



Patient Initiated Follow-Up (PIFU)

Frequently asked questions

Section 1 - Getting started on PIFU:

1. What is PIFU and why is PIFU becoming more common?

Most patients are familiar with the rheumatology team setting follow-up appointments on a regular basis, for example every 6-12 months. Patient Initiated Follow up, or PIFU for short, is a different way of organising care where the patient decides when they need to have follow up appointments, based on how they are feeling and what support they need. This means that patients see their rheumatology team when they need to, rather than going for an appointment when they are well and may not need to be seen.

The benefit of PIFU is that patients can ask for appointments when they need them, and rheumatology teams can focus on those patients who need help at the time. This can save both patients and the NHS time and money.

2. How is PIFU different from usual rheumatology care?

PIFU is different because patients can ask for an appointment instead of waiting for their rheumatology team to book it. Reasons for patients asking for an appointment could include concerns about their inflammatory arthritis, changes in symptoms, issues with their treatments or to see other members of the rheumatology team, such as:

PLEASE INSERT AVAILABLE HEALTH PROFESSIONALS HERE.



3. Can I choose whether I am on PIFU?

Being invited to go onto PIFU depends on several factors, including your rheumatology team, your diagnosis, your treatment, and your individual healthcare needs. You may be given the choice to switch to PIFU, if your team think that it would be a good option. Any decision about PIFU should be based discussions between you and your rheumatology team.

4. Who is PIFU suitable for?

Current NHS guidance suggests that PIFU can be suitable for patients who have:

- A type of inflammatory arthritis (e.g. rheumatoid arthritis, psoriatic arthritis, axial spondyloarthritis and other types of arthritis)
- Been diagnosed for at least 2 years
- Symptoms that are well controlled on current treatment*
- Patients who wish to manage their own health with the right support and have been told how to get in contact with the team.

**Some treatments might mean patients are not suitable for PIFU due to monitoring regulations. Your team will be able to tell you about your treatment.*



5. Who is PIFU not suitable for?

Current NHS guidance suggests that PIFU is not suitable for patients who:

- Have a rare or complicated rheumatological condition
- Someone who is newly diagnosed
- Patients who may be anxious or depressed or have another reason that may stop them contacting the rheumatology team, and who don't have other people very close to them who can contact on their behalf if needed.

6. What information is there to help me decide if PIFU is right for me?

Please see information below about PIFU and relevant patient organisations which may be helpful:

- **National Rheumatoid Arthritis Society**
National Free phone helpline: 0800 298 7650
Website: www.nras.org.uk
NRAS PIFU webpage: <https://nras.org.uk/pifu>
- **NRAS SMILE-RA e-learning programme**
Module entitled 'How to get the best out of your Consultation'. Register free of charge for SMILE here: www.nras.org.uk/smile
- **NASS Your SpAce programme for self-management**
<https://nass.co.uk/about-as/your-space>
- **Getting the most out of appointments**
<https://nass.co.uk/about-as/your-space/appointments>

PLEASE INSERT ANY LINKS HERE YOU FIND USEFUL REGARDING PIFU.



Section 2 - Contact with my team:

1. How do I contact the rheumatology team if I am on PIFU?

If you are on PIFU, your rheumatology team must inform you about how to contact them when you need to. This varies between hospitals.

At _____ hospital, you should contact

(include mode of communication too)

2. When should I contact the rheumatology team if I am on PIFU?

You can contact the rheumatology team for different reasons, for example:

- changes in your symptoms
- concerns or queries about your medication or blood tests
- access to information or support from other members of the rheumatology team such as

PLEASE INSERT AVAILABLE HEALTH PROFESSIONALS HERE.

These things might need telephone advice or an appointment at the hospital.

3. Does PIFU replace the call line?

PIFU does not replace the usual rheumatology advice service, but you can contact via that advice service for support.

4. If I am on PIFU, is there a limit on the number of times that I can contact the team?

No, there is no limit, and you can contact the team whenever you need help with your inflammatory arthritis. However, if you are experiencing lots of issues, such as your symptoms getting worse or your treatment not working well, PIFU might not be right for you at this time.

5. If I am on PIFU and I contact the rheumatology team, when should I expect a reply?

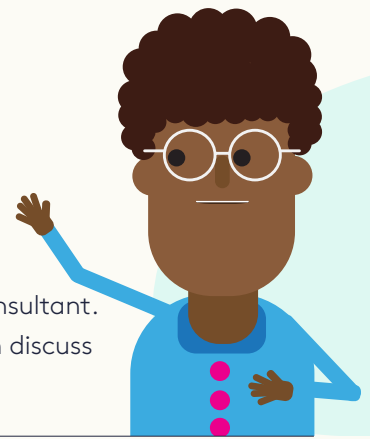
NHS guidance suggests that patients should receive some advice within 1 working day although pressures on rheumatology teams may mean that this takes a little longer. Sometimes, patients' queries will not need a face-to-face appointment and they can be answered with a telephone call. When a face-to-face appointment is needed, an urgent appointment should be within two weeks, and a routine appointment within approximately four weeks. Sometimes there are situations where your team cannot offer an appointment in this way. If this is the case, your rheumatology team will discuss options with you.



Section 2 - Continued...

6. Will my appointments always be with the same members of the rheumatology team if I am on PIFU?

Generally, rheumatology teams try to make sure that patients' care is with the same consultant. However, sometimes this is not possible, for example with urgent appointments. You can discuss options with the rheumatology nurse depending on the nature of your current problem.



7. If I am on PIFU, can a supporter or carer make an appointment for me?

Normally, patients make their own appointments. However, there are some situations where the rheumatology team do not mind someone else making contact for a patient. This might include patients who already rely on another person to help them access healthcare, for example those with memory difficulties or some types of neurodivergence.

8. If I am on PIFU, can I have appointments with health professionals such as physiotherapists and occupational therapists?

Yes. If you think that you need the support of health professionals such as physiotherapists and occupational therapists, you can contact the rheumatology team and ask for a referral.

Section 3 - Monitoring my health:

1. Will I still have routine appointments if I am on PIFU? If so, how often will they be?

Everyone on PIFU will have an appointment booked, but this may be a long time in advance.

At hospital, this is usually months

2. Will I need help to monitor my inflammatory arthritis if I am on PIFU?

Often people can notice if they need help with their long-term condition. Sometimes rheumatology services have other ways to monitor your arthritis, such as questionnaires or an app. These can be helpful, but they do not suit everyone. If you have questions about this, please ask your rheumatology team.

In hospital, we will...

3. Where can I find information about how I can look after my inflammatory arthritis if I am on PIFU?

If you have decided with your team to start PIFU, you should be confident that you know as much as you want to about your inflammatory arthritis and where to look if you want to find out more. All patients should receive information and guidance on how to manage their health between follow-up appointments. You should be signposted by your rheumatology team to the most appropriate patient organisation for your type of inflammatory arthritis. This should give you information, support, and access to self-management resources.



Section 3 - Continued...

4. What happens if I am on PIFU and worried about my health, but I am not sure if the rheumatology team can help?

There are many ways that you can access help in the NHS. If your query relates to your inflammatory arthritis, then you should contact the rheumatology team for advice. They may also advise you to speak to another service.

- The Emergency Department is for serious injuries and life-threatening emergencies only. It is also known as Casualty or Accident & Emergency (A&E).
- GP - your GP can support with all medical issues including prescriptions for some inflammatory arthritis medications and other related conditions.
- Pharmacy – your pharmacist may be able to answer queries about your medications.
- 111 (NHS online) can help if you think you need medical help right now but you're not sure what to do. You can check your symptoms on 111 online or call 111 to speak to someone.
- Patient organisations can offer further support and information and there may also be local support groups.



5. How will long-term issues, such as my bone health, heart health, and mood be considered if I am on PIFU?

Different services are likely to approach this in different ways.

Bone health information is available from the Royal Osteoporosis Society at <https://theros.org.uk>

Your rheumatology team usually only needs to review your bone health every few years, or if you have a broken bone between appointments (e.g., wrist, spine, or hip). If you have a broken bone, particularly if this occurs without much force, you should contact your rheumatology team.

Heart health information is available from the British Heart Foundation at <https://www.bhf.org.uk/informationsupport>

The rheumatology team usually only needs to review your heart health every few years and this is often managed with your GP. Some rheumatology teams work with local GP services to ensure your heart health is reviewed, as GPs often have better relevant information to do this.

If you have further questions, you should talk to your team about how this will occur locally.

Mental health support is available through your GP with a number of different resources in local areas. You can also get support from patient organisations and the Samaritans.

The patient organisations mentioned in this document also have helpful information and supported self-management services/resources which can support you to make helpful lifestyle adaptations to reduce the risk of things like heart, bone and mental health issues.

Add local links to mental health support, including local resources.

6. Will I get general health reviews as part of PIFU?

Yes, patients should have general health reviews if they are on PIFU. The reason for this is that patients with inflammatory arthritis can be at higher risk for other conditions including osteoporosis (bone thinning) and heart problems. How often you are invited to a general health review will depend on your inflammatory arthritis and your rheumatology team. Therefore, it is important to talk to your team about how often you should be monitored and whether this happens with your rheumatology team or your GP.

Hospitals input monitoring details here...

7. Can I stop being on PIFU if it is not right for me?

Yes, if you are on PIFU and find that it's not suitable or right for you, you should discuss this with your rheumatology team. In some situations, your rheumatology team may decide that PIFU is not working for you in your current circumstances. Healthcare decisions should always be based on what works best for you and your individual needs and this may change over time.

Your rheumatology team is there to support you and they can work with you to find the most suitable approach for your needs. Don't hesitate to communicate openly and discuss what works best for you in managing your health.



Patient organisations offering further support and information.



British Society
for Rheumatology
Bride House
18-20 Bride Lane
London, EC4Y 8EE