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Survey Information & Consent

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Study Title: A survey of exercise testing and training in cystic fibrosis clinics

Participant Information Sheet (Version 1 (08/06/2020), Reviewed by The University of Exeter Sport and Health Sciences ethics committee).

Brief Introduction:

We would like to invite you to take part in a research study about exercise testing and training in cystic fibrosis clinics. Taking part in the study is entirely up to you, so before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information and to discuss it with other people to decide whether you wish to take part or not. Thank you for taking the time to read this information

What's involved?

Being more physically active has important clinical benefits for people with cystic fibrosis e.g., improved lung function, aerobic fitness, sputum clearance, as well as psychological and social benefits e.g., improved self-confidence, socialisation and self-esteem. However, many clinicians and their support teams, whilst valuing the role of exercise testing and training are unsure how to utilise and promote it within their clinics.

We are asking clinicians and their support teams (healthcare providers, physiotherapists, nurses, technicians, etc) about their current use of exercise testing and training in their clinical practice. The present survey is being conducted by the Universities of Exeter and Portsmouth (UK), the Royal Hospital for Sick Children Edinburgh (UK) and Dalhousie University (Canada). The objective of the present survey is to identify and quantify the scope of exercise testing and training used currently in Cystic Fibrosis clinics in the UK and Ireland and to determine the importance assigned by clinic staff. The survey also serves as a follow-up to a previous study [Stevens D, Oades PJ, Armstrong N, Williams CA. A survey of exercise testing and training in UK cystic fibrosis clinics. *Journal of Cystic Fibrosis*. 2010; 9(5):302-6.] that was conducted over a decade ago. Please note that the findings will be summarised and no individual clinics will be named in the report. We thank you in advance for your time.

What would taking part involve?

We have invited you to take part because we are looking for healthcare professionals who work in cystic fibrosis clinics. Taking part will involve completing a short survey about the use of exercise testing and training in the clinical care of CF. We anticipate that it will take approximately 20

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minutes to complete the survey.

What are the possible benefits of taking part?

The main benefits of the proposed research are educational and there will be limited personal benefit to you and your team. However, the results will increase our understanding of current attitudes and behaviours surrounding exercise testing and training, and some of the barriers and facilitators that obstruct or promote its use. The information we obtain will help us develop educational materials to support clinical teams working with people with cystic fibrosis and to enable them to be physically fit and active without limitations.

What are the possible disadvantages and risks of taking part?

This is a very low risk study. We do not anticipate any risks of taking part. The main disadvantage is the time you will spend completing the survey.

Do I have to take part?

Please remember that participation in this study is entirely voluntary. It is up to you to decide whether you would like to take part or not and if you decide to take part you are free to leave the study at any time without giving a reason as to why you wish to do so. If you do decide to participate in this study you will be asked to check a box to indicate that you are happy to take part.

Are my results confidential?

Person-identifiable information will not be used in this study. All data will be stored on a password protected file within a locked office at the University of Exeter. With your permission, we may include some of the information you provide in a larger database for analysis at a later date. It will not be possible to identify you from any data we retain.

What will happen to the results of this study?

The results will increase our understanding of current attitudes and behaviours the implementation of exercise and testing in CF clinics. We will aim to publish the findings in research journals and to present them at conferences in the UK or abroad. Your data will always remain anonymous and your name will not appear on any results.

Who has reviewed this study?

All research activity at the University of Exeter is examined and approved by an ethics committee to protect your interests. This study has been approved by the Ethics Committee of Sport and Health Sciences, College of Life and Environmental Sciences, University of Exeter. This project has been reviewed by the Sport and Health Science Research Ethics Committee Exeter (ref:

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approval date:.....)

Funder:

Cystic Fibrosis Trust (Strategic Research Centre #008)

Contacts for further information:

If you would like more information or if you have any further questions about the study please contact the investigators using the details below:

Professor Craig Williams (Chief Investigator), University of Exeter: c.a.williams@exeter.ac.uk

Dr Owen Tomlinson (Study Coordinator), University of Exeter: o.w.tomlinson@exeter.ac.uk

Ms Gail Seymour (Research Ethics and Governance Manager), University of Exeter:
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Please
Check
Box

I confirm that I have read and understand the information sheet version 1 dated 08/06/2020 for the above study.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.


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

I understand that my name will not appear in any reports, articles or presentations.

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

I agree to take part in the above study.

Please check the box below to continue.

 I'm not a robot  reCAPTCHA
Privacy - Terms
**Section 1: You and Your Centre**

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You and Your Centre

Where is your CF centre located?

- England (Midlands)
- England (North)
- England (South East, including London)
- England (South West)
- Northern Ireland
- Republic of Ireland
- Scotland
- Wales

Is your centre adults, paediatric, or mixed?

- Adult
- Paediatric
- Mixed (Adults & Paediatric)

Present number of patients at your centre?

Number of patients with:

Mild CF (FEV1 above 70%)

Moderate CF (FEV1 40-69%)

Severe CF (FEV1 below 40%)

Number of patients on active transplant list?

Your position

- CF Centre Director/Manager
- Clinical Physiologist
- Clinician
- Nurse
- Physiotherapist (Lead CF Specialist)

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- Physiotherapist (CF Specialist)
- Physiotherapist (non-CF Specialist)
- Therapy Assistant/Technician
- Other (please state)

Section 2: Exercise Testing

Exercise Testing

Does your clinic use exercise tests to evaluate patient health?

- Yes
- No

Are these tests conducted in your department (i.e. by the CF MDT) or another department in your hospital/trust (i.e. cardiology, clinical physiology)?

- CF MDT
- Other (please state)

Which exercise tests are used in your CF centre? Please select all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Step Test - 3 Minute | <input type="checkbox"/> Shuttle Walk Test (15 Levels) |
| <input type="checkbox"/> Step Test - Incremental | <input type="checkbox"/> Shuttle Walk Test (25 Levels) |
| <input type="checkbox"/> Sit-to-Stand Test | <input type="checkbox"/> Treadmill Test (no gas analysis) |
| <input type="checkbox"/> 6 Minute Walk Test | <input type="checkbox"/> Treadmill Test (with gas analysis, i.e. CPET) |
| <input type="checkbox"/> Shuttle Walk Test (10 Minutes) | <input type="checkbox"/> Cycle Test (no gas analysis) |
| <input type="checkbox"/> Shuttle Walk Test (20 Minutes) | <input type="checkbox"/> Cycle Test (with gas analysis, i.e. CPET) |
| <input type="checkbox"/> Shuttle Walk Test (12 Levels) | <input type="checkbox"/> Other (please specify) |
| | <input type="text"/> |

If you use treadmill or cycle testing, please describe the test.

Which exercise tests is utilised **most** in your CF centre? Please select one only.

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- | | |
|--|---|
| <input type="radio"/> Step Test - 3 Minute | <input type="radio"/> Shuttle Walk Test (15 Levels) |
| <input type="radio"/> Step Test - Incremental | <input type="radio"/> Shuttle Walk Test (25 Levels) |
| <input type="radio"/> Sit-to-Stand Test | <input type="radio"/> Treadmill Test (no gas analysis) |
| <input type="radio"/> 6 Minute Walk Test | <input type="radio"/> Treadmill Test (with gas analysis, i.e. CPET) |
| <input type="radio"/> Shuttle Walk Test (10 Minutes) | <input type="radio"/> Cycle Test (no gas analysis) |
| <input type="radio"/> Shuttle Walk Test (20 Minutes) | <input type="radio"/> Cycle Test (with gas analysis, i.e. CPET) |
| <input type="radio"/> Shuttle Walk Test (12 Levels) | <input type="radio"/> Other (please specify) |
| | <input type="text"/> |

What equipment does your clinic have to facilitate exercise testing? Please select all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Cycle Ergometer | <input type="checkbox"/> Treadmill |
| <input type="checkbox"/> Electrocardiogram (ECG) | <input type="checkbox"/> None |
| <input type="checkbox"/> Metabolic Cart | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> Pulse Oximeter | <input type="text"/> |

Does your centre undertake cardiopulmonary exercise testing (CPET)?

- Yes
 No

Please state which measurements are recorded during CPET. Please select all that apply.

- | | |
|---|---|
| <input type="checkbox"/> Distance | <input type="checkbox"/> VCO2 |
| <input type="checkbox"/> Electrocardiogram (ECG) | <input type="checkbox"/> VO2 |
| <input type="checkbox"/> Heart Rate | <input type="checkbox"/> VCO2 at Gas Exchange Threshold |
| <input type="checkbox"/> Oxygen Saturation (SpO2) | <input type="checkbox"/> VO2 at Gas Exchange Threshold |
| <input type="checkbox"/> Rating of Perceived Effort (RPE) | <input type="checkbox"/> Work Rate |
| <input type="checkbox"/> Rating of Perceived Dyspnoea (RPD) | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> Respiratory Exchange Ratio (RER) | <input type="text"/> |

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Please state which exercise protocols are used for CPET. Please select all that apply.

- Incremental Ramp
- Step Test
- Other (please state)

Does your centre undertake field tests (e.g. shuttle walks, step tests)?

- Yes
- No

What measurements are recorded using field tests? Please select all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Distance | <input type="checkbox"/> VCO ₂ |
| <input type="checkbox"/> Electrocardiogram (ECG) | <input type="checkbox"/> VO ₂ |
| <input type="checkbox"/> Heart Rate | <input type="checkbox"/> VCO ₂ at Gas Exchange Threshold |
| <input type="checkbox"/> Oxygen Saturation (SpO ₂) | <input type="checkbox"/> VO ₂ at Gas Exchange Threshold |
| <input type="checkbox"/> Rating of Perceived Effort (RPE) | <input type="checkbox"/> Work Rate |
| <input type="checkbox"/> Rating of Perceived Dyspnoea (RPD) | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> <input type="text"/> | <input type="checkbox"/> <input type="text"/> |
| <input type="checkbox"/> Respiratory Exchange Ratio (RER) | |

Do you use reference values to evaluate the exercise test(s)?

- Yes (please state which values)

- No

When, and how often, are exercise tests carried out? Please select all that apply.

	Yes, exercise testing is undertaken at this point (Please check box if 'yes')	If Yes... On how many patients in the last 12 months?
<input type="checkbox"/>		

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	Yes, exercise testing is undertaken at this point (Please check box if 'yes')	If Yes... On how many patients in the last 12 months?
At annual review	<input type="checkbox"/>	<input type="text"/>
On an individual basis when patient reports breathlessness on exertion	<input type="checkbox"/>	<input type="text"/>
On an individual basis as part of lung transplant evaluation	<input type="checkbox"/>	<input type="text"/>
To determine impact following therapeutic intervention (e.g. antibiotics, modulators, nutritional changes)	<input type="checkbox"/>	<input type="text"/>
To evaluate fitness/function	<input type="checkbox"/>	<input type="text"/>
To prognostically stratify patients	<input type="checkbox"/>	<input type="text"/>
To prescribe individualised exercise programmes	<input type="checkbox"/>	<input type="text"/>
For research purposes	<input type="checkbox"/>	<input type="text"/>
Never	<input type="checkbox"/>	<input type="text"/>

Which member of the MDT normally supervises the exercise test and records the results?

- Clinical Physiologist
 Clinician
 Nurse
 Physiotherapist
 Therapy Assistant/Technician
 Other (please state)

Does your centre have a limit regarding the level of oxygen desaturation permitted during exercise testing?

- No limit
 Yes - when SpO2 is less than 90%
 Yes - when SpO2 is less than 85%
 Yes - when SpO2 is less than 80%
 Unsure
 Other (please specify)

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If you do not currently utilise exercise testing, is your centre currently considering incorporating exercise testing into its standard of care?

- Yes
- No

Does the availability of the following limit your ability to undertake exercise testing?

	Always	Usually	Sometimes	Sporadically	Rarely	Never
Equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personnel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Space	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What is the **main** barrier to conducting exercise testing in your centre? Please select one only.

- Equipment Availability
- Equipment Limitations
- Staff Availability
- Staff Training
- Not viewed as important in our centre
- No limits
- Other (please specify)

Using the scale below, please indicate the importance **you personally attach** to the value of exercise testing in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Using the scale below, please indicate the importance **your team** attaches to the value of exercise testing in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please state what, if anything, would enhance the role of exercise testing in your clinic (e.g. personnel, equipment, space).

Do you have any final comments on exercise testing in your centre?

Section 3: Exercise Training

Exercise Training

Does your clinic discuss exercise training and/or physical activity with patients?

- Yes
 No

How often is exercise training and/or physical activity discussed with patients in your clinic? Select all that apply.

- Every Appointment
 Only if mentioned by the patient
 When a patient begins to experience exercise difficulties
 Once a year (i.e. annual review)
 Never

Which member of the MDT normally **discusses** exercise training and/or physical activity with patients?

- Clinical Physiologist
 Clinician
 Nurse
 Physiotherapist
 Therapy Assistant/Technician
 Other (please state)

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Which member of the MDT normally **delivers** exercise training and/or physical activity with patients?

- Clinical Physiologist
- Clinician
- Nurse
- Physiotherapist
- Therapy Assistant/Technician
- Other (please state)

What advice is given to patients on the topic of exercise training/physical activity?
Please select all that apply.

- None
- General encouragement regarding exercise
- Exercise training recommendations that weigh up benefits and risks
- Individualised exercise programme based on exercise testing
- Specific activity encouraged (please state)

Are any specific guidelines followed regarding exercise prescription? (e.g. national physical activity guidelines)

- Yes (please specify)

- No

Does your clinic offer exercise training programmes for patients?

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Yes (please specify)

No

How are patients referred for exercise training? Please select all that apply.

- Patient/Self Referral
- Referral from Clinician
- Referral from another healthcare professional
- Not applicable
- Other (please state)

How does your centre triage/prioritise patients for exercise referrals? Please select all that apply.

- No system in place for prioritising patients
- Patients who are post-discharge for exacerbations are prioritised
- Patients with more severe respiratory disease are prioritised
- All patients are offered an outpatient exercise programme
- All patients treated equally
- Unsure
- Not applicable
- Other (please state)

How are aerobic exercise programmes **prescribed** at your centre? Please select all that apply.

- Results from CPET
- Results from field-based testing
- Target heart rates
- SpO2 measures
- Symptom scores
- Unsure
- Not applicable

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 Other (please specify)

How are aerobic exercise programmes **progressed** at your centre? Please select all that apply.

- Results from CPET
- Results from field-based testing
- Target heart rates
- SpO2 measures
- Symptom scores
- Unsure
- Not applicable
- Other (please specify)

Does your centre have a limit regarding the level of oxygen desaturation permitted during exercise training?

- No limit
- Yes - when SpO2 is less than 90%
- Yes - when SpO2 is less than 85%
- Yes - when SpO2 is less than 80%
- Unsure
- Other (please specify)

What level of supervision do you have for outpatient exercise training?

- Fully Supervised (face to face)
- Fully Supervised (telehealth, video calls etc.)
- Partially Supervised
- Unsupervised
- Unsure
- Not Applicable

If you do not currently discuss exercise training, is your centre currently considering incorporating exercise training into its standard of care?

- Yes

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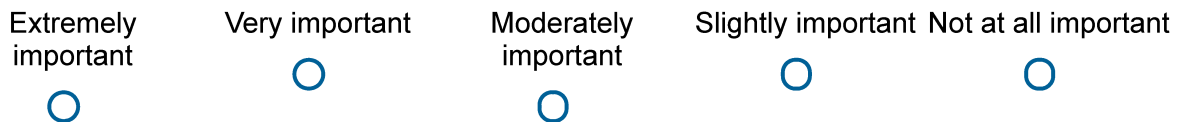
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No

Do any of the following limit exercise prescription in your clinic? Please select all that apply.

- Equipment Availability
- Equipment Limitations
- Staff Availability
- Staff Training
- Not viewed as important in our centre
- No limits
- Other (please specify)

Using the scale below, please indicate the importance **you personally attach** to the value of exercise training in the healthcare of people with CF.



Using the scale below, please indicate the importance **you personally attach** to the value of exercise training in the healthcare of people with CF.



Please state what, if anything, would enhance the role of exercise training in your clinic (e.g. personnel, equipment, space).

Do you have any final comments on exercise training in your centre?

Section 4: COVID-19

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Exercise & COVID-19

Has the COVID-19 pandemic affected your ability to deliver exercise **testing**?

- Yes
 No

How often are you able to undertake exercise **testing** due to the pandemic?

- Always Most of the time About half the time Sometimes Never
-

How has you centre adapted exercise **testing** in light of the pandemic (e.g. video tests, home visits, stopped altogether, no change)

Has the COVID-19 pandemic affected your ability to deliver exercise **training**?

- Yes
 No

How often are you able to undertake exercise **training** due to the pandemic?

- Always Most of the time About half the time Sometimes Never
-

How has you centre adapted exercise **training** in light of the pandemic (e.g. video tests, home visits, stopped altogether, no change)

What have been the major barriers to delivering exercise services (testing and training) during the pandemic?

What resources have you found to benefit your team in during the pandemic?

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Are there any changes you have made due to the pandemic that you **intend to keep and/or maintain**?

What questions have **your patients** been asking you in relation to exercise and COVID-19?

Have you been able to confidently answer your patients questions?

- Yes
 No

Do **you** have any questions with regards to exercise and COVID-19 for cystic fibrosis that you would like answering/addressing?

Do you have any final comments on exercise and COVID-19 in your centre?

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