

# Ensuring high quality care when using patient initiated follow-ups

November 2020 Version 1

## Introduction

[Patient initiated follow-up](#) (PIFU) was highlighted as a priority for COVID-19 recovery in the NHS phase 3 [letter](#) on 31 July. Many providers are now rapidly implementing PIFU to help manage their waiting lists, and face challenges balancing the risk of growing unmet need in the population with risks on individual patient outcomes. As PIFU is implemented at pace, it is important that patients placed on a PIFU pathway continue to experience safe, high quality care.

This guidance outlines how to ensure patients are tracked and experience a streamlined and personalised PIFU pathway. It is designed to be read alongside the guidance in the phase 3 [implementation document](#).

## What is patient initiated follow-up?

PIFU<sup>1</sup> is when a patient (or their carer) can initiate their follow-up appointments as and when required, eg when their symptoms or circumstances change. As well as giving patients timely access to support, this avoids unnecessary routine 'check in' appointments.

This can benefit patients through:

- empowering them to manage their own condition, and be part of the decision-making process ([shared decision-making](#))
- enabling them to have appointments when they need them (eg when their condition flares up or their symptoms change)

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<sup>1</sup> PIFU is not a new concept. It is sometimes called 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.

- reducing unnecessary trips to hospital and the associated travel costs, time needed to attend an appointment, lost income, anxiety
- improving their knowledge, skills and confidence to manage their condition ([patient activation](#)).

## Key considerations

Standards must be met in terms of safety, effectiveness and customer service when using PIFU. In implementing PIFU, 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.

### Identifying which patients are right for PIFU

A patient's ability to benefit from PIFU needs to be carefully considered. The full list of criteria is given in the phase 3 [implementation document](#), but as a minimum providers should:

1. Ensure they have locally developed or adapted clinical guidance in place in each specialty where PIFU is used.
2. Embed [shared 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.
3. 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.
4. 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 and good patient experience, as well as forecasting impact on demand for services. It is essential that providers:

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

## Safety nets

Providers must ensure:

6. 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.
7. 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.
8. Patients who contact the service while on a PIFU pathway have their PIFU end date reviewed and updated if necessary.
9. High risk patients who do not attend appointments are contacted to rebook their appointment
10. 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.

Systems and providers should develop their own risk registers and equalities health impact assessments, and regularly review these to ensure that risks to patients are fully mitigated. Particular consideration should be given to how PIFU may need to be adapted to work for vulnerable groups.

## Support offer

NHS England and NHS Improvement are committed to supporting systems and providers to implement PIFU. National resources are available on our [FutureNHS site](#); we are running a rapid adopter programme to support 22 providers implement PIFU; and providers can seek local support from their NHS England and NHS Improvement regional teams.

The NHS Cancer Programme is supporting the roll out of PIFU in cancer via the cancer alliances, as part of personalised stratified follow-up (PSFU) in the [living with and beyond cancer programme](#).