

# Patient Initiated Follow up (PIFU)

## Clinicians Handbook

Additional patient resources are available at <https://www.rheumatology.org.uk/>



# Patient Initiated Follow up (PIFU) Clinicians Handbook

## PIFU evidence summary

Draft guidance on implementing PIFU in adult rheumatology services has been developed by NHS England.[1] This guidance highlights the limited evidence around PIFU in inflammatory arthritis and the need for further information to optimise PIFU service design and patient selection. A Cochrane review in 2020, addressing research across all chronic diseases, included data on 3402 patients, of whom 909 had inflammatory arthritis.[2] These patients were taken from four single-centre studies of PIFU in RA patients only and their results have shown considerable variability.[3-6] There are no studies at all addressing other forms of inflammatory arthritis.

PIFU, with appropriate Shared Decision Making (SDM), may offer an opportunity to empower patients by signposting them to supported self-management resources supporting them to enable a sense of control over healthcare decisions. It may improve patients' experience of care and enable clinicians to focus their attention on those whose clinical need is greatest. This allows clinicians to see patients at greatest need within an increasingly pressurised health service.

However, there are concerns from patients and clinicians that PIFU should not compromise patients' short term or long-term outcomes, result in increased health inequity and that PIFU should be tailored to the individual patient need and the service concerned. Testimony from patients and clinicians who have trialled PIFU has shown that standardised, expert implementation with regular reinforcement is required to prevent clinical errors including patients with active disease not being seen in a timely fashion.

This handbook is a co-production between National Patient Organisations, clinicians with PIFU experience, and the British Society of Rheumatology. Its aim is to improve the experience and safety of PIFU through sharing key resources, hints and tips, and case studies highlighting different approaches to implementation.

Suggested edits or additions for future editions of this guidance should be sent to [bsr@rheumatology.org.uk](mailto:bsr@rheumatology.org.uk)

## NHS PIFU guidance

NHS England have developed guidance for PIFU in rheumatology, particularly focusing on inflammatory arthritis. This guidance document is available at <https://www.england.nhs.uk/wp-content/uploads/2022/05/B0943-implementing-patient-initiated-follow-up-services-in-adult-rheumatology-services.pdf>

Additional PIFU resources, including general guidance and a data insight pack, are available on the FutureNHS platform here:

<https://future.nhs.uk/OutpatientTransformation/view?objectID=15973424&done=OBJChangesSaved>

Both guidance references are correct as of July 2024 but will be updated when changes are released by NHS England.



## Hints and Tips for successful PIFU implementation

This list of hints and tips was compiled from patient and clinician input reflecting experience from multiple centres around the UK.

### Organisation and planning

- ✓ Health services are complex, and change takes time; balance speed and quality.
- ✓ Trust is essential, so consider who are the best messengers to discuss with patients.
- ✓ Consider the applicability and recognise limitations of best available evidence.
- ✓ Write a standard operating procedure: standardises and supports less experienced team members.
- ✓ Plan for technological solutions, and work with your existing resources where possible.
- ✓ Avoid creating siloed datasets – think about monitoring and quality assurance.
- ✓ Think about monitoring and quality assurance from the outset.
- ✓ Measure change and review iteratively; all targets can distort clinical priorities.
- ✓ Design the PIFU service to optimise patient experience, outcomes and disease management.
- ✓ Consider the whole rheumatology multi-disciplinary team (MDT) in the provision of PIFU care as different professions can help manage different needs.

### Patient identification

- Give patients the power to initiate PIFU and input into discussion about follow up.
- Where possible, utilise electronic remote monitoring with questionnaires to monitor patients between appointments.
- Lay the groundwork rather than springing it on patients – include in new patient education.
- Start with a patient population where PIFU is most likely to succeed to give the service a good first experience. Most current data relates to people with stable RA.
- Be intentional about planning PIFU for harder to reach groups who will require a more supported environment to enable safe implementation.
- Select patients by balancing disease activity, treatment stability and patient confidence through considering:
  - NHSE guidance (link above).
  - Defining PIFU eligibility criteria clearly, and thinking about patient factors beyond simply disease activity (literacy, language, etc).
  - Asking about emotional/mental wellbeing.
  - Consider two quick screening questions that may help initiate shared decision making discussion:
    - How confident are you with managing your own health?
    - How confident are you with accessing the teams providing your healthcare?

### Patient education

- Standardise education: patients, clinicians, others – this takes time.
- Ideally provide education for patients and involve someone else from their family/friends/support network.



- Consider signposting to national patient organisations such as National axSpA Society (NASS) and National RA Society (NRAS) and Psoriasis and PsA Alliance (PAPAA) who have a wealth of resources around PIFU and self-management, as well as any local resources.
- Consider giving people time to think about PIFU before they agree.
- Advise to contact rheumatology team for flares.
- Enable patients to contact for other issues that may have come up in routine appointments but may not be urgent, for example requiring referral or input from another member of the MDT (physiotherapist, orthotics, occupational therapist, nurse etc).
- Ensure patients and their support network understand the process to contact the rheumatology team.
- If patients are found not to do well on PIFU, consider why this is the case and whether the reasons can be safely mitigated, and if this is not possible then return to more frequent follow up.

## Follow up

- Consider timing of routinely booked safety net follow up interval. NHSE guidance recommends a 1-year review. Patient partners feel it could be  $\leq 2$  years. When planning this, consider what the safety net follow-up interval is seeking to achieve, and that the interval may be shorter to begin with as a service adjusts to a new way of working, and that this may subsequently be extended as the service matures and clinicians and patients get used to the new model.
- If routine follow up is longer than 1 year, consider monitoring disease using electronic questionnaires or an annual check in letter to ensure that patients know they are not forgotten (template available with this pack). As the service becomes more established and trusted, annual check in letters may not be required.
- Consider safety nets for patients within educational support and other materials from the team. In case of issues, who and how do they contact the team?
- A shared decision to be on PIFU should be reviewed periodically and should not be seen as temporarily or permanently irreversible if circumstances change.

## PIFU process

- Provide a single point of contact for patients for all queries – this allows triage for advice, telephone appointments or face-to-face appointments.
- PIFU breaks quickly: Patients requiring urgent face to face review should be seen within two week or 10 working days. Consider appropriate cover for this throughout the year to provide appropriate appointments.
- Consider service design and clinic templates. Patients attending PIFU appointments may need extra time as all are likely to need treatment input. Consider mitigation of this more concentrated staff workload.



## Key references

1. NHS England and NHS Improvement, *Implementing Patient Initiated Follow-Up (PIFU) in adult rheumatology services*. 2021: London.
2. Whear, R., et al., *Patient-initiated appointment systems for adults with chronic conditions in secondary care*. Cochrane Database Syst Rev, 2020. **4**: p. CD010763.
3. Hewlett, S., et al., *Patient-initiated hospital follow-up for rheumatoid arthritis*. Rheumatology (Oxford), 2000. **39**(9): p. 990-7.
4. Primdahl, J., et al., *Shared care or nursing consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis outpatients with low disease activity-- patient outcomes from a 2-year, randomised controlled trial*. Ann Rheum Dis, 2014. **73**(2): p. 357-64.
5. Fredriksson, C., et al., *Patient-initiated appointments compared with standard outpatient care for rheumatoid arthritis: a randomised controlled trial*. RMD Open, 2016. **2**(1): p. e000184.
6. Poggenborg, R.P., et al., *Patient-controlled outpatient follow-up on demand for patients with rheumatoid arthritis: a 2-year randomized controlled trial*. Clin Rheumatol, 2021. **40**(9): p. 3599-3604.

Additional patient resources are available at <https://www.rheumatology.org.uk/>



## Case studies of successful PIFU implementation

**Hospital name:** University Hospitals Plymouth

**When did you first launch PIFU?** 2012

**Which patients are considered eligible for PIFU? And how are they identified?**

PIFU, locally called Direct Access, is considered in all adults with an inflammatory arthritis for more than 2 years, where disease is in remission or stable, and the patient or a close advocate can initiate “when required” contact.

Diagnoses considered include rheumatoid arthritis, psoriatic arthritis, axial spondyloarthritis, seronegative and other inflammatory arthritis. Patients are identified through embedded departmental process.

**How are patients approached?**

PIFU is embedded in departmental processes, and at two years all clinical team members consider if PIFU, and transfer when it is appropriate. If PIFU is thought inappropriate at that time, the decision is reconsidered periodically by which time a patient’s circumstances may have changed.

**What education or advice is provided to patients?**

Conversation, standardised video, and patient/clinician shared decision making. Patients / carers are either shown a short video on University Hospitals Plymouth (UHP) website, or have a similar in person conversation, and their specific questions are then answered by Clinical Nurse Specialist or Rheumatologist. If patient moves to PIFU, then a brief written outline of service, most likely reasons for contacting the service, and Advice Line contact details are given.

**What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?**

Standard operating procedure (SOP) is available on UHP website. All new clinical and non-clinical staff read this SOP, and the decision tree is displayed in relevant areas.

**Has there been an impact from PIFU on staff?**

Overall impact on staff of the PIFU implementation and a decade of embedded service delivery has been very positive. However there have been many opportunities where we have learned from unintended negative consequences.

When PIFU is working well, the right people are put together in the right place at the right time to discuss relevant issues. This interaction enables staff to feel that they have made a difference. It has taken time to embed expectations in institutional and patient culture, and organisational processes.

When PIFU processes break down, everyone loses. One consequence can be that staff can feel burdened with a personal responsibility for an inability to deliver their ideal service, and then overbook clinics in an unsustainable manner. In parallel patients are sometimes left without the hoped for services with associated physical and psychological harms, and loss of trust in a service which may be hard to regain.

Our mitigation strategies of negative consequences include:

- Incremental implementation and evaluation over several years.
- Measurement and iterative review of small cycles of change.

- Systematically prioritising PIFU service business continuity to maintain staff and patient trust and wellbeing.

**Maximum follow up time:**

1 year (on b or tsDMARD), 2 years (on csDMARD), 3 years (no DMARD)

**How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?**

The balance between delivering urgent care, periodic review of slow-moving metrics, and safety netting review is tricky, and not one that is fully resolved locally. The UHP 2012 PIFU implementation was designed to solve the then problem of an overstretched and under resourced service which was unequivocally failing patients' urgent care needs.

We are still developing the right balance between responding to immediate needs and periodic review and continue to work closely with Primary Care and community services to systematically review relevant slow-moving metrics.

For those patients who do not contact within the predetermined safety net period, many of the slow-moving metrics are considered at the safety net review. Anecdotally those patients who fall into this group are often not those patients for whom the periodic review is most useful in identifying problems.

Much of Plymouth Primary Care services systematically review cardiovascular health, and the focus is on those communities who are most vulnerable. The Rheumatology Department opportunistically reviews bone health by ensuring a consultant overview every four years, and we are developing systematic processes to enable review of this and other slow-moving metrics as NICE.

**Remote monitoring:**

None

**Any other details on PIFU approach**

Further information available at:

- University Hospitals Plymouth – search “Direct Access Plymouth Rheumatology”, or <https://www.plymouthhospitals.nhs.uk/direct-access-service-health-professionals>

## Case studies of successful PIFU implementation

**Hospital name:** Royal National Hospital for Rheumatic Diseases, Bath

**When did you first launch PIFU?** October 2022

**Which patients are considered eligible for PIFU?**

Patients who are stable. Conditions include RA, PsA, axSpA, mild CTD, PMR on DMARDs. Selected during clinic appointments.

**How are patients approached?**

Patients watch video in the waiting room. During clinic appointment, PIFU is discussed as an option with appropriate patients.

**What education or advice is provided to patients?**

Conversation advice. We also have a website link for more information. We provide a printout for those who want it. We are now pointing patients towards the NRAS video.

**What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?**

Regular updates and figures at rheumatology team meetings. Website link also available for our GP colleagues.

**Has there been an impact from PIFU on staff?**

Some clinics are definitely more 'intense' – clinics predominantly attended by patients in flare/ sicker. No mitigations yet in place.

**Maximum follow up time:**

2 years

**How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?**

Advice line. Digital 'Rheumatology Advice Line Form (RALF)' which houses frequently asked questions. About to roll out digital platform to prompt PROMs completion between clinic appointments.

**Remote monitoring:**

Included for all patients (about to be rolled out) with ePROMs completion every 6 months.

**Any other details on PIFU approach?**

Website developed to aid self-management – links to external sites with self-management resources.

**Do you have one piece of advice from your experience that you would like to share?**

Before starting, write SOP, create clinician and patient resources. Have a good way of monitoring which of your patients are on PIFU.



## Case studies of successful PIFU implementation

**Hospital name:** Lancashire and South Cumbria Foundation Trust

**When did you first launch PIFU?** February 2022

### Which patients are considered eligible for PIFU?

Patients are identified in clinic to enable a shared decision-making conversation and provision of written PIFU information.

Eligibility criteria include inflammatory arthritis, diagnosis >2 years, stable disease. Patients must have a good understanding of their condition and self-management and the ability to initiate contact as required.

Exclusion criteria are as per NHS England guidance.

### How are patients approached?

In clinic – by any health care professional within the rheumatology team

### What education or advice is provided to patients?

The concept of PIFU is introduced via a shared decision-making conversation and service specific PIFU leaflet provided if the patient is happy to opt in or considering this in the future.

### What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?

The PIFU pathway was co-produced as a whole team, including patients, pre-rollout in 2022. A supporting PIFU procedure and patient information leaflet was produced and approved following review from the clinical team and patient representatives. Flare care appointment provision was increased, and availability monitored on an ongoing basis to ensure patients initiating contact can be seen in a timely fashion. Flare care provision is discussed at monthly team leads meetings.

An audit of PIFU against the procedure was completed in April 2024 and the key themes were explored and discussed in sequence in a focus group including the MDT and patients aided by a power point presentation of audit findings. Discussion deepened understanding of audit findings and led to the co-production of tangible actions to further improve the PIFU pathway and patient experience.

As PIFU has been co-produced the whole team has been on board with PIFU from commencement and recruitment to PIFU has been high.

### Has there been an impact from PIFU on staff?

**Negative:** Some of our less experienced nurses have been less confident to initiate PIFU however they have been able to discuss PIFU with patients and PIFU has often then been initiated at their next consultant appointment.

If a patient DNAs/cancels their planned follow up and they are on biologic therapy it can cause difficulties completing BlueTec and continuing their treatment. It is important not to recruit patients who have a history of non-attendance to PIFU.

We have only been utilising PIFU for 2 years – time will tell if patients have followed the PIFU pathway as planned over the next 2-3 years.

**Positive:** PIFU has released appointment time in both consultant, specialist nurse and physiotherapy led Axial Spondyloarthritis clinics and been accepted well by patients.

Flare care provision has met demand without additional pressure on the nurse advice line enabling patients to be seen when needed rather than routinely when they are well.

The PIFU model was accepted equally across our eligible patient demographic with equal numbers of male and female patients with an age range and condition ratio proportionate to our rheumatology caseload.

**Consideration:** Clinicians had focussed on PROMs and agreed disease activity thresholds for contacting to make an appointment. However, in practice pre-agreed thresholds were rarely set. During a focus group session patients voiced that they were not keen on pre-agreed PROM thresholds stating that it is important that they can speak to the team if they feel they are flaring. The support provided by our specialist nurses via the advice line is highly valued by our patients and helps them to understand their disease and cumulatively increases their expertise in recognising flare and managing their condition.

Two thirds of patients in the focus group felt that they were more confident and reassured by their consultant making the decision to commence a PIFU pathway.

**Maximum follow up time:**

Condition dependent, majority 12-months

**How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?**

Follow-up is put in place at maximum appropriate time – e.g 12 months for a patient on biologics so that they are not lost to FU.

Flare care provision is monitored monthly to ensure patients making contact can be seen within 14 days. Most patients are seen within 7 days.

**Remote monitoring:**

Optional for some patients – emphasis on patients contacting as required.

**Any other details on PIFU approach**

- The clinic letter will advise the patient's GP that the patient is on a PIFU pathway and the GP is made aware that the patient can trigger a follow-up when necessary. This is designed to minimise unintended consequences of PIFU on the GP.
- PIFU is evaluated via EMIS coding however there is no specific clinical code for PIFU which limits our ability to study patients who have withdrawn from or declined PIFU.

**Do you have one piece of advice from your experience that you would like to share?**

- Recruitment rates to PIFU have been high. This is likely due to the co-design of the pathway in service with the MDT and patients. Thought has been given to minimising unintended consequences.

## Case studies of successful PIFU implementation

**Hospital name:** University Hospital Monklands – NHS Lanarkshire

**When did you first launch PIFU?** 2022

**Which patients are considered eligible for PIFU?**

Patients with inflammatory arthritis, on conventional DMARDs with stable low disease activity or clinical remission

**How are patients approached?**

During planned clinic appointments

**What education or advice is provided to patients?**

During conversation with rheumatologist and provided with information leaflet

**What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?**

Primary care have been informed through discussion with Local Negotiating Committee and brief description in clinic letter. Clinical and non-clinical departmental staff have been provided with education through frequent updates during MDT and departmental meetings

**Has there been an impact from PIFU on staff?**

Implementation of PIFU has required the implementation of a new system of booking clinic appointments for all return patients (patient return lists). This has led to some loss of clarity about return arrangements for patients who are included in PIFU. Review of return outcomes and discussions within the rheumatology department has helped to reassure staff that return patients are still being provided with follow-up appointments appropriately

**Maximum follow up time:**

2 years

**How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?**

1. For many patients we have implemented a form of Patient Extended Follow-up whereby stable patients are provided with much longer intervals between follow-up appointments to allow ongoing review of other important issues
2. Increased use of nurse-led follow-up appointments for stable patients
3. The role and function of the existing rheumatology helpline was revised and protected
4. Urgent slots have been added to most outpatient clinics to facilitate rapid review of patients who experience flare after starting PIFU / extended follow-up

**Remote monitoring:**

None

**Any other details on PIFU approach**

Development of our PIFU pathway was informed through analysis of existing return clinic activity, patterns of return appointment and estimation of existing clinic capacity and likely demands. There was useful additional input from a focus group of patient representatives, colleagues from the health board management team, Department of Public Health and Healthcare analysts

**Do you have one piece of advice from your experience that you would like to share?**

Before implementing any changes to existing services, take time to analyse and understand your current return practices and your ongoing outpatient demand and capacity. Successful change will require buy in and support from Hospital management and administrative teams

## Case studies of successful PIFU implementation

**Hospital name:** Belfast Health and Social Care Trust

### When did you first launch PIFU?

At the moment we are in the process of developing a PIFU process starting with Axial SpA. We have not yet launched the pilot as we are awaiting a new patient software system being launched in the Trust (EPIC). This will be launched in June 2024. After the pilot, we plan to roll out to patients with PsA and RA.

### Which patients are considered eligible for PIFU? And how are they identified?

Starting with Axial SpA but potentially all patients who are computer literate to allow regular completion of PROMs.

### How are patients approached?

Patients to be approached at clinic and via letter from trust asking them to volunteer

### What education or advice is provided to patients?

Both written information and conversation

### What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?

Plan to roll out education to clinical and non-clinical staff prior to start of Pilot

### Has there been an impact from PIFU on staff?

We have a long waiting list of review patients locally. Patients and staff are keen to at least have PROMs as a way to monitor disease activity. Staff are enthusiastic to implement change to improve patient contact points from a low point post COVID. Given we have yet to get started we are not aware of impact on patients but from discussion with patients they seem enthusiastic to provide information on their conditions via a secure patient portal. The patients are keen to be able to express whether they need to be reviewed face to face or via telephone.

### Maximum follow up time:

3 years

### How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?

All patients with specific conditions will complete disease specific and general PROMS. Patients will be able to indicate whether they would like to maintain digital contact via PROMs or which to have telephone review or face to face review. Patient PROMs will be reviewed in specific clinics with the ability to review PIFU patients by telephone or in clinic.

### Remote monitoring:

Included for all patients

### Summary of remote monitoring approach

PROMs sent out to patients in advance of clinic. Plans to see if patients can complete PROMs through patient portal on electronic health record.

### Do you have one piece of advice from your experience that you would like to share?

We have not yet started but are in the planning stages. We have been waiting on the roll out of a new patient software system (EPIC/ENCOMPASS). This will be launched in June 24. We need IT support to set up PROMs on EPIC and the patient portal.

## Case studies of successful PIFU implementation

### Hospital name:

Behçet's Centre of Excellence Aintree Hospital, Liverpool University Hospitals NHS Trust

### When did you first launch PIFU?

December 2021

### Which patients are considered eligible for PIFU? And how are they identified?

To be considered for the PIFU pathway, patients must have a confirmed diagnosis of Behçet's syndrome, and their disease must be stable and well-controlled. The patient must also have a good understanding of their condition and the principles of self-care management and be able to recognize deterioration of their symptoms. Patients are not selected for PIFU where there are safeguarding, consent or capacity concerns that may hinder their ability to contact the clinical team when needed. Patients' potential suitability for PIFU are identified at a face-to-face review however, recently as clinician trust in the PIFU process has strengthened PIFU is being discussed at telephone reviews also.

### How are patients approached?

This is a discussion where the clinician explains the PIFU pathway emphasizing that this model will not compromise care nor lead to inequalities in clinical management.

### What education or advice is provided to patients?

Patients are verbally advised of the PIFU pathway in detail. A dedicated 'patient information leaflet' explaining the PIFU principle, process and contact details for both telephone or text is provided. This is supported by a subsequent onboarding 'text' message that is sent to all patients who are put to PIFU. This message incorporates links for initiating contact with the service at any time in the future.

### What education or advice is provided to clinical and non-clinical staff, in your organisation or other surrounding organisations?

Prior to launching PIFU in the Behçet's service a detailed 'service readiness pack' was developed and issued to all users. This pack detailed the systems and service overview and the process flow utilised in PIFU. A detailed Standing Operating Procedure was also included to give clarity to all users. Face to face education was also arranged for all users supported by training on the 'text' messaging platform utilised in the Trust.

### Has there been an impact from PIFU on staff?

PIFU has released valuable clinic capacity which has been utilised to facilitate urgent reviews and for biologic annual review not previously achieved in a timely manner. Scrutiny of clinic use to ensure no fallow PIFU ringfenced slots has been time consuming. The rheumatology department that hosts the Behçet's specialist service has invested in a 'clinic utilisation' clerk to maximise outpatient activity.

The PIFU process is heavily reliant on the nurse consultant, particularly in managing the patient's initial contact with the service. This workload is recorded and reviewed annually. To date it is manageable however support from Rheumatology colleagues in times of leave for example has been formally arranged.

Concerns that reducing the number of follow-up appointments of patients with well-managed disease will mean that most reviews in the clinic are with complex needs and/or acute cases. So far, this has not happened. However, this situation could develop in the future and would need to be addressed, for example, through the implementation of longer clinic slots.

**Maximum follow up time:**

Open ended – The Behçets PIFU pathway is not time limited but patients are typically also under review at a local centre with booked follow up times.

**How do you balance care between routine review and safety netting to ensure periodic review and other routine issues are covered?**

A Behçet's National centre is unique in the case that most patients also have a local Rheumatologist responsible for delivering treatment etc. This added layer of clinical review adds a safety net together with the Behçet's advice line if text contact has been lost. We are currently considering resending the 'text' PIFU onboarding message at regular intervals – possibly every 2 years.

**Remote monitoring:**

Patients who are not under a local rheumatology team have more frequent remote follow up included as clinically appropriate

**Summary of remote monitoring approach:**

This is supported by accessing GP consultation documentation and blood results via e-Xchange. The service also has a dedicated email for professional and patient use. Patients will also forward clinical letters / test results for our information using this email.

**Any other details on PIFU approach –**

Including clerical, secretarial and appointment booking staff prior to launching PIFU is recommended.

**Do you have one piece of advice from your experience that you would like to share?**

Having a dedicated nurse led advice line prior to introducing PIFU is invaluable.

## Rheumatology template letter

This letter is to inform you that you remain under the care of the Rheumatology team at [Insert hospital]. Our records show that you are currently on a Patient Initiated Follow-Up (PIFU)\* pathway.

*\*PIFU is when patients decide when they need to have follow up appointments, based on how they are feeling and what sort of support they need. Rheumatology teams still want to review patients on PIFU to discuss their inflammatory arthritis [or insert specific condition] and check their symptoms.*

You will be offered a Rheumatology Outpatient appointment for your review as follows:

Insert local information [Within X months you will be offered an appointment. If you do not hear back from us within this time, please call us at XXX].

**At your next review you can discuss any queries you may have. This could include:**

- changes in your symptoms (including pain, mobility, inflammation, fatigue, mental wellbeing)
- queries about your medication
- queries about other health conditions related to inflammatory arthritis
- access to information or support from members of the Rheumatology team [add in local information depending on team resources/members such as physiotherapists or occupational therapists]
- whether you want to continue on PIFU
- advice / support or signposting to things that can help you manage your condition yourself (known as supported self-management)

If you need help from the Rheumatology team before or after your next review, please contact us at XXX (personalised by site).

If you have moved out of the area or are no longer on PIFU, please let us know so that we can update our records. You can contact us at XXX (personalised by site) to let us know.

Further links to patient organisations and additional support below:

- **National Rheumatoid Arthritis Society**  
National Free phone helpline: 0800 298 7650  
Website: [www.nras.org.uk](http://www.nras.org.uk)  
NRAS PIFU web page: <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: <http://www.nras.org.uk/smile>
- **National Axial Spondyloarthritis Society (NASS)**  
For patients with axial Spondyloarthritis (axial SpA) including ankylosing spondylitis  
Helpline: 0208 741 1515  
Website: <http://www.nass.co.uk/>  
YourSpAce supported self-management: [Your SpAce | National Axial Spondyloarthritis Society \(nass.co.uk\)](#)
- **The Psoriasis and Psoriatic Arthritis Alliance (PAPAA)**  
Email: [info@papaa.org](mailto:info@papaa.org)  
Telephone: 01923 672837  
(Enquiry line open 9:30am - 4:30pm weekdays - Recorded message operates at busy times and out of hours)  
Operating hours: Monday-Friday 9.00am-5.00pm