

Classification: Official

Publication approval reference: B0943



Implementing patient-initiated follow-up (PIFU) in adult rheumatology services

29 June 2022 Version 1

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1. Introduction

Patient initiated follow-up (PIFU) is key to achieving the aims of [personalising outpatients](#) and reducing follow-up appointments that might not be needed by enabling patients to have more control of their care.

This guidance is to enable the safe, effective and standardised implementation and delivery of PIFU within adult rheumatology services. It supplements the [Implementing patient initiated follow-up guidance for local health and care systems](#). It has been developed following evaluation of the available evidence and in consultation with clinicians experienced in the use of PIFU within rheumatology and with relevant professional and patient bodies.

2. Why use PIFU in an adult rheumatology service?

Rheumatology services have traditionally reviewed a large proportion of their patients on a routine basis, offering regular ‘check-in’ appointments, over many years. The management of inflammatory arthritis dominates a rheumatology team’s workload. Inflammatory arthritis can have an unpredictable pattern, with fluctuating symptoms. Treatment is not curative; however, once stable on medication, many will have long periods when their condition is well controlled or in remission. During that time, individuals express a wish to get on with their lives rather than fit in with regular checks that they see as unnecessary ([Child et al 2015](#)).

In addition to placing a burden on patients, traditional models of follow-up increase demand and pressure on rheumatology services.

In contrast, PIFU personalises service delivery to the patient’s needs and eradicates the requirement for people to attend routine outpatient appointments when there would be little clinical value for them in them doing so. It reduces inconvenience, stress and expense to patients and it decreases the carbon footprint of the NHS. PIFU enables existing patients who are experiencing problems to be reviewed by the specialist in a timely way and it frees up capacity for clinicians to see new patients more quickly. In this way PIFU improves both patient outcomes and their experience of care.

Notably, many rheumatology departments were experiencing significant capacity pressures before 2020.

In response to these difficulties and to improve patient experience, many rheumatology teams had already opted to put stable patients on annual review, with the individual having the option of contacting the service (usually via a telephone advice line) between appointments should the need arise. This informal approach to PIFU has existed within many rheumatology departments for some time. However, in practice, if the patient did need to be seen urgently, before their scheduled appointment, it would often be challenging for the clinical team to do so in a timely way, without overbooking clinics.

The [Rheumatology Getting It Right First Time \(GIRFT\) programme national specialty report](#) supports the role of PIFU in addressing capacity pressures within rheumatology, stating: “follow-up appointments which are booked by the patient rather than the hospital are... a way to reduce unnecessary outpatient attendances. They can also make services more responsive to patients by seeing them when they need care”.

Pre-existing capacity pressures within rheumatology have intensified as a result of the COVID-19 pandemic. Meanwhile, delays in accessing services can result in patient harm, including pain and suffering in the short term and worse disease outcomes in the long term. These delays also increase pressure on primary care, as patients will often turn to their GP for help and advice in the meantime.

PIFU is seen as an important tool to support the COVID-19 recovery, as outlined in the [2022/23 priorities and operational planning guidance](#), and for the long-term sustainability of outpatient services, given increasing demand year-on-year.

In contrast to the informal models adopted previously, by taking a more formalised approach to PIFU, incorporating the three quality pillars detailed below, it is possible to achieve the benefits outlined above.

The three quality pillars that should underpin PIFU:

1. Clinicians should engage in [shared decision making](#) (SDM) conversations with patients about PIFU - see [Section 6](#) for further information. All patients and/or carers should have PIFU explained to them and the opportunity to ask questions and raise concerns. If they do not understand how or when to trigger an appointment, PIFU should not be used.
2. A standard operating procedure (SOP) that includes patient [safety nets](#) should be in place - see [Section 5](#) for further details
3. All patients moved to a PIFU pathway should be logged and tracked on the organisation's IT system, with the service able to report on key metrics, including the number of patients who are on a PIFU pathway.

3. The evidence for PIFU in adult rheumatology services

A [2013 systematic review](#) of studies evaluating the efficacy of PIFU in secondary care, which included one randomised controlled trial (RCT) involving patients with rheumatoid arthritis (RA), found no detrimental clinical effects of implementing PIFU. The review also found a trend within the PIFU group towards increased patient satisfaction and quality of life, reduced healthcare resource use and lower overall costs to the NHS.

A [2020 Cochrane review](#) of RCTs that compared PIFU with clinician-led appointment systems for people with chronic or recurrent conditions (which included four studies in a rheumatoid arthritis population) found that PIFU had no adverse outcomes in terms of patient experience, satisfaction, anxiety, depression, quality of life or adverse events.

Additionally, in relation to appointment utilisation, in an RCT which included 209 patients with RA followed up over six years in the UK, [Hewlett et al \(2005\)](#) reported that those in the PIFU arm had 38% fewer hospital reviews over the time period with only 34% receiving more than 10 hospital reviews over six years (compared to 85% of control patients). Furthermore, the number of visits to GPs for consultations about their arthritis was not significantly different between the groups. Of note, there

was no difference in terms of radiographic changes or Sharp scores at the end of six years.

Similarly, in an RCT involving 289 patients with RA followed up over two years in Denmark, [Poggenborg et al \(2021\)](#) found that, in the first year, the PIFU group had 16% fewer visits than the control group, with 31% fewer visits over two years. However, patients in the intervention group made more telephone calls to the team than the control group in both the first year and over the two years.

4. Which rheumatology patients are most likely to be suitable for, and to benefit from, PIFU?

Generic guidance and non-condition specific criteria for selection of patients for PIFU are given in the [Implementing patient initiated follow-up guidance for local health and care systems](#).

Rheumatology patients who are most likely to be suitable and benefit are those with:

- inflammatory arthritis (for example, RA, axial spondyloarthritis, psoriatic arthritis **and**
- disease duration of ≥ 2 years, where optimal disease control has been established or they are in remission, either on or off treatment **and**
- a good understanding of their condition, who are confident in their ability to manage it and have the skills to do so (see [Section 6](#) for further details of how you might assess this), including the ability to recognise a sudden or gradual loss of function suggesting a flare-up or reduction in efficacy of their treatment **and**
- the ability to initiate contact with the service in a timely way (be that the patient themselves or a carer/representative on their behalf).

Patients less likely to benefit include:

- Those with recent onset, or recently diagnosed inflammatory arthritis (e.g. diagnosis of < 2 years' duration), where optimal disease control has not been established and/or the individual is still learning about their condition.

- Those with rare, multi-system rheumatological disorders who may not have any clinical signs of a deterioration in their condition until damage to internal organs has occurred.
- Any individuals for whom the healthcare professional has safeguarding, consent, capacity or health literacy concerns.
- Any individuals with low levels of knowledge, skill or confidence in their ability to self-manage their condition.
- Any individuals who would not be able to contact the service in a timely way.

Many of these patients will typically be on a blended pathway, combining pre-arranged follow-up with the option of contacting the service in between scheduled appointments should they have a clinical need to do so. Therefore, while they may not be on a dedicated PIFU pathway, PIFU also benefits them by creating capacity so they can be seen between scheduled appointments, if required.

5. Designing a PIFU model for your rheumatology service

PIFU should not be used as a waiting list management tool, an alternative to discharge, or to enable patients to re-access services after the treatment episode would otherwise be considered complete. PIFU is, first and foremost, about personalising care to patients, and improving patient outcomes and experience.

It is important that PIFU is tailored to the needs of each specialty and to suit the service's casemix. The rheumatology clinical team should have overall responsibility for the development of clinical guidance, risk stratification protocols and a standard operating procedure (SOP) for the implementation and delivery of PIFU within their service.

The SOP defines the inclusion and exclusion criteria for PIFU within the service. It articulates relevant standards (such as the timeframe patients can expect to be seen within should they need to initiate an appointment) and the process, roles and responsibilities for:

- identifying which rheumatology patients PIFU might be suitable for

- providing patients with information about PIFU
- having a shared decision-making conversation with patients about PIFU
- determining the timescale of the PIFU pathway for the individual patient
- moving a patient onto a PIFU pathway
- recording and monitoring which patients are on a PIFU pathway
- patients contacting the service
- booking appointments initiated by patients on a PIFU pathway
- managing patients who do not initiate an appointment within the timescale of the PIFU pathway (including booking a safety net review at the end of the PIFU pathway)
- collecting data and monitoring and reporting compliance with standards.

Below are some considerations in relation to design elements of the PIFU model specific to rheumatology.

Triage

Regardless of how patients on a PIFU pathway contact the service for advice, support, help, or to receive an appointment (by telephone, email, or via a platform such as eConsult or similar), some form of clinical triage will be needed in the first instance. This is usually provided by experienced specialist nurses within the service. Most, if not all, rheumatology services already operate a nurse-led telephone advice line for their patients. Many services will opt to route the PIFU calls through to this. However, this will have implications for specialist nurse capacity to run clinics or engage in other activities. Triage must therefore be appropriately job planned to ensure appropriate response times can be maintained as this is critical to the overall success, and sustainability, of PIFU.

Target response times

If patients on a PIFU pathway are contacting the service via a telephone advice line, services will have to decide whether to ringfence time for the team to take 'live' calls or whether the patient will be required to leave a message to then be called back by a member of the team. There are advantages and disadvantages to both systems and many services will take a combined approach. Having some dedicated time slots for live calls can allow better management of calls and result in less administration, e.g. transcribing messages and following up with another call.

Whichever option, or combination of options is selected, it is important to be aware that [NICE Quality Standard 33](#) for the assessment and management of RA states: "Adults with rheumatoid arthritis and disease flares or possible treatment-related side effects (should) receive advice within 1 working day of contacting rheumatology services".

The evidence suggests that most patients contacting the service will not require a face-to-face appointment, as many problems will be amenable to resolving over the telephone. However, where a face-to-face appointment is necessary, those experienced in the use of PIFU in rheumatology suggest this should be undertaken within two weeks of the patient contacting the service (or within four weeks if non-urgent). This should be factored in when considering what capacity will need to be ringfenced for PIFU appointments as keeping to these timeframes is imperative to build patients' trust in this model of delivery. Again, evidence has shown that, where trust is built and maintained, patients will utilise the service less over time because they will be confident that any problem will be dealt with quickly and efficiently. It is therefore imperative to collect data, so that demand and capacity can be reviewed on a regular basis.

PIFU timescales, and action at the end of the timescale

When a patient is moved onto a PIFU pathway, this will be valid for a predefined timescale. In rheumatology, when managing conditions such as inflammatory arthritis, this timescale will relate to the length of time after which the patient will need a review. This review also acts as a 'safety net' appointment in the instance of the patient not contacting the service and potentially, otherwise, becoming 'lost' to follow-up.

It is important that the timescales attached to PIFU pathways are clinically relevant and personalised to the individual patient. For departments implementing PIFU in

their RA population it should be noted that [NICE Quality Standard 33](#) states: “adults with rheumatoid arthritis (should) have a comprehensive annual review that is coordinated by rheumatology services”. Many rheumatology services will therefore opt to have the default duration of a PIFU pathway set at 12 months, although some have, over time, increased this, for appropriate patients, to two years. Some services are opting to alternate these annual or biennial reviews between the specialist nurse and consultant workforce unless there are clinical reasons why the patient would benefit from seeing one over the other.

When considering PIFU pathway timescales in rheumatology it is worth noting that a proportion of inflammatory arthritis patients who would be appropriate for PIFU are likely to be on biologic disease modifying anti-rheumatic drugs (bDMARDs) or Janus kinase (JAK) inhibitors. The initiation and ongoing prescribing of these therapies must be undertaken by the specialist team. The clinical criteria that must be met for clinicians to initiate, and continue, these treatments are governed by NICE technology appraisal guidance. As they are high-cost therapies, excluded from the outpatient payment by results (PbR) tariff, commissioning bodies typically require notification when a patient begins a bDMARD or JAK inhibitor. They may also require regular updates that the patient meets the clinical criteria for the treatment to be continued. Therefore, when planning the implementation of PIFU within rheumatology it is helpful to identify, at the outset, what the service’s reporting requirements to commissioners are in relation to bDMARDs and JAK inhibitors as, in their current form, they may negatively impact on the possible duration of PIFU pathways for this patient group and, as a consequence, the benefits of PIFU to both patients and the service.

6. Implementing PIFU in rheumatology

Trusts have a legal responsibility to complete their own Equality and Health Inequalities Impact Assessment (EHIA) for the PIFU services they offer. This will help to better understand the potential positive and negative impacts of PIFU for patients and to identify effective interventions to address potential inequalities that could emerge. See the [health inequalities](#) section below for more information on health inequalities of particular relevance in a rheumatology population.

When planning the implementation of PIFU, it would be recommended to undertake Plan, Do, Study, Act (PDSA) small cycles of change, and it is suggested that PIFU

is rolled out for a few select pathways within the service in the first instance. In determining those pathways, teams should consider the cohorts of rheumatology patients for whom PIFU has been shown, within randomised controlled trials, to be both safe and effective (see [Section 3](#) and [Section 4](#), above).

Based on the experience of those who have implemented PIFU within the specialty, as a rule of thumb, teams may wish to ringfence 5x20 minute appointments per week per/100 patients going onto a PIFU pathway in the first instance. If not required, these urgent slots can be used for non-PIFU patients on the 'to be scheduled list', so the appointments are always utilised. Of note, the evidence suggests that, providing patient confidence in PIFU is maintained, the number of appointments that will need to be ringfenced per/100 patients on a PIFU pathway reduces over time. It is therefore important to capture and regularly review the data as this will inform service planning and organisation moving forwards.

Technology

As a specialty, rheumatology has a number of well-established, well-validated and widely used patient reported outcome measures (PROMs) at its disposal. For clinicians, capturing data regularly and observing trends can help inform the management of a patient's condition. From the patient's perspective, it can help to promote shared decision-making and empower them to engage in the long-term management of their condition.

Rheumatology services traditionally collect this data from patients at the time of their appointment (often via paper-based forms). However, by using an electronic (ePROMs) platform or app with the ability to push PROMs to patients at regular intervals or by patients using an app that enables them to share their data with their clinical team, the resulting information can be used to observe trends, help determine whether an appointment is required in the instance of the patient contacting the team and, if so, what type of appointment (virtual or face-to-face) might be appropriate. This type of technology can be an enabler therefore, to the safe and effective implementation of PIFU within the service. An example of such a platform would be the [British Society for Rheumatology's ePROMS platform](#), which currently includes the MSK-HQ, BASDAI, HAQ, DAS28, PHQ2/GAD2 and JIA questionnaires.

Personalised care

Deciding who might benefit from being on a PIFU pathway begins with a conversation with the patient, with a focus on quality [shared decision-making](#). Through this collaborative conversation the clinician can understand a person's preferences and needs, gauge their knowledge, skills and confidence in terms of self-managing and also provide tailored support and signposting.

Clinicians may wish to consider using the [Patient Activation Measure®](#), the [musculoskeletal health questionnaire \(MSK-HQ\)](#) (particularly questions 12 and 13), the Arthritis Self Efficacy Scale (ASES) or the Rheumatoid Arthritis Self Efficacy scale (RASE) to provide a proxy indicator of the individual's knowledge, skills and confidence beforehand as this may help them tailor this conversation accordingly. It is also good practice to have considered the patient's current emotional wellbeing, perhaps implementing the Hospital Anxiety and Depression Scale (HADS) or the Patient Health Questionnaire (PHQ-2 or PHQ-9) and Generalised Anxiety Disorder assessment (GAD-2 or GAD-7), as poor mental health may impact on the individual's ability to self-manage their condition.

Clinicians should consider which supported self-management resources they can signpost patients to. A number of health charities operate telephone advice lines for patients, community support groups and/or telephone peer support. They may also offer downloadable or printed patient information literature, as well as online learning resources. For example, the National Rheumatoid Arthritis Society (NRAS) has an e-learning self-management programme for patients, called [SMILE-RA](#). This includes a module on managing pain and flare-ups which may be useful for those going onto a PIFU pathway. Similarly, within their [My AS, My Life](#) programme, the National Axial Spondylitis Society (NASS) has regular webinars that can be watched live, or on-demand, to support patients to self-manage their condition. The Royal Osteoporosis Society also has a suite of four [online educational videos](#) for those newly diagnosed with osteoporosis.

Following an information giving and shared decision-making discussion around PIFU between the clinician and the patient, it would be encouraged that patients are provided with an outcome letter detailing the verbal discussion in clear language, the options (along with any associated risks, benefits and consequences) and the patient's decision. This letter should include a summary of how PIFU works and

what patients can expect. Ideally this outcome letter would be available to the patient within a digital, personally held, record.

Clinicians may also wish to consider providing their patients with a ‘PIFU passport’ which, in addition to containing specific information about how PIFU works within the specialty, what patients can expect from the service and how to get in touch, can be personalised to the individual to include relevant information about signs or symptoms for them to look out for and specifics around their medication and its monitoring.

Specialty specific risks when implementing PIFU in rheumatology

Please see the [Implementing PIFU guidance](#) for a discussion of more general risks that should be considered in the planning and implementation of PIFU.

Risk	Proposed mitigations
<ul style="list-style-type: none"> • PIFU models used in some clinical specialties will require the patient to be discharged at the end of the pathway. This model of PIFU is less appropriate for rheumatology and it must be ensured that patients with inflammatory arthritis are not lost to follow-up or discharged ‘by accident’ when the pathway comes to an end as this may result in: <ul style="list-style-type: none"> ➤ for the patient, poor clinical outcomes and/or ➤ for the clinician, non-compliance with the GMC good practice in prescribing and managing medicines and devices guidance in terms of prescribing in the absence of adequate clinical supervision. 	<ul style="list-style-type: none"> • Set the duration of PIFU pathways appropriately and build in a review appointment (may be face-to-face or virtual) at the end of the pathway if the patient has not needed to contact the service in between. • Adult rheumatology services typically operate ‘shared care’ with the patient’s GP. Ensure GPs are aware when their patient is on a PIFU pathway and that they can also trigger an appointment if necessary. • When designing how the PIFU process will work in practice, liaise closely with the patient access services team. • Ensure patients receive an outcome letter and PIFU passport (see Section 6). • Maintain an ‘incident register’ and review this regularly in the department’s governance meeting, to inform any revisions to the SOP.

- Given the nature of some rheumatological conditions, some patients may not recognise when seeking specialist help and advice would be beneficial.

For example, those with rare, multi-system rheumatological disorders may not be aware of a deterioration in their condition until damage to internal organs has occurred.

- Careful selection of patient pathways that may be suitable for PIFU, utilising the existing evidence base.
- Ensure patients have access to quality shared decision-making and that staff are adequately trained in this (for training opportunities please see the [Personalised Care Institute website](#)).
- Provide tailored patient education and information about their condition and relevant self-management strategies, ensuring that delivery (including the medium of delivery) is personalised to the patient and their needs.
- Signpost patients to available help and ongoing support/information provided by relevant organisations in the voluntary and charity sector.
- Utilise local social prescribing link workers, one of the new [primary care ARRS roles](#), to ensure people are able to access relevant community assets to support their wider health and wellbeing, including housing, finance and employment support.
- Consider measuring patient activation and/or self-efficacy (see [Section 6](#)) to inform who would do well on a PIFU pathway and who might need further support. For those with low levels of knowledge, skills and confidence consider signposting or referring to a health coach, one of the new [primary care ARRS roles](#), if available.
- Provide personalised guidance on when to contact the service, and how, in the outcome letter and the PIFU passport.
- Encourage patients to discuss the fact that they are on a PIFU pathway with those close to them as they may be better placed to spot any gradual deterioration in function or exacerbation of symptoms and alert the patient of this.
- A shared care model of delivery is common in rheumatology, particularly for patients with inflammatory arthritis. Within this model, GPs will often be prescribing medication and performing regular blood tests. Therefore, ensure GPs are aware when the patient is on a PIFU pathway and that they can trigger an appointment if necessary.
- Maintain an 'incident register' and review this regularly in the department's governance meeting, to inform any revisions to the SOP.

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| <ul style="list-style-type: none"> • The system may be overwhelmed with requests for non-urgent or non-rheumatological requests for review. | <ul style="list-style-type: none"> • Careful selection of patient pathways that may be suitable for PIFU, utilising the existing evidence base. • Provide tailored patient information and education about their condition, including relevant self-management strategies, ensuring that delivery (including the medium of delivery) is personalised to the patient and their needs. • Ensure the patient has guidance on when to contact the service in the outcome letter and PIFU passport. • Consider measuring patient activation and/or self-efficacy (see Section 6) to inform who would do well on a PIFU pathway and who might need further support. For those with low levels of knowledge, skills and confidence consider signposting or referring to a health coach, one of the new primary care ARRS roles, if available. |
| <ul style="list-style-type: none"> • Some patients may be reluctant to contact the service to seek help and advice, perhaps concerned about wasting the specialist's time or thinking nothing can be done, despite being aware that their condition is deteriorating. | <ul style="list-style-type: none"> • Provide tailored patient information and education about their condition, including relevant self-management strategies, ensuring that delivery (including the medium of delivery) is personalised to the patient and their needs. • Ensure the patient has guidance on when to contact the service, and how, in the outcome letter and PIFU passport. • Consider measuring patient activation and/or self-efficacy (see Section 6) to inform who would do well on a PIFU pathway and who might need further support. For those with low levels of knowledge, skills and confidence consider signposting or referring to a health coach, one of the new primary care ARRS roles, if available. • Encourage patients to discuss the fact that they are on a PIFU pathway with those close to them as they may be better placed to spot any gradual deterioration in function or exacerbation of symptoms and alert the patient of this. • A shared care model of delivery is common in adult rheumatology services, particularly for patients with inflammatory arthritis. Within this model, GPs will often be prescribing medication and performing regular blood tests. Therefore, ensure GPs are aware when the patient is on a PIFU pathway and that they can also trigger an appointment if necessary. • Maintain an 'incident register' and review this regularly in the department's governance meeting, to inform any revisions to the SOP. |

<ul style="list-style-type: none"> • Patients contacting the service cannot access specialist help and/or advice in a timely manner, resulting in them experiencing unnecessary pain and suffering and losing trust in the PIFU system. 	<ul style="list-style-type: none"> • When implementing PIFU, start small with a few select pathways (see Section 3 and Section 4). • When planning, consider PIFU as a 2 week wait pathway (see Section 5). • Adequate clinic capacity for urgent PIFU appointments must be ringfenced (see Section 6). • It is likely that specialist nurses will be instrumental in responding (at least in the first instance) to PIFU requests from patients or their representatives (see Section 5). This activity must be taken account of and job planned appropriately. • Maintain an ‘incident register’ and review this regularly in the department’s governance meeting, to inform any revisions to the SOP.
<ul style="list-style-type: none"> • Service does not have adequate admin or clinic management support to keep track of those patients who are on a PIFU pathway. 	<ul style="list-style-type: none"> • It is critical that the admin team and patient access services team are involved in creating the service specific SOP for PIFU. The SOP should specify how the process will work within that service and who will be responsible for which element. This ensures adequate admin/clinic management support can be allocated. • Evaluate patients’, clinicians’ and the admin teams’ experience of/satisfaction with PIFU regularly. • Ensure patients receive an outcome letter and PIFU passport (see Section 6). • Maintain an ‘incident register’ and review this regularly in the department’s governance meeting, to inform any revisions to the SOP.
<ul style="list-style-type: none"> • Staff burnout because everyone in the clinic has more complex problems that need resolving and the clinician has inadequate time to undertake this effectively. 	<ul style="list-style-type: none"> • Adjust the number of appointments on PIFU clinics and the appointment duration to enable clinicians to effectively deal with more complex problems.

Health inequalities

In terms of primary care consultation rates in the UK, evidence suggests that the consultation rate is 32% lower in men than women, with the most marked difference between the ages of 16 and 60 years. This difference is only partly accounted for when consultations for reproductive health are considered. Gender differences in consulting have also been demonstrated to be higher in people from more deprived areas than among those from more affluent areas ([Wang et al 2013](#)). These differences in consulting rates may have implications for PIFU and should be considered when thinking about who may do well on a PIFU pathway.

Studies have shown significant age and sex-dependent differences in the medical treatment, and outcome, of RA. In a large study (involving 2,837 patients in Sweden over eight years) younger men (less than 40 years of age) had the most favourable functional outcome over the study period. A significantly lower DAS28 over time was manifest, despite no obvious difference at diagnosis. This group (together with women under 40 years) was also more likely to be treated with bDMARDs. Women over 70 years of age experienced the smallest improvements in relation to disability and joint destruction over the study period, and were, together with men in the same age cohort, more likely to receive treatment with only glucocorticoids. The authors conclude that whether the differences in outcome were due to the phenotype of the disease or its treatment is not clear. However, they suggest that older age at onset may be a risk factor for a worse disease outcome ([Nilsson et al 2021](#)).

Studies have also shown that those with RA who live in more deprived areas have more severe disease, more co-morbidities and higher mortality ([Harrison et al 2005](#)). They also have significantly poorer function, as measured by the Health Assessment Questionnaire, at presentation. This variation in comparison to their peers from less socioeconomically deprived areas is maintained over time and is not attributable to differences in disease duration or concordance with treatment ([McEntegart et al 1997](#)).

When planning the implementation of PIFU within rheumatology, existing health inequalities must be considered, as must the impact of digital exclusion. For the purpose of monitoring the impact of the service change on health inequalities, it is important to consider whether it is possible to link to protected characteristics data.

It should also be noted that shared decision-making can be an enabler for addressing health inequalities because:











- it provides a more equal relationship by ensuring an open conversation in which clinicians seek to understand what is impacting on the individual's health and wellbeing
- it enables clinicians to explore the patient's skills and strengths, seeing the person beyond their symptoms and tapping into their locus of control by ensuring they feel valued as a whole person








- it supports people to connect with community assets, ensuring that options, choices and support go beyond clinical treatment.

Engagement with patients and patient groups

When planning and implementing PIFU within rheumatology, the engagement and involvement of patients is vital. Both pathways, and the resources to support those pathways, should be co-produced. Organisations that support the views and interests of patients may have affiliated local patient support groups and one or more of their members may be happy to be involved in the co-design of the service and associated patient-facing resources.

Examples of organisations that represent the views and interests of rheumatology patients include:

Versus Arthritis	 0300 790 0400
Versus Arthritis is the UK's largest charity dedicated to supporting people with all types of arthritis. It provides support and a wide range of information on its website. It also provides a telephone advice line for patients.  enquiries@versusarthritis.org	
National Rheumatoid Arthritis Society (NRAS)	 01628 823524
NRAS provides support and a wide range of information on its website for those affected by rheumatoid arthritis, their families, friends and carers. It also provides a telephone advice line for patients.  enquiries@nras.org.uk	
National Axial Spondyloarthritis Society (NASS)	 020 8741 1515
NASS provides support and a wide range of information on its website for those affected by axial spondyloarthritis, their families, friends and carers. It also provides a telephone advice line for patients.  admin@nass.co.uk	
Psoriasis and Psoriatic Alliance (PAPAA)	 01923 672837
PAPAA provides a wide range of information on its website for those affected by psoriasis and psoriatic arthritis, their families, friends and carers.  info@papaa.org	
Royal Osteoporosis Society	 01761 471771
The Royal Osteoporosis Society provides support and a wide range of information on its website for those affected by osteoporosis, their families, friends and carers. It also provides a nurse-led telephone advice line for patients and clinicians.  info@theros.org.uk	

Scleroderma and Raynaud's UK	 020 3893 5998
SRUK provides support and a wide range of information on its website for those affected by scleroderma or Raynaud's, their families, friends and carers. It also provides a telephone advice line for patients.  info@sruk.co.uk	
Lupus UK	 01708 731251
Lupus UK provides a wide range of information on its website for those affected by Systemic Lupus Erythematosus (Lupus), their families, friends and carers.  headoffice@lupusuk.org.uk	
Vasculitis UK	 01629 650549
Vasculitis UK provides support and a wide range of information on its website for those affected by different forms of vasculitis (examples include polymyalgia rheumatica and giant cell (or temporal) arteritis). It also provides a telephone advice line for patients.  info@vasculitis.org.uk	
British Sjogren's Syndrome Association (BSSA)	 0121 478 1133
BSSA provides support and a wide range of information on its website for those affected by Sjogren's, their families, friends and carers. It also provides a telephone advice line for patients.	

7. Evaluating PIFU in rheumatology services

Outpatient transformation has been highlighted as essential for elective recovery in the [2022/23 Priorities and Operational Planning Guidance](#). All systems are required to demonstrate progress in implementing PIFU and, since October 2021, providers and systems have been asked to evidence their progress with PIFU through returns to the Provider Elective Recovery Outpatient Collection (EROC) dataset.

It would be recommended that rheumatology services consider the following for inclusion in their PIFU evaluation plan. This list includes those metrics mandated within the Provider EROC return (these are in bold and 'checked' () in the list below).

Time	Evaluation activity
Months 1, 2 and 3	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Number of episodes (patients) moved to a PIFU pathway in month (appropriate where the expectation is that the patient will be seen again) <input checked="" type="checkbox"/> Number of episode (patients) discharged to a PIFU pathway in month (likely to be less relevant for rheumatology) <input checked="" type="checkbox"/> Total number of episodes (patients) on a PIFU pathway as of the first day of the month <input checked="" type="checkbox"/> Number of episodes (patients) taken off a PIFU pathway in month moved onto a PIFU pathway in month (either because the patient has been discharged or because they have been moved back to timed follow-up) <input checked="" type="checkbox"/> Number of appointments, in month, where the reason for booking was a PIFU appointment <input checked="" type="checkbox"/> Number of PIFU appointments, in month, where the patient did not attend (or arrived too late to be seen) <input type="checkbox"/> Number of patients discharged (this is a balancing measure) <input type="checkbox"/> Number of patients on a PIFU pathway who contacted the service requesting an appointment in month <input type="checkbox"/> (In month) number (and %) of patients on a PIFU pathway who contacted the service requesting an appointment in month who needed to be seen in a face-to-face appointment (as opposed to being given advice over the telephone) <input type="checkbox"/> (In month) average waiting time to be seen of those contacting the service for a PIFU appointment who required a face-to-face appointment (if an appointment was indicated) <input type="checkbox"/> Monitor patient satisfaction with/experience of PIFU (using a validated measure of shared decision-making) <input type="checkbox"/> At Month 3, review clinician satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary <input type="checkbox"/> At Month 3, review administrative staff's (secretarial and booking teams) satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary

- Months 4, 5 and 6**
- Number of episodes (patients) moved to a PIFU pathway in month (appropriate where the expectation is that the patient will be seen again)**
 - Number of episode (patients) discharged to a PIFU pathway in month (likely to be less relevant for rheumatology)**
 - Total number of episodes (patients) on a PIFU pathway as of the first day of the month**
 - Number of episodes (patients) taken off a PIFU pathway in month moved onto a PIFU pathway in month (either because the patient has been discharged or because they have been moved back to timed follow-up)**
 - Number of appointments, in month, where the reason for booking was a PIFU appointment**
 - Number of PIFU appointments, in month, where the patient did not attend (or arrived too late to be seen)**
 - Number of patients discharged (this is a balancing measure)
 - Number of patients on a PIFU pathway who contacted the service requesting an appointment in month
 - (In month) number (and %) of patients on a PIFU pathway who contacted the service requesting an appointment in month who needed to be seen in a face-to-face appointment (as opposed to being given advice over the telephone)
 - (In month) average waiting time to be seen of those contacting the service for a PIFU appointment who required a face-to-face appointment (if an appointment was indicated)
 - Monitor patient satisfaction with/experience of PIFU (using a validated measure of shared decision-making)
 - At Month 6, review clinician satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary
 - At Month 6, review administrative staff's (secretarial and booking teams) satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary
 - At Month 6, review GP satisfaction with/experience of PIFU – perhaps via a brief online questionnaire – and make any changes necessary

Months 7-12	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Number of episodes (patients) moved to a PIFU pathway in month (appropriate where the expectation is that the patient will be seen again) <input checked="" type="checkbox"/> Number of episode (patients) discharged to a PIFU pathway in month (likely to be less relevant for rheumatology) <input checked="" type="checkbox"/> Total number of episodes (patients) on a PIFU pathway as of the first day of the month <input checked="" type="checkbox"/> Number of episodes (patients) taken off a PIFU pathway in month moved onto a PIFU pathway in month (either because the patient has been discharged or because they have been moved back to timed follow-up) <input checked="" type="checkbox"/> Number of appointments, in month, where the reason for booking was a PIFU appointment <input checked="" type="checkbox"/> Number of PIFU appointments, in month, where the patient did not attend (or arrived too late to be seen) <input type="checkbox"/> Number of patients discharged (this is a balancing measure) <input type="checkbox"/> Number of patients on a PIFU pathway who contacted the service requesting an appointment in month <input type="checkbox"/> (In month) number (and %) of patients on a PIFU pathway who contacted the service requesting an appointment in month who needed to be seen in a face-to-face appointment (as opposed to being given advice over the telephone) <input type="checkbox"/> (In month) average waiting time to be seen of those contacting the service for a PIFU appointment who required a face-to-face appointment (if an appointment was indicated) <input type="checkbox"/> Monitor patient satisfaction with/experience of PIFU (using a validated measure of shared decision making) <input type="checkbox"/> At Month 12, review clinician satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary <input type="checkbox"/> At Month 12, review administrative staff's (secretarial and booking teams) satisfaction with/experience of PIFU – perhaps in a team meeting – and make any changes necessary <input type="checkbox"/> At Month 12, review GP satisfaction with/experience of PIFU – perhaps via a brief online questionnaire – and make any changes necessary
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Other metrics

In addition to process measures and patient experience/satisfaction data, it would be recommended that disease specific, patient reported, clinical outcomes data is

captured regularly.

8. Further resources

A selection of documents, tools and resources can be found in the Empowering Patients section of the FutureNHS collaboration platform: [Outpatient Transformation Platform – FutureNHS collaboration platform](#)

British Society for Rheumatology ePROMS platform:
<https://www.rheumatology.org.uk/practice-quality/eproms>

Goodwin V et al (2017) Bridging the second gap in translation: a case study of barriers and facilitators to implementing patient-initiated clinics into secondary care. *European Journal for Patient Centred Healthcare*; 5(1):129-137.
<http://www.ejpch.org/ejpch/article/view/1248>

Hewlett S et al (2001) Development and validation of a self-efficacy scale for use in British patients with rheumatoid arthritis. *Rheumatology* 40: 1221-1230.
<https://academic.oup.com/rheumatology/article/40/11/1221/1783960>

NHS England (2018) patient activation measure quick guide:
<https://www.england.nhs.uk/wp-content/uploads/2018/04/patient-activation-measure-quick-guide.pdf>

NICE guidance for the implementation of shared decision-making:
<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

Personalised care: <https://www.england.nhs.uk/personalisedcare/>

Personalised Care Institute (for free online training in shared decision-making):
<https://www.personalisedcareinstitute.org.uk/>

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