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Setting up patient-initiated follow-up services for people with heart failure

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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 guide is intended to support systems and trusts in setting up formalised patient-initiated follow-up in their services. It is intended to supplement the Implementing patient-initiated follow-up PIFU guidance for local health and care systems.

This guidance has been developed with the involvement and feedback of key stakeholders including patients, cardiologists, cardiac scientists, general practitioners and specialist heart failure nurses. These represented organisations such as Pumping Marvellous, British Heart Foundation, Primary Care Cardiovascular Society, as well as the Getting It Right First Time (GIRFT) programme and other colleagues across NHS England and NHS Improvement.

1. Why use PIFU in heart failure?

Specialty context for heart failure and continuous PIFU pathway management

There are an estimated 920,000 people living with heart failure in the UK and around 200,000 new diagnoses every year. This represents a significant group of people living with a progressive long-term condition, many of whom require care and support to live well with self-management advice and a clear clinical point of contact in the event of worsening symptoms.

Heart failure is a common cause of unplanned hospital admission in the UK with more than 100,000 hospital admissions each year.

NICE guidance recommends that heart failure should be managed by a multidisciplinary team (MDT) in an integrated way across care settings. The MDT plays a co-ordinating role, helping all heart failure patients to understand their condition and avoid hospitalisation, ensuring where possible they have an appropriate care plan and are referred to services they need in either secondary care or community care.

Ideally, the MDT should act as a first contact point for all heart failure patients during exacerbations of their condition and they should work collaboratively with all stakeholders to provide co-ordinated care that holistically supports the patient, carers and their families.

All heart failure patients should have access to a PIFU pathway if the clinician thinks they are suitable. Generally, PIFU uses:

- timed PIFU pathways, where PIFU is offered as a service for a predetermined length of time before discharge back to the GP
- continuous PIFU pathways, where a long-term condition means the patient requires on-going access to a specialist team when the patient feels it is necessary.

As heart failure is a long-term condition, these patients should be placed on a continuous PIFU pathway so they can access the heart failure MDT for ongoing help and support. This will avoid the need to go back to their GP for another referral, which may unnecessarily delay their care and access to expert help. PIFU enables the patient to connect back with the heart failure MDT when they need help because their condition has an uncertain disease trajectory. It is highly likely that specialist input will be required during periods of decompensation that will warrant a clinical review.

There may be exceptional cases where a continuous PIFU pathway may not be suitable. Placing a patient on any type of PIFU pathway is always at the discretion of the clinician in agreement with the patient. When patients are placed on a PIFU pathway they need a comprehensive understanding of the PIFU process, how and when to call for help and appropriate education and support in self-managing their condition.

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 and health care systems.

Heart failure patients who are most likely to be suitable and who might benefit

Heart failure criteria:

- Heart failure with reduced ejection fraction (HFrEF).
- Heart failure with preserved ejection fraction (HFpEF).
- Heart failure with mid-range reduced ejection fraction (HFmrEF).

Regardless of the type of heart failure, all patients should be stable and have medicines optimised before transfer to PIFU.

Patient details:

- The patient is aged 18 and over.
- The patient or carer understands and/or accepts the meaning and principles of a continuous PIFU pathway or has a carer who is willing to accept responsibility for monitoring the patient's heart failure condition on behalf of the patient.
- The patient or carer understands and feels confident using the heart failure traffic light system for managing symptoms and knows how and when to call for help. Understanding the PIFU process will require patient and carer education from the heart failure MDT.

Patients not suitable

Heart failure criteria:

- Patients with outstanding investigations or decisions to be made regarding further options for care.
- Patients who are potential candidates for device therapy (CRT and/or ICD) according to NICE/ESC guidelines but are still awaiting further diagnostic investigations and/or therapeutic interventions.
- Heart failure patients with uncontrolled symptoms.
- Heart failure patients who are being managed on an end-of-life care pathway.

Patient details:

- The patients who are unable to contact the service in a timely way(eg, lack of access to telephone/internet).
- The patients with low levels of knowledge, skills, and confidence to manage their follow-up care and/or no carer support.

2. Designing a PIFU model in your heart failure service

We recommend that organisations adopt a consistent approach for PIFU, and it is important that this is tailored to the needs of each heart failure MDT and adapted to suit the service's case mix. The heart failure team should have overall responsibility for the development of clinical guidance, risk stratification, protocols or a standard operating procedure (SOP) relating to the implementation and delivery of a continuous PIFU pathway within their service.

Considerations specific to heart failure are:

Placing a patient on a heart failure continuous PIFU pathway

- The decision to put a patient on a continuous PIFU pathway lies with the heart failure clinician in charge of the patient's care in consultation with the patient.
- It is essential that all patients on a PIFU pathway are placed on a register such that they can be tracked to avoid any immediate or long-term harm in their management. Please refer to the PIFU handbook for further guidance.
- If a patient needs to be removed from a continuous PIFU pathway this should not necessarily be dependent on the decision of the heart failure MDT or GP but could also include hospital teams such as the dementia team, care home, social prescribers, and pharmacists so long as this is fed back to the heart failure MDT and the relevant clinical records and patient administration tracking systems are updated.
- If necessary, these teams should be able to contact the heart failure PIFU service on the patient's behalf should the patient be unable to do so.
- Carers should also be able to contact the heart failure PIFU team on the patient's behalf and have conversations with them about any concerning symptoms.
- Ambulance teams should also be aware of the PIFU service and how it impacts on a patient pathway should they become involved in assessing and managing a heart failure patient.
- If a patient is placed on a recommended summary plan for emergency care and treatment (ReSPECT) process or end-of-life pathway all teams involved in the patient's care should be informed and the patient should be removed from the PIFU pathway and managed in the most appropriate way for their care needs.
- PIFU is not an alternative to discharge and suitable patients should be discharged using routine trust guidelines.
- The patient should have the option to decline PIFU if it does not suit their needs with reassurance that their decision will not affect their on-going care.

Shared decision making

Once PIFU has been considered as a suitable option, a shared decision making conversation should take place with the clinician, patient and/or carer. Shared decision making is a collaborative process that involves the patient/carer and their health care professional working together to reach a joint decision about care.

To be able to achieve this the patient and/or carer needs to be able to understand the risks, benefits and any consequences of a PIFU pathway. It should cover:

- why the patient is suitable for PIFU
- comprehensive information and education of the traffic light system for managing symptoms
- how to contact the PIFU helpline with appropriate leaflets, websites and phone numbers given to the patient and/or carer in a suitable format that they can easily understand
- the expected timescales within which to expect a response from the heart failure MDT if the patient and/or carer calls for help
- how a continuous PIFU pathway works between primary and secondary care and any other organisations involved in their care
- how the PIFU pathway links with any community-based heart failure services such as cardiac rehabilitation or community heart failure specialist nursing teams
- how PIFU links with any remote monitoring devices or additional timed follow up appointments (eg, for medication monitoring, symptom management, blood tests)
- how PIFU works with their heart failure care plan (if they have one) and how the two elements work together
- watching/listening to any videos available that explain the PIFU process in more detail
- encouraging questions and discussions about PIFU and checking the patient and / carer understands about how the service works
- clarifying that the patient can change their mind about PIFU and revert to traditional follow up if it is not working for them at any time.

Shared decision making conversations, copies of care plans and remote monitoring services should be recorded in the medical records and copies of care plans given to the patient and/or carer and a copy sent to the GP. Ambulance and out of hours services including 111 primary care should be proactively involved in the PIFU scheme to support admissions avoidance and unnecessary use of emergency care departments.

When PIFU has been confirmed the clinician should record this on the trust clinical outcome form (COF). The COF, either paper or electronic, will need to specify that the patient is now on a PIFU pathway for heart failure. The GP will be informed that the patient has moved to this pathway by letter.

A change in a patient's situation while on PIFU

While on a PIFU pathway a patient may become unwell with another clinical condition (eg develop dementia) or the patient's carer may become unwell, or the patient may be moved to a care home. The risk is that the patient may no longer be safe on a PIFU pathway. Should this situation arise, the GP or member of the primary/community care team would need to contact the heart failure MDT and update them on the change in the patient's circumstances. A change such as this will enable the MDT to decide if a continuous PIFU pathway remains the safest way to care for the patient or if an alternative plan needs to be made.

Triage

Continuous PIFU pathway management using the traffic light system

Heart failure symptoms for patients on a continuous PIFU pathway can be managed using a traffic light system to help patients and/or carers decide when to call for help and which service is the most appropriate to use.

Criteria for activation	Symptoms	Action
RED: TAKE ACTION Not suitable for contacting the PIFU service	Severe breathlessness, chest pain, palpitations and syncope, symptoms of infection, other medical conditions worsening, transient loss of consciousness, feeling confused about medication, diarrhoea or vomiting for more than 24 hours.	Urgent advice from GP or dial 999 or NHS 111 out of hours
AMBER: STAY ALERT Suitable for PIFU help and support	Weight increase by four pounds or two kilograms over 3 days AND feeling more breathless than usual, leg swelling, breathless at night, needing more pillows to sleep, less active than usual, feeling muddled, other conditions are worsening, carer is unwell and unable to look after the patient	Contact the PIFU service for advice and consider a review with the HF MDT

GREEN: KEEP WATCH Suitable for PIFU help and support	Weight has increased/not increased by four pounds or two kilograms over three days BUT no more breathless than usual, ankles no more swollen than normal, all medical conditions are stable, active, and mobile as normal, carer is well and able to look after the patient	Contact the PIFU service for advice if necessary

Target response times

- The target response time should be two days working from the patient calling the PIFU helpline to speaking to a member of the heart failure MDT. The responding clinician will decide if the patient requires any tests and/or a consultation and the timescales within which this should occur.

  It is strongly recommended there is a robust process in place to clinically assess and monitor the turnaround time of calls and clinical reviews. Should there be response time delays or lack of clinic capacity for patients needing to be seen this should be raised urgently with the heart failure clinical lead and outpatient performance manager.

  Any response time delays should be communicated to the patient and/or carer and if there are safety concerns about the patient's condition an alternative plan should be created and communicated to the patient and/or carer.

  Patients experiencing red flag symptoms should seek urgent advice from GP or dial 999 or NHS 111 out of hours as per the table above, and this should be explained clearly to the patient at the start of the pathway.

- Any safety incidents relating to patient management on a PIFU pathway should be documented and an appropriate incident form completed. There should be a robust process in place for regularly reviewing any clinical incidents related to heart failure patients on PIFU pathways with the trust patient safety team and lead heart failure clinician. Similarly, safety concerns about PIFU pathway management in primary and community care should be fed back to the lead heart failure clinician.

Technology

Where appropriate technological devices should be utilised to manage the patient as efficiently as possible.

- Consider use of Telehealth to identify early signs of decompensation and aid medication optimisation.

- Consider use of mobile Apps for HF to reinforce criteria for PIFU with clear points of contact, Red, Amber, Green signs to prompt self-referral, mood monitoring, medication prompts, prompts for appointments and educational videos.
- Remote monitoring through devices which detect fluid overload and detect and treat arrhythmias as appropriate.
- Around 25% of HF patients are followed up regularly in pacing clinics (either remotely/face-to-face) which enables rapid detection of new atrial fibrillation/decreased biventricular pacing/change in symptoms/hours of patient activity/optical or other alarms.

Personalised care

Personalised care approaches operated through the PIFU pathway can offer more effective ways to empower and enable patients to better manage their own condition. Continuous PIFU pathways, personalised care and remote monitoring are interlinking elements of integrated care that enable the patient to receive their care close to home while remaining under the care of the heart failure MDT.

Where possible, patients should be given a heart failure care plan to support the PIFU pathway. Local services based in the community such as social prescribing, peer support and cardiac rehabilitation should be offered to enhance the quality of the PIFU pathway and maximise the opportunities for the patient to manage their care as independently as possible within their local community.

Health inequalities

About 10% of people with heart failure have significant cognitive impairment that can prevent them from being able to engage with the PIFU process, where appropriate it is important to involve carers with this process to support the patient. 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

Engagement with patients and patient groups

Through listening and talking with patients and/or carers about PIFU these are the things that they say matter to them most about the process:

- Discussions around PIFU should start at the point of diagnosis as PIFU is part of their whole treatment and care pathway. Discussing PIFU early in the pathway means that patients have plenty of time to think, ask questions and raise concerns as they move through their treatment.

- Patients can suffer with information overload if too much complex information is provided in one consultation. Having more than one conversation about PIFU means that the patient has time to absorb information and reflect on what it means to them.

- Careful consideration should be given to the significant emotional impact of a heart failure diagnosis and the effect it has on the patient's daily life. As part of PIFU and their ongoing care, patients have asked that specific attention is given to their emotional well-being and the extra support they may need to cope with their diagnosis.

- It is important that the MDT, primary and community care management of PIFU is well co-ordinated and clearly communicated. Obtaining regular feedback from patients and carers about their experience of PIFU will enable the MDT to understand the patient experience and ensure that services are adapted to meet their needs where possible.

The involvement of patient and patient groups in the development of any local PIFU guidance, standard operating procedures, or patient information leaflets is recommended to ensure the patient and carer voice are represented in these materials. Engagement can be obtained through organisations such as GP patient participation groups. NHS England has produced guidance on patient and public participation for all commissioners of health services, both within NHS England and CCGs.

Appendix 1

We are grateful to the following stakeholder members of the Advisory Group for their involvement in the development of this document.

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