

Classification: Official

Publication approval reference: PAR801



# Implementing patient initiated follow-up

Guidance for local health and care systems

Version 1, 17 May 2022

# Contents

Foreword .....	2
Introduction.....	3
What is patient initiated follow-up? .....	3
Benefits of patient initiated follow up .....	5
Who is patient initiated follow-up suitable for?.....	6
Specialties patient initiated follow-up is suitable for.....	8
How to set up PIFU in your organisation .....	9
Implementation approach .....	9
Getting ready for implementation .....	10
Developing your standard operating procedure .....	10
Developing your clinical resources .....	11
IT system changes.....	12
Staff engagement .....	12
Patient engagement.....	13
Evaluation .....	13
Mitigating risks to implementation.....	14
High quality PIFU and patient safety .....	16
Identifying which patients PIFU is right for.....	16
Tracking patients .....	17
Safety nets.....	17
Risks to quality of care and their mitigation.....	18
Health inequalities .....	20
National and regional support.....	23

# Foreword

NHS outpatient services deliver essential care for patients. However, we all know of occasions when patients attend routine appointments that they do not need because they are well and their circumstances have not changed. Outpatient services need transforming to better suit modern lives – with patients having access to a specialist when they need this, rather than according to a routine schedule – as well as to tackle the challenges we face in healthcare delivery.

The COVID-19 pandemic brought this into stark contrast. We witnessed a step change in how outpatient care is delivered: clinicians, staff and services quickly adapted to new approaches that will improve patient experience of outpatient services now and in the future.

Patient initiated follow-up (PIFU) is one of these positive changes. It empowers patients to take control of their care – and ensures they can see a specialist sooner than planned if they need to, as well as avoid an unnecessary trip to hospital if they have no need to be seen. It also helps clinicians manage their waiting lists in a safe and effective way.

For patients, this means more choice and flexibility around when they access care. For clinicians, it means fewer appointments of low clinical value, freeing up time to support the patients most in need.

Providers should make this change because it is right for patients, staff and the long-term sustainability of outpatient services. I encourage you to use the advice and practical support in this implementation guidance to adopt PIFU safely and effectively across your services.

**Steve Powis, National Medical Director, NHS England and NHS Improvement**

# Introduction

[Patient initiated follow-up](#) (PIFU) gives patients control over their follow-up care, allowing them to be seen quickly when they need to, while avoiding the inconvenience of appointments that are of low clinical value. This is a key part of the focus on empowering patients and delivering [personalised care](#) in the NHS.

The [2022/23 operational planning guidance](#) asks systems to:

- accelerate progress already made towards a more personalised approach to follow up care, reducing outpatient follow ups by a minimum of 25% against 2019/20 activity levels by March 2023.
- expand the uptake of PIFU in all major outpatient specialties, moving or discharging 5% of outpatient attendances to PIFU pathways by March 2023.

PIFU is key to delivering a personalised outpatient model, further guidance [available here](#).

Implementation of PIFU in outpatient services should always be locally led, supported by strong system and trust leadership. This guidance supports NHS providers to do this. It sets out the main considerations and best practice for implementation, drawn from learning from people, clinicians, services, trusts and systems across England.

## What is patient initiated follow-up?

Follow-up appointments have traditionally been offered at routine intervals depending on a person's condition. Some people might need to be seen sooner than their scheduled next appointment but do not know to get in touch with their clinical team, and even if they do they may not be seen for several weeks. Others may be invited to attend appointments at a time when their condition is stable, potentially causing them unnecessary inconvenience and anxiety.

**PIFU describes when a patient, or carer, can initiate follow-up appointments when they need one.**

PIFU gives patients or their carers control over their follow-up care. By allowing them to be the ones who initiate follow-up appointments, patients can be seen quickly when they need to be, such as when their symptoms or circumstances change, and otherwise avoid the inconvenience of appointments of low clinical value. This is a key part of the focus on empowering patients and delivering [personalised care](#) in the NHS.

PIFU can be used in a wide variety of specialties, for people of any age, with short and long-term conditions, and for single and multiple conditions.

This is not a new concept, and PIFU commonly goes by a number of other names, including open access follow-up, patient led follow-up, patient triggered follow-up, patient initiated appointments, supported self-managed follow-up, self-managed follow-up, see on symptom, open appointments, open self-referral appointments or patient activated care. In the context of cancer, this is often part of [personalised stratified follow-up](#).

Within the above definition, PIFU must meet three minimum quality standards:

1. 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 (see information on [shared decision-making](#)).
2. A standard operating procedure (SOP) that includes patient safety nets should be in place.
3. All patients moved to a PIFU pathway should be logged and tracked on the organisation's IT system, and the service able to report on key metrics including the number of patients who are on a PIFU pathway.

# Benefits of patient initiated follow up

<p><b>Benefits to patients</b>          “It feels like I am in control if I can book a follow-up appointment as I need rather than when one is due whether or not I need it.”          (patient, Cambridge University Hospitals NHS Foundation Trust)</p>	<ul style="list-style-type: none"> <li>• Empowers people to book appointments when they need them</li> <li>• Reduces inconvenience, time, cost and stress associated with hospital appointments that do not benefit them</li> <li>• Improves satisfaction<sup>1</sup></li> <li>• Improves people’s engagement with their health (patient activation)</li> <li>• Services are more responsive due to improved management of waiting lists</li> </ul>
<p><b>Benefits to clinicians</b>          “Within my hospital department a dedicated team of advanced nurse practitioners have run a PIFU service for our arrhythmia patients for over 10 years. Our patients like it because they know they can see the specialist team if they need to or contact them for advice. It helps me know that the specialist team will discuss any concerns about the patient with me and I can concentrate on seeing patients who need the extra specialist support.”          (Prof Nicholas J Linker, National Clinical Director for Heart Disease, NHS England and NHS Improvement and Consultant Cardiologist, South Tees Hospitals NHS Foundation Trust)</p>	<ul style="list-style-type: none"> <li>• Gives confidence that they are seeing the patients who need them the most</li> <li>• Gives confidence that patients know how to contact services if they need to</li> <li>• Provides a way to jointly develop plans and ‘what if’ scenarios with patients, and share the clinical risk</li> <li>• Helps manage caseloads and waiting lists in a safe and effective way</li> </ul>
<p><b>Benefits to providers and systems</b>          “Adopting PIFU across the ICS has improved access and experience for our patients. It is having a positive impact on our waiting lists, helping services to recover from the pandemic while helping clinicians to spend time with the patients who really need them.”          (Dr Rachel Joyce, Director of Clinical and Professional Services, Herts &amp; West Essex ICS and CCGs)</p>	<ul style="list-style-type: none"> <li>• Reduces waiting times and waiting lists due to net reduction in follow-up appointments (early data indicates 0.8–1.8 appointments are avoided per patient moved to PIFU<sup>2</sup>)</li> <li>• Reduces unmet need and clinical risk from patients waiting for follow-up appointments</li> <li>• Reduces did not attends (DNAs) as patients can decide when they need an appointment</li> <li>• Enables delivery of the <a href="#">NHS Long Term Plan</a> aim of reducing unnecessary outpatient appointments by 30%. The associated reduction in travel will reduce CO<sub>2</sub> emissions and support the ambition of delivering a <a href="#">‘Net Zero’ NHS</a></li> </ul>

<sup>1</sup> [Hewlett S, et al. Patient initiated outpatient follow up in rheumatoid arthritis: six year randomised controlled trial. \*BMJ\* 2005; 330: 171.](#)

<sup>2</sup> [Converting PIFU activity to avoided future appointments](#)

Using this [modelling](#) these are example estimates of avoided appointments.

Specialty	Appointments avoided per patient on a PIFU
Audiology	1.77
Trauma and orthopaedics	1.24
Rheumatology	1.08
Ear, nose and throat	0.96
Urology	0.83
Pain management	0.81

## Who is patient initiated follow-up suitable for?

PIFU can be used for patients of any age, provided the patient and their clinician agree it is right for them. In some cases, it may be appropriate for the patient to share the responsibility for initiating appointments with a carer or guardian.

PIFU can be used alongside routine timed appointments if the patient requires appointments at regular intervals but would still benefit from being able to book an appointment between these if they experience a change in symptoms.

Individual services should develop their own guidance, criteria and protocols on when to use PIFU and be clear that it should not be used as a substitute for the appropriate timely discharge of patients. We are developing speciality-specific best practice guides on patient selection and other considerations for implementing PIFU. Please check our [FutureNHS site](#) to see what we have added. Below we give general guidance on patient selection.

Patients need to meet the following conditions for PIFU to be able to benefit them:

- is at low risk of urgent follow-up care and satisfies criteria established by the specialty<sup>3</sup>
- has the health literacy and knowledge, skills and confidence to manage their follow-up care (patient activation). If they do not, the patient might benefit from support to improve these areas in line with the [personalised care](#) approach
- is confident and able to take responsibility for their care for the time they will be on the PIFU pathway, eg they do not have rapidly progressing dementia, severe memory loss or a severe learning disability<sup>4</sup>
- understands which changes in their symptoms or indicators mean they should get in touch with the service, and how to do so
- has the tools (eg devices, leaflets, apps) they need to understand the status of their condition, and understands how to use them
- understands how to book follow-up appointments directly with the service, and how long they will be responsible for doing this. For some patients who are unable to book their appointments directly, administrative staff at their care home or GP surgery may be able to help.

If the patient meets any of the following conditions, the appropriateness of PIFU for them needs to be carefully considered:

- the patient's health issues are particularly complex
- there are clinical requirements to see the patient on a fixed timescale (timed follow-ups), although it is important to note that a blend of PIFU and timed follow-ups can be offered (eg for cancer pathways)
- the clinician has safeguarding concerns
- the patient's takes medicines that require regular and robust monitoring in secondary care
- the patient's is unable to contact the service easily (eg lacks access to a telephone<sup>5</sup>).

---

<sup>3</sup> [Whear R, et al. Patient initiated clinics for patients with chronic or recurrent conditions managed in secondary care: a systematic review of patient reported outcomes and patient and clinician satisfaction. \*BMC Health Serv Res\* 2013; 13: 501.](#)

<sup>4</sup> [Batehup L, et al. Follow-up after curative treatment for colorectal cancer: longitudinal evaluation of patient initiated follow-up in the first 12 months. \*Support Care Cancer\* 2017; 25: 2063–73.](#)

<sup>5</sup> [Goodwin VA, et al. Implementing a patient-initiated review system for people with rheumatoid arthritis: a prospective, comparative service evaluation. \*J Eval Clin Practice\* 2016; 22\(3\): 439-445.](#)



# Specialties patient initiated follow-up is suitable for

From engagement and data from the newly established [Provider Elective Recovery Outpatient Collection](#) (EROOC), we know that PIFU is already used in over 180 outpatient specialties nationally.

Some specialties where PIFU is being used effectively are listed below. It is particularly popular in trauma and orthopaedics and physiotherapy; these specialties nationally put 14,000 and 8,000 people respectively on a PIFU pathway in September 2021.

- audiology
- breast surgery
- cardiology
- colorectal surgery
- dermatology
- diabetes
- disablement services
- ear, nose and throat
- endocrinology
- gastroenterology
- general surgery
- geriatric medicine
- gynaecology
- hepatology
- mental health
- neurology
- oncology
- ophthalmology
- orthoptics
- paediatrics, including dermatology, ENT, epilepsy, gastroenterology, neurology, ophthalmology, orthopaedics, plastic surgery and rheumatology
- pain management
- palliative medicine
- physiotherapy
- plastic surgery
- podiatry
- rehabilitation
- renal medicine
- respiratory medicine
- rheumatology
- thoracic medicine
- trauma and orthopaedics
- urology
- vascular surgery

# How to set up PIFU in your organisation

## Implementation approach

There is a consistent series of steps to take to implement PIFU, summarised below. Further information is available in the comprehensive [PIFU implementation plan and pre-implementation checklist](#).

How long it takes to deliver PIFU will depend on the size of the service, current service demand, maturity of any existing PIFU, staff engagement, IT system set up and the time and capacity the team leading this work has. Providers consistently told us they underestimated the time it would take to implement PIFU, particularly to develop a SOP, engage with clinical teams and get clinical buy-in, and make changes to their IT systems to support PIFU. It can take three months to implement PIFU in the first tranche of specialties, whereas subsequent waves can be quicker.

We suggest starting with at least five specialties, and to include both medical and surgical specialties, and a mix of short and long-term pathways of care so that you can develop a flexible model of PIFU for your organisation. Within those specialties, we recommend phasing your launch; for example, by starting with particular pathways or clinicians.

We also recommend starting by implementing PIFU with specific cohorts of patients within your chosen specialties (eg psoriasis patients for dermatology), before expanding it to cover the rest of the specialty.

For each chosen specialty, engage with clinical staff to understand which pathways they see PIFU as having the greatest value for patients. Work with your business intelligence teams to estimate the number of patients and clinicians this change might affect and pick areas where larger numbers of patients could benefit. We recommend engaging with providers already using PIFU in that specialty (your [regional PIFU lead](#) can connect you).

Once you have gone live with PIFU at a small scale in your chosen specialties, good practice is to spend a few weeks testing and refining how PIFU works before large-scale launch. This should include reacting to feedback from staff on how things are working so far and testing safety nets and [recording and reporting](#). Patients are unlikely to initiate an appointment within the first few weeks of running a PIFU service so you will need to monitor this continually after any launch.

## Getting ready for implementation

Before starting your implementation, make sure you have everything ready to avoid any delays. A full pre-implementation checklist can be found [here](#). This includes:

- establishing a project team (including someone responsible for the day-to-day management of the rollout, IT leads and clinical leads for your chosen specialties)
- understanding the [organisation's current position](#) with respect to PIFU: which specialties are you using PIFU in and [how formalised](#) is its use?
- understanding your system's priorities for implementing PIFU and local requirements for meeting the expected scale of PIFU uptake
- looking at which services might have the biggest opportunities, eg the ones that have the longest follow-up lists or see the most patients
- choosing which specialties you will start with by looking at the [national dashboard](#), [national specialty resources](#) and [case study data](#). If you are unsure where to start, we recommend starting with specialties for which national guidance has already been published, eg dermatology, or specialties where PIFU is commonly used in other providers
- building a plan and getting sign-off for your business case.

## Developing your standard operating procedure

Once you have identified which specialties you will first implement PIFU in, you should develop a PIFU SOP to ensure that the care patients receive through this pathway is consistent and high quality. A template for local adaptation is [available](#).

The SOP should be developed collectively by staff from clinical, operational, administrative, information and performance teams, and should cover how to:

- identify which patients PIFU is right for

- move a patient onto a PIFU pathway
- how patients should make contact with the service
- ensure [availability of clinic slots](#) to accommodate patients who initiate an appointment
- book appointments which have been initiated by a patient
- manage patients who do not initiate an appointment within the PIFU timescale
- manage the end of a patient's PIFU timescale
- communicate with patients
- monitor compliance
- mitigate risks to safety and reflect actions identified to [mitigate and reduce health inequalities](#).

It is also important to define how PIFU will form part of the organisation's approach to outpatient transformation and continuous improvement.

## Developing your clinical resources

You also need to develop these local clinical resources, to ensure clinical effectiveness in your services and help gain clinical buy-in:

- examples of conditions a PIFU pathway may work well for
- the associated target service response times if a patient does make contact
- how long a PIFU pathway would run for different patient groups, and what would happen after that time has elapsed, eg contact the patient, appointment to review or discharge from the service
- any safety nets specific to the specialty or a particular condition.

You can refer to these nationally developed [guides and provider examples](#) as a starting point.

It is important when driving PIFU uptake in a specialty to ensure it is not used in place of discharging patients appropriately. You may wish to provide supporting guidance on when to discharge patients from the care of the service instead of using PIFU.

## IT system changes

Work with your IT teams and IT system supplier to understand what changes will be required to implement PIFU, including for the recording and reporting of PIFU and necessary safety nets, and whether these will be the same across the organisation or differ by specialty/service level. It is particularly important to start this step early as otherwise it can delay rollout. Information on how providers have approached recording and reporting on their IT systems is available [here](#). Details on current and future national reporting requirements can be found in the [provider EROC guidance](#) and on the [NHS Digital website](#).

Once you have scoped the necessary IT system changes, establish whether you can phase them in or if they need to be completed in one go, and plan how you will test that the system is working as it should. Check that the system codes (eg outcome codes) you plan to use are not already being used for another purpose elsewhere in the service/organisation.

After you have implemented any necessary IT system changes, check you can record patients as being on a PIFU pathway and generate necessary reports.

## Staff engagement

Consider how the rollout will affect staff, including their capacity, confidence and morale. Ensure you have support in place for them, including through identifying clinical and operational champions for each service. Run some engagement workshops with staff to understand their perspectives ahead of rollout.

To alleviate any concerns around capacity, plan how services will manage their capacity over the implementation phase, for instance through ringfencing appointment slots for patients who trigger an appointment.

To build confidence, train clinical staff in how to discuss PIFU with patients, how to log patients in the system and how triage will work, and administrative staff in how to manage clinics and queries from patients. You should give staff the opportunity to ask questions and raise risks and concerns, and signpost them to further information and support should they need it during the implementation. This flexible support should be available during the first few weeks of using PIFU.

This level of change can be challenging and it is important to celebrate early successes and recognise staff efforts.

## Patient engagement

Identify or set up patient groups for each specialty or condition and ask them what is important to them so that you can adapt your plans to best meet their needs and preferences, and address any concerns they have. Examples of feedback from patients can be found [here](#).

## Evaluation

As part of your business case, agree how you will assess the initial small scale rollout. You may not see any reduction in demand for a service until at least half the typical PIFU timescale for that service has elapsed. We therefore suggest evaluation at three time points.

Typical PIFU timescale for the specialty	Estimated time to realise full benefits of PIFU	Early stage evaluation	Mid stage evaluation	Late stage evaluation
6 weeks	4.5 months	2–4 weeks	3 weeks	6 weeks
6 months	9 months	2–4 weeks	3 months	6 months
12 months	18 months	2–4 weeks	6 months	12 months
18 months	2 years +	2–4 weeks	9 months	18 months

### Early-stage evaluation

- Number of patients moved onto a PIFU pathway as a result of a normal appointment (ie not a waiting list review). Compare this to national data available on the [provider EROC dashboard](#).
- Total number of patients on a PIFU pathway.
- Number of patients who have initiated an appointment and their feedback.
- Clinical staff experience and feedback.
- Administrative staff experience and feedback.
- Patient experience and feedback.
- Service discharge rates (as a balancing measure).

- Estimate future demand on administrative services, eg booking follow-up appointments.

## Mid and late-stage evaluation

You will be in a better position to predict the impact PIFU will have on demand once you have been using PIFU for a few months. For each specialty, use the activity data at this point to model demand over the next year. At the late-stage evaluation revisit and add confidence to the results of your mid-stage evaluation. Exactly when you conduct the mid and late-stage evaluations will depend on the timescales for PIFU for your chosen specialties.

At the mid and late-stage evaluations you should also revisit the areas covered in the early-stage evaluation – you may be able to build a more complete picture as patients will have more experience of the different parts of the pathway.

Also review data on PIFU for services that have not been part of the formal rollout; some providers have noticed uptake from clinicians in other specialties through word of mouth.

## Mitigating risks to implementation

Potential challenges organisations may face when implementing PIFU or formalising existing processes are given below.

Challenge	Mitigation measures	Resources available to support
Staff may lack engagement and confidence in PIFU, reducing uptake and pace of rollout	<ul style="list-style-type: none"> <li>• Actively engage with clinical and non-clinical staff to understand their concerns and build plans to address them</li> <li>• Ensure staff understand the benefits of PIFU, including how it will help manage service demand. For services that are already using something similar to PIFU, ensure the benefits of formalising this process are understood.</li> <li>• Consider starting implementation in services where there is/are: <ul style="list-style-type: none"> <li>– strong clinical engagement</li> <li>– good take-up in the system/region</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Guidance on <a href="#">formalising PIFU</a></li> <li>• National and regional <a href="#">specialty-specific resources and webinars</a> where clinicians share experience of implementing PIFU</li> <li>• <a href="#">Staff survey templates</a></li> <li>• <a href="#">Patient experience survey results</a> from Cambridge</li> <li>• <a href="#">Benefits calculator</a> translates PIFU activity into achieved benefits to help engagement</li> </ul>

Challenge	Mitigation measures	Resources available to support
	<ul style="list-style-type: none"> <li>– case studies from other providers</li> <li>– something like PIFU already being used; all that may be required is some tweaks to formalise it.</li> <li>• Monitor whether clinics are overrunning and consider modifying clinic templates to accommodate longer appointment times if required</li> <li>• Share impact on outcomes and patient and staff feedback to widen confidence and engagement</li> <li>• Ensure staff have access to day-to-day support in the new ways of working, eg through training and staff champions</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Planning tool</a> helps services measure avoided activity through PIFU</li> </ul>
PIFU may be used as a substitute for discharging patients at the end of their care	<ul style="list-style-type: none"> <li>• Monitor the proportion of patients who are discharged without being put on a PIFU pathway as a balancing measure</li> <li>• Address in clinical guidance to ensure only patients who may require follow-up are placed on the PIFU pathway</li> </ul>	<ul style="list-style-type: none"> <li>• National benchmarks (in development)</li> </ul>
Implementing PIFU across multiple services too quickly may impact on quality	<ul style="list-style-type: none"> <li>• Establish routine reporting and monitoring of PIFU uptake and quality</li> <li>• Ensure measures are in place to record patient and staff experience</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Staff survey template</a></li> <li>• <a href="#">Patient experience guidance</a></li> </ul>
IT/PAS issues hindering PIFU implementation	<ul style="list-style-type: none"> <li>• Engage with other providers using similar system who may have overcome similar issues</li> <li>• Engage with PAS suppliers to understand their plans for supporting PIFU reporting following the <a href="#">Information Standards Notice</a> for <a href="#">CDS v6.3 update</a></li> </ul>	<ul style="list-style-type: none"> <li>• National resources on <a href="#">IT systems and PIFU</a></li> <li>• Contact <a href="#">regional leads</a> for support</li> <li>• Locally developed approaches, eg Sheffield Teaching Hospitals' guidance on <a href="#">SystemOne and Lorenzo</a> and <a href="#">Walton Centre system SOP</a> on how to include PIFU outcomes in PAS systems</li> </ul>



## Case study: Sherwood Forest Hospitals NHS Foundation Trust

The trust set up its Outpatient Innovation Programme to realise the ambition of avoiding 30% of unnecessary outpatient attendances. One of its five strands was to establish PIFU. The trust implemented this for patients whose conditions were stable. Instead of routinely booking a follow-up appointment for them, these patients were put 'on hold' for a set time, and given instructions on how to contact the service if their condition exacerbated.

Over six months (the most common timescale used for PIFU in the trust), only 20% of patients needed a follow-up appointment. By extrapolating this data, the trust estimates PIFU will avoid 10,000 appointments over the next year.

The trust is currently moving circa 1,500 patients to PIFU every month.

# High quality PIFU and patient safety

Safety, effectiveness and patient experience standards must be met while PIFU is being implemented. There is no evidence to date that PIFU increases patient risk or affects service quality.

Providers and systems should adopt the following measures for selecting patients, tracking patients and safety netting. Those that have already introduced PIFU should review their existing practice against these measures and address any identified gaps. These should be embedded as part of the service SOP and clinical protocols.

## Identifying which patients PIFU is right for

A patient's ability to benefit from PIFU needs to be carefully considered. As a minimum providers should:

- Ensure they have locally developed or adapted clinical guidance in place in each specialty where PIFU is used.

- Embed [sharing decision making](#) in their local processes to ensure that patients are fully involved in the decision on whether or not to move onto a PIFU pathway. PIFU must not be used to move people off the waiting list without a shared decision-making conversation with them about their progress managing their condition (normally done via an appointment).
- Embed consideration of patients' knowledge, skills and confidence ([patient activation](#)) into the PIFU decision-making process, ensuring only patients with sufficient activation are moved onto a PIFU pathway.
- Ensure that patients who are on a PIFU pathway can return to a traditional timed follow-up pathway if PIFU is not working for them.

## Tracking patients

Tracking patients at all stages of the pathway helps ensure a safe service as well as good [patient experience](#). It is essential that providers:

- Ensure robust processes are in place to log patients who are on a PIFU pathway. This should include logging the review or end date for their PIFU window, so that regularly generated reports will identify those patients whose PIFU requires a review or is about to expire.

## Safety nets

Providers must ensure:

- Clinicians identify patients who will need a review at the end of their PIFU window and a process is in place to ensure that necessary reviews take place. Only patients who have been clinically assessed at their last appointment to be safe to discharge without a review should be discharged without one (an example process map is available in the [SOP template](#)).
- Patients on a PIFU pathway are seen at a frequency that complies with clinical guidance (eg annual reviews for patients with some long-term conditions). If patients do not initiate an appointment within that timeframe, they should be contacted and offered an appointment.
- Patients who contact the service while on a PIFU pathway have their PIFU end date reviewed and updated if necessary.
- High risk patients who do not attend appointments are contacted to rebook their appointment.

- A process is in place to ensure that tests (eg bloods, scans) are reviewed in a timely way for patients on a PIFU pathway, even if that patient does not initiate an appointment.
- Any incidents or near misses related to a patient on the PIFU pathway failing to initiate an appointment at the appropriate time and having poor outcomes as a result should be reported and investigated through established incident reporting mechanisms. Learning from the outcome of such incidents should be shared across PIFU services so any patient, for whom PIFU is not appropriate, is not put on this pathway.

## Risks to quality of care and their mitigation

Risk	Mitigation measures	Resources available to support
<p>People may be moved to PIFU without having the required knowledge, skills and confidence to manage their follow-up care, leading to poor outcomes</p>	<ul style="list-style-type: none"> <li>• Local service guidelines should include patient suitability criteria for PIFU</li> <li>• The decision to go on the PIFU pathway is a <a href="#">shared decision</a> with the patient, and not through a desktop review. Give patients the option to go back to the traditional timed follow-up pathway if PIFU is not working for them.</li> <li>• Clinicians must check patients understand when and how to initiate an appointment when they are moved to PIFU.</li> <li>• Process in place to involve families or carers where appropriate, eg when the patient has diminished mental capacity.</li> <li>• Report and investigate any patients who had poor outcomes when on a PIFU pathway through established incident reporting mechanisms. Learning to be shared across services.</li> </ul>	<ul style="list-style-type: none"> <li>• This guidance lists reasons why PIFU may not be suitable for a patient</li> <li>• Training available to clinicians through the <a href="#">Personalised Care Institute</a> on shared decision-making and patient activation, etc.</li> </ul>
<p>Patients may forget when and how to get in touch during the time they are on PIFU or they may not want to 'bother' services, leading to worse outcomes or added pressure on primary care</p>	<ul style="list-style-type: none"> <li>• Send information both digitally (eg via email, SMS) and hard copy (eg leaflet posted to patients) where possible. Consider additional reminders to patients eg via SMS.</li> <li>• Monitor whether people have opened links on emails/SMS and re-send as required.</li> </ul>	<ul style="list-style-type: none"> <li>• Rheumatology direct access information available on the <a href="#">United Hospitals Plymouth NHS Trust website</a></li> <li>• Patient information leaflets and personal PIFU plans (developed by <a href="#">Northern</a></li> </ul>

Risk	Mitigation measures	Resources available to support
	<ul style="list-style-type: none"> <li>• Develop good communication resources such as patient information leaflets and videos so patients understand the PIFU process and its objectives.</li> <li>• Include PIFU service details and contact information on provider websites.</li> <li>• Keep patients' GPs informed so they can signpost the patient to the service if required, and so that they understand when they should inform secondary care about risks, eg if a patient is diagnosed with a new condition such as dementia.</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Lincolnshire and Goole NHS Foundation Trust</a> copied to patients and GPs</li> <li>• <a href="#">GP letter template</a> in toolkit</li> </ul>
<p>Poor outcomes if people are moved to PIFU when they require timed follow-ups</p>	<ul style="list-style-type: none"> <li>• Local service guidelines should state which conditions PIFU can be used with, including whether PIFU can be used on its own or if it should be used in conjunction with timed appointments.</li> <li>• SOPs should include processes to ensure patients on a PIFU pathway are seen at a frequency that complies with clinical guidance, eg annual reviews for some patients. If patients do not initiate an appointment within that timeframe, they should be offered an appointment.</li> <li>• SOPs should include processes to ensure that tests (eg bloods, scans) are reviewed in a timely way for patients on a PIFU pathway, even if a patient does not initiate an appointment.</li> <li>• High-risk patients who do not attend appointments are contacted to re-book their appointment.</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Specialty-specific guidance</a> lists conditions suitable for PIFU and when to use it along with timed follow-up pathways, eg <a href="#">rheumatology PIFU guidance</a> and the <a href="#">dermatology guidance</a></li> <li>• <a href="#">SOP template</a> includes process map incorporating the safety nets; example from <a href="#">Royal Surrey NHS Foundation Trust</a></li> <li>• Locally developed clinical protocols such as for <a href="#">diabetes</a> and <a href="#">continence</a> from Sheffield Teaching Hospitals NHS Foundation Trust</li> </ul>
<p>Services may find it difficult to identify patients on a PIFU pathway, resulting in patients who contact the service having to wait for an appointment</p>	<ul style="list-style-type: none"> <li>• Record patients on the PIFU pathway on IT systems. Include a date on which action needs to be taken for the patient (eg date to contact patient/book appointment/discharge if clinically appropriate)</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">SOP template</a> includes an example of what needs to be recorded for each patient</li> </ul>

Risk	Mitigation measures	Resources available to support
<p>Patients may become disengaged with PIFU if it takes too long for them to access an appointment with the service</p>	<ul style="list-style-type: none"> <li>• Ensure administrative teams are trained in how to identify patients on this pathway</li> <li>• Put in place target wait times for patients on a PIFU pathway, including capacity and demand management and processes to ensure quick access for urgent PIFU appointments where slots may be difficult to find</li> <li>• Record and share patient and staff experience of PIFU, including on whether they were seen in a timely manner if they made contact</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Self-assessment framework</a> to ensure implementation aligns to the standards required</li> <li>• <a href="#">SOP template</a> includes section on roles and responsibilities of staff for booking appointments within agreed timescales</li> <li>• Provider SOPs, eg <a href="#">Royal Surrey NHS Foundation Trust</a> (having sufficient clinic slots as per their access policy); <a href="#">Walton Centre</a> (ringfenced PIFU slots in clinic templates)</li> <li>• <a href="#">Patient experience guidance</a></li> </ul>

## Health inequalities

PIFU is likely to confer benefit on all suitable patients, including those with protected characteristics and from other vulnerable groups. However, PIFU is not a ‘one size fits all’ approach and if it is not implemented well – like for any intervention – there is a risk it could exacerbate health inequalities for some individuals or groups.

All groups should be given equal opportunity to be offered PIFU if it is clinically appropriate.

Systems and providers need to consider two main areas when thinking about health inequalities and PIFU:

1. **Selecting patients for PIFU and shared decision-making**, ie all groups are given equal opportunity to be offered a PIFU if it is a clinically relevant and a safe option for them; and the decision to go on a PIFU pathway needs to be a shared decision between the clinician and the patient, taking into consideration the patient's (or carer's) knowledge, skills and confidence.
2. **Ability to access service as required**, ie all groups have an easy and convenient way to access the service if they have any symptoms or concerns.

If some people are likely to struggle to make contact with a service, eg because they do not have a phone or internet access, clinical teams should consider whether suitable mitigation can be put in place so that they can still be offered a PIFU. Some people may need to be empowered and supported to increase their knowledge, skills and confidence, so that they are able to initiate an appointment if their symptoms change.

Key actions for systems and providers to address health inequalities are listed below. It is important that throughout the implementation there is continued engagement with patients on a PIFU pathway across a representative cross-section of patients and communities to understand how it is working for them, eg their understanding of the PIFU process, and experience of being moved to PIFU and accessing an appointment when needed.

## **Actions before implementing PIFU**

- Complete [equality health impact assessments](#) (EHIA) at provider/system level and for specialties as appropriate. Mitigation measures identified through the assessment should be put in place to ensure that (a) all patients are equally offered a PIFU when clinically appropriate; and (b) all patients on the PIFU pathway are able to initiate their appointment when required, so they can receive timely care.
- Look at local data (eg SUS data) to identify groups with protected characteristics experiencing inequalities in access, experience and outcomes and set local priorities for improvement (inequalities data is available in the Inequalities Dashboard on Foundry – request access [here](#)).
- Ask staff involved in PIFU to consider any risks to exacerbating health inequalities as part of the implementation.
- Put in place training for clinicians in personalised care approaches, including shared decision-making when offering PIFU to patients (eg through the [Personalised Care Institute](#)).

- Ensure PIFU can be used in conjunction with timed appointments where appropriate for patients.
- Ensure processes support use of PIFU alongside remote consultations where clinically appropriate.

### **Actions within the first three months of implementing PIFU**

- Develop local personalised care support (eg health coaching, link workers, measures for patient activation) and support clinicians to use this as part of the PIFU offer.
- Ensure alternative contact options are available for patients who are unable to use a phone, app or online booking service.
- Ensure patient information on PIFU process and symptoms to look out for do not require a high reading competency, and are available in easy read format, large print and other languages.
- Ensure patient information is written in a gender-neutral format and include diverse images of patients and staff.
- Consider including a non-discrimination policy in patient information.
- Ensure information about PIFU is copied to patients' GPs.
- Capture and report activity datasets routinely and report/evaluate performance to assess the impact of PIFU on any inequalities in access, experience and outcomes for people with protected characteristics and other communities, including in the bottom 20% of IMD scores
- Evaluate the patients placed on PIFU against protected characteristics to understand whether all groups are being offered an equal service.
- Report on quality measures such as reported concerns/complaints and safety incidents related to PIFU so that patients are not lost to follow-up across any equality groups.

### **Actions within one year of implementing PIFU**

- Review the proportion of patients on a PIFU who initiate an appointment to understand whether some groups are more likely to do so than others.
- Produce information for patients in other formats, eg videos.
- Consider offering phone lines free of charge for increased opening hours.
- Consider monitoring demographic information about patients initiating follow-ups to ensure that patients from all groups are doing so.

- Build in options to capture patients' preferred means of communication and provide information in a way that suits them.
- Consider offering targeted education programmes to specific groups to improve symptom recognition and self-management.

# National and regional support

Whatever the stage you are at with implementation, we recommend you contact your [regional PIFU leads](#) so that they can include you in their local support offer and connect you to organisations that have already implemented PIFU in your chosen specialties. They can also make you aware of further guidance and support materials for PIFU.

The National Personalised Follow Up team can also provide support; they run support webinars, and signpost to specialty-specific guides for PIFU, clinical advisers, investment and advice from the NHS Transformation Directorate on appropriate technology, and analytical insight on existing and potential PIFU activity.

In addition, we recommend you use our practical resources on the Outpatient Transformation FutureNHS [pages](#). You will need to request access to the workspace:

- [PIFU implementation plan and pre-implementation checklist](#)
- [PIFU standard operating procedure template](#)
- [Equality health impact assessment for PIFU](#).

You may also find it helpful to ask other providers using PIFU questions through our [national PIFU forum](#).



Contact us:

[enquiries@england.nhs.uk](mailto:enquiries@england.nhs.uk)

NHS England and NHS Improvement  
Skipton House  
80 London Road  
London  
SE1 6LH

This publication can be made available in a number of other formats on request.

© NHS England and NHS Improvement 2021

Publishing approval reference: PAR801