

Remote monitoring for interstitial lung disease (ILD)

This leaflet explains more about monitoring your health at home using handheld medical devices and an application (app) provided by patient power.

It will answer some of the questions you have about using the app, handheld spirometer and oximeter devices. If you have any questions, please speak to the doctor, pharmacist or nurse caring for you.

Contents

PatientMpower	2
What you need to take part	2
The set up process (for the app, home spirometer and oximeter).....	3
Home spirometry	5
Pulse oximetry.....	7
Questionnaires	8
Who to contact for advice	8
How you can help yourself	8
Length of the programme.....	9
Cleaning your spirometry device.....	10
Safety.....	10
Contact details	11

Introduction

Remote monitoring (monitoring your health at home) involves doing tests at home using handheld medical devices, and completing questionnaires. This information is sent to your clinical team using a mobile phone or tablet, and an app called patientMpower.

Remote monitoring helps us to monitor your condition, response to treatment, and helps us to give you the care you need more quickly.

You can discuss the app with your specialist team and the patientMpower team before you start using the app and devices. They will answer any questions you have.

patientMpower

patientMpower is the digital health company that manages the remote monitoring programme. The team work with us to arrange delivery of the devices (such as home spirometer or oximeter), and help you to:

- download and connect the patientMpower app
- set up the devices

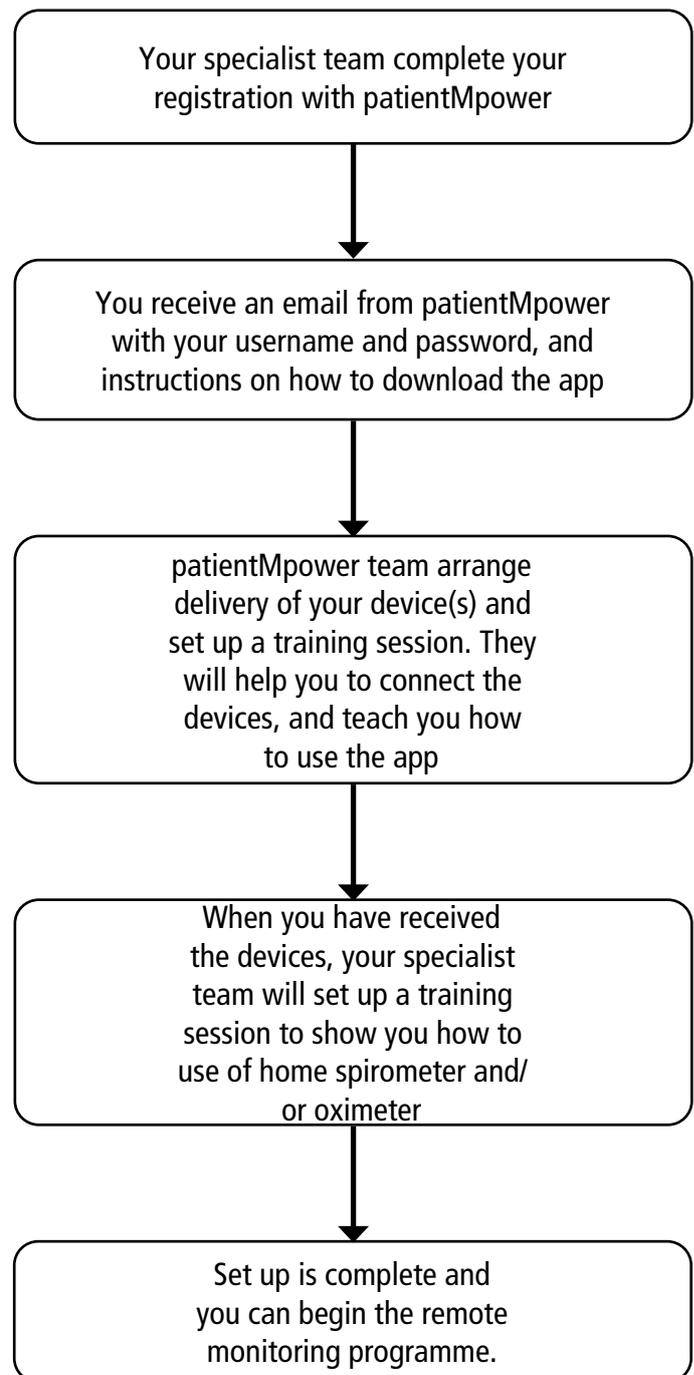
They will continue to provide technical support at home if you need help.

What you need to take part

You will need:

- a smart phone or tablet (iOS 13 or higher, Android 5 or higher) with Bluetooth Smart 4.0 or higher connectivity
- internet access to download the patientMpower app and to send your results to your specialist team when you take them
- to be able to communicate (telephone and/or email) with your specialist team, including reading written instructions and completing questionnaires

The set up process



Downloading the patientMpower app

You will need to download the patientMpower app to your smart phone or tablet with an internet connection. You will receive an email with username and password. If you do not receive an email, please check your spam or junk folder. If there is no email, please contact your specialist team (details at the end of this leaflet).

To download the app, you can visit the website where you usually get your apps, or point the camera on your device at the QR codes on the right.

For Android:

<https://play.google.com/store/apps/details?id=com.maithu.transplantbuddy>



For iOS:

<https://apps.apple.com/gb/app/patientmpower/id1077787395>



You can watch a video guide to setting up the patientMpower app:

<https://youtu.be/Ffp-PB7Gf6M>



Home spirometry

Spirometry is a basic breathing test that measures the amount of air that you can blow out. It is useful to monitor your condition, response to treatment, and to know if your lung disease is getting worse. This test is normally done in the chest clinic.

You will be sent a home spirometer, and patientMpower will guide you through the setup of your device and pairing it with the patientMpower app. This will let you send your measurements to your specialist team. You will need to make sure that Bluetooth is turned on, on your smart phone or tablet.

You can watch a video guide to setup the home spirometer here:

<https://www.youtube.com/watch?v=IFAXh1mgeQg>



Your specialist team will teach you how to do the spirometry test. We would like you to do a **single blow** on the home spirometer **every week**.

If you feel the blow was not quite right, for example, it was interrupted by a cough, rest and recover for a while and then try another blow. You can try a third blow if you need to, but it is best not to do more than 3 at any one time. If you are having trouble with your device, please contact the patientMpower team (details at the end of this leaflet).

Every recording will be sent to your specialist team immediately. Your results will be reviewed by your specialist team frequently. If you notice a change you are concerned about, but have not heard from your specialist team, please contact us as soon as possible.

We will compare your home spirometry reading to your latest lung function tests.

Your baseline forced vital capacity (FVC) is

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It is normal for your FVC to go up and down a little bit. If you are feeling unwell or your symptoms are getting worse, your FVC might go down more.

If your FVC falls to less than (about one tenth) of its volume, we suggest repeating your FVC each day for a week. If your FVC has stayed low for 3 days in a row, you should contact your specialist team.

Your recorded height is

Spirometry – Technique

Please note your FVC may reduce due to technique. Ensure you perform the test correctly to obtain an accurate result:

- You should perform the test sitting, upright, neck at 90 degree angle facing forward – it is important to be consistent every time.
- Take a deep, full and fast breathe in (the more you breathe in the more you can breathe out)
- As soon as you feel full, do not hesitate and blow out
- Blow out as fast as you can – this is to obtain the FEV1 (Volume exhaled in the first second of forced expiration)
- Continue to blow for as long as you can.
- You may feel you are empty but try to maintain the blow for as long as possible – the longer you blow out the more accurate the FVC result.
- It is common to feel lightheaded or cough, make sure you are sitting comfortably and have a glass of water

To get the best reading each time, we recommend you:

- try not to smoke in the 24 hours before the test
- try not to drink alcohol on the day before the test
- avoid eating large meals for 2 hours before the test
- avoid vigorous exercise for 30 minutes before the test
- wear non-restrictive, comfortable clothing during the test

Pulse oximetry

Pulse oximetry is a way of measuring blood oxygen saturation. People with ILD might have a lower oxygen level. People with a resting stable oxygen saturation of 92% or less might be referred for blood gas assessment to see if oxygen therapy might help.

If you do not already have one, you will be sent an oximeter, and patientMpower will guide you through setting up your device.

You can watch a video guide to setting up the oximeter here:

https://www.youtube.com/watch?v=HX_Yxp6vLc0&t=8s



Your specialist team will teach you how to do the pulse oximetry test. We would like you to **take a single reading** on the oximeter **every week**.

If you have a Bluetooth device that is compatible with the app, each time you take a measurement, your results will be sent immediately to the specialist team. If you are not using a Bluetooth device, or one that is not compatible with the app, you will need to add your results to the app manually.

If you are having trouble with your device, please contact the patientMpower team.

Questionnaires

As well as reviewing your weekly FVC results, it would be useful for us to have a better understanding of your symptoms and how you are feeling. We would like you to complete a number of questionnaires at the beginning, and after months 1, 3, 6, 9 and 12.

Your patientMpower app will remind you to complete the questionnaires, which are in the app.

Who to contact for help or advice

You should contact your specialist team when you need to. If you have any concerns about your symptoms, lung condition, or the remote monitoring programme, please call the ILD helpline or via MyCare.

You should contact patientMpower for any technical support with the app or devices.

How you can help yourself

Look out for chest infections

It is important to know what is normal for you, and what might be symptoms getting worse.

You might have an infection if:

- you are more breathless
- you are producing more phlegm than usual
- your phlegm is a different colour
- you have a new cough, or it gets worse
- you have a sore throat or fever

You might notice a change in your spirometry and oximetry readings. If this happens, start your **rescue medicine** (if you are prescribed this) and tell your GP as soon as you can. Contact your GP again within 3 days of taking your rescue medicine if your symptoms have not improved. You can also contact your specialist team.

Look out for your condition getting worse

Your condition might be getting worse if you don't have other signs of an infection, but you:

- feel more breathless
- have a cough that is getting worse
- have a poor appetite
- have lost weight without trying

You might also notice a change in your spirometry and oximetry readings. If this happens, you should contact your GP or specialist team for advice.

Length of the programme

We recommend you follow the remote monitoring programme for a least 12 months. We will continue to offer you regular review with your specialist team, and hospital-based spirometry tests (when appropriate).

We can regularly review you if you would like to continue the programme after the 12 months. If you decide not to continue at any stage, you can still keep the devices or return it to us, and you can come to the hospital for regular tests.

Please stop the home spirometry measurements and contact your specialist team if you have any of the following:

- pneumothorax (collapsed lung)
- recent heart attack or stroke
- uncontrolled angina (chest pain)
- aneurysm (bulges in blood vessels)
- pulmonary embolism (blocked blood vessel in your lungs)
- ischaemic heart disease (narrowed heart arteries)
- high blood pressure
- recent chest (thoracic), eye or tummy (abdominal) surgery
- perforated ear drum

Cleaning your home spirometry device

You should clean your device each week.

To clean, wipe the surfaces with a soft damp cloth and allow to air dry, or dry with a soft cloth. Make sure all surfaces are completely dry before using again.

Never put the device into water or other fluids.

Safety

Your devices are only to be used by you. Please do not share the devices with anyone else.

Contact details

ILD Helpline

If you have any questions or concerns about your condition, please call our helpline.

t: 07395 283159 (this is an answerphone service; we aim to respond to your call within office hours (except weekends and bank holidays)

If you need technical support about using the app or your devices, please call patientMpower, **phone** 020 3322 4121 or **email** support@patientpower.com

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS):

t: 01392 402093 **e:** rde-tr.PALS@nhs.net

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 **w:** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

additional support:



**Action for
Pulmonary Fibrosis**

We provide support to families, raise awareness, campaign and educate to improve access to the highest standard of care for everyone. We are committed to finding a cure through funding research.

We are here for you:

Website: www.actionpf.org

Support line: 01223 785725

Email: info@action.pf.org

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