of physical activity and exercise in the healthcare of the patient.

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q5 When do you discuss physical activity / exercise with patients with CF?

- Never (1)
 - Once a year (2)
 - When the topic is raised by the patient (3)
 - At every appointment (4)
 - During inpatient admission (5)
 - Other (please specify) (6)
-

Q6 Who is primarily responsible for discussing physical activity / exercise with the patient?

- Doctor (1)
 - Nurse (2)
 - Dietician (3)
 - Physiotherapist (4)
 - Psychologist (5)
 - Pharmacist (6)
 - Manager (7)
 - Technician (9)
 - Other (please specify) (8)
-

Q7 Is advice given to patients on the topic of physical activity / exercise?

Yes (1)

No (2)

Display This Question:

If Is advice given to patients on the topic of physical activity / exercise? = Yes

Q7.1 Is the advice written or verbal?

Written (1)

Verbal (2)

Both (3)

Display This Question:

If Is advice given to patients on the topic of physical activity / exercise? = Yes

Q7.2 Please specify what advice is given to patients

Display This Question:

If Is advice given to patients on the topic of physical activity / exercise? = Yes

Q7.2 Is this advice based on guidelines? If so, which guidelines?

Not based on guidelines (1)

Based on guidelines (2) _____

Q8 Does the clinic offer a personalised physical activity / exercise training program for patients?

Yes (1)

No (2)

Display This Question:

If Does the clinic offer a personalised physical activity / exercise training program for patients? = Yes

Q8.1 Please describe any personalised physical activity / exercise training programs available to patients

Display This Question:

If Does the clinic offer a personalised physical activity / exercise training program for patients? = No

Q8.1 Please explain why the clinic does not offer a personalised physical activity / exercise training program (e.g., time, resources, lack of need etc)

Q9 What would improve your ability to facilitate patient physical activity or exercise?

End of Block: Physical activity and exercise

Start of Block: Exercise testing

Q10 Using the scale below, indicate the importance that you personally attach to the topic of exercise testing for the assessment of patient health

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q11 In the last 12 months, which of the following tests have been performed in the clinic?

Don't know (1)

Walking test (please describe/name test) (2)

Shuttle tests (please describe/name test) (3)

Maximal test (please describe/name test) (4)

Cardio pulmonary exercise test (7)

Treadmill or cycle (5)

Other (please describe) (6)



Q12 If known, in the last 12 months, how many patients have completed an exercise test?

Q12.1 If known, in the last 12 months how many patients have completed each type of test?

- I don't know (1)
 - Walking test (2)
 - Shuttle test (3)
 - Maximal test (4) _____
 - Cardio pulmonary exercise test (5)

 - Treadmill or cycle (6)

 - Other (7) _____
-

Q13 What access to equipment does your clinic have to facilitate exercise testing? Please tick and indicate number

- Treadmill (1) _____
 - Pulse oximeter (2) _____
 - Metabolic cart (3) _____
 - Cycle ergometer (4)

 - ECG equipment (5) _____
 - Other (please specify) (6)

-

Q14 On average, how often do you carry out exercise tests with patients?

Q14.1 When do you carry out exercise tests with patients?

- Don't know (1)
- Never (2)
- On an individual basis with patients who report difficulties (3)
- On an individual basis as part of an evaluation for transplant (4)
- Routinely with all patients (5)
- Routinely with a subset of patients (please explain) (6)

- Other (please explain) (7)

Q15 Who usually has responsibility for operating and conducting the exercise tests?

- Doctor (1)
 - Nurse (3)
 - Dietician (2)
 - Physiotherapist (4)
 - Psychologist (5)
 - Pharmacist (6)
 - Manager (8)
 - Technician (9)
 - Other (please explain) (7)
-

Q16 Please indicate factors that restrict performing exercise tests on patients

- Infection control restraints (8)
 - Time (1)
 - Space (7)
 - Equipment (3)
 - Finance (2)
 - Experience (4)
 - Patient willingness (5)
 - Other (please explain) (6)
-

Q17 What would improve the role of exercise testing in your clinic?

Q18 Is there anything else you would like to say about physical activity / exercise and CF?

End of Block: Exercise testing

Start of Block: People with CF



Consent to take part Thank you for agreeing to take part in our study. Before you begin, please read the [participant information sheet](#) and tick the boxes below to indicate that you are willing to take part.

- I have read and understand the information sheet for the study (1)
 - I understand that I am free to stop taking part at any time (2)
 - I understand that some things I say may be published in medical magazines or websites so that other doctors can read, but my name will not appear in any reports, articles or presentations (3)
 - I am happy for some data I provide to be combined with data collected from other studies and used at a later date (6)
 - If under 16 - my parents or guardians have agreed that I can take part in this study (4)
 - I agree to take part in the study (5)
-

Q1 Which age bracket are you in?

- Under 12 (1)
 - 13-18 years (2)
 - 19-35 years (3)
 - 36-60 years (4)
 - Over 60 years (5)
-

Q2 Are you

- Male (1)
 - Female (2)
-

Q3 Where (which country) do you currently live?

End of Block: People with CF

Start of Block: Physical activity

Q4 Please use the scale below to indicate how important being physically active is to you

0 (0)

1 (1)

2 (2)

3 (3)

4 (4)

5 (5)

6 (6)

7 (7)

8 (8)

9 (9)

10 (10)



Q5 Please use the scale below to indicate how important you think being physically active on a regular basis is for your CF

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q6 Please use the scale below to indicate how confident you are in your ability to be active on a regular basis

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q7 Please use the scale below to indicate how much you enjoy being physically active

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q8 Which of the following activities do you do on a regular basis (i.e., at least once a week)

- Walking (1)
 - Jogging / running (2)
 - Swimming (3)
 - Cycling (4)
 - Gym (5)
 - Fitness classes (6)
 - Lifting (7)
 - Dancing (8)
 - Climbing (9)
 - Horse riding (10)
 - Team sports (11)
 - Other (please explain) (12)
-

Q9 If relevant, please use the space below to provide any further detail about the activities you do on a regular basis (e.g., which fitness classes you do, which team sports you do, etc.,)

Q10 Which (if any) activities would you like to do more?

Q11 What (if any) are the main barriers that stop you being able to the activities that you listed above?

Q12 When you are physically active, who are you most likely to be active with?

- School friends (1)
 - Friends outside of school (2)
 - Family (3)
 - Hospital staff (4)
 - By myself (5)
 - Other (please describe) (6)
-

Q13 When you are physically active, what is the main reason for your activity?

- Parent encouragement (1)
 - School / teacher encouragement (2)
 - Hospital staff encouragement (3)
 - Health (4)
 - Enjoyment (5)
 - Time with friends (6)
 - Time with family (7)
 - Other (please describe) (8)
-

Q14 Which of these regularly (i.e., at least once a week) prevent you from being active?

- Lack of time (1)
 - Tiredness (2)
 - Lack of enjoyment of physical activity (3)
 - Feeling unwell (4)
 - School / homework pressure (5)
 - Peer pressure (6)
 - Would rather do something else with spare time (7)
 - Concerns about weight loss / nutrition (8)
 - Concerns about symptoms (e.g., coughing in public) (9)
 - Concerns about physical activity with CF (10)
 - Unclear what type / intensity of activity to do (11)
 - Family concerns (12)
 - Other (please specify) (13)
-

Q15 What would help you be more active (e.g., access to information about exercise with CF, access to gyms, affordable personal training etc)?

End of Block: Physical activity

Start of Block: Physical activity and exercise in the clinic

Q16 How often do you have an exercise test during appointments?

- Every appointment (1)
 - Some appointments (2)
 - Only if I request it (3)
 - Never (4)
 - Other (please explain) (5)
-

Q17 Which of these members of staff regularly (i.e., most appointments) talk to you about physical activity / exercise?

- Nurse (1)
 - Physiotherapist (2)
 - Clinician (3)
 - Dietician (4)
 - Psychologist (5)
 - Exercise specialist (6)
 - None (7)
 - Other (please state) (8)
-

Q18 Which of the following topics have been discussed with you?

- Your current activity levels (1)
 - Any changes in your activity levels (2)
 - Ways of increasing your activity (3)
 - How much physical activity you should be doing (4)
 - Types of activities you could do (5)
 - Optimal intensity of activities (6)
 - Results of exercise tests (7)
 - Specific concerns that you have about physical activity (please state) (8)
-
- None (9)
 - Other (please specify) (10)
-

Q19 Do you have any questions or concerns about physical activity / exercise that have not been answered by the clinic?

- Yes (1)
- No (2)

Display This Question:

If Do you have any questions or concerns about physical activity / exercise that have not been answered... = Yes

Q19.1 Please explain



Q20 Is there anything else you would like to say about physical activity / exercise?

End of Block: Physical activity and exercise in the clinic

Start of Block: Parent / carers



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I confirm that I have read the participant information sheet (1)

I understand that my participation is voluntary and that I am free to withdraw at any time (2)

I understand that any information given by me may be used in future reports, articles or presentations by the research team. (3)

I understand that my name will not appear in any reports, articles or presentations (4)

I am happy for some of the information I provide to be included in a larger database for analysis at a later date (5)

I agree to take part in the study (6)

Q1 How old is your son / daughter with CF?

Q2 Is your child male or female?

Male (1)

Female (2)

Q3 Country of residence

Q4 Do you currently live with your child?

- Yes (1)
- No (2)
- Other (3)

End of Block: Parent / carers

Start of Block: Physical activity

Q5 Please use the scale below to indicate how important it is for you to be physically active

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q6 Please use the scale below to indicate how much you enjoy being physically active

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q7 Please use the scale below to indicate how important you think it is for your child to be physically active

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 (8)
 - 9 (9)
 - 10 (10)
-

Q8 Please use the scale below to indicate how much you think your child enjoys being active

0 (0)

1 (1)

2 (2)

3 (3)

4 (4)

5 (5)

6 (6)

7 (7)

8 (8)

9 (9)

10 (10)



Q9 Which of the following activities does your child do on a regular basis (i.e., more than once a week)

- Walking (1)
 - Running / jogging (2)
 - Swimming (3)
 - Cycling (4)
 - Gym (5)
 - Fitness classes (6)
 - Dancing (7)
 - Lifting (8)
 - Climbing (9)
 - Horse riding (10)
 - Team sports (please specify) (11)
-
- None (12)
 - Other (please specify) (13)
-

Q10 Do you regularly participate in physical activity with your child?

- Yes (1)
- No (2)

Display This Question:

If Do you regularly participate in physical activity with your child? = Yes

Q10.1 How often?

Q11 Which of the following barriers regularly prevent your child from being active?

- Lack of time (child) (1)
 - Lack of time (parent) (13)
 - Lack of enjoyment of activity (2)
 - Tiredness (3)
 - Unwell (4)
 - School / homework pressure (5)
 - Peer pressure (6)
 - Would rather do something else with their time (7)
 - Concerns about weight loss / nutrition (8)
 - Concerns about symptoms (coughing in public etc) (9)
 - Concerns about physical activity with cystic fibrosis (10)
 - Unclear what type / intensity of activity to do (11)
 - Other (please state) (12)
-

Q12 Do you have any concerns about your child being physically active?

Yes (1)

No (2)

Display This Question:

If Do you have any concerns about your child being physically active? = Yes

Q12.1 Please describe any concerns you have about your child being physically active

Q13 What do you think are the main factors that would help your child to be more physically active?

End of Block: Physical activity

Start of Block: Clinical experience of physical activity

Q14 How often does your child have an exercise test during clinical appointments?

- Every appointment (1)
 - Some appointments (2)
 - When requested by me / my child (3)
 - Never (4)
-

Q15 Which of these members of the team talk to you and your child about physical activity / exercise?

- Nurse (1)
 - Physiotherapist (2)
 - Clinician (3)
 - Dietician (4)
 - Psychologist (5)
 - Exercise specialist (6)
 - None (7)
 - Other (please describe) (8)
-

Q16 Which of these topics are discussed?

- Queries about your child's current activity levels (1)
- Queries about any changes in your child's activity levels (2)
- General encouragement for your child to be physically active (3)
- How much physical activity your child should do (4)
- Types of physical your child should do (5)
- Results of exercise tests (6)
- Specific concerns that you or your child have about being physically active (please state) (7) _____
- Other (please state) (8) _____

Q17 Do you have any concerns about physical activity / exercise that have not been answered by the clinic?

- Yes (1)
- No (2)

Display This Question:

If Do you have any concerns about physical activity / exercise that have not been answered by the cl... = Yes

Q17.1 Please explain



Q18 Is there anything else you would like to say on the topic of physical activity / exercise?

End of Block: Clinical experience of physical activity
