



Royal Berkshire
NHS Foundation Trust

Inflammatory Bowel Disease Patient- Initiated Follow-Up (PIFU)

Information for patients,
relatives and carers

PIFU direct tel: 0118 322 8391

Email: rbb-tr.cat4@nhs.net

This leaflet explains what the Inflammatory Bowel Disease Patient-Initiated Follow-Up (PIFU) service is and how it can help you manage your condition.

What is Patient-Initiated Follow-Up (PIFU)?

Patient-initiated follow-up (PIFU) puts you, the patient, in control of when you are seen by the Gastroenterology Department.

Attending regular outpatient appointments scheduled by the hospital can cause unnecessary anxiety – e.g. time taken to travel, park and wait for the appointment – if your condition is stable.

Sometimes, regular outpatient appointments may not result in any change to your treatment. In fact, your condition may flare up in between regular booked appointments and it is during this time that you really do need our input. PIFU will put you in control of making an appointment when you need it the most.

For all other concerns, or if you are feeling unwell, your GP will remain your first point of contact.

How does PIFU work?

The Inflammatory Bowel Disease (IBD) Team will advise you whether your condition is now suitable to have your follow-ups via PIFU, rather than regular appointments scheduled by the hospital.

Your clinician will have advised you about the process and given you this patient information leaflet for you to consider if you want to have your follow-ups in this way; **it is your decision.**

Will you still be looking after me if I do not call for a PIFU?

Yes, we will arrange a routine follow-up appointment after five years to check that your condition is still stable.

What if I am worried and change my mind about this style of follow-up?

Just tell us and we will go back to booking regular hospital appointments for you to attend for a review. Please discuss any concerns with a member of the team who will be happy to help. You can do this by calling the number on the front of this leaflet.

When should I call for a PIFU?

You should call if you experience a flare-up of your symptoms and need to be seen in the clinic. You may also have the opportunity to speak with a specialist nurse for immediate advice, if required.

When not to use PIFU

If you require urgent medical advice you should contact your GP, NHS 111 or your local Walk-in centre. If you are really unwell and it comes life threatening, call 999 or attend your local Emergency Department (A&E).

Colonoscopic surveillance

If you have a diagnosis of proctitis, a surveillance colonoscopy is not required as there is no increased cancer risk.

If you have had a diagnosis of left-sided or total colitis for 10 years or more, you are likely to require a surveillance colonoscopy every 5 years. Eligible patients will be notified as per national bowel cancer screening guidelines when their investigation is due. If you have not been contacted and think you are due a colonoscopy, please contact the gastroenterology team on 0118 322 8391 or email: rbb-tr.cat4@nhs.net.

How would I book a PIFU appointment?

Booking an appointment to see the team is a quick and easy process. Just follow the four easy steps below and a member of our administration team will arrange an appointment for you within three weeks of your request.

They may ask some questions to determine if this is face to face or telephone but you will be offered the first available appointment.

Booking a PIFU in four easy steps:

- 1** Call the IBD Team on 0118 322 8391 (between 8am and 5pm) or email rbb-tr.cat4@nhs.net
- 2** Explain you are an IBD patient on the PIFU pathway and want to have a follow-up appointment. They may ask some questions to determine if this is face to face or telephone. If you need urgent same day advice they will arrange for a specialist nurse to contact you.
- 3** Agree an appointment date and time.
- 4** Attend your clinic appointment.

In the event you need to leave a message when you call, please leave the following information:

- ✓ Your full name and date of birth.
- ✓ Your hospital number and/or NHS number.
- ✓ A telephone number where we can call you during normal hours between 8am – 4pm.
- ✓ **Date of your last specialist appointment.**

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.