

## IBD home monitoring patient information

#### What is home monitoring?

We have developed a home monitoring service which allows Inflammatory Bowel Disease (IBD) patients to easily share information with their clinical team from home. Patients can use a phone, tablet, laptop or computer to do this. We are working in partnership with a company called Big Picture Medical who have developed the technology for the home monitoring service. The service is for UHB patients with Ulcerative Colitis or Crohn's disease who meet the eligibility criteria.

#### Why have we set up home monitoring?

There are several benefits to home monitoring, the most important of which are:

- The new service enables a monitoring schedule based on the patient's needs, allowing the IBD team to provide more personalised, proactive and timely care
- Many patients benefit from the convenience that this service offers, reducing the need to travel to hospital and the accompanying carbon footprint

It is important to note that home monitoring does not replace any of the existing services that patients can access, for example the IBD helpline.

#### How does it work?

#### In your appointment:

There are several eligibility criteria that patients need to meet and the clinician will discuss these with you in your appointment. If you meet the criteria, you will be invited to the home monitoring service. If you decide that home monitoring is not for you, there will be no impact on your care and you will continue to access IBD services at UHB as normal.

If you would like to join home monitoring, your clinician will check some details and ask for your preference for faecal calprotectin testing – you can opt for home testing, or laboratory testing where you will need to drop a stool sample off at the UHB lab. The clinician will also ask you some questions to determine how often you will need to share information with the clinical team, using the home monitoring system.

#### At home:

You will receive a reminder email from UHB and Big Picture Medical seven days before you are due to submit information using the home monitoring system. On the submission date, you will receive a further email containing a link to the secure web application which you will need to click. You will then be prompted to login (you can use your <a href="https://www.needical.com/needica

Once logged in, you will be prompted to enter the faecal calprotectin result from your home test (or specify that a stool sample has been sent to the lab if you opted for this method), unless the clinical team do not require this information from you. Following this, you will be asked to complete a short questionnaire about your symptoms, as well as other information relevant to your IBD and care.

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Your information will be automatically made available to the clinical team who will review your information and decide on next steps:

- If your symptoms and disease are stable, the clinical team will set the date of the next home monitoring review
- If your treatment needs to change, you may be invited to attend clinic to speak with the specialist nurse or consultant

The outcome of the review including next steps will be summarised in a letter which will be sent to you and your GP.

\*These are the same details you use for the NHS App. Find out more about NHS login at https://www.nhs.uk/nhs-services/online-services/nhs-login/.

#### What is home testing?

Home faecal calprotectin (FC) tests can help identify if a patient's IBD has relapsed and allows patients to monitor their own FC levels. Home testing requires the patient to have a smartphone, a list of compatible smartphones is available on the support page (link below). Home testing kits generally contain a stool sample collection kit, a sample extraction tube, FC extraction solution, test plate, a smartphone camera calibrator and a smartphone app to interpret and transmit the results.

IBDoc is the home testing product used by UHB. More information can be found at https://www.ibdoc.net/support/.

## Support with the Big Picture Medical web application

If you are unable to login or having difficulty using the web application, please contact your IBD helpline in the first instance.

#### **Contact information**

If you have any questions about home monitoring, please contact your IBD helpline:

Queen Elizabeth Hospital Birmingham - 0121 371 5905 - IBDHelpline@uhb.nhs.uk

Heartlands Hospital - 0121 424 0434 - IBD.nurses@uhb.nhs.uk

Good Hope Hospital – 0121 424 9687 – IBDNurses.GHH@uhb.nhs.uk

If you are a user of the IBD home monitoring service and have any suggestions on how it could be improved, please send your feedback via email to: Transformation@uhb.nhs.uk.

#### Frequently asked questions

#### What is home monitoring?

Home monitoring is the process of using technology to monitor and review a patient's health outside of a hospital setting. The IBD home monitoring service with Big Picture Medical allows patients to input information about their condition from home, which are reviewed by the clinical team in the hospital via a 'remote' or 'virtual' review.

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Home monitoring helps the IBD service be more flexible and allows patients whose IBD is stable to continue managing their condition at home; making more resources available to respond quickly to patients whose condition is worsening or flaring. This flexibility allows the hospital to better manage clinical appointments and prioritise those patients who need to be seen quicker.

#### Am I eligible to join home monitoring?

To be considered for home monitoring, you will need access to the internet and your own individual email address that is not shared with another person.

#### How often will I have to complete a questionnaire and provide a stool sample?

This will be determined by your IBD clinical team. Most patients are asked to submit information on average every three to six months. There are occasions when the clinical team do not require a stool test, in which case patients will only need to complete the questionnaire.

You will receive a reminder email from Big Picture Medical seven days before your information is due, so that you can start to think about your symptoms and anything you may want to share with your IBD team. You will then receive a further email from Big Picture Medical, with a link which you will need to follow to provide your information.

You may find it helpful to put a note of your submission date in your calendar or diary. If there are any changes to how often you need to complete a questionnaire or stool sample, your clinical team will be in touch.

If you are unable to share your information when you receive your reminder email, please let us know at the earliest convenience by contacting your IBD helpline.

## What if I forget to complete my questionnaire and stool sample?

You will receive a reminder email seven days after your submission date. If, after 14 days, we have still not heard from you, one of the administrative team will give you a call to check-in with you.

## What information do I need to provide?

- Information about your symptoms; we are using a range of validated clinical questions to help the clinical team make the most informed decision for your care.
- We may also ask you to complete a stool test, either at home or by submitting a sample to the hospital lab.

## How do I change the way I provide my stool sample?

If you would like to change the way you provide a stool sample, please contact your IBD helpline and the clinical team will be able to update your preferences.

## What if I don't want to be under the home monitoring service anymore?

You can withdraw your consent at any time by contacting your IBD clinical team.

#### How is my data used by Big Picture Medical?

Your personal data (including your contact details and the health data provided by you, or by us) are used to provide health care and this is the legal basis by which it will be collected and processed.

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It may also form part of anonymised and aggregate data used to improve how the software functions, create statistics, and obtain scientific analysis to identify health trends and patterns.

#### Your rights

You may be entitled to request to access, rectify, erase, and restrict your personal data, and/or obtain more information about the processing of your personal data and the applicable safeguards. You can withdraw your participation from IBD home monitoring at any time and it will not affect your health care.

For more detailed information on how we process your personal data, including how to exercise your rights, please refer to the privacy notice provided to you or available online at https://www.uhb.nhs.uk/privacy-notice/patients.

We will assist you in any privacy requests or concerns that you may have. More information on the Big Picture Medical privacy policy can be found on their website at https://landing.bigpicturemedical.com/privacy-policy.

What happens after my questionnaire and stool sample have been sent in? After you have submitted your questionnaire and stool sample, a member of the IBD clinical team will review them.

- If your symptoms and disease are stable, the clinical team will set the date of the next home monitoring review
- If your treatment needs to change, you may be invited to attend clinic to speak with the specialist nurse or consultant

The outcome of the review including next steps will be summarised in a letter which will be sent to you and your GP.

#### Can I have copies of my home monitoring records?

Yes. You can do this by sending a request to the Access to Health Records department. You will be required to provide your:

- Name
- Date of birth
- Hospital registration number (if known)
- Hospital where you are being treated

Full details are available on the access to health records page at www.uhb.nhs.uk/get-intouch/access-to-health-records/.

## I am worried about my symptoms, what should I do?

If you are worried about your symptoms, please contact your hospital IBD clinical team via the helpline and leave a voicemail:

Queen Elizabeth Hospital Birmingham: 0121 371 5905 – <a href="mailto:IBDHelpline@uhb.nhs.uk">IBDHelpline@uhb.nhs.uk</a>

Heartlands Hospital: 0121 424 0434 – IBD.nurses@uhb.nhs.uk

Good Hope Hospital: 0121 424 9687 – IBDNurses.GHH@uhb.nhs.uk

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The IBD helpline is not an emergency service. If you experience an emergency or a rapid decline in symptoms and need urgent care, please call 999 or attend your local Accident and Emergency Department.

#### Where can I find my outcome letter from my clinical team?

After you have submitted a home monitoring questionnaire, the information will be reviewed by the clinical team who will decide on next steps. A digital letter explaining the next steps will be made available to you in the home monitoring system. You will be notified by email that a new document is available for you to read. Using the link provided in the email, you will be asked to login to the home monitoring system to view your letters.

Letters from the home monitoring system will not be viewable on other NHS platforms, such as the myhealth@UHB portal.

## How do I request more home faecal calprotectin test kits?

To request more faecal calprotectin test kits, please contact your IBD clinical team using the contact information provided in this leaflet.

# How do I change the email address I use to receive home monitoring notifications?

Please contact your IBD clinical team to update your email address.

Your new email address will be updated in your hospital record and in the IBD home monitoring system. We will send an email to your new email address instructing you how to authenticate the new email address. Once you have completed this step, any future notifications will be sent to your new email address. If you do not authenticate the new email address, the notifications will continue to be sent to your old email address.

## What support is available for patients with IBD?

Below are some links to useful resources for IBD:

https://crohnsandcolitis.org.uk/

https://www.nhs.uk/conditions/inflammatory-bowel-disease/

https://www.crohnscolitisfoundation.org/

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email interpreting.service@uhb.nhs.uk

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