

Implementing patient initiated follow-up (PIFU) in dermatology services

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This guide supports dermatology services in setting up formalised patient initiated follow-up (PIFU). It supplements the [Implementing patient initiated follow-up guidance for local health and care systems](#) and is supported by resources developed in collaboration with the [British Association of dermatologists](#).

This guidance has been developed with the involvement and feedback of key stakeholders including patients, dermatologists, GPs and specialist dermatology nurses, and relevant organisations such as the British Association of Dermatologists (BAD), National Eczema Society, Psoriasis Association, Primary Care Dermatology Society, British Dermatological Nursing Group, and the Getting It Right First Time (GIRFT) programme.

1. Why use PIFU in dermatology services?

PIFU is not a new concept for dermatology specialist services. Historically many departments offered open access follow-up, particularly for people with long-term skin conditions such as psoriasis and eczema; the process often linked to a nurse-led helpline. Patients welcomed and valued this service.

In recent years commissioning and contracting arrangements have made it more difficult to offer open access follow-up. Patients are now often discharged from specialist care at the end of treatment and then need to obtain a new referral and re-join the routine waiting list when their skin condition flares up.

The emphasis on personalised follow-up and PIFU in the [2021/22 Priorities and Operational Planning Guidance](#) provides an opportunity to create a robust process to ensure people can access timely specialist dermatology care as and when they need it. The opportunity to formally manage the PIFU process where an informal approach currently exists will mean patients have better and more reliable re-access to services when they need it, as well as enabling services to better understand and forecast demand.

2. Which patients could benefit?

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](#).

People with skin conditions most likely to be suitable and who might benefit

- People with long-term skin conditions such as psoriasis and eczema who are capable of effectively managing their condition and feel confident in noticing and acting on changes in their symptoms and initiating an appointment. These skin conditions can flare up unpredictably, and prompt access to specialist care will ensure swift control of the disease.
- People who have been assessed by a specialist and started treatment where there is flexibility about the need for and timing of a review appointment. Generally they will have a moderate inflammatory skin disease that is controlled with topical treatments.
- People who have completed phototherapy (eg people with psoriasis). Their prompt re-access to specialist assessment is essential as their condition can remit and relapse over a period of many years.

Patients who are less likely to be suitable

- People on long-term systemic treatments (such as biological treatments) who need to be reviewed at regular intervals to meet the monitoring requirements. However, PIFU could be used alongside planned review appointments provided it is agreed with the patient when PIFU is appropriate.

Patients for whom the PIFU pathway is not suitable

- Patients with low levels of knowledge, skills, and confidence to manage their follow-up care and/or no carer support Any individuals for whom the healthcare professional has safeguarding, consent, capacity or health literacy concerns.

PIFU and people with skin cancer

- People with a diagnosis of skin cancer will usually have their needs met by the standards set for skin cancer services including access to key worker support as required.
- The development of [personalised stratified follow-up](#) (PFSU) for people with skin cancer may change these arrangements.
- Some organisations may choose to use PIFU for patients with skin cancer. However, by developing the PIFU pathway for people with other skin conditions, the opportunity for people with conditions other than skin cancer to re-access care in a timely fashion will be increased.

3. Designing a PIFU model in your dermatology service

We recommend that organisations adopt a consistent approach for PIFU and tailor this to the needs of each specialty and to suit the service's casemix. The dermatology 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. Resources are available to support developing and implementing the PIFU process and have been developed in collaboration with the [British Association of Dermatologists](#).

Considerations particularly relevant to dermatology are:

- PIFU should not increase specialist activity but rather ensure that the right patients can access specialist care when they need it, particularly those with long-term skin conditions, which can remit and relapse over many years.
- Careful patient selection supported by clear explanation of PIFU (verbal and written) and shared decision-making will support the delivery of a good service without the need for additional specialist activity and resources.
- Where appropriate PIFU will be negotiated with the patient, but in the case of a child with the parent and with the carer for a patient who lacks mental capacity.
- PIFU can be activated by healthcare professionals, including those in primary care, on a patient's behalf.
- Consideration should be given to innovative approaches to the delivery of PIFU services, eg offering PIFU appointments in an integrated local community service rather than an acute hospital setting.

- PIFU should not compromise continuity of care; this should be maintained wherever possible.

Process

During consultations with patients for whom PIFU is suitable, the clinician will explain the PIFU pathway, how it would work for the patient (ie as an alternative to or in combination with regular review appointments) and how PIFU could benefit them.

For patients who agree that PIFU is appropriate for them, the clinician will:

- Provide information about how to manage their skin condition, remind them how to obtain their regular prescribed treatments and discuss the symptoms to watch out for that might necessitate specialist review.
- Explain how to access a PIFU appointment if this becomes necessary and be clear about the expected timescale for a response from the dermatology service.
- Agree the PIFU timeframe (may be up to five years for some patients especially with psoriasis) and explain what will happen at the end of this, ie patient will be discharged or have a clinical review.
- Explain that they have the option to go back onto the traditional timed follow-up pathway at any stage if PIFU is not working for them.
- Give the patient the opportunity to ask questions. The decision whether PIFU is right for them should be a shared one.

4. Implementing the PIFU model for dermatology services

You are likely already to be using some form of informal PIFU in your dermatology service. Therefore, as a first step to implementing formalised PIFU, you may find it helpful to review your current set up to understand how it is currently working, specifically:

- Which patients are you using PIFU with in some form?
- Is this recorded in your system (eg Patient Administration System)?
- What communication do patients receive?
- What safety nets do you have in place?
- What data do you have available? Do you have data on which patients are being treated under different pathways?
- Which other services in the organisation are using PIFU (or PSFU for cancer)?
- What technology does the organisation have that would support your approach (eg patient portals)?

Once you have understood your current set up in detail you can then start to plan your rollout. It may be helpful to contact your NHS England and NHS Improvement regional teams who may be able to connect you to organisations who have already rolled out PIFU in dermatology.

We suggest rollout of formalised PIFU starts with specific groups of patients (eg people with psoriasis) before expanding it to cover most of the dermatology service.

To support internal engagement it will also be especially important to communicate the benefits of formalising PIFU for both patients and clinicians.

The specialty clinical team will be responsible for developing clear guidance to inform the delivery of the PIFU service for people with skin conditions. This guidance document should provide clear criteria for who is suitable for the service and will include statements and details about the following:

- Written information for the patient about how the service works for people with skin conditions and information for the GP.
- The contact telephone number or email address for patients to access the PIFU service.
- Specialist teams may choose to use an answerphone service to allow dermatology administrative staff to screen messages, with triage to relevant clinicians as appropriate.
- Arrangements for either call-back or email response to the patient to understand the symptoms they are experiencing, within an agreed timeframe, usually two working days.
- The importance of the request for a PIFU being passed to the healthcare professional who agreed PIFU with the patient; a decision can then be made about appropriate next steps.
- An agreed process for the timely booking of the clinical interaction in response to the PIFU; as appropriate to the patient this could be a telephone, video or face-to-face consultation.
- Administrative process for recording patients on a PIFU with a clear plan for what will happen at the end of the PIFU timeframe.
- Clear guidance on measurement of outcomes of PIFU appointments (referral for phototherapy, consultant review, back on PIFU, regular follow-up) and the impact of the service including on patient experience.

5. Duration of the PIFU timeframe and end of PIFU review arrangements: personalised care

Patients with long-term skin conditions, particularly psoriasis, may have prolonged periods of remission between episodes of severe widespread disease. A pragmatic and personalised approach towards the duration of PIFU and its review will be necessary.

- The clinical team should agree the process for reviewing PIFU; this could involve a notes review followed by a text message or a phone call to the patient.
- The PIFU duration should take account of the maximum length of time that the clinician feels is appropriate in terms of not seeing the patient.
- People who have been seen for a first appointment by a specialist for a moderately severe inflammatory skin disease which can be controlled with topical treatments may have a relatively short PIFU so that their response to treatment can be assessed.
- For patients with long-term conditions, particularly psoriasis and especially guttate psoriasis, PIFU for two years may be appropriate, with review and possible extension at the end of this.
- Patients should not be discharged at the end of their PIFU timeframe, unless the clinical decision is to do so.

Personalised care approaches operated through the PIFU pathway empower and enable patients to better manage their own condition. It is particularly important that there is a shared decision with the patient on whether PIFU is right for them. In dermatology that may include a discussion on coping with flare ups.

6. Risks

- Patients may access the service more frequently than their condition requires, increasing rather than decreasing the workload for clinicians and administrative support staff.
- PIFU requires the patient to be proactive. Patients with long-term skin conditions have often shared with the patient organisations their reluctance to seek help and advice from specialist services. Patients may not activate a PIFU appointment early enough and stronger treatments may be needed as a result.
- Although patients are experts by experience, they are not always best placed to recognise when specialist help and advice may benefit their care.
- Loss of continuity of care. The patient may be seen by a different clinician when they attend on a PIFU pathway; ideally there should be continuity of care.

- Lack of clinical and/or administrative capacity to support the PIFU service effectively; in particular for ensuring that the patient is contacted at the end of the PIFU period to agree next steps.

Mitigating these risks

Many of these risks can be mitigated with careful selection of patients for PIFU from assessing their knowledge of their condition and skill and confidence in self-managing it, as well as by providing patients with detailed verbal and written information about self-management and the circumstances when they should activate their PIFU appointment.

Resource to support, develop, implement, monitor and evaluate PIFU will be necessary, and the detailed specialty-specific clinical guidance fully developed before the service is implemented. A shared decision-making approach when agreeing PIFU will also mitigate risk.

Health inequalities

As with all aspects of a specialist dermatology service it is important to provide access to PIFU services by telephone, video and face-to-face consultations to avoid inequality of access to care. When selecting people suitable for this service, their accessibility to the service should be considered. 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.