



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Gastroenterology Patient- Initiated Follow-Up (PIFU)

Inflammatory Bowel Disease

Information for patients, relatives and carers

① For more information, please contact:

Outpatient Services

The York Hospital
Wigginton Road, York, YO31 8HE
Telephone: 01904 726400

Or

Scarborough Hospital,
Woodland Drive Scarborough YO12 6QL
Telephone: 01723 385432

Contents	Page
What is Patient-Initiated Follow-Up (PIFU)?	3
What are the potential benefits of PIFU?	3
Are all patients with IBD suitable for PIFU?	4
How does PIFU work?.....	4
How do I book a PIFU appointment?	5
When should I arrange a PIFU appointment?.....	6
What will happen following my PIFU appointment?	6
When is it not appropriate to contact PIFU?.....	6
Will the hospital still be looking after me even if I do not need to contact the PIFU team?.....	7
What are the arrangements for surveillance colonoscopy and blood monitoring?.....	7
What if I have concerns and change my mind about PIFU?	8
Getting in touch	9
Feedback	9
Tell us what you think of this leaflet	10
Teaching, training and research.....	10
Patient Advice and Liaison Service (PALS).....	10

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

Many patients with long-term health conditions such as inflammatory bowel disease (IBD) do not need regular follow-up with their hospital team if their disease is stable. This is because research has shown that regular clinic visits do not prevent the condition from returning. Instead, it is more important that patients can access care when they need it, and this is the purpose of patient-initiated follow-up (PIFU). Rather than being offered regular clinic appointments with a doctor or specialist nurse at fixed time points, PIFU patients can make their own appointment when required, for example if they are experiencing a flare-up of their disease.

What are the potential benefits of PIFU?

PIFU puts patients in control of their own care and provides direct access to the hospital team when needed. This is often more convenient for patients and reduces unnecessary travel to the hospital and time spent waiting in clinic for routine follow-up appointments.

Are all patients with IBD suitable for PIFU?

No. For now, only patients with ulcerative colitis are eligible for the PIFU service. Patients with Crohn's disease are not suitable. In addition, patients need to have stable disease meaning that they do not have troublesome symptoms currently and also that they have not had a flare in the previous 12 months.

Patients taking mesalazine to control their colitis (e.g., Asacol, Pentasa, Octasa) are eligible for PIFU, but those requiring other immunosuppression, such as azathioprine, or biologic drugs, such as infliximab, are not suitable.

How does PIFU work?

During your next clinic appointment or telephone review, the doctor or specialist nurse will review your condition, your symptoms, and your treatment. They will discuss whether you could be suitable for PIFU rather than regular scheduled hospital appointments. Managing your appointments via PIFU is optional and it is your decision. The information provided in this leaflet is designed to help you to make this choice.

If you decide to manage your appointments using PIFU you will also be provided with a PIFU card. This provides the contact details for the PIFU team which are also available in this leaflet. We will write to your GP to explain that you will be managing your appointments using PIFU.

How do I book a PIFU appointment?

The service is quick and easy to use. If you experience a flare or other problems with your condition, simply call the PIFU team using the contact details provided on your PIFU card and in this leaflet. This is the usual IBD helpline number.

Explain to the team that you are experiencing problems and an IBD specialist nurse will get in touch to discuss this with you. If necessary, an appointment will be arranged for you to see a doctor or specialist nurse. This will be within the next 28 days, but is likely to be sooner than this. Alternatively, it may be possible to resolve the problem over the telephone.

Please remember that if an appointment is arranged for you it is very important that you attend. If you find that you are no longer available and need to rearrange your appointment, please tell us in advance so that we can give your appointment to someone else who needs it.

When should I arrange a PIFU appointment?

You should call the PIFU team if you are experiencing a flare of your disease, problems with your condition or treatment, or if you feel that you need to be seen for another reason. Your PIFU card gives details of flare symptoms to look out for, to help you to decide when you should contact us. The most common symptoms of a flare of ulcerative colitis are loose or more frequent bowel movements (diarrhoea), bleeding from the back passage, and abdominal pain.

What will happen following my PIFU appointment?

Following your appointment, the doctor or specialist nurse will discuss with you whether to remain under PIFU or whether to go back to regular appointments.

When is it not appropriate to contact PIFU?

If you require urgent medical advice you should either contact your GP, or call NHS 111. If you are really unwell, you should attend your local Emergency Department (A&E). For all other medical concerns, your GP remains your first point of contact.

Will the hospital still be looking after me even if I do not need to contact the PIFU team?

Yes. We will contact you to arrange a follow-up appointment if you have not contacted the PIFU team after a fixed period of time. This will be a period of between three and five years. Your doctor or specialist nurse will agree this timescale with you depending on the details of your condition.

What are the arrangements for surveillance colonoscopy and blood monitoring?

If you are due a surveillance colonoscopy then this will be arranged separately to your PIFU care. If you receive an appointment for colonoscopy then you should attend this; however, you do not need to contact the PIFU team.

Your doctor will review the results of the colonoscopy and communicate these to you separately. If your results require you to be reviewed in clinic then we will inform you of this and arrange an appointment.

If you are taking mesalazine you will require a monitoring blood test once a year. This will be arranged by your GP. We will inform them of this requirement when you start PIFU care. If there are any problems with your blood test your GP should contact us. If your results require you to be reviewed in clinic then we will inform you of this and arrange an appointment.

What if I have concerns and change my mind about PIFU?

Even though many patients appreciate the flexibility offered by PIFU, some patients may become worried about no longer having regular contact with the hospital. If you wish to go back to booking regular hospital appointments just let us know and this can be arranged.

Getting in touch

PIFU contact details

To book an appointment please contact the PIFU team using the IBD helpline number below:

York patients
01904 726154

Scarborough patients
01723 236323

Feedback

We appreciate and encourage feedback. If you have any comments or suggestions regarding PIFU then please let us know using the contact details below. Please note that we may be in touch in the future to ask you about your experience.

Outpatient Services, York Hospital, Wigginton Road,
York, YO31 8HE
Telephone: 01904 726400

Outpatient Services, Scarborough Hospital, Woodlands
Drive Scarborough YO12 6QL
Telephone: 01723 385432

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Outpatient Services, c/o Patient Leaflet Team, 98 Union Terrace, York, YO31 7ES, telephone 01904 721045 or email us at patient.information2@york.nhs.uk.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

Please telephone or email if you require this information in a different language or format, for example Braille, large print or audio.

如果你要求本資 不同的 或 式提供 , 電
或發電

Jeżeli niniejsze informacje potrzebne są w innym języku lub formacie, należy zadzwonić lub wysłać wiadomość e-mail

Bu bilgileri değişik bir lisanda ya da formatta istiyorsanız lütfen telefon ediniz ya da e-posta gönderiniz

Telephone: 01904 725566

Email: access@york.nhs.uk

Owner	Rhiannon Winfield, CG1 Operational Manager, York & Elaine Dixon, CG2 Service Manager, Scarborough
Date first issued	December 2021
Review Date	December 2024
Version	1 (issued December 2021)
Approved by	CG2 & CG1 Quality Committee
Document Reference	PIL 1537 v1
© 2021 York and Scarborough Teaching Hospitals NHS Foundation Trust. All Rights reserved.	