

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

Findings from a rapid mixed-methods study

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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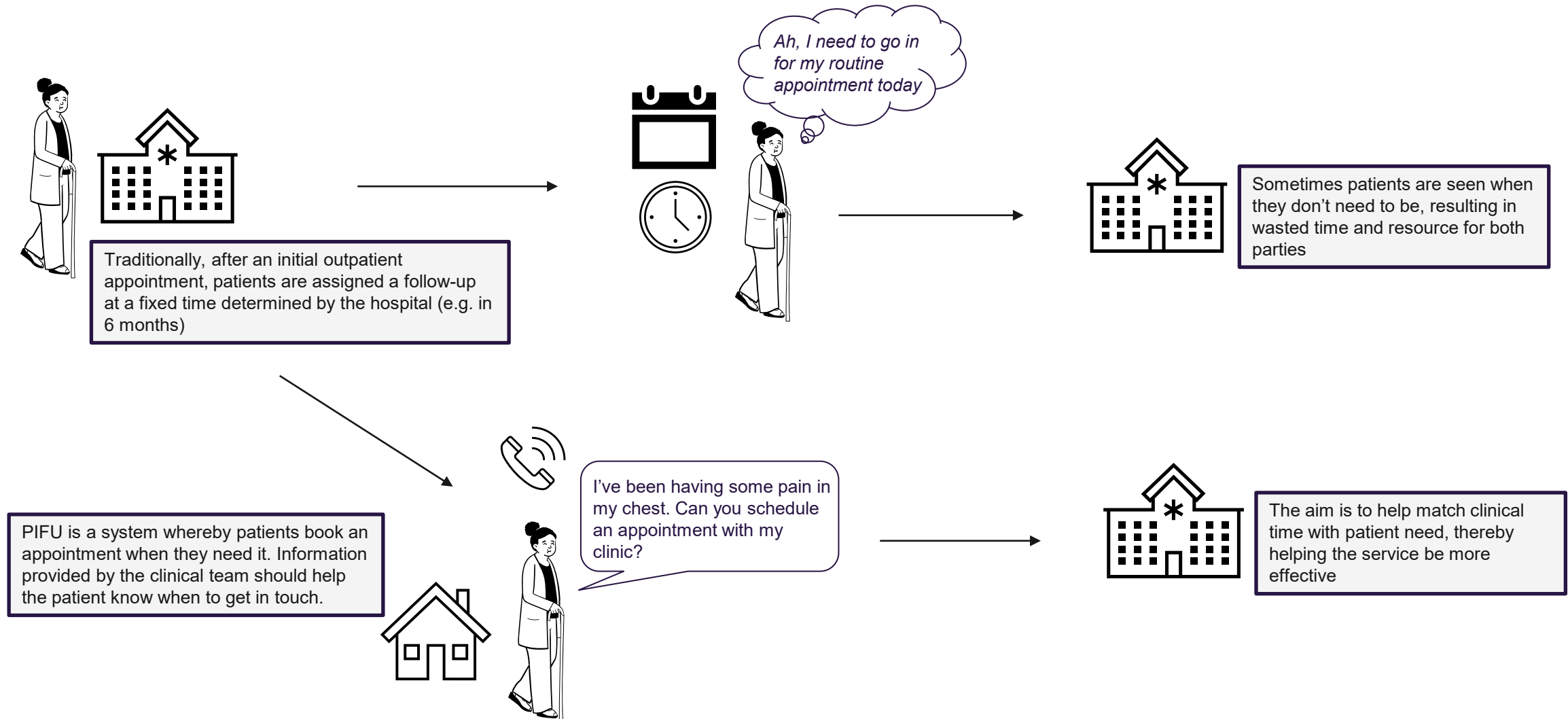
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1. Background and methods

A background to the design of the study
and an overview of the methods used

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?

Mixed methods design

Date	Stage	Quantitative approach	Qualitative approach
Aug. 2022	Evidence review		Literature review
June to Sept. 2022	Phase 1	Analysis of national datasets	Interviews with national stakeholders and local hospital staff in clinical specialties where PIFU more established (3 sites).
Jan. to July 2023	Phase 2	Analysis of national and local datasets	<p>Interviews with patients and local hospital staff in clinical specialties with longer term pathways (2 sites).</p> <p>Interviews with primary care providers.</p> <p>Workshop for staff on challengers and enablers for PIFU.</p> <p>Evaluation guide.</p>

Available datasets

Provider Elective Recovery Outpatient Collection (P-EROC)

Patients transferred to PIFU pathways each month by trust and specialty (aggregate data).

Hospital Episode Statistics (HES)

Hospital activity including outpatient attendance (individual patient level)

No record as to whether a patient is on a PIFU pathway

Emergency Care Dataset (ECDS)

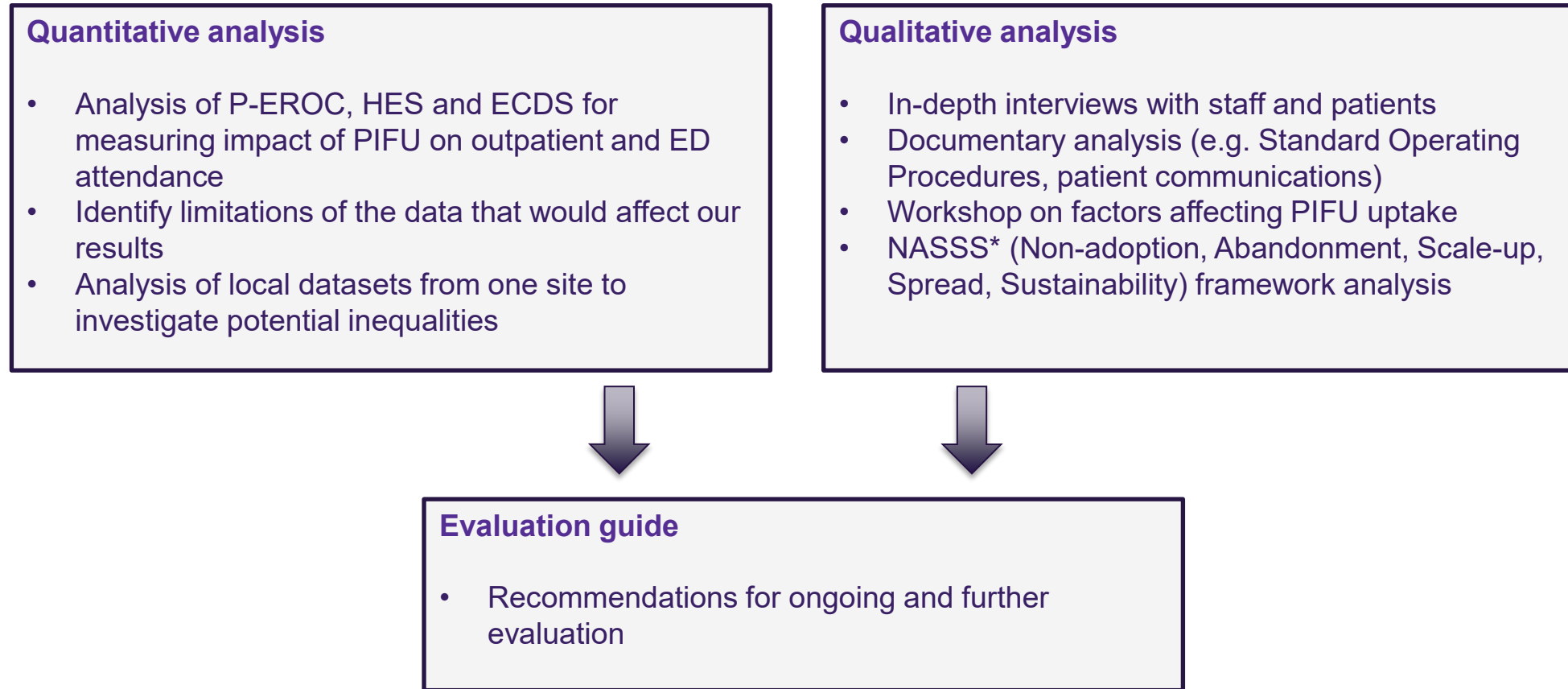
Hospital ED attendance (individual patient level)

No record as to whether a patient is on a PIFU pathway

Local data

Data specifically for people on PIFU pathways including return rates and patient characteristics (aggregate data).

Methods



*Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, *et al.* Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. *J Med Internet Res* 2017;**19**:e367. <https://doi.org/10.2196/jmir.8775>

Characteristics of trusts selected as case study sites

	Characteristic	Trusts (n=5)
Geography	Rural	2
	Urban	3
Size	Small	1
	Medium (500 – 850 beds)	2
	Large (>850 beds)	2
Academic status	General	1
	Teaching	4
Deprivation	Higher levels of deprivation	2
	Lower levels of deprivation	2
	Mixed levels of deprivation	1
Ethnicity	Higher levels of ethnic diversity	2
	Lower levels of ethnic diversity	3
Length of time delivering PIFU	<5 years	3
	5+ years	2

Staff and patient interviews

Evaluation phase	Location	Number of staff interviews			Number of patient interviews
		Operational	Clinical	Primary care	
Phase 1	Site 1	2 (trust-wide)	2 (specialty level)	n/a	n/a
	Site 2	2 (trust-wide)	2 (specialty level)	n/a	n/a
	Site 3	1 (trust-wide)	2 (specialty level)		
	National	1	1		
Phase 2	Site 4	3 (trust-wide)	1 (trust-wide) 8 (specialty level)	3	3 (breast care)
	Site 5	2 (trust-wide) 1 (specialty level)	1 (trust-wide) 4 (specialty level)		1 (gynaecology)

Note: where we have used quotes in this slide set they have been labelled according to whether the individual held a trust-wide specialty level role, and if their role was clinical or operational.

2. Rapid evidence review

Evidence from previous studies of patient-initiated follow-up innovations for outpatients

Key findings – evidence review

- 17 studies satisfied selection criteria for review.
- 15 of these measured the impact of PIFU on the frequency of outpatient appointments compared to fixed follow-up, of which:
 - 8 found significant reductions.
 - 7 found no evidence of any difference.
- Studies showed limited effects on clinical outcomes or patient quality of life, with some evidence that PIFU might improve patient experience.
- Most studies rated as low quality.
- It is hard to generalise these findings as half the studies were outside of the UK and in a limited number of clinical areas.

Key gaps in evidence

1

How might PIFU work differently by specialty or condition and which adaptations are required?

2

How does PIFU affect activity in other service areas? (e.g. primary care or A&E).

3

How do patients experience PIFU, and how might it affect health inequalities?

4

How might different approaches or models of PIFU affect implementation?

3. The implementation of PIFU

How PIFU is being set up and implemented across trusts and services.
Enablers and barriers to PIFU implementation

Key findings – implementation of PIFU

How is PIFU being used?

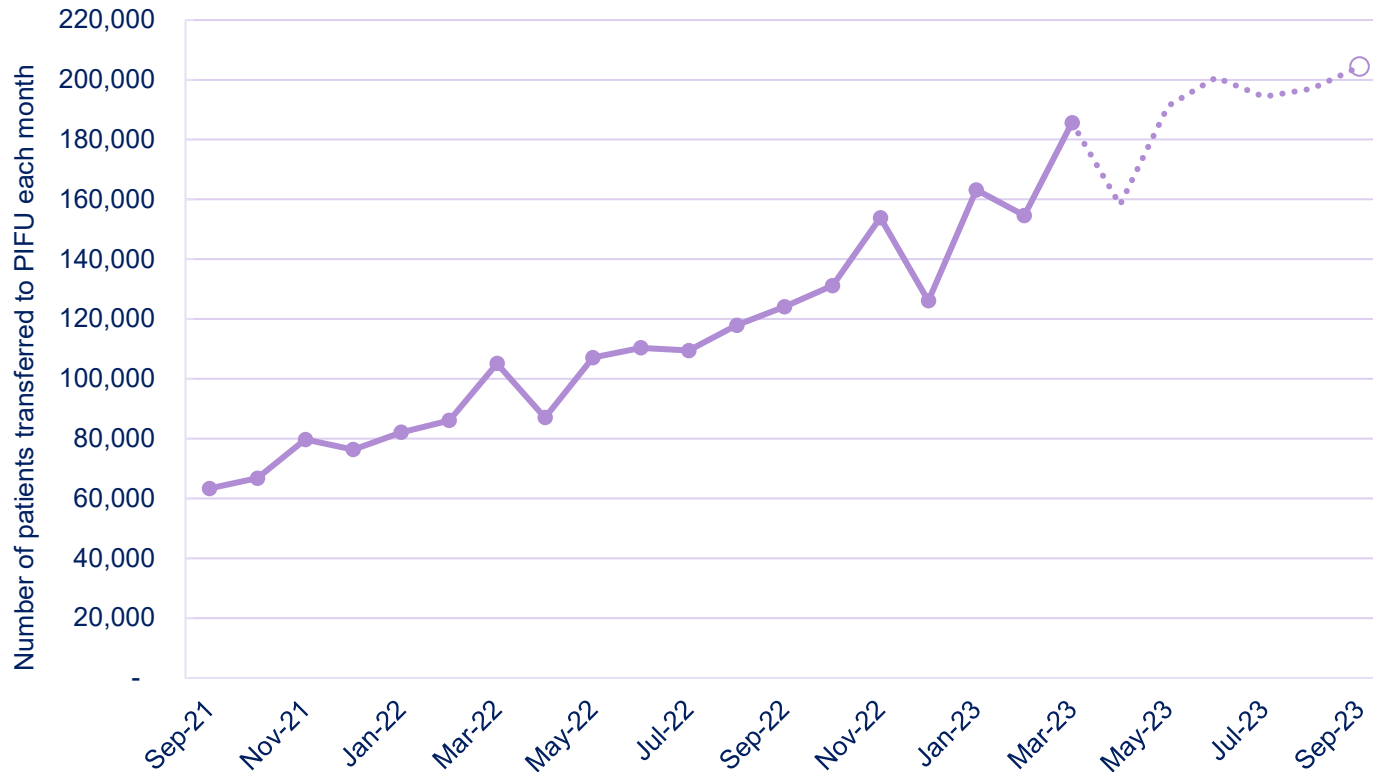
- In the NHS, PIFU is most commonly being used in short-term pathways (e.g. physiotherapy or following surgery) although there are several examples where it is being used for people with long-term conditions.
- Models of PIFU vary widely between trusts and clinical areas in the approach to patient selection, 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 use of PIFU has increased over time

Total transfers to PIFU reported in P-EROC each month
All trusts and specialties: Sept. 2021 to Sept. 2023

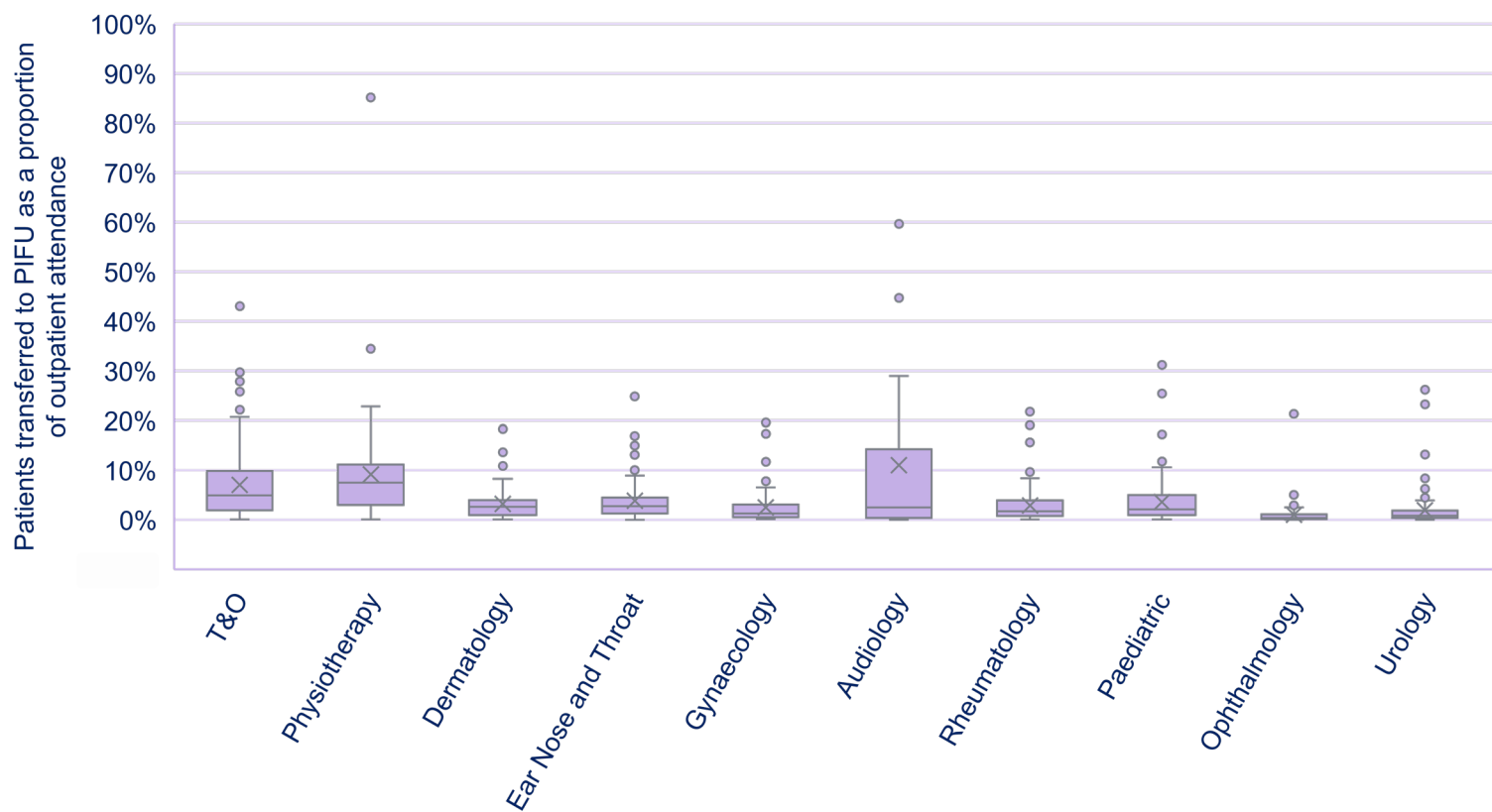


Between Sept 2021 and Sept 2023, the number of patients reported as transferred (i.e. moved or discharged) to PIFU more than tripled.

Note: The solid line represents reported values from our analysis. The values from April 2023 are based on data from NHS England's publication, '*National PIFU Data Insight*' released in December 2023.

PIFU activity varies between trusts within each clinical specialty

Variation in rate of PIFU transfers by specialty and trust: Top 10 specialties by PIFU volume: Oct 2022 to Mar. 2023



The mean rate of PIFU transfers per outpatient attendance are below 10% for most specialties

There is notable variation within most of these specialties, with a few over 40%

Notes:

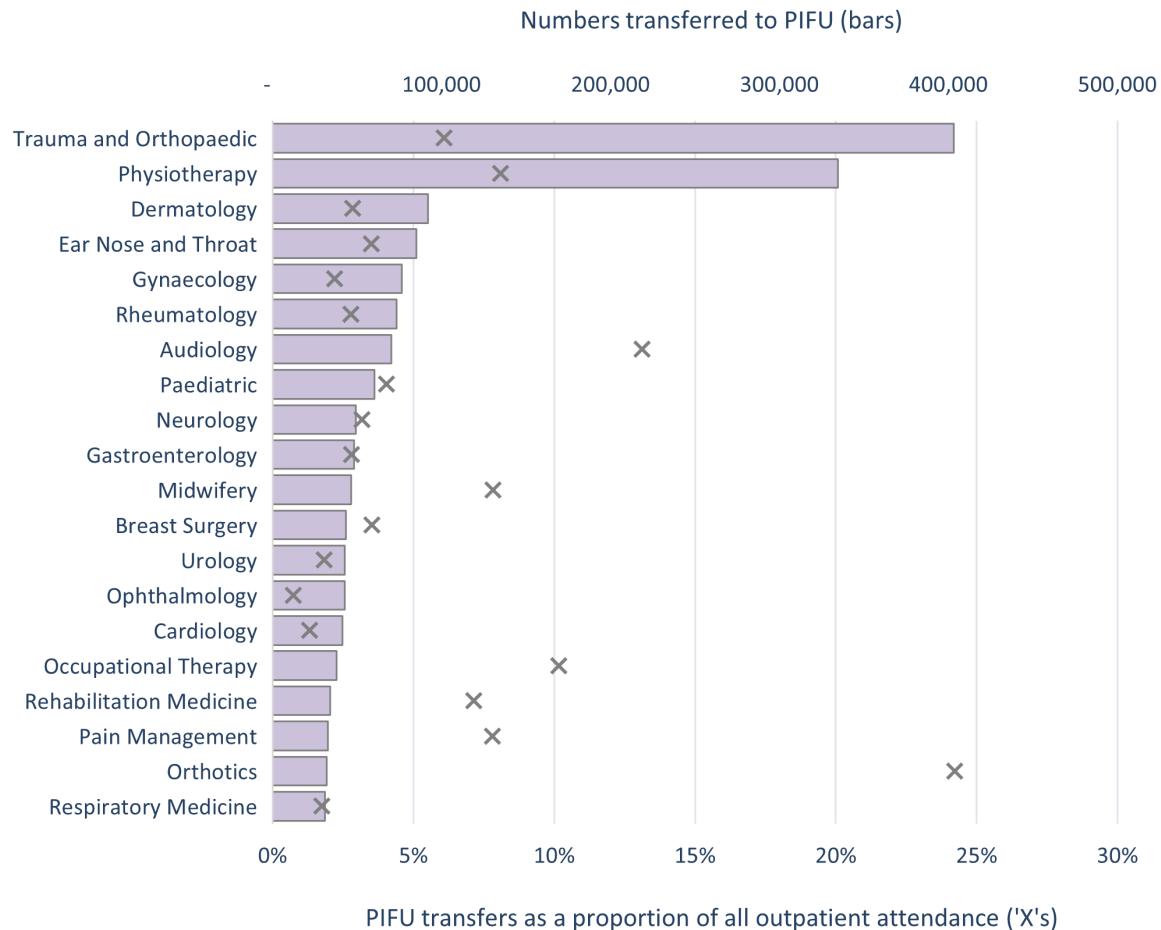
The mean value is marked by an 'X' for each specialty, while the median value is marked by a horizontal line across the box. The boxes represent the interquartile range. The whiskers represent the full range of values excluding outliers. Outliers were defined using the IQR (inter-quartile range) x 1.5 threshold.

Only trusts that record at least 100 outpatient attendances a month and PIFU activity in P-EROC for these specialties are included.

'T&O' stands for Trauma and Orthopaedics

PIFU activity varies by clinical specialty

PIFU activity (total transfers and rate of transfers) reported in P-EROC.
 Top 20 specialties by PIFU volume: Sept. 2021 to March 2023



Numbers of patients transferred to PIFU have been dominated by trauma and orthopaedics and physiotherapy.

As a proportion of outpatient activity, of the top 20 specialties, patients have been most commonly transferred to PIFU in orthotics (24%).

Note: Only trusts that record PIFU activity in P-EROC for these specialties are included

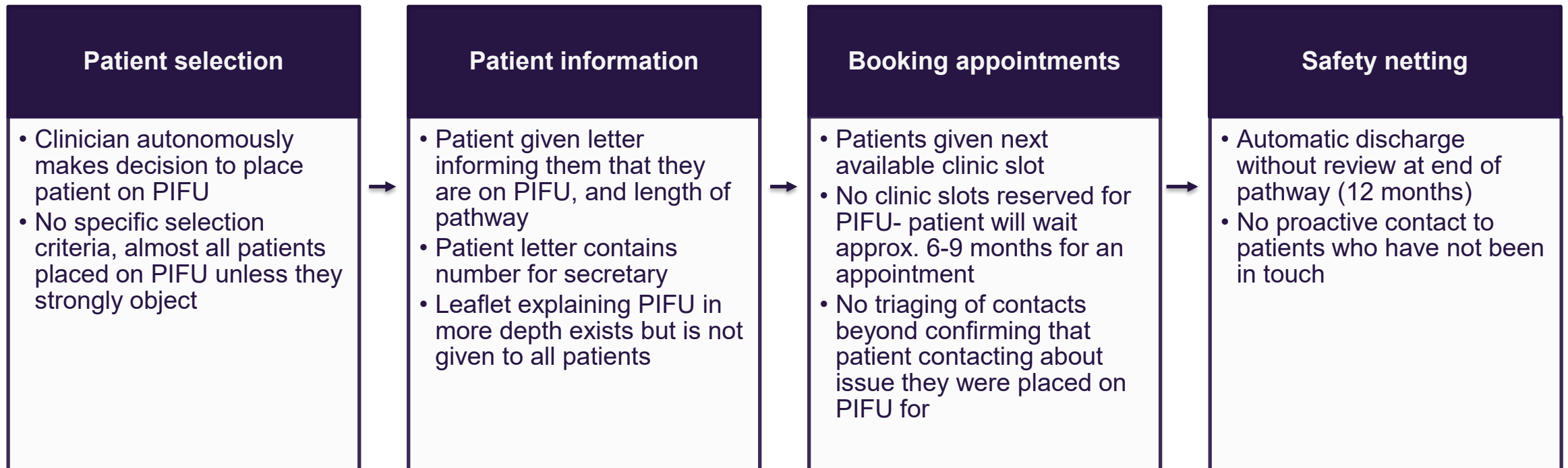
Models of PIFU vary widely between trusts and clinical areas

Aspect of patient pathway	What does a low level of input from services look like?	What does a high level of input from services look like?
Selection	Clinical judgment and loose criteria	Localised protocols and clinical guidance
Induction and sign on	PIFU by default (all patients placed on PIFU)	In person consent, multiple conversations and information about PIFU
Monitoring and tracking	None	Digital dashboards and remote monitoring
Booking and contact	Phone/ email and no ringfenced capacity	Multiple booking methods and capacity/ slots reserved for PIFU patients
Escalation and triage	Everyone requesting an appointment gets one	Clinical assessment, questionnaires
Safety netting	Only patient initiates contact	Regular clinical reviews for patients as well as relevant tests and scans
Discharge	Automatic discharge at end of pathway (no proactive contact)	All patients have clinical review and appointment with clinician

Example PIFU pathway from our case study sites

1. Gynaecology

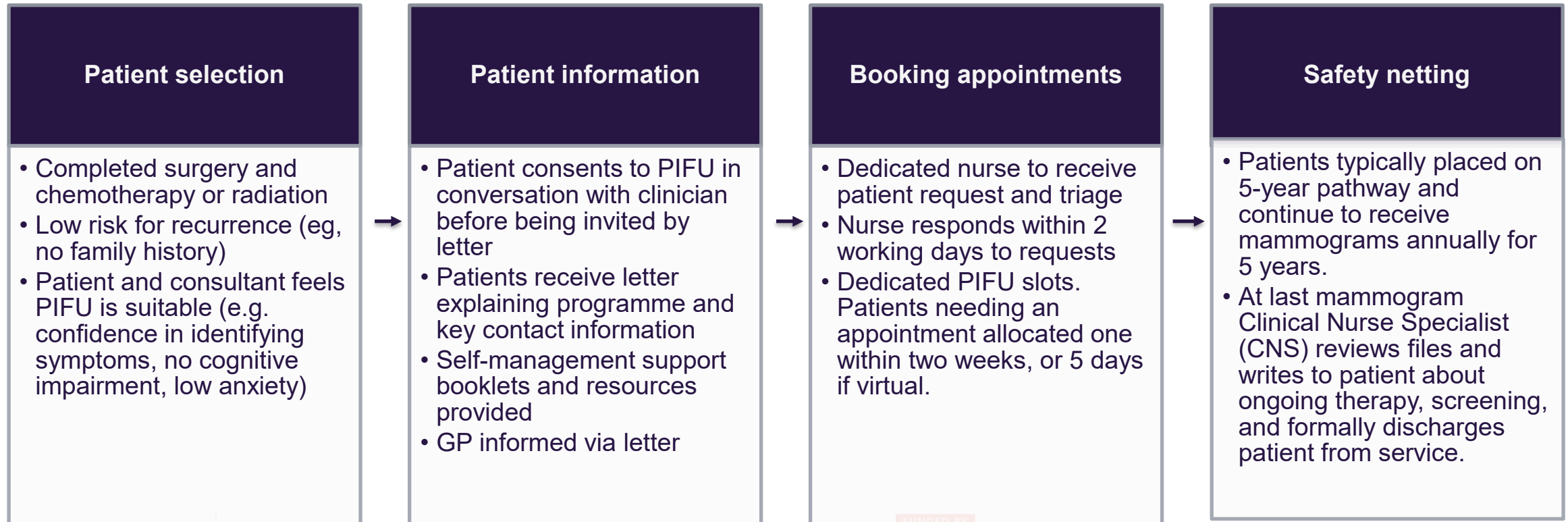
- Does not include gynaecological cancers – pathway is geared towards shorter term interventions for patients with long-term gynaecological conditions
- PIFU primarily perceived as mechanism for reducing unnecessary outpatient follow-ups
- Almost all patients are placed on PIFU once they have completed their treatment



Example PIFU pathway from our case study sites

2. Breast cancer

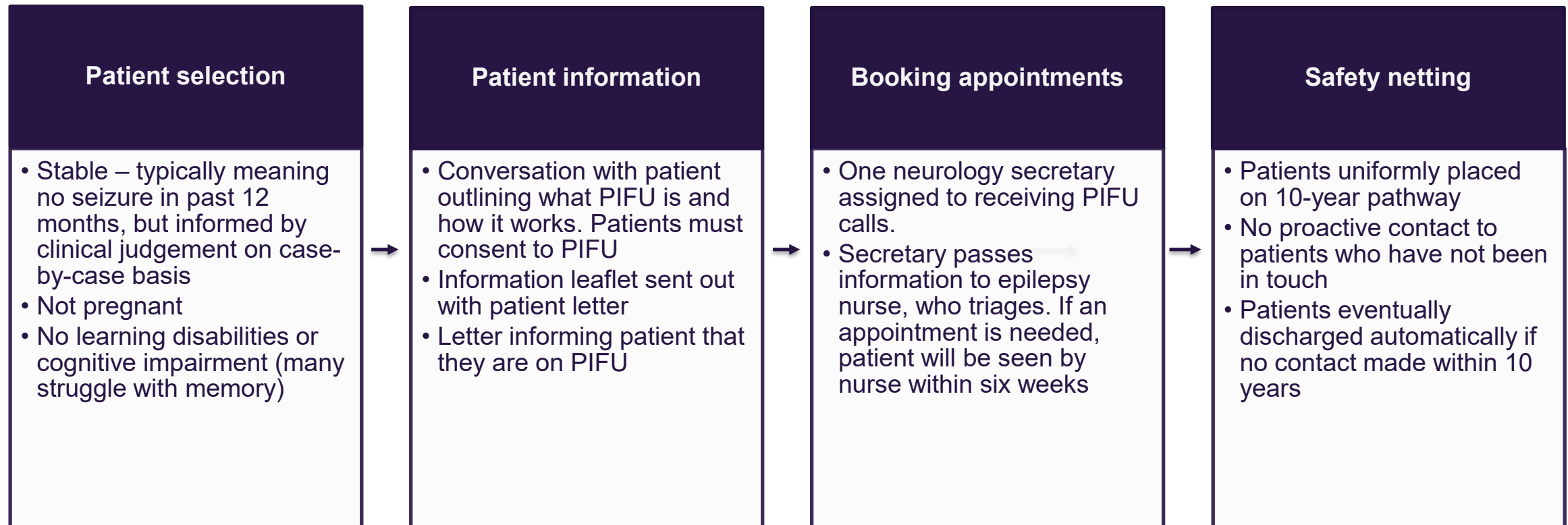
- **Note – within cancer services, PIFU is often referred to as ‘Personalised Stratified Follow-Up.’*
- PIFU pathway happens alongside routine mammograms and is intended to help reduce unnecessary patient appointments and patient anxiety.
- The pathway design was clinically-led based on consultant experience in another trust and a history of open-booking within specialty although not all consultants in the team use PIFU. The service received dedicated funding to hire PIFU specific roles (e.g. a nurse).



Example PIFU pathway from our case study sites

3. Neurology (epilepsy)

- This was a nurse-led epilepsy pathway.
- Previously patients had to go back through GP if issues came up, but PIFU was seen as a way to create a route back to specialist care.
- Deciding whether patients are suitable for PIFU is challenging, and only a small proportion are considered eligible.



Enablers and barriers to PIFU implementation

	Enablers	Barriers
Nature of condition / sociocultural factors	<ul style="list-style-type: none"> • Conditions with lower complexity, easily detectable fluctuations or changes in symptoms • Patients with higher degrees of agency to self-manage and clinical/ digital literacy • Clinician’s experience with shared decision-making vs more paternalist models of care 	<ul style="list-style-type: none"> • Lack of willingness from patients to acknowledge/ engage in managing condition • Cost of living crisis/ ‘busyness’ impacting ability to attend appointments • Some conditions more associated with cognitive impairment (e.g. epilepsy)
Staff engagement	<ul style="list-style-type: none"> • Clinical champions / clinical ownership over pathway design • Condition-specific clinical guidance or tools Starting small with pilots 	<ul style="list-style-type: none"> • Concern patients will get ‘lost’ in the system • Anxiety that using PIFU would lead to an increased number of GP referrals/ more complex interactions where appointments do occur (impact of workload still felt to be unknown) • Contradictory clinical guidelines or targets (e.g. oncology or surgery) • Limited understanding of aims of PIFU and how it is different to previous approaches e.g. open booking • Differing values amongst healthcare team – paternalistic approaches to patient management
Patient engagement	<ul style="list-style-type: none"> • Dedicated PIFU triage support to manage patient requests 	<ul style="list-style-type: none"> • People preferring regular contact/ concern about getting lost in the system

Enablers and barriers to PIFU implementation

	Enablers	Barriers
Technology / digital capability	<ul style="list-style-type: none"> • Flexible / customisable electronic record systems to be able to select different follow-up options / monitor patients on different pathways • Integrated patient communication and self-monitoring / self-management support 	<ul style="list-style-type: none"> • IT systems incompatibility with PIFU or recording PIFU
Organisational factors	<ul style="list-style-type: none"> • Flexible scheduling to hold open slots / appointments to be able to accommodate PIFU patients • Funding for dedicated transformation leads / admin staff to manage and design pathway • Time to educate / train staff on quality patient conversations 	<ul style="list-style-type: none"> • Administrative issues - central booking teams being unfamiliar with process and need for ringfencing appointments/ patients, staff/ staffing and capacity constraints • Mergers and / or different operating systems and approaches to outpatient management
Wider system context	<ul style="list-style-type: none"> • Targets / national drive to create focus and priority • Support from clinical and professional bodies • Long elective waits and lack of capacity in primary care creating a push for new alternatives to organising care 	<ul style="list-style-type: none"> • Competing targets or events taking capacity and resource away from PIFU implementation (e.g. 78-week waiters/ industrial action)

4. The impact of PIFU on activity and outcomes

How PIFU affects outpatient and ED attendance, limitations of existing data and views of staff.

Key findings: measuring impact

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.

Methods overview

Measurement of PIFU activity:

- The number of people transferred to PIFU over a period divided by the total number of attendances over the same period. Calculated for each combination of trust and specialty.

Selection of providers and specialties:

- All NHS trusts reporting PIFU activity in P-EROC between Sept. 2021 and March 2023 (n=142).
 - Included both complete and partial submissions.
 - Analysis for the top 30 specialties by volumes of patients transferred to PIFU pathways between Sept. 2021 and March 2023.

Interviews of staff at the study sites and feedback from the workshop:

- Views on the impact of PIFU.
- Experiences of the data being collected.

Two analytical approaches

Rationale

- Individual patients on PIFU pathways could not be identified in the national hospital data (HES and ECDS).
- We therefore had to make assumptions about how to measure PIFU activity at a trust/specialty level and therefore further assumptions about interpreting the P-EROC data.
- Two approaches to the analysis allowed us to handle these different assumptions.

The two approaches

Approach 1: Analysis of outcomes at trust and specialty level (Poisson regression)

Approach 2: Analysis of outcomes at a patient attendance level (Survival analysis)

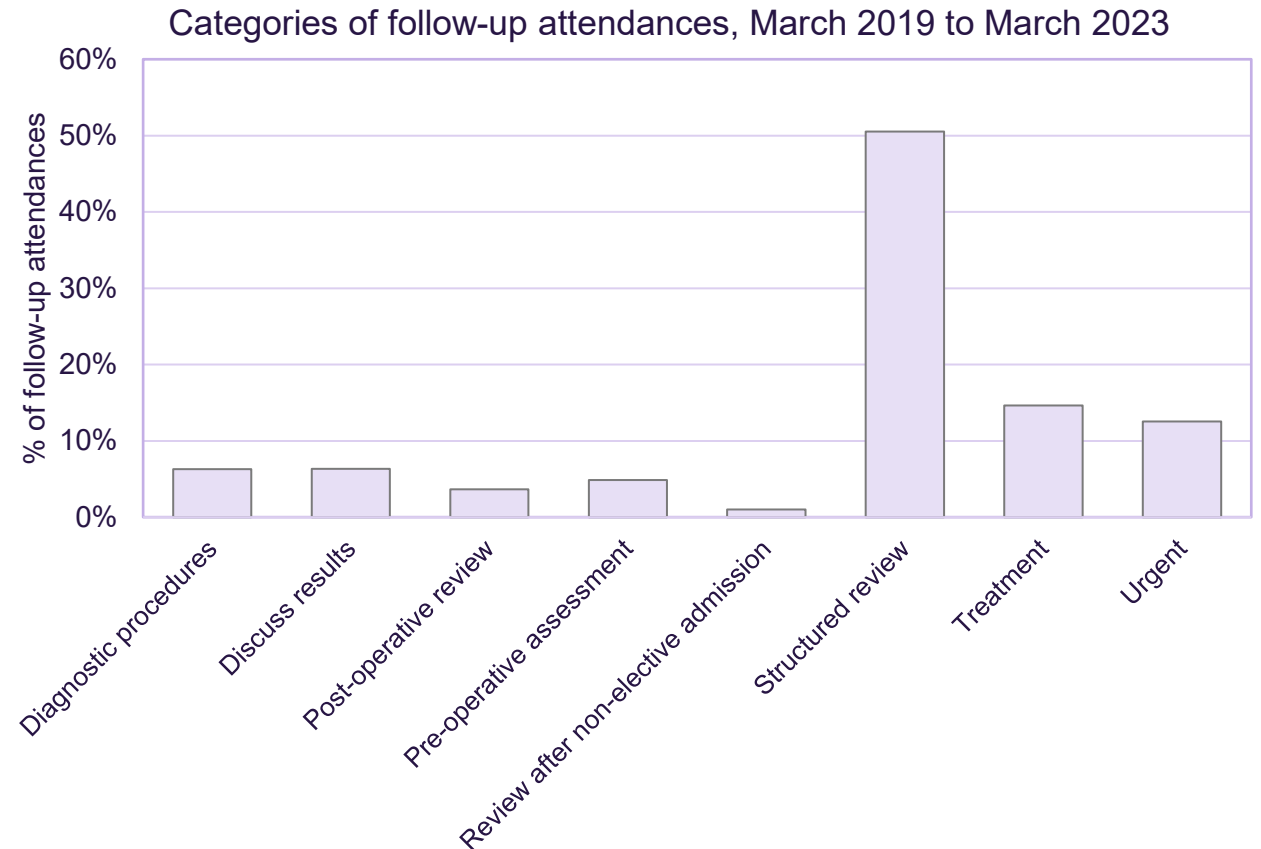
With both approaches we analysed outcomes across all specialties at once (**multi-specialty model**) and for individual specialties (**single specialty models**).

Identifying outpatient attendances that are more likely to be affected by PIFU

We applied an algorithm developed by the Strategy Unit and modified by NHSE to classify outpatient attendances by function.

“**Structured review**” attendances were defined as not being in any of the other categories shown in the chart. They comprised more than half of all follow-up attendances.

We assumed that these were the most likely to be affected by PIFU and were therefore a particular focus in our analysis.



General assumptions

Sample of sites	Any NHS provider reporting P-EROC data between Sept. 2021 and March 2023
Measurement of PIFU activity	The number of people transferred to PIFU divided by the number of outpatient attendances over the same period
Completeness of reporting and missing data	We used P-EROC data from providers that reported either complete or partial submissions (see Appendix). Missing data was assumed to be unknown and thus excluded.
Selection of treatment specialties	We selected the 30 specialties with highest volumes of PIFU activity (88% of all patients transferred to PIFU).

Outcome measures

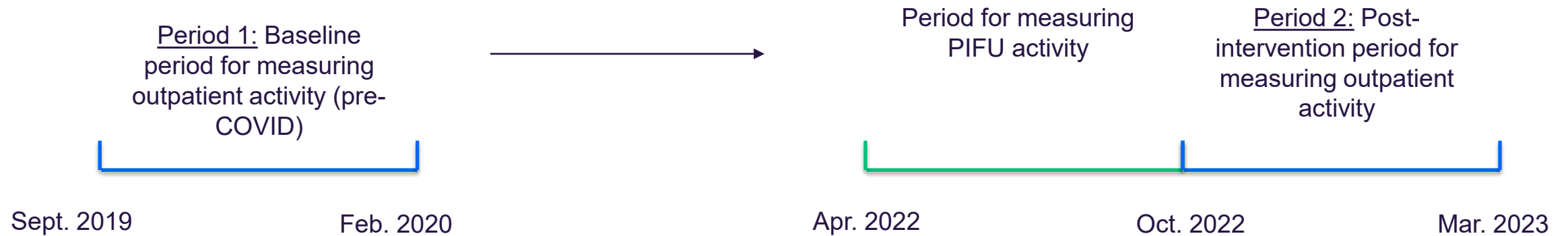
Both approaches investigated outcomes relating to the frequency of attendances or missed appointments.

- For Approach 1 frequency was measured as outcomes per patient or proportions of appointments of a certain type – all at the trust and specialty level.
- For Approach 2 we measured frequency as the time to the next attendance or non-attendance.

Outcomes measured using Approach 1 (trust and specialty level)	Outcomes measured using Approach 2 (attendance level)
Outpatient attendances per patient	Next outpatient attendance
Outpatient attendances recorded as 'follow up' per patient	Next follow-up outpatient attendance
Follow-up attendances identified as 'structured review' per patient	Next structured review follow-up attendance
Proportion of outpatient attendances that are reported as 'structured review'	
Proportion of missed appointments	Next missed appointment
	Next emergency department (ED) visit

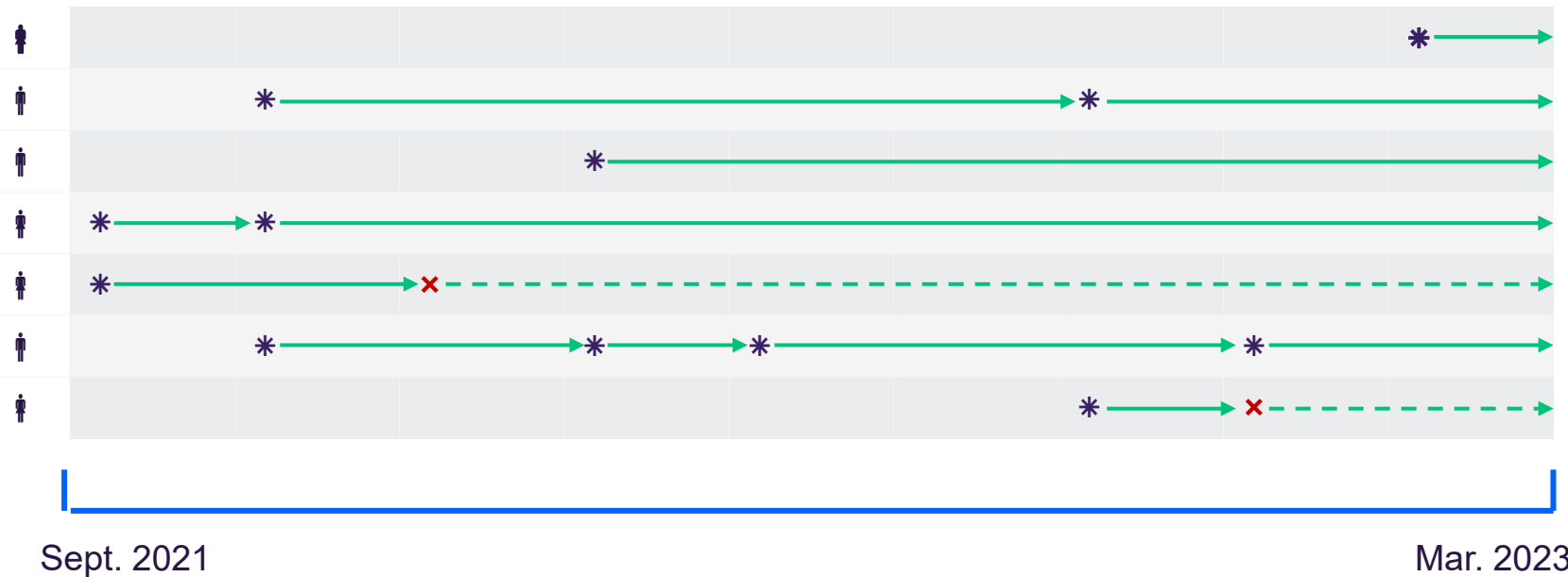
Approach 1: Design

We assumed a six-month lag before changes in PIFU activity had an impact on outcomes:



Poisson regression model for outpatient attendances (models for other outcomes are similar)			
Dependent variable	Exposure	Explanatory variables	Random effect
Number of outpatient attendances within trust and specialty	Number of unique patients within trust and specialty attending outpatient clinics over the period	<ul style="list-style-type: none"> • Period • PIFU activity in the previous six months (assumed zero for period 1) • Specialty (in multi-specialty model) 	NHS trust

Approach 2: Time to next event ('survival') analysis at attendance level



Whenever a patient had an outpatient attendance, we estimated the amount of PIFU within the trust and specialty, and investigated the relationship that had with **the time to the patient's next attendance** (or ED visit).

We adjusted for: patient age and sex, time, complete/incomplete P-EROC (and specialty, for multi-specialty model). We also stratified by trust and censored appropriately for each analysis outcome.

KEY:
 * - Outpatient attendance
 X - ED visit
 → - time to next event (or end of data)

The outputs of the statistical survival models were Adjusted Hazard Ratios (HRs).

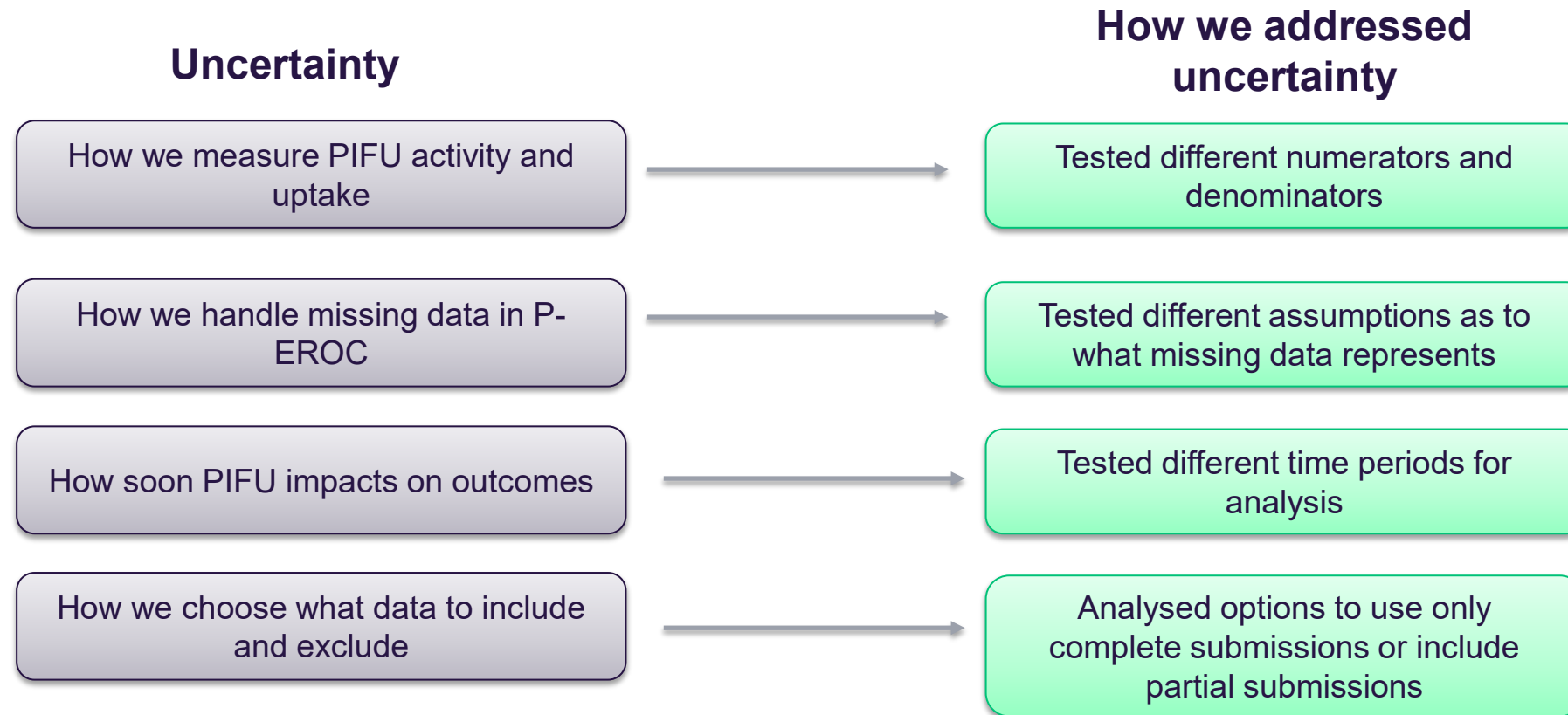
These measured whether **higher PIFU rates** were associated with **less frequent** (HR < 1) or **more frequent** (HR > 1) subsequent attendances or ED visits.

Data limitations

- Individual patients on PIFU pathways could not be identified in the national hospital data (HES and ECDS).
- P-EROC is reported at clinical specialty level so we were unable to look more deeply into specific conditions.
- We have assumed that specialties are coded consistently between P-EROC and HES.
- Missing data in P-EROC could either reflect no PIFU activity or unreported PIFU activity.
- Due to data availability, measurement of impact was limited to outpatient and ED attendance.

Analysing different scenarios

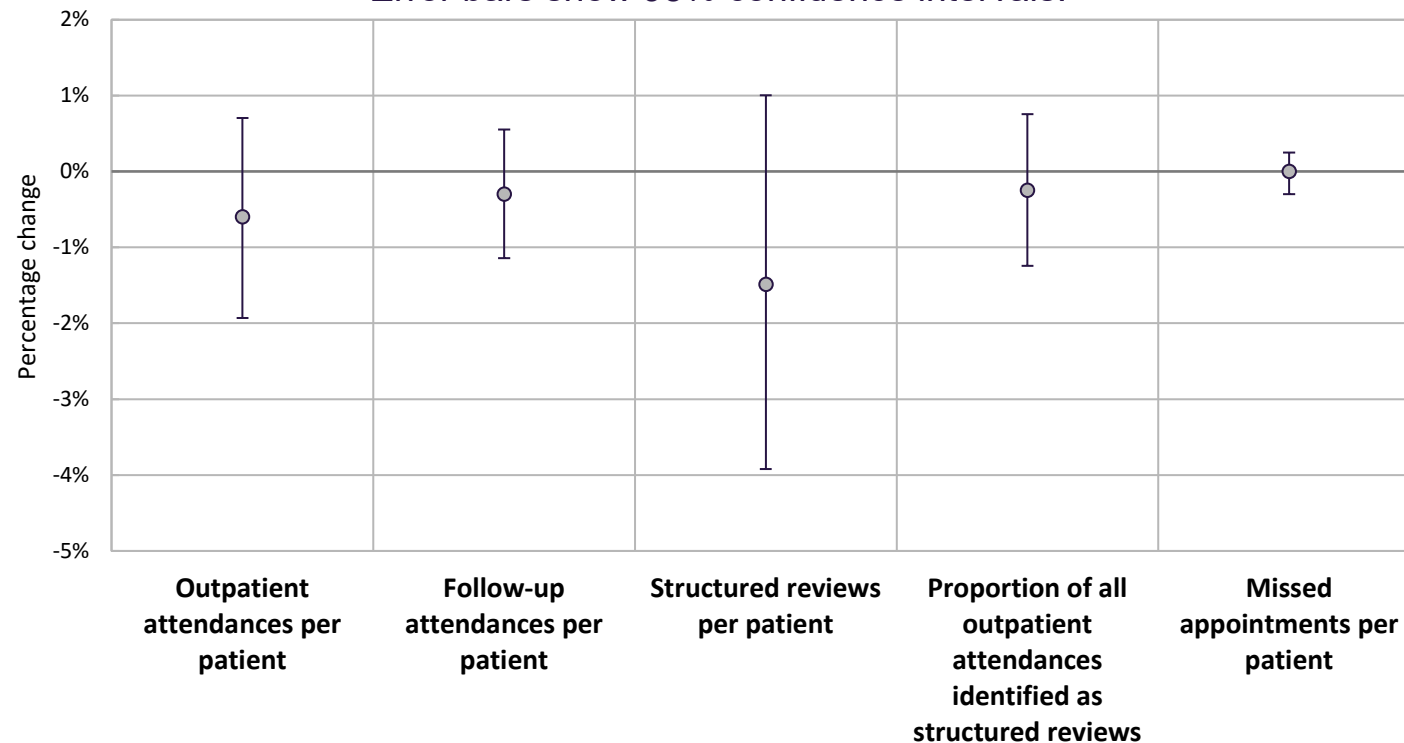
We addressed uncertainty by analysing different scenarios reflecting different assumptions and choices and to see what effect they have on our findings.



Results from multi-specialty analysis: Analysis at trust and specialty level (Approach 1)

Relationship between the PIFU rate and outpatient activity.

Change in outcomes associated with a 5% increase in PIFU rate.
Error bars show 95% confidence intervals.

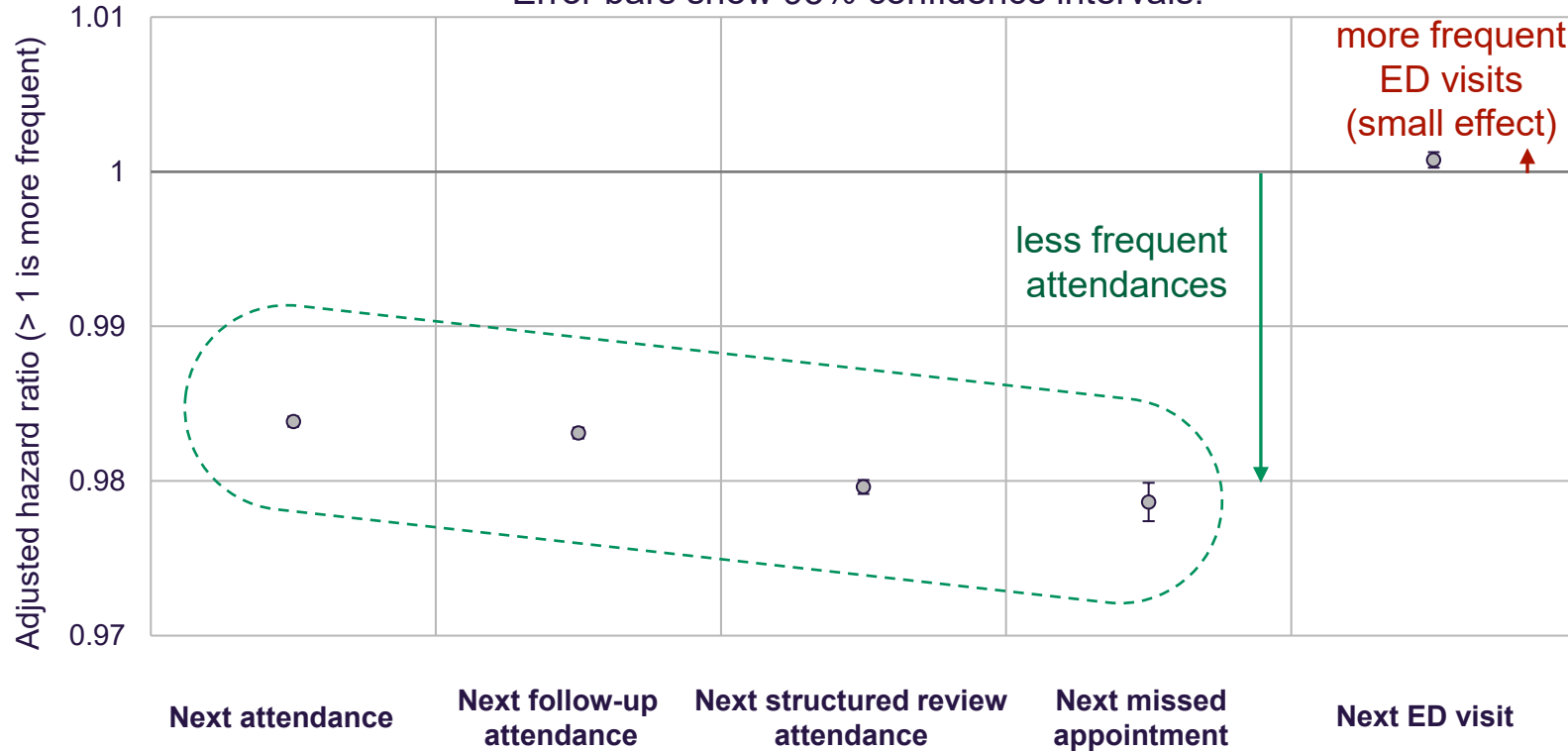


116 trusts were included in this analysis.

We found no statistically significant relationship between the PIFU rate and each measured outcome.

Results from multi-specialty analysis: Time to next event ('survival') analysis at attendance level (Approach 2)

Adjusted hazard ratio, each 5% point increase in PIFU.
Error bars show 95% confidence intervals.



We analysed 56.7 million attendances in 29 clinical specialties.

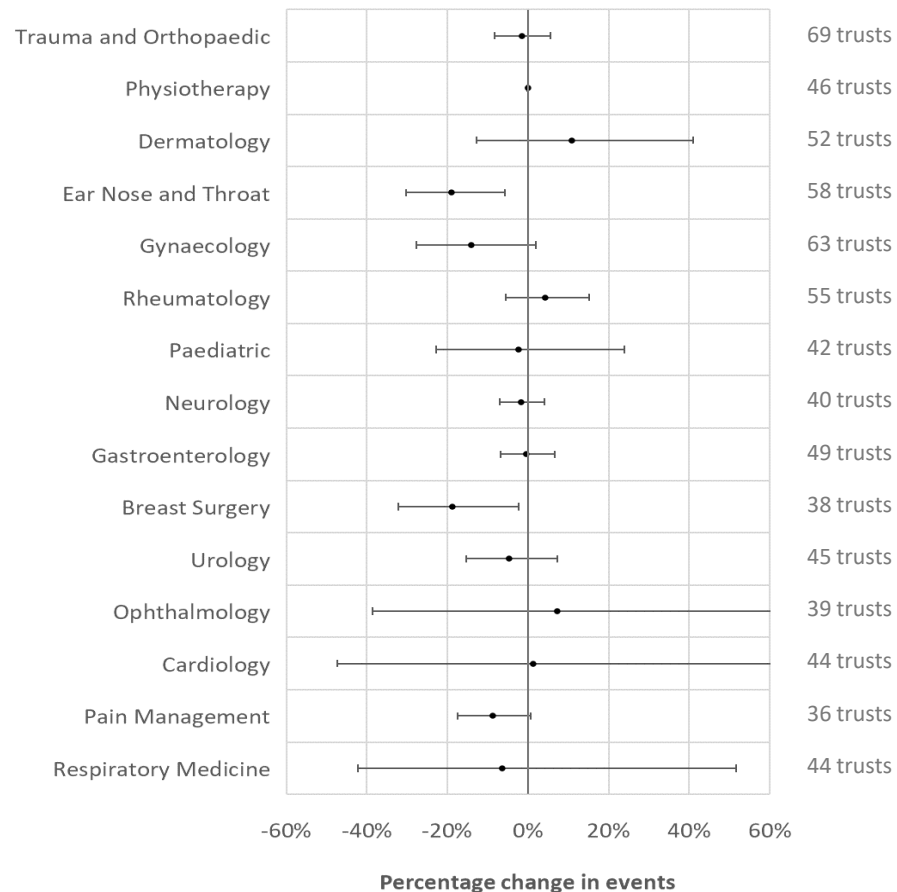
We found, for every 5% point increase in PIFU rate:

- Approximately **2% lower** probability of a subsequent attendance, or a missed appointment (on any given day, where a patient had not already had one)
- A very slightly higher probability of an ED visit (may not be practically significant)

All results were statistically significant at 95% confidence levels.

Results from individual specialty analyses: Analysis at trust and specialty level (Approach 1)

% change in **structured review** attendance per patient for every 5% point increase in PIFU rate. Error bars show 95% confidence intervals.



15 specialties had sufficient data for this analysis (reported by 30 or more trusts).

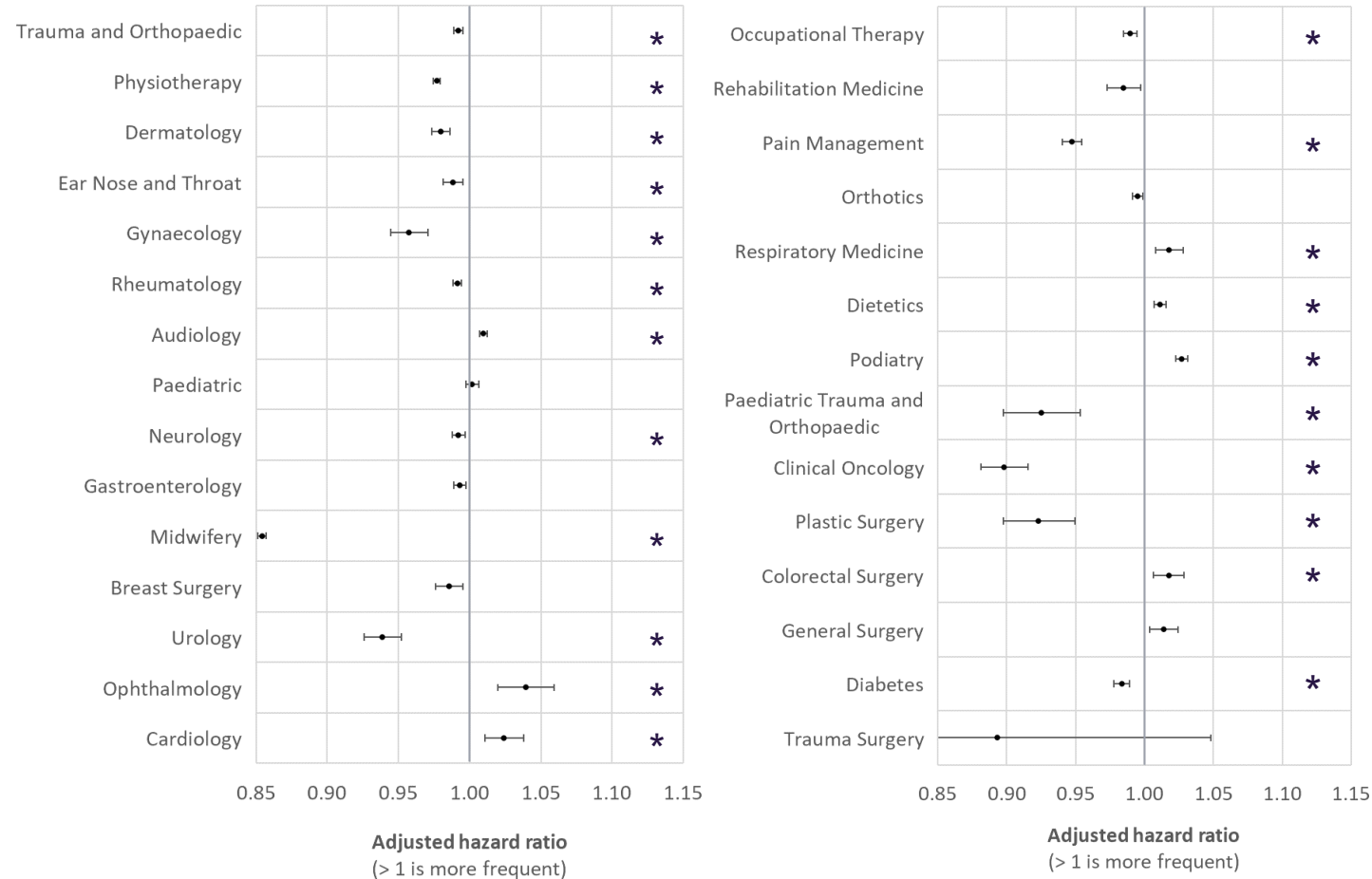
After adjusting for multiple testing, none of these results are statistically significant at the 5% level.

Significant results for other outcomes

Outcome	Specialty	% change for every 5% point increase in PIFU rate (95% confidence interval)
All outpatient visits per patient	Urology	-4.2% (-6.8% to -1.5%)
	Respiratory medicine	-15.4% (-23.8% to 6.1%)
Follow-ups per patient	Urology	-3.4% (-5.3% to -1.6%)
Missed appointments	Urology	-15.4% (-24.2% to 5.6%)

Results from individual specialty analyses: Time to next event ('survival') analysis at attendance level (Approach 2)

Adjusted hazard ratios, next Structured Review, each 5% point increase in PIFU



Single-specialty model results are shown, for subsequent structured review attendances.

Specialties are in order from most PIFU (top left) to least (bottom right)

* = statistically significant results (at 95% confidence, adjusting for multiple testing)

In summary:

15 specialties: Higher PIFU associated with **lower** frequency of attendances

7 specialties: Higher PIFU associated with **higher** frequency of attendances

See appendix for other types of attendance.

Staff perceptions and experiences

Perceptions on the impact on follow-up attendances

- Staff believed that PIFU should be reducing follow-up appointments and missed appointments.
- Because of backlogs in seeing patients, some providers are not seeing reductions in overall numbers of outpatient visits.
- Also, it can be difficult to see an impact in specialties which had been already using open appointments.

Perceptions on the wider impact

- Reductions may be offset by non-reported increase in telephone conversations between patients and nurses or non-clinical staff.
- It is unclear to what extent demand is shifted to other parts of the system, e.g. primary care.

Perceptions on the data

- There is a lack of data collected by many providers beyond what is required for P-EROC. This is partly due to:
 - The capabilities of local electronic patient record systems.
 - Staff capacity.
- Better evidence on the benefits of PIFU would stimulate better data collection.

“It hasn’t released anything necessarily, but I think it’s definitely helped patients not having to keep coming back to the hospital all the time.”

Operational staff, specialty level

“PIFU certainly hasn’t helped our backlog yet in terms of outstanding outpatient appointments. I think it will be difficult to measure the impact of PIFU on system because there are so many variables.” Operational staff, trust-wide

5. Health inequalities

How PIFU might affect patients from different backgrounds and how services are measuring this.

Key findings: 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.

How are sites measuring the impact of PIFU on health inequalities?

- There was limited insight from our staff interviewees into how (if at all) the impact of PIFU on health inequalities was being measured within services although it was sometimes considered as part of broader Equality Impact Assessments on outpatient services.

“I don't think we've identified anything related to PIFU, but we certainly have identified issues related to health inequity within outpatient settings. But it's baby steps at the moment. We need to do so much more.” Operational staff, trust-wide
- There is an ambition to look at health inequalities but is hindered in many trusts by lack of alignment between demographic and PIFU data.
- We heard limited examples of specific actions taken to address or mitigate against potential inequalities.

What is the perceived impact on health inequalities? (1)

- It is important to not make assumptions about engagement because of certain patient characteristics, but there is also concern that staff may not be putting people on to PIFU who may benefit. Staff reflected on the valuable role of formal and informal carers in supporting people on PIFU pathways.
- The opposite was also raised, namely that decisions may be made without proper interaction with patients (this was felt to be particularly likely in areas where the overt focus of PIFU was reducing activity, rather than on supporting patients).

“Clinicians shouldn’t make assumptions that because [they] have an older patient they won’t use PIFU or that a younger patient necessarily will use PIFU.” Operational staff, trust-wide

- There was some concern about people of different ages or people who may be digitally excluded. Regarding digital exclusion, the extent to which this was currently a problem was considered limited given that there are usually non-digital ways to contact the services.

What is the perceived impact on health inequalities? (2)

- The ability, willingness and motivation of patients to advocate for themselves could influence how PIFU impacts health inequalities - this was felt to be in part linked to socio-economic status, as well as how patients had experienced outpatient services in the past.

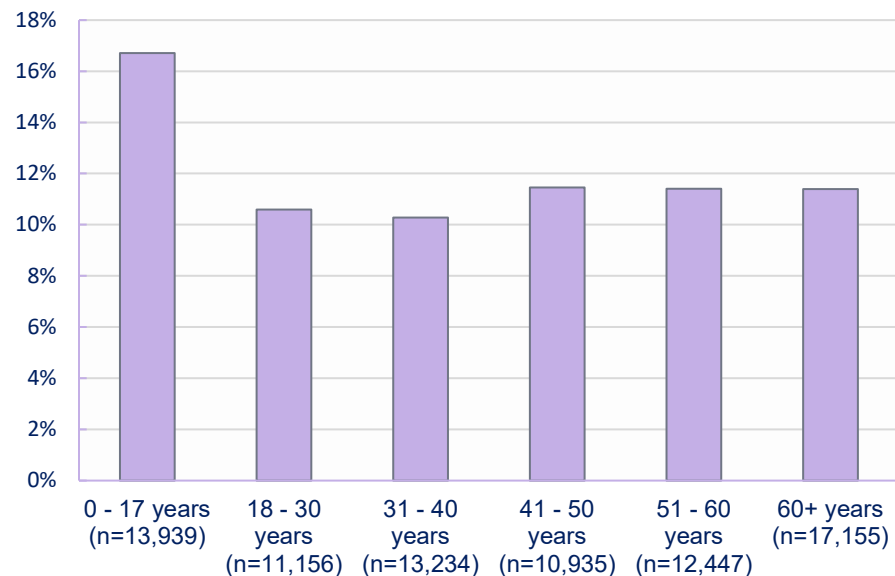
“If I'm really honest, does it close the gap [on health inequalities], probably not – it probably increases the gap actually because it's the activated, it's the motivated, it's the well-educated who are more likely to navigate the system quickly and effectively.” GP

- PIFU could be better for people who may, for whatever reason, be unable to engage with a more fixed appointment schedule and reduce missed appointments. But there is a concern they may be the least likely to be put on to PIFU, or that they would be put on PIFU without proper discussion.

“I have a gentleman who's homeless. We put him on PIFU because every appointment we gave to him, he DNA'd, so by giving him the ability to phone when he needs and setting an appointment that will work for him, actually he's attended.” Clinical staff, specialty level

Impact on PIFU engagement by patient characteristics: data from one acute trust

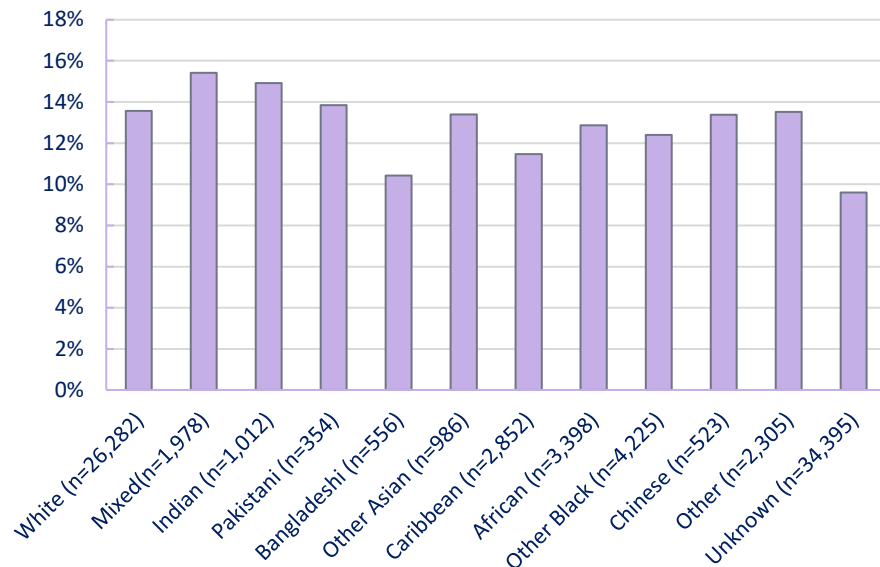
The proportions of patients on a PIFU pathway who make a return appointment within a year, by age group.



- For children and adolescents between the ages of 0 to 17, 16.7% of those placed on a PIFU pathway scheduled a return appointment within a year.
- This compares with an average of 11% for those aged 18 and above.

Impact on PIFU engagement by patient characteristics: data from one acute trust

The proportions of patients on a PIFU pathway who make a return appointment within a year, by ethnicity



- Variation among reported ethnicities ranged between 10.4% for the Bangladeshi population and 15.4% for people reported as mixed ethnicity.
- It is not clear from these data whether these results reflect underlying ethnic barriers to engaging with the service after being put on to a PIFU pathway.
- Differences could result due to different ages and case mixes among different ethnic groups and/or the nature of the condition.

6. Staff views and experiences

How staff perceive the aims, objectives and potential risks of PIFU, the impact of PIFU on staff experience, workload and roles.

Key findings: 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 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.
- While 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).

What staff think PIFU is trying to achieve (1)

- Interviewees felt aims depend on who you ask
- Overall recognition of benefits for patients compared to fixed follow-up
- Awareness of aim to reduce outpatient activity but scepticism whether this will be achieved

<p>For patients – improving access and experience and embedding more patient-centred care</p>	<p><i>"It's the right thing for patients... being able to get in at the time when you need to be seen."</i> Operational staff, trust-wide</p> <p><i>"It's about giving [patients] control over their care and how they interact with healthcare services... making sure that they are in the driving seat as it were, but also that they understand how to drive the car."</i> Operational staff, trust-wide</p>
<p>For staff - directing clinical time towards those with greatest clinical need and planning capacity appropriately</p>	<p><i>"By formalising PIFU, with appropriate documentation, we actually know how many patients are being brought back and can ensure we have the right capacity in the clinic and are not overbooking because they suddenly have an urgent request. It's still quite new here, but going forward PIFU would help us make appropriate provision within the capacity we have for each speciality to ensure that there is enough outpatient capacity and PIFU patients can be slotted in easily."</i> Operational staff, trust-wide</p> <p><i>"It's very much part of our everyday working now. And when I see that magic word PIFU, I think thank goodness that's one more off the list that we can then see somebody else."</i> Operational staff, specialty-level</p>

What staff think PIFU is trying to achieve (2)

<p>For trust and services - ability to reduce unnecessary follow-ups</p>	<p><i>"We all came together and said, look, we have X number of women that are waiting for follow up and we cannot see these women within that certain amount of time... we cannot keep going at the rate that we were going."</i> Operational staff, specialty-level</p> <p><i>"I mean it hasn't released anything necessarily but I think it's definitely helped patients not having to keep coming back to the hospital all the time."</i> Operational staff, specialty-level</p>
<p>For service - safer way to do what's already happening</p>	<p><i>"For years some clinicians have had a system of 'call me when you need me'... but lacked governance or any systematic process or shared-decision around it...PIFU creates more structure, safety netting, and patient engagement."</i> – clinical staff, specialty-level</p> <p><i>"It seemed to be historical, and whoever saw the patient last then did exactly the same thing as what the previous clinician did."</i> operational staff, specialty-level</p>

What staff think PIFU is trying to achieve (3)

But scepticism that PIFU will be sufficient to reduce elective backlog and bring down waiting lists...

"Let's be honest, the reason the NHS is pushing this is because we've got such a mess with wait lists. And I support this, but only if done properly and with proper intentions... otherwise, it creates more work down the line if patients don't know why they're on PIFU and they're trying to engage back into the system, but don't know what they're supposed to do." – Clinical staff, specialty level

"From the trust point of view the intention around PIFU is also to try and manage that outpatient backlog. When we modelled what would it take to clear all of that backlog and ensure every single patient was seen in a timely manner we would need something preposterous like an additional 60 to 80 clinics running every single week, and we simply do not have the workforce, the physical infrastructure to deliver that." Operational staff, trust-wide

"ICBs will talk about using PIFU to reduce the number of follow-ups. I've seen beautiful spreadsheets where it says how much clinician time would be saved by reducing follow-ups... But the reality is we are years from that, because we have such significant backlogs – not actually gaining any time." – Operational staff, trust-wide

Other considerations

- Some suggestion that PIFU used as a “workaround” to avoid patients needing to be re-referred by their GP - challenge to ensure PIFU not used as an alternative to discharge (context of patient trust in and access to services)

PIFU can affect the type of work staff are doing

- Impact depended on the extent to which PIFU was a departure from previous practice. The extent to which changes were felt was also affected by the overall volume of PIFU patients in the specialty.

“It’s not had much of an impact really – it’s what we do for all our patients all the time.” Clinical staff, specialty level

- PIFU can add additional responsibilities for staff, such as patient monitoring and end-of-pathway clinical reviews.

“Those who are placed on a PIFU list might be monitored and certainly when it gets to the end of that PIFU period there should be a form of clinical review.” Operational staff, specialty level

- PIFU can increase staff workload. Admin teams were often most affected, especially when Trust Electronic Patient Records are poor at recording PIFU, or the information passed on by colleagues was poor.

“...for non-clinical staff, I think it’s been a nightmare. Because they have to deal with all the outgoing patients, and which pathway and partial booking list [to place patients on]. And also, clinicians are not writing particularly clear letters” Clinical / Operational staff, specialty level

- Clinicians’ outpatient shifts can become more intense. PIFU, by design, gets rid of “routine” attendances, which leads to higher average intensity of appointments and, in turn, scheduling challenges and risk of burnout.

“The more patients are placed on to PIFU, the higher proportion of patients will have greater acuity (because those being seen have a particular reason for initiating that appointment, vs. a fixed follow-up).” Clinical staff, specialty level

How PIFU is being used affects staff attitudes

- Some staff felt confidence that patients could be seen when most needed, without further straining staff capacity. However, others worried PIFU might make some patients less likely or able to be seen when needed.

“Now we have the option of going, ‘if there's any problems then you can contact us and we can get you an appointment however it's needed, be it face-to-face or telephone.’” Clinical staff, specialty level

- Some staff welcomed PIFU as a step towards more personalised, empowering models of care, which reduced waste of staff and patient time.

“I've been in the NHS a long time and you would find that patients would be brought back every six months, every 12 months, you know it's just ridiculous amounts of follow-ups that were happening... it seemed to be historical... now we know that that's not necessary.” Operational staff, specialty level

- The framing of PIFU aims affected satisfaction. There was cynicism towards target-driven initiatives and more positivity towards patient benefit-led framings.

“Currently I think they feel it's something that they [staff] are kind of being forced to do, especially with the ICB asking how many patients are on PIFU pathways all the time. So I guess it's really about, actually, can we turn the conversation around and not say how many people, but who would this benefit, who would be better off?” Clinical / Operational staff, specialty level / trust-wide

Where do staff see future opportunities for PIFU?

- Safe expansion of PIFU to more conditions, including those typically perceived as high risk.
- Adapted approaches and ways of working which better facilitate the use of PIFU, e.g. lengthening clinic slots to manage higher levels of average attendance complexity.
- Greater use of PIFU to manage people currently on waiting lists (although this is not currently recommended policy).
- Better use of technologies, e.g. easier recording of PIFU on EPR systems, data analysis (facilitating better understanding of impact of PIFU on certain groups, etc.)
- Creation of new roles, i.e. healthcare navigators and expanding/shifting existing roles for more efficient service delivery

“We’ve been able to move people [clinicians] doing a lot of follow-up to doing mainly fast-track. Demand for new patient appointments has rocketed. It allows us to flex things.” Clinical staff, specialty-level

- Better information sharing, including between outpatient departments and primary care. Involvement of primary care voices in broader PIFU conversations, including pathway design.

“Make sure that all parts of the system affected are represented in the discussions... You know, active engagement and constructive discussions and making sure that the discharge summaries come back to primary care and the patient on time.” GP

What are the perceived risks of PIFU?

- Patients on PIFU not being seen when needed, due to failures of the service (e.g. IT) or them not initiating contact when they have relevant clinical need.

“I think the biggest risk is that patients will not recognise their deterioration.” Operational staff, trust-wide

- Inequalities in ability to access care between those deemed eligible for PIFU, and those not deemed eligible.

“So you’re not put on it because you’re not deemed stable and therefore you wait on a long waiting list.” GP

- Increased pressure on the service and individuals because of more demand for appointments, or new responsibilities and changed ways of working (see slide 54).
- Displacement of activity to primary/emergency care if outpatient departments fail to adequately respond to demand for PIFU appointments.

“If it works really well you shouldn't see an impact in primary care because they should go directly back [to outpatient teams], but if not there is a high risk there will be push back into primary care.” GP

7. Patient engagement and experience

How patients engage with and experience PIFU and how services are measuring patient experience

Key findings: 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.

How are trusts measuring patient experience?

- Staff reported that limited activity had taken place to capture patient feedback although some had done short surveys within specialties or engaged with broader patient groups about PIFU and outpatient transformation more generally.
- There was an ambition to capture more formal feedback but most staff reported on anecdotal experience based on whether patients had agreed to being on a PIFU pathway and how they had subsequently engaged.
- Perceptions of patient experience were sometimes based on a lack of contact or complaints rather than positive comments ('no news is good news').

“I can't remember a complaint that has ever come in that said you've discharged me and I didn't want to be. So as far as I'm aware, patients are happy with it.” Operational staff, trust-wide

- Where patient feedback had been collected, a common theme was that patients were not aware they were on PIFU which led to concerns about access to clear and consistent information.

“We've done surveys, but [the] feedback was all about trust communications – so [I'm not sure] whether clinicians are having shared decision-making conversations with patients...” Operational staff, trust-wide

How do staff perceive patient experience? (1)

- None of our case study sites captured data on the numbers of patients who declined PIFU.
- Staff reported on the reasons why patients preferred to keep to a fixed schedule. This included: having the security, structure and routine of a follow-up appointment and reassurance of attending an appointment where everything is fine

“Initially when you explain PIFU to patients, [they] seem quite keen on it. You either have a patient who will be very accepting of it and think it's a good idea or you'll have that patient that wants to know that there is appointment on the system for them.” Clinical staff, specialty-level

- PIFU was perceived as a more desirable approach to ensure the patient does not feel abandoned and to prevent the need for people to go back to their GP (this was particularly true for people with long-term conditions which may be managed across both primary and secondary care).
- Where patients were on PIFU staff had received positive feedback, including that it was more convenient, people felt more in control of appointments, and there was less anxiety around attending hospital.

How do staff perceive patient experience? (2)

- Reasons for contacting included reassurance about symptoms, medication or information, which were managed in different ways. Where they had captured reasons, staff had been able to identify unmet need (e.g. information on medication side effects)
- But views were mixed about whether patients were contacting the service when they needed to.
- Some staff considered if patients were unhappy about PIFU they would contact the service, although others were concerned that not hearing from patients did not necessarily mean good news (and may mean that patients were either unaware of, or unwilling to contact the service when they needed).

“It’s a situation of known unknowns – if someone is on PIFU and they don’t trigger an appointment, you don’t know if they’re running into trouble until you see them. If they are triggering an appointment, is it because they truly need a clinical appointment, or is it something else?” Clinical / Operational staff, specialty level / trust-wide

How do patients experience PIFU?

- Patients given contact details of the service and a letter outlining process. PIFU largely presented as standard approach across the specialty, in one instance, described as an ‘open appointment’.
- Patients saw PIFU as being able to contact the service directly, contrasting with needing to go back via their GP.
- Everyone we spoke to had or planned to contact the service. This was for a variety of reasons and their interactions had different outcomes (including a request for information, telephone appointment with a nurse, appointment with a consultant, and reassurance).

“When I wanted them, they were there for me.” Patient, breast care

- But there was some anxiety about what would happen at the end of the pathway

“At the moment I feel that I’ve got the support if I need it. In two years’ time when you fall off the list altogether it will be back to square one... trying to get an appointment with the GP. Will they be available then? I don’t know.” Patient, breast care

What factors affect patient engagement?

- Individual health situation and characteristics could be relevant including where people are in their treatment or care, and their attitude and approach to self-management.

“I would recommend it but there are people who it will [not] work for because they’re not in the same position [cancer free]. They’re not in the same mentality. We’re all so different, I can see why it wouldn’t work for others.”

Patient, breast care

- Communication was essential – it was important for patients to have a clear understanding of what PIFU is and how it works from their healthcare team.
- Trust and confidence in the process is key. This includes clear avenues of communication for people to contact the service and reassurance that someone will be there to respond to their requests.

“The patient-initiated system should work for everyone but some people won’t trust it and I think that’s going to be the problem.” Patient, breast care

- Wider context was also relevant, especially the general anxiety around accessing services such as primary care. Patients were concerned about whether they would be able to get appointments and how long they would need to wait.
- Condition specific factors such as having specialist nurses and ongoing monitoring (e.g. regular mammograms) were also relevant. This meant there were dedicated people to support the service who patients were familiar with, and a supportive infrastructure.

8. Evaluation guide

An outline of a guide to help NHS trusts evaluate their implementations of PIFU in the longer term

Overview of the evaluation guide

Aims	To support PIFU service leads to conduct an evaluation at a specialty level
Audience	PIFU service leads and the 6-10 people they recruit to help them plan and deliver the evaluation (e.g., data analytics, clinicians, IT)
What it covers	<ul style="list-style-type: none">• Stakeholder group: Who is going to help with the evaluation?• Planning: What data is available? What is the preferred timeline? Why are we doing this evaluation – what questions are we trying to answer?• Building a programme theory: Sketch out how and why will work in this specialty• Choosing metrics: Which data do we need to start collecting now? Which indicators might be most suitable early and later on in the PIFU journey?
Development	<ul style="list-style-type: none">• Co-produced with commissioners and end-users
Considerations	<ul style="list-style-type: none">• Data challenges will make an outcome evaluation very challenging• NHSE aims for PIFU may vary from local aims for PIFU

Understand PIFU impacts on patients

Possible evaluation questions that involve collecting information about PIFU patients	
Patient outcomes	<ul style="list-style-type: none"> • What are the relevant patient outcomes for evaluating the impact of PIFU services? • What impact does PIFU have on patient outcomes?
Patient experience	<ul style="list-style-type: none"> • What are patient experiences of engaging with PIFU services? • What is the level of patient engagement with PIFU?
Patient safety	<ul style="list-style-type: none"> • How are patients' preferences accommodated in the PIFU decision making process (shared decision making)? • What is the level of understanding of information patients were given at their appointment ? • How often do patients want to make contact whilst on PIFU but are not able to?
Effectiveness	<ul style="list-style-type: none"> • How confident are patients in following the advised care plan? • How has patient confidence changed over the period of their care?
Health inequalities	<ul style="list-style-type: none"> • Is there variation in how different patient populations access and engage with PIFU?

Action for PIFU programme leads

- Work with your evaluation stakeholder group to decide which 1-2 evaluation questions are most interesting to your specialty and trust.
- Each evaluation question asked has resource implications. One practical route to choosing involves prioritising questions based on data availability.

9. Implications for policy and practice

What our findings mean for ongoing implementation of PIFU and for wider outpatient policy.

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.

Implications for policy and practice (2)

- **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.
- **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.

Implications for policy and practice (3)

- **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.

9. Recommendations

Recommendations for policy makers and research

Recommendations for national policy makers

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 health care 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.

Recommendations for further research (1)

Outcomes

- Further quantitative evaluation of measurable outcomes of PIFU should be undertaken that includes the impact on patients and staff workload. Analysis of patient outcomes (including analysis of inequalities) will be enhanced when the identification of patients on PIFU pathways is more widely reported within hospital patient administration systems and thus linkable to other secondary care events.

Staff experiences

- More research should be conducted on the views and experiences of staff relating to PIFU, particularly in clinical specialties not covered by our own evaluation. There would be value in exploring how PIFU impacts on role and workload for different groups of staff, including GPs.

Sharing evidence

- Research evidence should be shared with local services to help inform their implementation and running of PIFU.

Recommendations for further research (2)

Patient experiences

- More research on patient views and experiences of PIFU, in particular, comparing shorter-term and longer-term pathways (targeted approach within specific services may be more appropriate).
- Further research is needed to understand the reasons why people may decline to use PIFU to understand the perceived and actual barriers and potential action required to address these.
- Better understanding of how different populations access, engage with and experience PIFU. Also, better understanding of how services can be designed and adapted to mitigate against potential inequalities including how services are already adapting or tailoring their services and approach to account for this.
- There remains a lack of reliable information on how many people are getting back in touch with PIFU services and whether this is appropriate. Without this information it is difficult to determine whether patients with a clinical need can access healthcare services.

10. Strengths and limitations

Strengths and limitations of the methods and findings of the evaluation

Strengths

- The study team conducted a mixed-methods rapid evaluation, following established methodology and guided by previous evidence of implementation, while engaging with published literature. This enabled the team to develop a comprehensive understanding of the introduction and rollout of PIFU in NHS outpatient services in England.
- The approaches we used have been influenced by our qualitative findings and triangulation across different data sources. For example, the wide variation in implementation has informed us of the importance of analyses for individual specialties.
- Qualitative findings have also helped with our interpretation of quantitative outcomes. For example, why attendance frequency may increase in some specialties and informing us of other factors unrelated to PIFU that may be influencing results.
- Our study benefitted from a multi-site case study approach which enabled us to examine PIFU across several organisations and clinical areas. Staff interviews included people with clinical and operational roles, at both specialty and trust level, enabling us to capture a range of different perspectives. The workshop also allowed us to reach a wider range of participants. We captured patient feedback on their experiences with PIFU which revealed important considerations. We triangulated our findings across our qualitative data sources to test and confirm our findings.

Limitations – qualitative work

- Conducting a rapid study of an intervention which is still being rolled out alongside other interventions, where data are limited and at a time when there were significant pressures on NHS staff capacity, introduced considerable challenges.
- PIFU is implemented in a variety of ways which may not all have the same impact (such as on the number of follow-up appointments). Within clinical teams there can be inconsistencies in how PIFU is implemented, and some sites are adapting their pathways through experience which means we are not evaluating a stable process.
- Given the variation in how PIFU is being implemented, it may be that their experiences are not representative of PIFU across the NHS. Our sample size both in terms of case study sites and interviewees is also small. Engagement was more limited than anticipated given the considerable pressures facing NHS sites and staff at the time of data collection. A focus on specialty at a high level may also have masked nuance within specialties.
- We experienced significant challenges with patient recruitment and as a result were only able to conduct four interviews with patients within our time frame.
- Given the variation and small sample, it is not possible to generalise the feedback across other patients, services or specialties. Although our intention was to sample patients across a range of demographic characteristics, the sample was too small to do this.

Limitations – measuring impact

- We have only been able to analyse at trust or specialty level. Yet within specialties PIFU may be implemented differently for different conditions.
- Some hospital specialties have been running open appointment systems for several years, which have similar features to PIFU, but these have not been reported as such. This could obscure any impact PIFU might be having where there has been a more marked change in service.
- Discharges to PIFU could include patients who in other circumstances may have been discharged and removed from a care pathway. This might cause an increase return visits, at least in the short term, since many of these patients would not have had the opportunity to make a new appointment outside of PIFU.
- With the P-EROC data we have needed to make assumptions about how to interpret missing data and submissions reported as 'complete' and 'partial'.
- It is not clear how accurate the ratio of new PIFU transfers to total outpatient activity is as a measure of PIFU activity.
- When linking between P-EROC and HES we have assumed specialty coding is consistent between the two datasets.