



Information for patients, relatives, and carers

Autoimmune haemolysis (AIHA) Patient Initiated Follow-Up (PIFU)

What is Patient Initiated Follow-Up (PIFU)?

Not all patients with autoimmune haemolysis – also known as autoimmune haemolytic anaemia (AIHA) - need regular follow-up with their hospital team. Many patients will not require repeat treatment, and regular clinic visits are unlikely to coincide with new anaemia, nor do they prevent anaemia occurring. Instead, it is more important that patients can access care when they need it. 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 contact the team to arrange an appointment if or when required.

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 also reduces unnecessary travel to the hospital and time spent waiting in clinic for routine follow-up appointments. It means concerns can be acted on quickly, rather than waiting to discuss them in a planned appointment.

Are all patients with autoimmune haemolysis suitable for PIFU?

Your haemoglobin (Hb), the measurement used for anaemia, will need to be safe and stable following completed treatment. You will have been monitored in clinic for at least one year. Your named consultant will agree that PIFU is appropriate for you as an individual.

How does PIFU work?

Once a patient has been identified as suitable for PIFU by their consultant, this will be discussed with them by an appropriate member of the haematology team, be that a doctor, specialist nurse or physician associate. Patients being transferred to PIFU will receive this information leaflet and a contact details card for the specialist nursing team, which are also stated in this leaflet. We will write to your GP to explain that you will be managing your appointments using PIFU.

When should I contact the specialist nursing team?

You should call the haematology specialist nursing team if you have any of the following symptoms:

- Unexplained, new shortness of breath, particularly during exertion.
- Unexplained light-headedness, particularly on being upright.
- Yellow tinged skin (jaundice).

Planned operation or procedure when the team carrying out the procedure are not planning a blood count check in advance. You should always mention your history of autoimmune haemolysis if a health care professional prescribes new medication for you. A small number of medications can trigger haemolysis. The prescriber can look this up. In such cases, you would need a blood count shortly after starting the medication.

You should have a blood count check around 10 days following any vaccinations, as there are some rare cases of haemolysis being triggered by vaccination. However, please do go ahead with vaccinations, as the benefit outweighs this small risk.

How do I contact the specialist nursing team?

The specialist nurses are available Monday-Friday 08:30-17:00 (excluding bank holidays) on the following numbers: 01904 72 5815 (York) and 01723 34 2976 (Scarborough). If you get an answerphone, please leave a message with your name, contact number and ideally hospital number and your call will be returned.

What happens when I contact the specialist nursing team?

A specialist nurse will discuss your concerns and symptoms with you and arrange for an urgent blood count. If required, you will then be reviewed by a doctor the same day and/or a follow up appointment made in the consultant clinic.

What will happen following my PIFU appointment?

Following your appointment, the doctor or specialist nurse will discuss with you whether to remain on the PIFU pathway.

When is it not appropriate to contact the specialist nurses?

If you require urgent medical advice, you should either contact your GP, or call NHS 111. If it is an emergency, you should dial 999 or attend your local Emergency Department (A&E). For all other medical concerns, your GP remains your first point of contact.

What will happen if I do not need to contact the team?

Whilst we are only using the PIFU service for patients who do not require regular follow up, we will be prompted to review your hospital records if you have not contacted us requiring a PIFU appointment after a period fixed by your consultant.

❗ If you have further concerns about your condition, please contact:
Outpatient Services, York Hospital, Wigginton Road, York, YO31 8HE.
Telephone: (01904) 726400.

Patient Advice and Liaison Service (PALS)

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 yhs-tr.PatientExperienceTeam@nhs.net.
An answer phone is available out of hours.

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.

