

# An evaluation of patient-initiated follow-up (PIFU) outpatient services in the English NHS

Executive summary

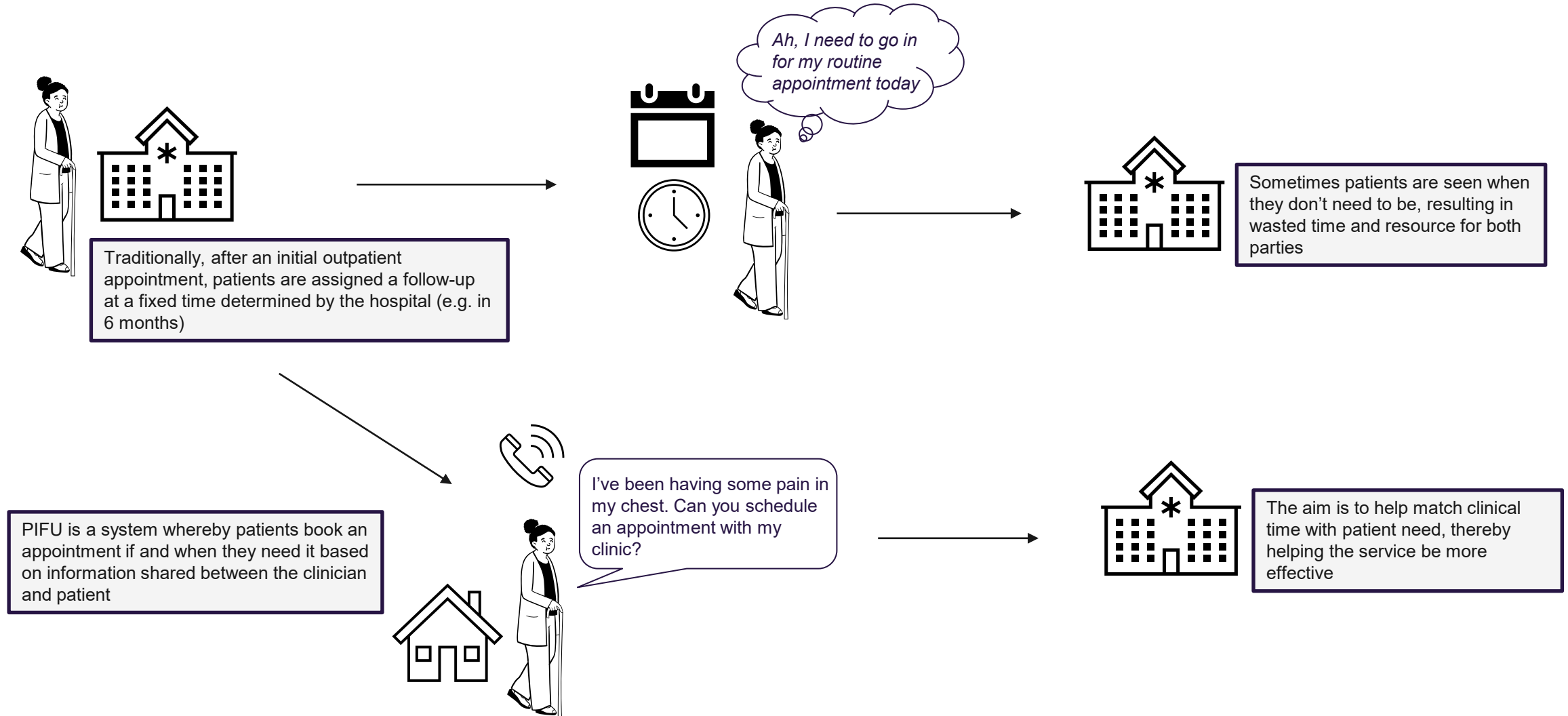
# Statements

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*The NIHR Rapid Service Evaluation Team ('RSET') comprises health service researchers, health economists and other colleagues from University College London, the Nuffield Trust and University of Cambridge who have come together to rapidly evaluate new ways of providing and organising care.*

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# What is patient-initiated follow-up (PIFU)?



# Evaluation questions

## Implementation

- How is PIFU being implemented?
- What components and processes does it involve?

## Measuring impact

- What are the relevant outcomes for evaluating the impact of PIFU services?
- To what extent can we measure the different impacts of these services?
- How are the data being used to monitor the progress against these outcomes and how can the data be used?

## Health inequalities

- What strategies have been adopted to address potential inequalities along the PIFU pathway?
- What data are being collected to understand potential disparities?
- Is there variation in how different patient populations access and engage with PIFU?

## Staff views and experiences

- What are staff experiences of delivering PIFU?
- What is the impact on staff satisfaction, workload and capacity across different roles?

## Patient views and experiences

- What are patient experiences of engaging with PIFU services?
- What is the level of patient engagement?

# Methods

We conducted a rapid mixed methods evaluation over the course of 14 months which included:

- Combining routine hospital outpatient data with data on the uptake of PIFU services to analyse relationships between the use of PIFU and outcomes.
- Analysing local data to assess health inequalities.
- Semi-structured interviews with:
  - 31 clinicians and operation leads across five acute NHS trusts and two with national roles.
  - Three primary care professionals (GPs, Integrated Care Board managers).
  - Four patients.
- Analysis of key documents (e.g. standard operating procedures, equality impact assessments).
- A workshop with NHS trust staff on factors affecting PIFU uptake.

# The implementation of PIFU

## How is PIFU being used?

- In the NHS, PIFU is most commonly being used in short-term pathways (e.g. physiotherapy or following surgery) although there are several examples where it is being used for people with long-term conditions.
- Models of PIFU vary widely between trusts and clinical areas in the approach to patient selection, monitoring and discharge. The nature of the condition was a key influence on how PIFU was implemented.

## Enablers and barriers to successful implementation

- Where PIFU had been implemented successfully, enablers included conditions where symptoms and deterioration were easy to identify, clinical engagement, supporting guidance, champions, dedicated staff capacity and flexible recording systems.
- Barriers to successful implementation included patients not being aware they were on PIFU, perceptions of challenges accessing care, staff resistance, competing priorities and limited capacity to dedicate to PIFU, a lack of engagement with primary care and challenges updating Electronic Patient Record (EPR) systems to record PIFU activity.

# The impact of PIFU on activity and outcomes

## Impact on outpatient attendance and missed appointments

- Increasing PIFU rates appear to be associated with less frequent outpatient attendance and rates of missed appointments, particularly within certain clinical specialties. However, within some specialties increased PIFU rates seem to be associated with more frequent visits.
- This complements findings from interviews with staff and our workshop in that the variety of ways PIFU is implemented can lead to different impacts.

## Impact on visits to ED

- We found no practically significant association between PIFU rates and frequency of ED visits overall (results were statistically significant but of negligible effect size), but a small number of specialties appeared to have less frequent ED visits associated with higher PIFU rates.

## Limitations of data

- Staff at study sites described limitations of their PIFU data for monitoring outcomes locally.
- Existing data is not currently able to capture wider consequences such as the impact on primary care.
- These findings need to be interpreted with the understanding that national patient-level data does not currently record which patients are on PIFU pathways and that there is uncertainty about the completeness of the available PIFU data.

# Health inequalities

## What is known about the impact of PIFU on different patient groups?

- Addressing health inequalities is a priority across the NHS. There is currently limited understanding of the impact of PIFU on different patient groups and it is recognised as needing more investigation.
- Digital exclusion, demographic characteristics, socio-economic status and patient characteristics were all thought to be relevant to how patients engage with or are impacted by PIFU.

## Local evaluation of inequalities due to PIFU

- Local evaluation of outcomes and inequalities is difficult in many trusts due to the problems of reporting PIFU activity on the local electronic patient administration system.
- Data from one site reported differences between children and adults with 17% of children put on to PIFU pathways having a return visit within one year, compared to 11% of adults.

## Staff should avoid making prior assumptions about individuals

- It is important not to make assumptions about how a patient would engage with PIFU because of their characteristics.
- There is also a concern that staff may not be putting people on to PIFU who may benefit.



# Staff experiences

## Staff experiences depend on how PIFU is being used

- The specific characteristics of the model of PIFU being used in a service, as well as the extent to which it is a departure from previous practice, significantly affects how it is experienced by staff.
- The extent to which staff are confident that their service can implement PIFU as intended affects their levels of satisfaction.
- Staff feel strongly that PIFU should act primarily to benefit patients, and their attitudes are often shaped by the extent to which they believe adoption is being driven by this, versus an attempt to meet organisational targets.

## Impact on staff roles and workload

- PIFU can entail significant changes to the roles of clinical staff including taking on new responsibilities and the creation of new, PIFU-specific roles.
- Whilst PIFU has the potential to reduce outpatient attendances, it could increase staff workload in other ways (for example, additional administrative tasks and by interactions which do occur becoming more complex).

# Patient experiences

## Do patients like being on a PIFU pathway?

- We heard from staff that limited activity had taken place to formally capture patient feedback, but they reported anecdotally that patients were positive about PIFU as an approach and the support they had received.
- We were only able to speak four patients as part of our evaluation. But those we spoke to were positive about their experiences and liked the option of contacting a specialist when they needed to.

## Why do some patients decline?

- Reasons for declining PIFU included preference for regular interaction, desire to stick to their routine and concerns about getting appointments.

## Patient engagement with the outpatient service

- Staff were unclear if patients were always contacting the services when they needed to. But, when they did, they did not all require a face-to-face appointment with a consultant.
- Enablers to patient engagement include clear routes to support, communication and ensuring patients don't feel abandoned.
- Barriers to patient engagement included lack of awareness and understanding about PIFU, wider context on access to services and condition-specific factors.

# Implications for policy and practice (1)

- **Realising the impact of PIFU:** Due to existing pressures on the NHS it may be some years before any impact of PIFU on overall capacity is realised. Also, although the number of patients on PIFU is broadly in line with what the NHS have expected, it is currently small in comparison to all outpatient activity.
- **Varied implementation:** Although it is desirable to ensure that PIFU is implemented in a way that is appropriate to individual specialties and organisations, this has implications for understanding how it is being used and for assessing its impact.
- **Communication:** Clear, consistent and accessible information on PIFU and its purpose, to both staff and patients, is key to successful implementation. This includes clarity (for patients and staff) on the difference between PIFU and discharge.
- **Impact on staff and workload:** This largely depends on how PIFU is adopted within services, the numbers of people contacting these services and how clinics are configured. Compared to routine follow-up appointments, clinical interactions could be more complex and time-consuming. There may be greater activity for some roles, for example, nurse specialists having telephone calls with patients.
- **Capacity and demand:** If the numbers of patients placed on PIFU continues to increase it could be that more or alternative capacity will be required – for example to review or monitor patients on PIFU, respond to requests or conduct/ manage clinics. What this looks like will depend on the characteristics of individual services.

# Implications for policy and practice (2)

- **PIFU within the wider system:** PIFU must be considered as part of a wider approach to patient care including its interaction with other interventions such as advice and guidance and self-referral. Engagement with all parts of the system is an important part of this and should be a focal point of the expected Outpatient Strategy.
- **Wider context:** Challenges accessing appointments, particularly in primary care, are well-known. Public satisfaction with the NHS is currently at its lowest level with waiting times for appointments a key factor. There was a particular concern from individuals who had experienced difficulties or long waits for appointments and diagnoses in the first place about what would happen once they were no longer supported by the hospital. This may contribute to patient engagement and attitudes towards PIFU as people may be anxious about whether they will be able to get an appointment when they need one.
- **Engagement:** There is a lack of reliable information on the numbers of people engaging with services with no news often taken as positive. May not be the case for every specialty and may mask situations where individuals are not contacting services when they need to or are receiving care elsewhere (such as ED or primary care).
- **Health inequalities:** There is also a lack of systematic data collection on the impact of PIFU on health inequalities. Lack of staff time may hinder detailed conversations with patients who may require additional support. It is also important to consider digital exclusion. Addressing health inequalities is a priority across the NHS and it is important to consider the impact of PIFU as part of this.
- **Data collection:** Improved data collection processes will be vital to ensuring robust evaluation of impact is possible, including more patient-centred outcomes and changes to staff-patient interactions. The challenge of recording PIFU activity within local IT systems was a consistent theme in this study.

# Recommendations for national policymakers

## Communication and Guidance

- Clear, consistent and accessible information on PIFU and its purpose, to both staff and patients, is key to successful implementation.
- Continue to develop specialty and condition-specific guidance, and share this learning through, for example, a community of practice.

## PIFU within the wider healthcare system

- PIFU must be considered as part of a wider approach to patient care including its interaction with other interventions such as advice and guidance and self-referral. Engagement with all parts of the system is an important part of this and should be a focal point of the expected Outpatient Strategy.

## Data for monitoring and evaluation

- Data collection within services needs to be improved to enable effective evaluation of PIFU and other outpatient innovations. This should include more patient-centred outcomes and monitoring of health inequalities. Outcomes could include PROMS (patient-reported outcome measures) or be derived from primary care data and other secondary care datasets.

## Health inequalities

- Services should assess whether there are disparities in the abilities of different groups of patients to make use of PIFU services and subsequent impacts on their health and care. Cross-organisational bodies (for example, Integrated Care Boards or Commissioning Support Units) may be able to support this work.