

Patient initiated follow-up: Frequently asked questions

Version 2.0

Published 15 June 2021

This document addresses some of the commonly asked questions providers and systems have around implementing PIFU in their organisation. Additional FAQs are available in the [Elective Recovery Fund PIFU FAQs](#) on the FutureNHS workspace. If you have a question that is not covered in either of these documents, please ask it on the [community forum](#) or contact your [regional PIFU lead](#).

About patient initiated follow-up

- What is patient initiated follow-up?

[Patient initiated follow-up](#) (PIFU) describes when a patient (or their carer) can initiate their follow-up appointments as and when required, e.g. when symptoms or circumstances change. As well as giving patients timely access to support, this avoids unnecessary routine 'check in' appointments.

PIFU is not a new concept and is known by other names such as 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 (SOS), open appointments, open self-referral appointments or patient-activated care.

PIFU can be used for patients with long or short-term conditions and following treatment or surgery. Decisions as to whether patients should be moved to a PIFU pathway should take into account the individual person's situation, needs and preferences.

- [Why use PIFU?](#)

PIFU makes it easier and more convenient for patients to receive care and support when they need it, whilst avoiding unnecessary trips to hospitals and clinics, saving them time, money and stress. It helps empower patients to manage their own condition and plays a key role in enabling shared decision making and supported self-management in line with the [personalised care agenda](#).

For clinicians, it means more time and opportunity to see patients who most need their support. It helps providers and systems to manage waiting lists and see patients most in need more quickly.

A [benefit calculator](#) that illustrates quantifiable outcomes such as patient time saved, associated with avoiding unnecessary appointments is available on FutureNHS.

Delivering PIFU is part of the outpatients transformation requirements laid out in the [2021/22 Operational Planning Guidance](#) and is a key part of the [NHS' response to the COVID-19 pandemic](#).

- [How does PIFU relate to personalised follow-up?](#)

PIFU is one aspect of personalised follow up which describes the broader concept of when a patient's follow up care is tailored to their individual clinical need, circumstances and preferences.

- [How does PIFU relate to personalised stratified follow-up \(PSFU\) in cancer?](#)

PIFU is an integral part of PSFU. While [PSFU ensures delivery of personalised care within a cancer follow-up pathway](#), including the PIFU option alongside 'traditional' follow-up (e.g. scheduled cancer surveillance tests and scan appointments) means that patients also have the ability to initiate an appointment if they have any symptoms they are concerned about. Sometimes, in this context, PIFU is called “supported self-managed follow-up”.

Quality of care and PIFU

- Is PIFU suitable for all patients? How does it work when you are dealing with patients who are particularly vulnerable?

PIFU is not going to be right for everyone and there will always be a cohort of patients for whom PIFU is not the best option. A list of characteristics which may add to the risk of putting a patient on a PIFU, is given on p21 of the [Phase 3 implementation guidance](#). PIFU must be implemented carefully to ensure all patients placed on the PIFU pathway experience safe, high quality care – [guidance](#) for this is available on the PIFU FutureNHS workspace.

- How can we ensure safe, high quality care for patients on the PIFU pathway?

PIFU must be implemented carefully to ensure all patients placed on the PIFU pathway experience safe, high quality care – [guidance](#) for this is available on the PIFU FutureNHS workspace.

It is important that services avoid the risk of any patients getting 'lost' in the system and missing important changes in their condition. A list of [list of risks and their mitigation](#) options are also available in the PIFU Future NHS workspace.

- What impact can PIFU have on health inequalities?

Providers, STPs and ICSs should thoroughly examine the potential impact of PIFU on local health inequalities by doing an EHIA for PIFU - an example template is available [here](#). PIFU will not be right for everyone, and it is important to consider whether key groups or individuals will miss out on the opportunity to be offered a PIFU and how to address this. Some areas to consider as part of this include:

1. Are some groups likely to have lower patient activation, and therefore would not be safe to put on a PIFU as they may not initiate appointments when required? Consider addressing this through supporting them to improve their knowledge, skills and confidence, or sharing the responsibility of booking an appointment with a carer.
2. Are some key groups in society likely to struggle to make contact with a service, e.g. due to not having a phone line, internet access, fixed home address or facing a communication barrier? To address these inequalities, it is important to offer flexible routes for people to access services.

Programme implementation

- What support is available to help us implement PIFU?

If you are interested in implementing or spreading PIFU in your organisation, please contact your NHS England and NHS Improvement [regional outpatients transformation colleagues](#) to understand their local offer.

A [PIFU implementation plan and pre-implementation checklist](#) is available on the PIFU FutureNHS workspace in the [implementation toolkit](#) which includes a range of support materials such as SOPs and templates. The workspace also provides colleagues with a forum to share, learn and connect with others working on this programme. We encourage you to register to Future NHS to access this workspace or you can request access by emailing: nhsi.outpatient-transformation@nhs.net.

- We are new to PIFU – which specialties should we start with?

PIFU can be used in a wide range of specialties, some of which are listed on page 23 of [this guidance](#).

In our [implementation plan and pre-implementation checklist](#), it is recommended that to develop the most flexible model, you can start with three to five specialties including both medical and surgical specialties, and to cover a mix of short and long term pathways of care. You may agree your wave 1 specialties to pilot PIFU based on your local system priorities, clinical engagement and the data available for your services.

Specialty-specific resources, including PIFU guidance and protocols relating to some specialties are available on the PIFU FutureNHS workspace [here](#).

- We already use open access follow up/open appointments (or something else similar to PIFU) in some specialties. Do we need to do anything to formalise its use?

If you are already using PIFU or its equivalent in some specialties, we encourage you to use [this self-assessment tool](#) to understand how well-established your set-up is and identify opportunities for improvement.

A wide range of tools and resources on best practice, formalised PIFU can be found on the [FutureNHS Collaboration Platform](#). The following criteria are considered minimum quality standards.

- All patients (or carers) should have PIFU explained to them and have 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.
- A standard operating procedure is in place and includes the consideration of safety nets (a template SOP can be found [here](#))
- All patients moved to a PIFU pathway are logged and tracked on the organisation's IT system, and reports can be generated in line with data reporting requirements.

As PIFU becomes more widely adopted, further practices will likely be added to the minimum quality standards, such as the evaluation of patient outcomes and experience measures.

PIFU process

- **Should there be a centralised booking for PIFU appointments or can specialties manage their own booking systems?**

Different providers have used different approaches for booking appointments – some do it centrally through their contact centre whereas in some specialties, patients contact the service directly or through a patient portal.

- **What information should be given to patients when they are put on a PIFU pathway?**

Clinicians should ensure that patients have a good understanding of PIFU and how and when to contact services. Patients should be provided information on which symptoms to watch out for, when to contact the service and details on how to contact the service for an appointment. The information can be sent both digitally (e.g. via email and SMS messages) and as a hard copy handed/posted to the patient so they can keep track of their PIFU information. Some examples of [patient information resources](#) from providers are available on the FutureNHS workspace.

The information should also be communicated to the patient's GP so they are kept informed.

- **How should providers manage clinic capacity to accommodate PIFU appointment requests?**

Evidence shows that PIFU helps to reduce waiting times and service waiting lists due to a net reduction in follow-up appointments ([Hewlett S et al, 2005](#); [Wickham-Joseph R et al,](#)

[2019](#)). A [planning tool](#) that estimates avoided outpatient activity for PIFU is available on FutureNHS workspace.

Providers may wish to accommodate PIFU slots in established clinics or by setting up PIFU-only clinics. In either case, the following considerations should be made:

1. **Establish acceptable waiting times** to ensure patients are seen in a clinically appropriate time.
2. **Establish booking process** to ensure patients can access services easily and any unused PIFU slots are utilised.
3. **Measure and adjust on an ongoing basis**, to ensure capacity is appropriate for demand.

It is important to consider that using PIFU will mean that patients who are managing well are unlikely to need an appointment and as a result, clinicians may see more patients with complex needs, which may require more time.

- [Is there a risk that the demand for follow up appointments in some services could increase?](#)

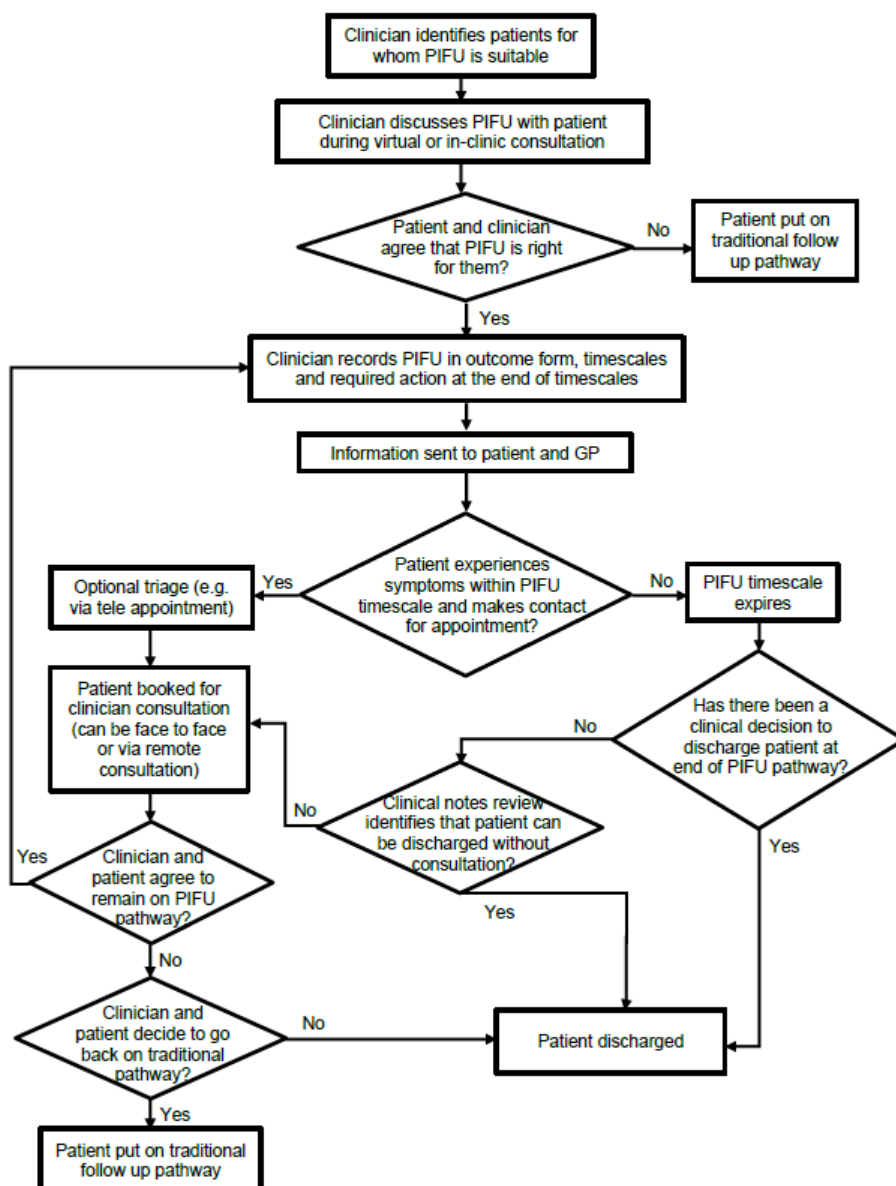
Generally, services tend to see a reduction in the number of appointments. If a service finds that the number of appointments is increasing, it is likely to reflect that the service has significant unmet need.

- [What does a typical PIFU pathway look like?](#)

An example process map for a typical PIFU pathway is available in the [SOP template on FutureNHS](#) (see figure below). It is recommended that

- How long a patient is placed on the PIFU pathway should be a clinical decision depending on service, patient's condition and their individual circumstances. This may range from, for example, 6 weeks for post-operative patients, to 5 years for patients with long term conditions.
- Patients who contact the service while on a PIFU pathway should have their PIFU end date reviewed and updated as necessary. Depending on the service, patients may be discharged to primary care after a length of time on a PIFU pathway, or for acute conditions, they may have an appointment booked to check in or to run tests.
- While on the PIFU pathway, patients will be seen at a frequency that complies with the clinical guidance for their condition, e.g. annual reviews for patients with some

An example PIFU Process



long term conditions. If these patients do not initiate an appointment within that timeframe, they should be contacted by the service for an appointment.

- If the clinician has assessed that the patient is suitable for discharge to primary care without clinical review at the expiry of the PIFU period, this should be recorded in the patient's records (at the start of the PIFU pathway ideally). If there is no further request for an appointment from the patient, services can set up automatic discharges. In other cases, a clinical review for the patient before discharge to primary care will be required.
- For patients who require a review at the end of their PIFU pathway, the clinician and patient may decide to extend their PIFU depending on the service, patient's condition and their individual circumstances.

- [What is the role of primary care in PIFU?](#)

Services should communicate with the patients' GPs to ensure they are kept informed (such as through copying patients' letters) so that they can signpost the patient to the service if the patient contacts them.

If a patient loses mental capacity, for instance through an advancing of dementia, it may mean that PIFU is no longer appropriate for them (although in some cases, the responsibility of initiating appointments can be shared with a carer). In such instances, primary care should inform the service so the patient can be moved back to the timed follow-up pathway. It is therefore vitally important that primary care are consulted and informed about the system's approach to using PIFU and when to contact secondary care with any concerns.

It is good practice that both the patient and GP are informed when the PIFU window is closed and the patient is discharged by the service. After this time, the patient will need to get a new referral from their GP if they need further care.

- [Can remote monitoring be used with PIFU?](#)

Remote monitoring describes when the clinical team initiate an appointment based on clinical information obtained through monitoring the patient's condition. This might be done through using wearable technologies, apps, clinical questionnaires or from test results.

This can be used alongside PIFU. Through remote monitoring, the clinical team can trigger an appointment when required, based on clinical information obtained from monitoring the patient's condition. A patient can be on both pathways for the same condition at the same time.

Data and reporting

- [What PIFU data should we report nationally?](#)

The [recording and reporting PIFU guidance](#) outlines how providers should report PIFU to national datasets.

Data on PIFU will be captured in the Commissioning Data Set (CDS) as part of the version 6.3 upgrade. These are covered in NHS Digital's webinar [here](#), and the Information Standards Notice [here](#).

For Elective Recovery Fund related data requirements, please refer to the [ERF PIFU FAQs](#).

- What data should we use to help manage our services?

Before moving any patients onto a PIFU pathway, we would recommend that you ensure that you have a robust process for monitoring the number of patients on a PIFU pathway:

Headline metrics	Process measures	Other outcomes and experience measures
Total number and proportion of patients on the PIFU pathway Patient outcomes, e.g. recovery rates, relapse rates Waiting times DNA rates	Number and proportion of patients who are: <ul style="list-style-type: none"> • put on a PIFU pathway following an appointment • discharged to primary care from PIFU pathway • discharged to primary care without being put on a PIFU pathway • taken off the PIFU pathway and put back on the routine follow-up pathway Average time between an individual patient's appointments at different stages of treatment Number of patients on the PIFU pathway who: <ul style="list-style-type: none"> • made contact with the service and had an appointment booked • made contact with the service but had their issues resolved without requiring an appointment Patient demographics and numbers of patients for whom specific conditions are being managed	Patient and staff experience measures Changes in patients' knowledge, skills and confidence (activation) Workforce productivity measures

- What is the difference between patient episodes recorded as 'discharged to PIFU' or 'moved to PIFU'?

In both cases, patients are placed on the PIFU pathway and have the option of booking a follow-up appointment if they have a change in symptoms or circumstances. We are aware that different providers/services have either of the two systems in place - some providers discharge the patients on the trust system (these are recorded as 'discharged to PIFU') whereas others do not discharge them and they remain on the trust system (recorded as 'moved to PIFU').