Patient-initiated follow-up

Findings from Phase 1 of a mixed methods evaluation

Main report





How this report is structured

- 1. Measuring the impact of PIFU
 - i. Methods and overview of PIFU activity
 - ii. Data quality
 - iii. Impact on outpatient attendance
 - iv. Impact on time to next appointment
 - v. Caveats and conclusions
- 2. Qualitative findings (interviews and document analysis)
 - I. Aims and features of PIFU models
 - II. Barriers and Facilitators
 - III. Staff and patient experience
 - IV. Health inequalities
- 3. Evaluation opportunities: considerations for Phase 2
- 4. Reflections and recommendations
- 5. Appendices





Research questions

Quantitative workstream

- 1. How well can national data be used to evaluate PIFU?
- 2. What are the impacts of PIFU on measures of outpatient activity, especially with regard to frequency and time to follow up attendances?

Qualitative workstream

- 1. How is PIFU being implemented, including its aims and expected outcomes, components and processes?
- 2. How have staff engaged with PIFU and what is their experience of delivering the service?
- 3. What are staff perceptions of the opportunities and risks associated with PIFU?
- 4. How are data being used by services to monitor progress against expected outcomes?





MEASURING THE IMPACT OF PIFU

Methods and overview of PIFU activity





Methods overview

For the analysis of impact, we have used two National datasets:

Hospital Episodes Statistics (HES) – provides data on outpatient appointments at an individual patient level

Provider Elective Recovery Outpatient Collection (P-EROC) – provides monthly data on PIFU activity.

We have only analysed "essential" data items within P-EROC, namely: patients transferred to PIFU pathways and numbers of total PIFU episodes.

Our analysis includes the following stages:

- Description of the available data
- Assessment of data quality and interpretation of missing data
- Before and after analyses of outpatient attendance per patient with levels of PIFU usage as an explanatory variable
- Analysis of time to next attendance using survival analysis comparing trust-specialty combinations with different levels of PIFU usage





How can we measure PIFU activity?

Ratios of new PIFU episodes to overall outpatient activity

| | Numerator (from P-EROC) | | Denominator (from HES) |
|---|--|----|--|
| 1 | Patient episodes moved or discharged to PIFU pathways | V. | Total outpatient activity over the same period |
| 2 | Patient episodes moved or discharged to PIFU pathways | V. | Number of unique individuals with outpatient appointments over the same period |
| 3 | Total PIFU episodes at the start of each month | V. | Estimates of the total number of people on an outpatient pathway at the same time* |

None of these are precise measures because we do not know how many patients are not on a PIFU pathway at any given time.

In our analysis presented in these slides we have adopted the **first measure** listed.

*Derived from information about whether patients are given a follow-up appointment





PIFU overview

Volumes



Rates







Rates of PIFU activity per speciality

% of trusts with different rates of activity for the top 20 specialties by PIFU volume.

Rates measured as numbers of episodes moved or discharged to PIFU per outpatient attendance from Sept. 2021 to June 2022.

Data for 50 trusts declaring complete data over the whole period.







MEASURING THE IMPACT OF PIFU

Data Quality





Reporting of PIFU in P-EROC: data quality

Among trusts declaring complete data over the period between Sept. 2021 and June 2022:

Some trust/specialties reporting larger changes in total episodes than numbers discharged or moved to PIFU.

 In particular, empty or zero movements or discharges but positive increases in total episodes. This is most significant in a few trusts.

Some trusts/specialties reporting no total episodes, but positive numbers of patients moved or discharged to PIFU.

Likely misinterpretation of data requirements

- Some trusts reporting all transfers to PIFU as "discharges" or as "moved".
- "Total episodes" occasionally interpreted as the sum of patients moved or discharged to PIFU in the same month.





Specialty coding HES v P-EROC

Cases exist where P-EROC reports activity against a specialty within a trust, yet HES reports no activity.

<u>Examples</u>: (no activity reported in HES for either specialty)

Podiatry: East Cheshire – 451 patients moved or discharged to PIFU between Nov. '21 and March '22 Cardiology: Stockport – 248 patients moved or discharged to PIFU between Sept. '21 and June '22

This suggests some wider inconsistencies between the two data sources which may affect the results of linking the HES and P-EROC data by specialty.





Mitigating data quality and missing data issues

We developed four scenarios for handling missing data and anomalies. These range from:

Scenario A: We include all P-EROC data on numbers moved or discharged to PIFU pathways where the records are declared to be complete. For any specialty that we know is operating at a trust (either from P-EROC or HES) any missing values in P-EROC are assumed to be zero.

to:

Scenario D: We include all P-EROC data on numbers moved or discharged to PIFU pathways where the records are declared to be complete. However, any missing data is assumed to be unknown.

The analyses presented in the main part of this report use **scenario A**. Further details of the other scenarios and corresponding results are provided in **Appendix 2: Sensitivity Analysis**





MEASURING THE IMPACT OF PIFU

Impact on outpatient attendance





Changes in attendance per patient: Methods

Q: Has the introduction of PIFU changed the frequency of outpatient appointments per patient?

Periods of analysis

Two 6-month periods were chosen two years apart:

- Sept. 2019 to Feb. 2020 and Sept. 2021 to Feb. 2022
- Both contain the same months of the year
- The first period stops just before COVID influenced activity
- The second period starts when P-EROC reporting became mandatory

<u>Analysis</u>

Linear regression models relating attendance per patient to levels of PIFU activity, accounting for specialty and trust

Selected data

- 56 trusts declaring complete PIFU records from Sept. '21 to Feb. '22.
- These have 36% of outpatient attendances from Sept. '21 to Feb. '22.
- 3,063 trust/specialty combinations.

<u>Assumptions</u>

- No PIFU (or relatively small amounts) of activity in any of the trusts in the earlier period.
- Missing data scenario A: missing data treated as zero

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• PIFU activity defined as episodes moved or discharged to PIFU per outpatient attendance



Changes in attendance per patient: overall

Overall changes in attendance over the two periods for all 56 trusts combined



Overall changes in attendance rates over the two years have been very small





Classifying PIFU usage by trust and specialty

Classification based upon reported activity between September 2021 and February 2022

PIFU usage category:

- No PIFU 1,920 trust/speciality combinations (63%)
- 0 to 1% PIFU 549 (18%)
- 1 to 5% PIFU 389 (13%)
- > 5% PIFU 205 (7%)





Changes in attendance per patient: Impact of PIFU

Changes in attendances per patient relative to no PIFU between the 6-month periods Sept. '19 to Feb. '20 and Sept. '21 to Feb. '22.



Findings summary

Relative to trust/specialty combinations with no PIFU, there are significant reductions in attendances per patient when all specialties are included.

If we restrict our analysis to only the top 30 PIFU specialties by volume, these changes are no longer significant.

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MEASURING THE IMPACT OF PIFU

Impact on time to next appointment





Time to next appointment: methods

Q: Was the level of PIFU related to the length of time between appointments?

Period of analysis, and selected data

- Ten-month long period: September 2021 to June 2022
 - Start date when P-EROC reporting became mandatory
 - End date due to limit of data availability
- Selected all attended appointments in 30 specialties, from outpatient HES data (n = 43.1M)
- Included only those where P-EROC "complete" for provider trust in specific month of attendance (n = 21.3M)

Analysis

• For all 21.3M attendances:

Find person's next appointment in same trust-specialty & record **time to next**: 1 day to ~300 days (56%), or none (44%) Record basic demographic info: age, sex Assign to each attendance a % PIFU level (categorised as above)

- Carried out Cox proportional hazards regressions, separately by specialty, adjusting for: age and sex, time period, provider trust (stratified similar to clustering)
- The regression aims to test the probability of having a subsequent appointment at future time *t* following an initial attendance, by PIFU level

Notes and assumptions

- PIFU activity was defined as episodes moved or discharged to PIFU per outpatient attendance, in trust, specialty and month
- Two P-EROC submitting providers were excluded (n = 146 included). One a private provider, the other for data reasons
- The 30 selected specialties accounted for ~90% of PIFU activity
- We ignored same day appointments (within trust-specialty), and specific attendance/appointment types (so all appointments valid, not just follow ups). Multiple attendances per person in the period were allowed
- Analysis akin to scenario A: absent PIFU data treated as no PIFU
- There was no direct linkage between PIFU data and outpatient attendances – not an analysis of actual PIFU cohorts
- Methodology able to account for varying follow up times, but interpretation not necessarily straightforward

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"Time to next appointment" - how does this vary by specialty? Time to next appointment, days For attendances in Sept 2021 who had a further appointment (see right hand chart) % with a next appt by Centiles shown: 5%, 25%, 50%, 75%, 95% 30 June 2022 0 50 100 150 200 250 0% 50% 100% 560 Midwife episode 103 Breast Surgery Top 20 specialties 651 Occupational Therapy (accounting for ~80% of 650 Physiotherapy PIFU activity) 314 Rehabilitation 653 Podiatry 110 Trauma & Orthopaedics 2.5M attendances in Sept 330 Dermatology 2021 502 Gynaecology 130 Ophthalmology 101 Urology 658 Orthotics 191 Pain Management 301 Gastroenterology 320 Cardiology 840 Audiology 410 Rheumatology 120 Ear, Nose & Throat (ENT) 420 Paediatrics 400 Neurology





"Time to next appointment" - how does this vary by hospital?

Focus on one large specialty: Trauma and Orthopaedic

370K attendances in Sept 2021







Results: single specialty example



Results: top 10 PIFU specialties



Key:

Results:

- *****: higher PIFU associated with <u>less frequent</u> appointments
- +: no association between PIFU levels & frequency of appts
- -: mixed, or higher PIFU associated with more frequent appts



See **Appendix** for next 10 specialties, and an attempt to run a multi-specialty model

● 1-5% PIFU ● >5% PIFU

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Variable results by specialty – further work needed to understand

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● No PIFU ● 0-1% PIFU

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MEASURING THE IMPACT OF PIFU

Caveats and conclusions





Caveats

Before-after analysis

- Several trusts may have been operating a PIFU-type process in the earlier period where we assume none.
- Six-month periods may not be long enough to observe the true impact on attendance per patient.

General

- With aggregated data there needs to be enough PIFU activity to be able to observe an impact.
- Although we have mitigated some problems with data quality and missing data by running different scenarios, variable quality and reporting consistency may still have an impact.
- Findings observed over a period of transition may not carry over to when PIFU becomes more embedded.





Conclusions on the impact of PIFU

- Implementation of PIFU appears to be associated with a lower frequency of outpatient attendances per patient, but further analysis is required to establish the robustness of this finding.
- For individual specialties, findings are more mixed with lower frequencies observed in some (e.g., trauma and orthopaedics, rheumatology), but not others (e.g. ENT).

However..

- It is currently difficult to use national routine data to accurately measure PIFU activity within hospitals and it is not possible to directly observe the impact on cohorts of patients moved to PIFU pathways.
- The accuracy of P-EROC data and consistency of coding between P-EROC and HES may have **an important influence on evaluating the** effectiveness of PIFU.





QUALITATIVE FINDINGS





Methods overview: Qualitative workstream

Qualitative workstream

We conducted a **structured review** of key documents, including standard operating procedures and equality impact assessments in each site to understand how PIFU is being implemented and how different risks are being considered

- Using a semi-structured interview schedule, we interviewed 13 clinicians and operational leads across three sites between June 2022 and September 2022 to understand staff perceptions of PIFU and key barriers and facilitators for implementation.
- We validated findings and filled gaps in our analysis with our **project advisory group** composed of clinical experts and a patient representative -- in September 2021.
- All interviews were recorded and transcribed. The responses were then codified and entered into RAP sheets to support a structured analysis.





QUALITATIVE FINDINGS

Aims and features of PIFU models





How are aims of PIFU being framed to patients/staff?

Staff

Patients

- Release clinicians to see patients with the greatest needs
- Reduce waiting times for patients
- Reduce unnecessary patient visits
- Deliver Covid-19 recovery and LTP goals

- Reduce unnecessary visits to the hospital for routine checks
- Improve outcomes and increase satisfaction
- Reduce patient anxiety
- Improve patient ownership over health
- Help save time and money by reducing the number of journeys for unnecessary appointments

"The biggest win for clinicians is to allow capacity to see the patients who have the biggest needs – while [PIFU] might not reduce overall numbers of appointments (given the size of waiting lists) it gives clinicians more time to see the right people"

– Operational lead

Sample PIFU patient comms for long-term condition

"The reason we offer [PIFU] is because we want to give you more choice and flexibility and reduce unwanted and unnecessary visits to the hospital. This will help improve patient experience, reduce cost of travel and parking and reduce waiting times for appointments."

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Some patient materials emphasise improvements to clinical outcomes, although evidence is currently inconclusive

Sample patient communication for long-term PIFU pathway:

"[PIFU] allows you to take a greater role in the management of your condition. This has been designed for patients following a procedure or treatment. It allows you to access your clinical team if you, a family member, or carer feel you need to prior to being removed from the waiting list, rather than having a prearranged or regularly scheduled appointment.

This service improves patient satisfaction levels and clinical outcomes as you are seen when it is appropriate for your condition while reducing waiting times"





How models compare: overview

Lower intensity input from services or triage / prioritisation

Higher intensity input from services or triage / prioritisation

| Clinical judgement / loose crite | Localised clinical protocols | |
|--|---------------------------------|---|
| PIFU-by-default | Patient Induction and Sign-on | In-person consent |
| None | Patient monitoring + tracking | PIFU dashboards + remote monitoring |
| Phone/email + no ringfenced capacity Patient booking / cont | | Multiple booking methods + capacity reserved for PIFU |
| Everyone requesting appt gets | Pre-questionnaires / assessment | |
| Only patient initiates contact | Safety netting | Annual clinical review |
| Automatic discharge | Discharge | Face-to-face clinical review |



Patient selection

Lower intensity input from services

Higher intensity input from services

Clinical judgement / loose criteria

Local specialty-level protocols

- Patient selection criteria tends to vary by specialty and involves a high degree of clinical input
- In some sites, every specialty has developed their own standard protocol, where in others patient selection depends more on individual clinical discretion
- Variation in how and extent to which non-clinical criteria are considered (e.g. patient confidence to self-manage, digital literacy, etc.)

"It's identifying the most appropriate patients, who can adapt to the technology on PIFU, and who is less able to... But it's for clinicians to decide [who is selected for PIFU] and this is why the PIFU protocols are so important to have in place -- we did put a line down which is, you know, that's not for us to decide – clinical teams need to get the PIFU protocols in place" **Operational lead**

Patient induction + sign-on

Lower intensity input from services Higher intensity input from services

PIFU-by-default

In-person consent

- In some specialties (e.g. physiotherapy), patients are automatically placed on PIFU as that is already the standard of care and no fixed follow-up alternative is offered.
- Many services have established protocols, including patient-information sheets with details for when and how to make an appointment, and guidance to clinicians for seeking patient consent and developing personalised support plans. However, the extent to which protocols are adhered to and understood by staff varies.
- Sites tend not to include a formal patient education as part of PIFU pathway (though some sites with shared-care records provide resources to help patients self-manage).

Patient Booking + Contact

Lower intensity input from services

Higher intensity input from services

Phone/email + no ring-fenced capacity

Multiple booking methods + capacity reserved for PIFU

Ways of booking appointments

• Sites typically only offer telephone and email as methods of booking appointments, despite ambitions to implement other methods (e.g. app-based, SMS)

Ring-fencing of slots/capacity

- Variation between service providers as to whether they reserve slots, especially for PIFU
- Some kept time aside for PIFU appointments to some degree, either formally or informally, whilst others place PIFU patients in next available slot
- General capacity strains used to explain lack of ringfenced capacity

"We don't hold a specific kind of ring-fenced capacity for them... capacity overall is a real problem for us" – Clinician
Escalation and Triage

Lower intensity forms of triage/prioritisation

Higher intensity forms of triage/prioritisation

Everyone requesting appointment gets one

Pre-questionnaires / assessment

Forms of triage

- Variation in the degree of triage across sites, with some offering appointments to all patients with a request.
- In other sites patients are first assessed and prioritised for their need for an appointment, either through phone consultation with a clinician or through web-based prequestionnaire (though still not fully operational in some sites)

Factors influencing whether triage used

- Complexity of symptoms (e.g., short-term pathways where fluctuations are more visible appear less likely to involve triage compared to longer-term pathways where the appropriate course of action is more varied)
- Clinician's judgement of patient or carer's ability to assess severity of symptoms

On the difficulty of triage with children / carers: "[With parents] they're either overly optimistic about their children's potential behaviour... or they're overreacting" – **Clinician**

Safety netting + Discharge

Lower intensity input from service

Higher intensity input from service

Automatic discharge to GP

- **Annual clinical review**
- Approach to safety netting and discharge varies by specialty and patient need
 - Automatic discharge, when occurs, tends to be limited to short-term pathways and / or patients with low risk ("no news = good news")
 - Long-term pathways tend to incorporate safety netting as standard, including set check-ins / reviews and coordination with other services
 - Safety-netting ranges from questionnaires / phone consultations to a review of notes
 - Timing and approach to safety-netting informed by clinical judgement of patient circumstances e.g., ability to self-management and reliably monitor symptoms
 - In some sites, clinicians reported giving some degree of leniency (a few months depending on pathway length) for patients to make appointments without having to restart the referral process

On the decision to discharge: "In one of our specialties, they were nervous about the short term PIFU pathway about the patients just being discharged. So for a short amount of time, it was agreed that their pathway, those patients would be clinically reviewed before they removed from the pathway."– **Operational Lead**

Patient monitoring and tracking

Lower intensity input from service

Higher intensity input from service

None

PIFU dashboards + remote monitoring

- Integration with tech platforms
 - Reliance of PIFU on internal administration tools and processes (placing onto pathway, monitoring, discharge)
 - Potential to use patient-facing platforms to facilitate (e.g., remote monitoring data, symptom reporting)

Remote/self-monitoring

- Broad discussion of potential of technology such as wearable devices and online reporting tools (e.g., questionnaires designed to track recovery) to be integrated with PIFU. However, not currently utilised by providers we interviewed
- Concerns raised about potential administrative burden of integration

"...the software is designed to send them questionnaires at a fairly regular intervals... the problem is that we need a dedicated, probably a specialist, nurse to run it" – **Clinician**

QUALITATIVE FINDINGS

Facilitators and barriers

Facilitators for the set up, design, and delivery of PIFU





What factors help the set-up of PIFU? (1/2)

Having a clear and well thought-through model from the start:

- Having access to examples of good PIFU practice from elsewhere
- Starting with specialties where some form of PIFU / open booking is already in place (recognising this
 may not necessarily lead to big changes in appointment numbers)
- Protecting time for staff to implement and adapt approach in response to challenges
- Drawing from regional networks as well as support from NHSEI and NHS Futures

Targets can accelerate implementation, although some felt targeted goals would help reflect differences in populations.

"NHSE have put in some targets associated with [PIFU]...my only feedback was whether those targets were based on evidence or [...] case studies done elsewhere. A lot of PIFU work has been done in [...] Southwest and Northwest England where sometimes the population doesn't necessarily reflect..." – **operational lead from highly urban and ethnically diverse area**





What factors help the set-up of PIFU? (2/2)

Engaging the right staff is critical to set-up:

- **Clinical:** Across sites, clinical leads have acted as vital champions in developing localised protocols, gaining traction among peers, determining patient selection and engagement, and working out what data is needed to monitor impact.
- Administrative: Sites noted the importance of administrative and operational support with firm understanding of how to record different pathways and support triage. This includes IT expertise to navigate between digital and non-digital PIFU pathways (where implemented)
- Senior leadership: As with any service change, senior leaders have supported implementation by signalling PIFU as an organisational priority, leading on working groups, and providing direct managerial support.

The digital maturity of trusts, especially integrated booking systems and patient portals, seen as 'central' to driving implementation.





What factors help the delivery of PIFU?



Ensuring accessibility and patient safety netting, through:

Proactive outreach with patients who do not make contact within a given timeframe (and follow-up would be expected), and systems to reprioritise appointments when appointments are cancelled.

Clear guidelines about which patients are not suitable for PIFU

Improved access to 24/7 hot lines and increasing appointments that fall outside of routine hours.

| LЕ | | | |
|----|--|--|--|
| ED | | | |
| | | | |

Providing clear communication to patients, through:

Clear patient information sheets that outline how to contact the service, tools for selfmanagement, examples of when to contact the service (and when not to).

Covid created some opportunity to push more digital solutions for patients and increase comfort with digital.



Monitoring inequalities and adopting mitigations, including through:

Equality impact assessments within each specialty to assess the impact of PIFU on different groups

Focus groups at early stages and throughout implementation to collect feedback

Developing digital alternatives to avoid digital exclusion





QUALITATIVE FINDINGS

Facilitators and barriers

Barriers to the set up, design, and delivery of PIFU





What hinders the set-up of PIFU models?

Time and resource to implement PIFU needs to be in place from start

- Protocols, governance, inclusion and exclusion criteria must all be worked out within local dynamics and setting.
- Time required (esp. of clinicians) during implementation described as offputting; reassurances needed around value of PIFU and clarity around model.

Poor engagement from key individuals and conflicting priorities can limit the speed at which PIFU is rolled out • Lack of senior leadership to lead on working groups and prioritise specialties, internal politics, overlapping innovations, and pressures such as Covid, winter, and elective backlog, all listed as reasons for delays.

Insufficient guidance and protocols that are targeted to clinical setting/specialty can slow down implementation

 Many national protocols are a 'one-size-fits-all' and do not necessarily reflect needs of long-term conditions. This can lead to delays in setting up PIFU, e.g., in diabetes or endocrinology.

Existing tech capability and IT systems within Trusts influences pace of rollout

• Where systems are not well integrated and automated, the set-up will have a bigger burden on administrative staff.

What hinders the delivery of PIFU? (1/2)

Staff resource and engagement are key to running PIFU, but clinical resistance has hindered delivery, particularly in some specialties.

- **Clinical staff:** sites noted risk aversion among clinicians as a key barrier and a need for 'cultural shift'. Some clinicians also resisted PIFU because of potential increases to workload and disruptions to workflow that have not been fully accounted for, and concerns that PIFU would not benefit patients clinically.
- Administrative staff: size of & impact on admin teams has varied, but there are concerns about additional work for these staff. This has been mitigated in some settings through a more 'central' monitoring of PIFU patients.

"For some providers, PIFU has made discharge a more time-consuming procedure (vs. other 'open appointment' forms), whilst for others it removed some steps, like clinical review...some clinicians anxious about discharging without review, where others feel burdened by need to review (and that this defeats the objective of *PIFU*)" – **Operational lead**

"the criticism from some people is... you're still forcing me to do further clinical admin" – Clinician





What hinders the delivery of PIFU? (2/2)

Choice of patient and condition affect PIFU uptake and how likely it is to have an impact on outpatient attendances.

- **Patient selection:** The number of patients eligible for PIFU will vary by site and condition, and come down to a patient's ability to self-manage, understand their symptoms and contact the service.
- Condition: people we interviewed reported some conditions such as ophthalmology, diabetes, endocrinology, paediatrics, hepatology or heart failure have not necessarily embraced PIFU as they carry more risk.

| How triage is conducted varies across sites and can carry risk | In some settings, a call handler is used for triage. This has occasionally led to increased appointments where they are given to every PIFU patient who calls. As a result of capacity, some patients are not reviewed or seen in a timely way. This can undermine patient trust in the service. | | | |
|--|---|--|--|--|
| | numbers of patients to contact services. | | | |





QUALITATIVE FINDINGS

Staff and patient experiences

Patient experiences





Making PIFU work for patients: Staff perceptions

Facilitators to patient engagement

- Effective triage when patients contact the service (influenced by patient understanding of their symptoms and condition)
- Clarity about what the service can and can not offer and when need to seek support from elsewhere
- Reminders for patients about what PIFU is and how it works
- Clear written and verbal communication
- Shared principle across the service "normal' or "typical" pathway
- Importance of patients understanding that they will be discharged after a period of time





Making PIFU work for patients: Staff perceptions

Barriers to patient engagement

- Difficulty understanding how PIFU works (i.e. importance of providing patient information, ways to address queries)
- Lack of targeted information or engagement approaches with higher risk patient groups e.g. those with learning disabilities or those less engaged with outpatient services more generally, non-English speaking
- Familiarity with existing model of care longer length of time on a traditional pathway the more resistance to change
- Fears that patients won't be able to access timely support if they experience recurrent problems or symptoms
- Some patients prefer scheduled follow-up appointments (e.g. patients with more complex health needs or those accessing services for a longer time)





QUALITATIVE FINDINGS

Staff and patient experiences

Staff experiences





Making PIFU work for staff: staff perceptions

Perceived benefits to capacity

- Value seeing patients who most need to be seen "the right care at the right time" "responsive to need" "more urgent support for people who need it"
- Helps to address capacity challenges
 - "Freeing up capacity for new patients" by not bringing in patients unnecessarily
 - Able to clearly see who needs appointment (removing patients from followup waiting list)
 - Good way to ease patients towards discharge who have been accessing service for a long time
- Formalises what is already happening in some specialties
- Wider impact of PIFU helping to ease the burden on primary care (i.e. if patients need to be re-referred)





Making PIFU work for staff: staff perceptions

Perceived concerns for capacity

- PIFU already exists informally across many services and can therefore be perceived as a tick box exercise to achieve target
- Capacity concerns around number of patients requesting an appointment, risk of not being able to see patient within reasonable time period, and managing patient expectations around timing of appointments
- Time and resources needed for setting up pathway
- PIFU is not perceived as appropriate for certain specialties (i.e. certain conditions and risk level)





QUALITATIVE FINDINGS

Risks and unintended consequences: health inequalities





Health inequalities: Perceived risks

Sites have limited data or ways of examining any impact on health inequalities, and are only in the early stages of understanding how PIFU affects patient experience

Time is needed to establish the service before examining health inequalities data (i.e., understanding who is accessing the service and the impact for different groups) Patient selection depends on a clinician's assessment of subjective (and non-clinical) criteria – e.g., patients with perceived low digital literacy, caring responsibilities, etc. may not be offered PIFU Inequities in access may be widened if certain factors, (e.g., mental health, relationship to / expectation of the NHS), make it more difficult for individuals to make an appointment

Current evidence is not reflective of different population groups, and whether different population groups are reflected in the targets (e.g., considering the local context and population).

PIFU might violate patient trust if patients aren't seen in a timely manner







Health inequalities: what strategies are sites adopting?

For digital PIFU, the importance of foreign language options and easy read text including large print (however it can take time to implement changes within platforms) Use of accessible and straightforward language in patient communication materials, particularly if delivering PIFU alongside remote monitoring or dashboards (e.g., supporting patients to understand test results)

The importance of non-digital options and equitable access to service regardless of whether digital or nondigital pathway Involvement of carers, particularly if supporting patients to understand test results. and liaising with other services where appropriate.







EVALUATION OPPORTUNITIES: CONSIDERATIONS FOR PHASE 2





Reflections on local use of data

| Variation in local data being collected | Variation in extent of local data being collected across organisations depending on capability of systems. Importance of patient administrative systems to support local monitoring and data sharing. |
|--|--|
| Limited data collection on health inequalities and patient experience, and variation in how it's being considered and prioritised. | More data needed to look at health inequalities in order to evaluate impact of PIFU across different populations Services at early stages of thinking about health inequalities, with intentions to collect and analyse inequalities related data as programme matures |
| Data is being used as PIFU is being rolled out with other specialties – to help shape decisions | Use of dashboards and weekly reports to share data and information on PIFU with services and clinicians themselves to identify what is going well or not so well and engage teams. |
| Variation in level of user involvement across services | Some sites identified patient input lacking and expressed wanting more user involvement such as engaging with patient forums, involvement in pathway development. One site already had a user engagement group, while others were planning a patient experience survey |
| Limited data to evaluate the wider impact of PIFU | Limited good quality data that can be linked to evaluate impact of PIFU on other parts of the system e.g., if patients visit the emergency department |

Looking ahead to phase 2: challenges

It is important to understand where trusts are starting from in terms of how different PIFU is to existing practices (and what the scope of improvement really is)

- Many services and specialties already implementing PIFU informally
- Differences in terminology and definitions used to describe PIFU across services

In many services, it is too early to understand any impact on service demand and capacity (e.g., it might take several months before any changes are observed)

How to best distinguish impact from wider improvements in outpatient services, other innovations being implemented and fluctuating waiting lists.





Looking ahead to phase 2: areas for further qualitative exploration

Gaps between protocols and standards being set for PIFU and actual practice

Ways of supporting local data collection and evaluation to supplement national data

Causes of variation and potential effects in how PIFU is being set up, designed and delivered for patient and staff experience

Potential adaptations and opportunities for avoiding or managing unintended consequences of PIFU (eg, health inequalities)





Looking ahead to phase 2: quantitative assessment of impact

Further sensitivity analyses using other definitions of PIFU activity.

Re-assessment of longitudinal data analysis with longer time series.

Guidance on data capture and analysis to be added to an evaluation framework.

In depth analyses of inequalities.

More refined analysis using the Strategy Unit classification to identify more relevant outpatient attendances in HES.

Updating analyses as more P-EROC data become available.

Use of local data, subject to availability.





REFLECTIONS AND RECOMMENDATIONS





Recommendations (Data and analysis)

- The quality of P-EROC needs to be reviewed, including the reporting of complete submissions.
- Local trusts should capture data at an individual patient level for their own monitoring and evaluation reporting which can be linked to (or incorporated within) their own Patient Administration System (PAS). For example:
 - $\circ~$ When a patient is moved or discharged to PIFU
 - \circ $\,$ When a patient is removed from PIFU $\,$
 - $_{\odot}$ Use of a PIFU flag whenever an outpatient record is added to the PAS.





Recommendations and Opportunities: National and regional teams

- To help achieve adoption by specialties where uptake has lagged, NHS England may consider further working with clinical societies to develop condition-specific guidance and with NICE to adapt guidelines.
- Initial targets have been helpful in accelerating a shift towards PIFU, but there is an opportunity to gain further support if NHS England explained the basis for targets, and adapted them for specific conditions or specialties. For some specialties with longer-term pathways and higher risks and complexity in detecting fluctuations or progression in disease (eg, ophthalmology) the scope for PIFU uptake may well be lower.
- Frequent meetings with NHS England and opportunities for regional collaboration (e.g. through monthly networks and Future NHS platform) have been beneficial for Trusts.





Recommendations and Opportunities: Trusts

- Patient trust is essential for PIFU to work, and there is some risk that patient materials may overstate the benefits of PIFU in terms of clinical outcomes, where evidence is inconclusive.
- Collecting more data to understand how PIFU affects patient outcomes and experience should be a priority, both to mitigate inequalities and to support local adoption of PIFU pathways.
- PIFU, like many complex service changes, is helped by senior leadership support who can give the approach visibility and raise it as a priority within trusts.
- While the extent of resources and time needed to set up PIFU will vary depending on each organisation's context, protecting staff time to develop and adapt PIFU approaches and engage with clinical teams is vital to delivery.





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APPENDICES





APPENDIX 1

Time to appointment analysis, Additional information





Time to appointment analysis: Classifying PIFU usage

For each trust, specialty, and month, we calculated a % PIFU indicator:

Number moved to PIFU + discharged to PIFU (numerator), divided by

Number of outpatient attendances (denominator)

In the analysis, each of the 21.3M attendances 'experiences' the PIFU level of the relevant trust/specialty/attendance month



We pragmatically categorised these % PIFU levels:

Categorised PIFU level groups:

- No PIFU 42% of all attendances (not shown)
- >0-1% PIFU 26% of all attendances (median 0.3%)
- >1-5% PIFU 21% of all attendances (median 2.2%)
- >5% PIFU 10% of all attendances (median 9.5%)

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Survival chart - introduction

The chart summarises 10M attendances from the top 30 PIFU specialties (a random sample of 21M attendances between Sept 2021 and June 2022)

The lines group attendances by categorised PIFU level

"<u>Survival</u>" here just means **not had a subsequent appointment**

28 days after a 1st attendance: 73% of the highest PIFU group & 67% of the no PIFU group - had **not had** a subsequent appointment.

In the no PIFU group, half had had a subsequent appointment by the 65th day after an initial attendance. In the highest PIFU group this was the case nearly a month later (the 98th day).

But: not adjusted - no sensible interpretation.

(Note also that lines on this particular chart cross – which means that there are problems a formal analysis has to solve.)





Hazard ratios (HR) - introduction

Top 30 PIFU specialties (as previous slide)





Hazard Ratio = 0.83 for 1-5% PIFU group (example)

= 17% lower chance of subsequent appointment at any point in time among patients yet to have one, versus No PIFU group So: "less frequent" attendances

HR > 1 would be higher chance ("more frequent")



NIHR National Institute for Health Research nuffield trust

Results: next 10 largest specialties



| | (200) | () | (000) | () | (====) | | () | | () | (000) |
|--|---------------------|-------------------|-------------------|---------------------|----------------------|------------------|-------------------|-------------------|---------------------|-------------------|
| Count of PIFU in analysis (% of all PIFU) | 11,550 (1.3%) | 10,162 (1.2%) | 1,048 (0.1%) | 9,581 (1.1%) | 11,702 (1.3%) | 8,547 (1.0%) | 8,118 (0.9%) | 7,216 (0.8%) | 8,937 (1.0%) | 4,980 (0.6%) |
| Count of OP atts in analysis (% of all in analysis) | 1,137,850 (5.3%) | 651,488 (3.1%) | 132,422 (0.6%) | 1,139,442 (5.3%) | 2,388,763 (11.2%) | 57,532 (0.3%) | 303,307 (1.4%) | 176,753 (0.8%) | 1,392,152 (6.5%) | 112,017 (0.5%) |

Results:

- *****: higher PIFU associated with less frequent appointments
- + : no association between PIFU levels & frequency of appts
- -: mixed, or higher PIFU associated with more frequent appts



Key: 🔵 No PIFU 🛑 0-1% PIFU 🔵 1-5% PIFU 🔵 >5% PIFU




Results: attempted combined model

Top 20 PIFU specialties together



Compared to the no PIFU group, we found:

0.6% **higher** chance of subsequent appointment in 0-1% PIFU group 3.7% **higher** chance of subsequent appointment in 1-5% PIFU group

4.7% **lower** chance of subsequent appointment in >5% PIFU group

- However, these results do not appear to align with individual specialty models (e.g. see 1-5% group)
- May indicate that our modelling approach across multiple specialties needs to be reviewed – (next phase of work)

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> Individual specialty models might be more appropriate



APPENDIX 2

Sensitivity analyses





Sensitivity analysis

We undertook sensitivity analysis to:

- understand how different assumptions as to what is reported in the P-EROC data affect our results.
 - These assumptions cover how missing values are interpreted and how we treat inconsistent reporting.
- see how our results might alter if we changed what we measure,
 - for example, by only analysing follow-up attendances.





Four scenarios for handling missing data and anomalies

| Criterion | Scenario | | | |
|--|--------------|--------------|--------------|--------------|
| | А | В | С | D |
| Declares complete data each month | \checkmark | \checkmark | \checkmark | \checkmark |
| Specialties for the trust that appear in HES but not in P-EROC (if included, these are assumed to have no PIFU activity) | \checkmark | \checkmark | \checkmark | X |
| Missing data exists in both numbers moved to PIFU and numbers discharged to PIFU (if included this is assumed to reflect no PIFU activity) | \checkmark | \checkmark | X | X |
| Total episode data is not consistent with numbers transferred to PIFU | \checkmark | X | x | × |

 \checkmark = included, **x** = excluded





Different approaches to data handling have a large impact on the numbers in each PIFU activity category

| PIFU activity rate | Number of trust/ specialty combinations under each scenario (%) | | | | | | | |
|----------------------------------|---|--------|------------|--------|------------|--------|------------|--------|
| | Scenario A | | Scenario B | | Scenario C | | Scenario D | |
| No PIFU | 1,920 | (63%) | 1,884 | (65%) | 1,796 | (77%) | 13 | (2%) |
| 0 – 1% PIFU | 549 | (18%) | 482 | (17%) | 149 | (6%) | 149 | (26%) |
| 1 – 5% PIFU | 389 | (13%) | 337 | (12%) | 238 | (10%) | 238 | (42%) |
| > 5% PIFU | 205 | (7%) | 194 | (8%) | 163 | (7%) | 163 | (29%) |
| All trust/specialty combinations | 3,063 | (100%) | 2,897 | (100%) | 2,346 | (100%) | 563 | (100%) |





Scenario comparisons

Changes in attendances per patient relative to no PIFU between the 6-month periods Sept. '19 to Feb. '20 and Sept. '21 to Feb. '22.



There is no significant relationship between higher PIFU use and attendances per patient under scenarios C and D. However, numbers in the no PIFU comparator group under scenario D are small so the results for that scenario are not robust.





Scenario comparisons: follow-up attendances only

Changes in follow-up attendances per patient relative to no PIFU between the 6-month periods Sept. '19 to Feb. '20 and Sept. '21 to Feb. '22.



The results are very similar to those after analysis of all attendances. Again, numbers in the no PIFU comparator group under scenario D are small so the results for that scenario are not robust.





Scenario A and D comparison



Follow up comparison



APPENDIX 3

Qualitative data collection





Qualitative data collection

Number of interviews and availability of documentation for analysis at each site:

| | National | Site 1 | Site 2 | Site 3 | Total |
|-------------------------|----------|--------|--------|--------|-------|
| Interviews completed | 2 | 4 | 4 | 3 | 13 |
| Documentary analysis | | | | | |

Site sampling criteria included:

- Geography (rural vs urban)
- Size (i.e. small <500 beds, medium 500-850 beds, large 850+ beds)
- Patient demographics (i.e. age, ethnicity, deprivation)
- Academic status (general vs teaching)
- Length of time delivering PIFU



