

## Guidance: Patient Initiated Follow Up in Neurology Services

### - Background, case study and principles

## Introduction

For many people with neurological conditions, ongoing NHS care is needed. This is often in the form of follow up appointments after an initial assessment appointment(s) or following an intervention such as surgery or a course of treatment.

In recent years the personalised care agenda has focussed on changing the way healthcare is conceived of, planned and undertaken. It has increasingly been affording individual patients equal participation alongside healthcare professionals in decision-making about their care and treatment. One of the initiatives that has developed is Patient Initiated Follow Up (PIFU).

Broadly, PIFU changes how appointments are allocated. Rather than being given a routine follow-up clinic appointment at a given time interval after the last, PIFU puts the onus on the patient to get in contact to make an appointment if/when they feel they need one. So rather than having a regular or prearranged clinic visit, PIFU enables the patient to judge when they need an appointment based on their symptoms and related concerns. Research in other clinical specialities (MSK, oncology) has suggested that having a regular or prearranged outpatient follow-up does not either help to prevent people's condition returning or identify new problems.

PIFU stands in contrast to the standard (professional led) follow up pathway whereby individuals continue to have scheduled face to face, video, phone, or email contact with their clinical team as part of continuing follow up. This may be clinically triggered follow up, when the clinical team initiate an appointment when required based on clinical information obtained through monitoring the patient's condition (e.g., using wearables, apps or clinical questionnaires) or from test results. Or it may be timed follow up, when a patient's next appointment is planned during an appointment, with the length of time between appointments based on the individual patient's needs. In either case, these follow ups are led by doctors, nurses or specialist allied health professionals.

PIFU is not a new concept and has already been used in many different contexts. It 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.

It should be noted that patient initiated follow up is different from patient expedited follow up. In the former, the patient is put on the PIFU pathway for a given period of time, and then usually discharged to primary care unless they have triggered a follow up. Under patient expedited follow up, a patient is given a follow up appointment some time in the future (the latest they ought to be seen by) but given the option to get in touch to trigger an appointment sooner if needed.

## Recent context

In the NHS England and NHS Improvement paper on [Implementing phase 3 of the NHS response to the COVID-19 pandemic](#) published August 2020, there is a section on using PIFU as part of the NHS COVID-19 recovery. This paper suggests that PIFU could play a key role in facilitating provider recovery, as a tool to be used alongside clinical waiting list reviews, remote consultations and a

‘digital first’ approach. The paper signals the win/win approach of enabling shared decision-making and supporting individuals with self-management, by helping them know when and how to access the right clinical input, with concomitant reductions in waiting times and waiting lists due to net reduction in follow-up appointments.

Since this paper was published back in August, we have experienced unparalleled pressures on the health and care system as COVID-19 cases surged over the winter.

Analysis of HES data for periods May – June 2019 and May – June 2020, found that there had already been a heavy impact on the care of those with neurological conditions in the NHS during the first surge in COVID-19 cases. There was on average a drastic decrease in the total number of appointments across inpatient and outpatient care compared to the same period in 2019, although the extent of change differed between localities. All specialties were negatively impacted during the period where the number of cases of Coronavirus were the worst (April – May 2020). These also seem to confirm reports from people with neurological conditions about disruptions to their care. In a Neurological Alliance survey of more than 1,600 people with neurological conditions<sup>1</sup>, conducted in May/June 2020, over 7 in 10 respondents reported delays to their medical appointments during the first peak of the pandemic, and 4 in 10 people didn’t know when their appointment had been delayed until.

The need for solutions to help services re-start and tackle the likely massive back log of delayed appointments is therefore ever more pressing. This paper aims to lay out some principles we believe must underpin the use of PIFU with people with neurological conditions, in light of the recommendation in the Implementing phase 3 of the NHS response to the COVID-19 pandemic document that “individual services should develop their own guidance, criteria and protocols on when to use PIFUs”.

## Review of the literature

In 2020 The Neurological Alliance undertook a short literature review on PIFU, drawing predominantly on studies from other specialties, due to a lack of relevant neuro-specific studies. A very mixed picture of PIFU emerged. Surprisingly, it seemed PIFU made little difference in terms of patient experience, service contacts or adverse effects – although this relied on low-quality evidence. More research is certainly needed. One study suggested that introducing PIFU required strong leadership, teamwork and motivation to make it work properly – suggesting the context for introduction may influence whether or not PIFU works. The single neuro study (epilepsy) did not appear to find the expected results – i.e., improved patient self-management and satisfaction or less use of resources. Finally, an inflammatory arthritis study found while patients welcomed the flexibility and control, they needed adequate information to be able to make decisions and wanted to be able to consult their specialist and specialist nurse. In the qualitative comments, some patients felt obliged to become more alert and felt the overall responsibility for their care should remain with HCPs otherwise it was ‘frightening.’

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<sup>1</sup> From 9 to 20 June 2020 the Neurological Alliance surveyed 1672 people with neurological conditions on the impact that COVID-19 had had on their care – the results were published as part of our [Re-start report](#).

## PIFU in practice case study – learnings from its use in Essex

*[Taken from a presentation to our Policy Group meeting Feb 2021, given by Jane Anderson (Lead Consultant Neurologist, The Princess Alexandra Hospital NHS Trust)]*

### **Description of service under development**

Patient initiated follow ups are used for individuals on an inactive pathway – i.e., for use with those who the neurologists think are stable/have had a one off episode but don't want to discharge lest they deteriorate/experience additional episodes or similar.

The clinician has a conversation with the person with a neurological condition at their outpatient appointment to assess their suitability and whether they want to be on a PIFU pathway. Being put onto the pathway is a joint decision. Those who decide they don't want to be on that pathway are put onto the usual follow up pathway.

If a person is deemed not suitable for PIFU this is flagged on the system – so that colleagues are kept aware in future when they come to make similar considerations.

Those on PIFU pathway are given telephone numbers and booking system – and it is explained to them that the onus is on them to make an appointment. It is explained to them that the PIFU pathway is for their already diagnosed condition, and that it is not an emergency pathway. If they do not activate an appointment within the given timeframe, they are then discharged. Communication is key – it is communicated to both the patient and their GP that they're on this pathway. This enables the GP to activate the PIFU pathway in case of need.

PIFU appointment slots are reserved on the basis that we know 10% of those on PIFU pathway may make an appointment. They are used as needed to allow review within 8 weeks of the patient initiating the follow up, or if not needed, released to patients on the usual follow up pathway.

### **Suitability**

Suitability should be determined by clinical risk and patient capacity. Key exclusions could include those with who haven't got capacity/those who are vulnerable (safeguarding) or with serious mental health problems (apathetic – may not make appointments) should not be on a PIFU inactive pathway. Or those who do need to be seen for a follow up. As such, it tends to be less suitable for those with chronic progressive conditions.

On the contrary it tends to work well with people with migraine, peripheral neuropathy, one-off episodes, or those whose care is being transferred e.g., to tertiary centre.

Suitability/otherwise is based on the knowledge and experience of the clinician rather than any particular screening tools – given the complex set of factors. Decision-making take into account condition and the patient's level of engagement and health literacy varies. Believe this decision needs to be clinician guided but patient appropriate.

Patients with very high health anxiety (who tend to book up appointments very quickly, at the detriment to others) may need a minimal intervention period specified on their PIFU record – to prevent them making unnecessary appointments to quickly.

### Experiences of people using the service

A proper patient experience survey/outcomes evaluation has not yet been done. Wants to look at how PIFU impacts acute admissions/non-elective episodes.

However, Cambridgeshire and Peterborough did a patient survey with 6,000 respondents, which showed that almost 50% said they would be happy to have a number to call if they had concerns rather than a routine follow up appointment.

### Benefits

- Empowering patients, and ensuring they are seen when they need it most
- Most patients like the PIFU flexibility
- Ensures that only patients who really need a follow up have one – so pressure on waiting lists goes down. Only 10-20% of those on PIFU go on to have an appointment.

### Next steps/developing the service

Need to think about using a patient expedited follow up – for patients who we know we do need to see again, but to give the patient the ability to bring the appointment forward if they want to be seen sooner.

The consultant isn't always best placed to provide the follow up needed. In an ideal world a care coordinator would have a role when the person phones up in arranging who they see. Should be pooling all the specialities feeding in/become more integrated. Need to form a web with patient at centre – which includes non-NHS services.

Going forward we need to be more coordinated with primary care – follow up doesn't always need to be in secondary care setting e.g., where there are specialist nurses working in the community.

## Principles

It is widely recognised that PIFU isn't suitable for everyone and that a decision must be made about whether or not this type of follow up pathway is suitable for individuals. In this section we aim to build on the principles for suitability already identified in the In the NHS England and NHS Improvement paper on [Implementing phase 3 of the NHS response to the COVID-19 pandemic](#) and to lay out principles for how PIFU must operate in practice.

### Implementing phase 3 of the NHS response to the COVID-19 pandemic, page 21

For PIFU to be suitable for a patient, they should meet the following conditions:

- at low risk of urgent follow-up care and satisfies criteria established by the specialty

- is confident and able to take responsibility for their care for the time they will be on the PIFU pathway, e.g., they do not have rapidly progressing dementia, severe memory loss or a severe learning disability
- 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 to understand the status of their condition (e.g., devices, leaflets, apps) and understands how to use them
- has the health literacy and knowledge, skills and confidence to manage their follow-up care (patient activation); if they do not, the patient may benefit from support to improve these areas in line with the personalised care approach.
- understands how to book their 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 any of the following conditions are met, the appropriateness of PIFU for the patient 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 also be offered
- the clinician has concerns about safeguarding for the patient
- the patient takes medicines that require regular and robust monitoring in secondary care
- the patient is not able to contact the service easily (e.g., lack of access to a telephone).

#### **Additional principles for PIFU suitability for people with neurological conditions**

- **Age (adult)** PIFU should not be used with children and young people. It is important that children and young people continue to be seen regularly due to much of the support network for education, therapeutic interventions, home adaptations, and welfare benefits depending heavily on clinical reports. Optimisation of such wider supports is essential to secure the best outcome for the child, over the longer term.
- **Self-efficacy** Individuals must understand the importance of making an appointment if they have concerns and indicate a ready willingness to do so. Those who would be reluctant to 'bother the doctor', should be considered ineligible.
- **Likelihood of deterioration** In general PIFU should not be used with those with progressive conditions.
  - If in exceptional circumstances its use is being considered with an individual with a progressive condition, an individual risk assessment should be undertaken both to determine suitability and enable steps to be taken to minimise any risks identified.

## Principles for PIFU in operation in neurology services

- **Following an appointment** PIFU pathways should only be applied following an appointment during which the person's condition and needs can be fully understood - and suitability for the PIFU pathway assessed.
- **Shared decision making** The decision to initiate a PIFU pathway must be taken jointly between clinician and individual with a neurological condition. PIFU should only be entered into where an individual has actively chosen this follow up pathway, and how this fits in with their goals for their treatment and care have been discussed.
- **Written guidance** Individuals must be given clear written guidance about how PIFU applies in their circumstances, including guidance on which changes in their condition or symptoms mean they should get in touch with the service, and how to do so. This should be written up as part of the individual's care plan, which is centred on their goals and needs.
- **Service integration/MDT working** Clarity is needed whether the PIFU pathway is operating solely in relation to the neurology outpatients service, or whether a person can be on a PIFU pathway linking a number of different services. Ideally services should be working in an integrated way, such that it needs to be worked out how PIFU works in relation to service integration.
- **Care coordination** Those on a PIFU pathway should still have a named care coordinator, who is responsible for and empowered to bring any additional services the individual is accessing together around their goals and needs. When the individual initiates a follow up, and where services are working in an integrated way, their care coordinator should be responsible for assessing who this needs to be with from the wider multi-disciplinary team and making the necessary arrangements.
- **Mental health** In addition to their neurological symptoms, individuals' mental health should always be taken into account in considerations of suitability for a PIFU pathway. Those whose mental health could prevent them from undertaking self-management and/or contacting the service should their neurological symptoms change should be considered ineligible for PIFU – and signposted to mental health services. Consideration should be given to the use of existing mental health screening tools to help identify mental health needs.
- **Carers' role** Where appropriate, carers should be welcomed, involved and consulted in the shared decision-making process, with their role explicitly acknowledged.
- **Access to new treatments/therapies** If individuals are on a long-term PIFU pathway, they must not miss out on new treatments or services that they might benefit from. People on a PIFU pathway who may benefit from a new treatment or service should, where possible, be proactively invited to discuss this with an appropriate member of their health and care team. To support this and effective service planning more broadly, services should undertake regular horizon-scanning of emerging treatments, therapies and interventions.
- **Co-production** Services should work with their local community, including people with neurological conditions and patient groups, from the outset of planning and throughout pathway development and initiation. Regular feedback loops between people with neurological conditions and the service should be established.

- **Monitoring and evaluation/feedback loops** Evaluation and audit of PIFU pathways should be undertaken as standard. This should include monitoring of patient outcomes and experience, as well as assessment of how the PIFU service is impacting capacity, waiting times, and non-elective admissions.
- **Safeguards** Services developing a PIFU offering must carefully consider how to ensure that these principles are consistently and rigorously applied, and what mechanisms must be put in place to ensure no one is inappropriately placed on a PIFU.
- **Timeframes** Services should be clear on timeframes – how long individuals will be on PIFU pathways, with a named end date, and a protocol for what happens at this point – be it discharge to primary care, or other option.
  - There should be clarity on whether it is a patient initiated follow up service, or patient expedited follow service i.e., where a patient is given an appointment date but has the option to expedite their appointment as needed – or whether a blended model is being used.

## Future of PIFU in neurology

The principles above should be applied by new and existing PIFU services operating within neurology. Longer term, screening tools could be developed to support the identification of people who could be considered eligible for PIFU.