

Briefing August 2022

Patient-initiated follow-up: will it free up capacity in outpatient care?

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Why patient-initiated follow-up?

As the NHS seeks to clear the backlog of elective care that has built up in the wake of the Covid-19 pandemic, one of the solutions being turned to is more personalised follow-up in outpatient care.

NHS leaders have called for an ‘industrial’ drive to cut the number of unnecessary outpatient appointments and better prioritise clinical time where it adds the most value – setting the target to reduce outpatient follow-ups by 25% against 2019/20 activity levels by March 2023.^{1, 2} To deliver this, NHS England has set the ambition that 5% of outpatient attendances will be moved to *patient-initiated follow-up* (PIFU) pathways by March 2023 – a target that is likely to increase in the future.²

PIFU aims to give more flexibility and choice to patients over the timing of their care and allow them to book appointments as and when they need them rather than follow a standardised schedule. The rationale behind this shift is straightforward: one of the most fundamental challenges in outpatient care is the mismatch between patient need and access.

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In England, the total volume of outpatient hospital appointments increased by two-thirds between 2008/09 and 2019/20, to 125 million a year³ with follow-ups accounting for two-thirds of all appointments.^{4, 5} This is the largest increase in activity of any hospital service, and long waiting times, delayed appointments and rushed consultations have become increasingly common. The Covid-19 pandemic has only exacerbated these challenges, with the number of patients waiting for a first appointment with a specialist now more than six million – an increase of more than a third since the start of the pandemic.⁶ This has placed extra strain on services, which have struggled to keep pace with demand for some years.

Part of the problem is that under standard pathways, patients with long-term conditions or following surgery are automatically called back for outpatient appointments at regular intervals (for example, every six months). These timings are not necessarily decided by clinical need or when a patient wants extra support. This means that when follow-ups do occur, they can fail to lead to further investigation or any meaningful change in patient management.⁷ Conversely, when a patient's symptoms or circumstances do change, they may experience a long wait for an appointment as capacity has been devoted to routine follow-up.

But as the NHS seeks to expand PIFU further, there are several open questions about how well it works, and for whom:

- What is the evidence that PIFU reduces unnecessary appointments and frees up clinical capacity for patients who need it the most?
- How do patients experience PIFU, and what risks might it involve?
- How might PIFU affect health inequalities?
- Are there differences in how patients are selected for PIFU?
- Are there differences in how well patients are able to access care once on a PIFU pathway by race, age, gender or other patient factors?

This analysis explains what we know from the available evidence and earlier evaluations of PIFU about how personalising follow-up impacts service use and patient experience and outcomes. We also discuss key implementation considerations for the NHS as it seeks to mainstream this approach.

A note on methods and study limitations

This analysis is based on a systematic review of 17 studies that met our inclusion criteria – for details of the search strategy, see Appendix. We conducted a search across four databases for relevant studies published in English between January 2015 and June 2022, both in the UK and internationally. To be included, studies had to examine the effects of patient-initiated or open-access approaches to follow-up on service use (for example, waiting times, referral rates, attendances, missed appointments and costs), as either a primary or secondary outcome, given the focus on personalising follow-up to help bring down waiting times and reduce backlogs as part of the NHS’s elective recovery strategy. We also report on patient outcomes (where they were a focus of the included studies), but they were not the primary focus of this review.

Several review limitations should be noted. First, despite our systematic search strategy and adoption of broad search terms, there is considerable variation in the terms used to describe PIFU, therefore it is possible that our search was not exhaustive in its identification of relevant evidence. Second, the search only included articles published from 2015 onwards (excluding any literature published before this). And third, the broad scope of the review (that is, study designs and outcomes) makes it challenging to synthesise findings across studies, outcomes and models, but we have tried to do this where possible.

What does PIFU look like?

Figure 1 below illustrates a typical outpatient pathway. Figure 2 on the following page shows how follow-ups might change under PIFU, when follow-up appointments are initiated by the patient or their carer rather than following a fixed or standardised schedule.

Figure 1: Typical outpatient pathway

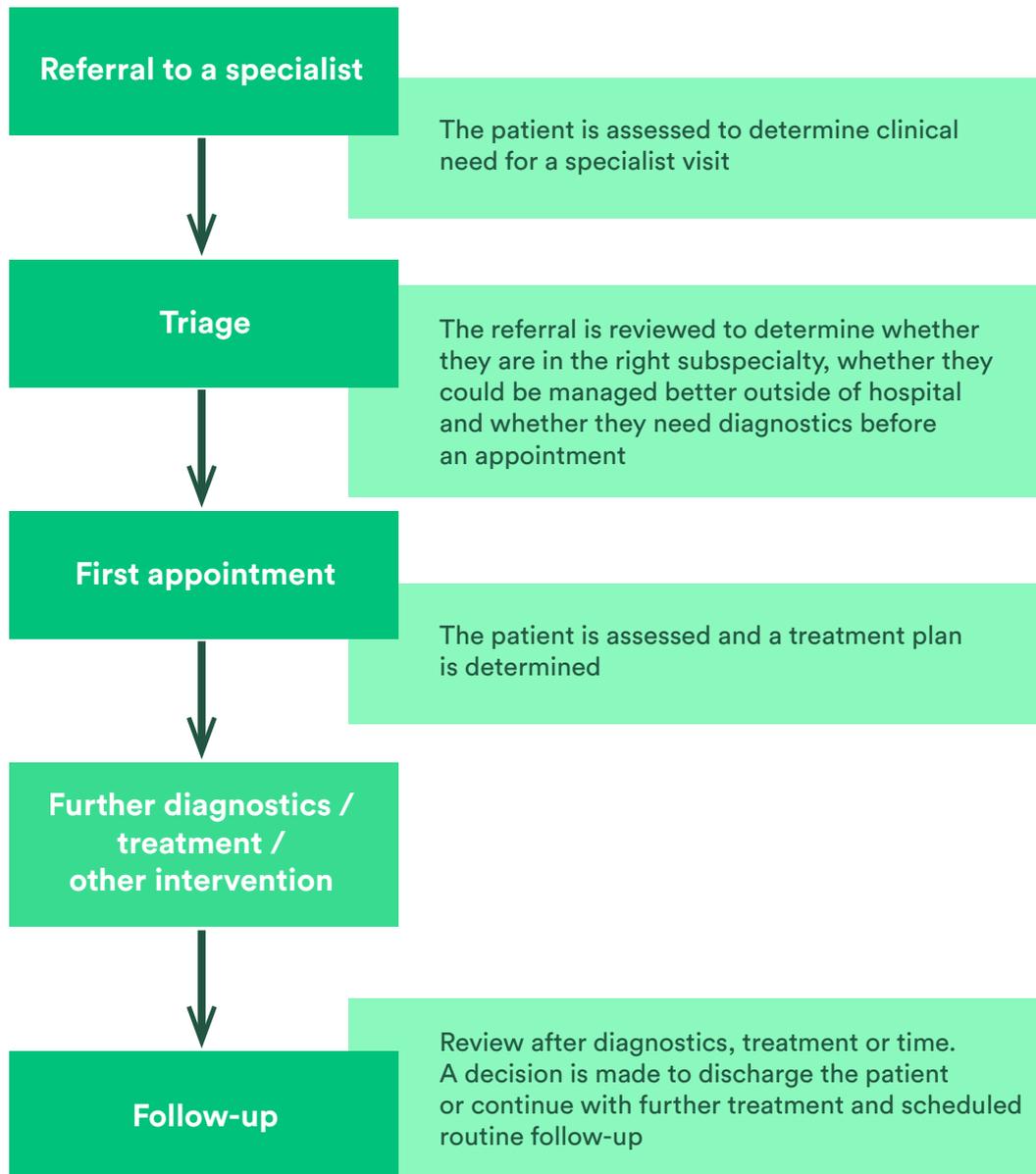
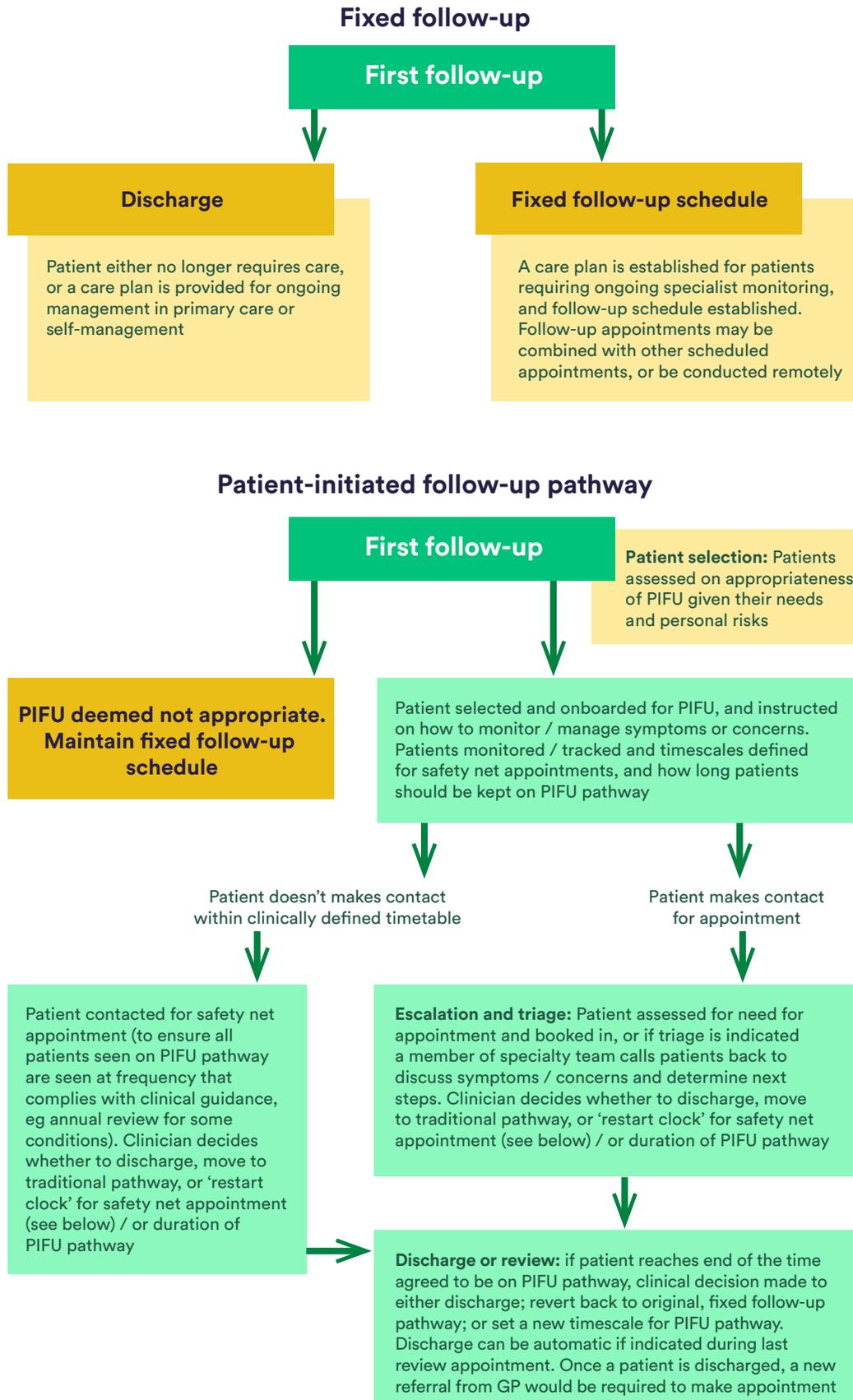


Figure 2: Fixed follow-up outpatient schedule (standard pathway) versus personalised follow-up schedule (PIFU pathway)



Patient-initiated pathways can take many forms, but typically patients are first assessed on whether this approach is appropriate for them and would benefit them given their individual circumstances. Criteria will vary from condition to condition, but patients who have particularly complex health needs, who are on medications that require robust monitoring or who are unable to contact health services easily are unlikely to be good candidates for PIFU.⁸

Once patients are on a PIFU pathway, they typically receive guidance on how to contact the service, and how to monitor fluctuations in their condition to know when to seek support. Operating procedures are also developed for how to escalate and triage appointment requests from patients and ensure adequate clinical capacity to accommodate appointments for when patients need them. Another core component of a PIFU pathway is a safeguarding or safety-net appointment, to manage patients who do not initiate contact with the service within a defined timescale. The service may contact these patients proactively to arrange an appointment for them or ask them to provide monitoring data to ensure stability in their condition. Decisions must also be made about how long a PIFU pathway should run for and at what point a patient should be discharged from secondary care, with their ongoing care needs managed in primary care or through self-management.

Each stage of a PIFU pathway involves different design and implementation choices (see Table 1 below) and the approach taken will depend on a range of contextual factors. For example, a patient-initiated pathway for a patient with a long-term, chronic symptomatic condition might have very different requirements and considerations than one for a short term or temporary condition, like surgery or injury -- particularly when it comes to managing risk and safety netting. Other considerations will also apply depending on whether a patient has multiple conditions or a single one, the degree of complexity in the patient's life and level of risk involved.⁹ Each of these choices will affect how the intervention is adopted and the ultimate impact it has on patients and staff, in terms of health outcomes, experiences, satisfaction and workload.

Table 1: Key design choices in the PIFU pathway

Patient selection	<ul style="list-style-type: none"> • Which patients will benefit/are a good fit for PIFU? • How will risk be assessed (for example, to make sure patients have the skills, knowledge and confidence to manage their own follow-up)? • What condition-specific factors/criteria should be considered?
Patient induction and sign-on	<ul style="list-style-type: none"> • What education/training will patients receive before joining the pathway, and how will it be delivered? • How will patients' concerns/questions be answered? • How will patients be supported to manage their care at home?
Patient monitoring and tracking	<ul style="list-style-type: none"> • How will symptoms or fluctuations in patients' condition(s) be monitored (for example, patient questionnaires, routine lab testing or remote technology)? • What role will the digital/remote monitoring of patients' condition(s) play?
Patient communication/contact	<ul style="list-style-type: none"> • How will patients contact the service with questions or concerns (for example, a telephone hotline, a patient portal, a designated web form or an email with a follow-up response within a certain time period), and which staff will manage requests?
Escalation/triage	<ul style="list-style-type: none"> • How will patients requesting appointments be prioritised (for example, triage)? • How will clinic slots be managed to ensure capacity for incoming requests? • What is the maximum waiting time for a consultation? • If an appointment is deemed necessary, will it be virtual or in person and how will patient preferences be understood?
Safety-netting	<ul style="list-style-type: none"> • How will patients be contacted if they have not been seen within a reasonable clinical timeframe (for example, a scheduled annual clinical review, or a patient questionnaire if enough time has elapsed)?
Discharge or review	<ul style="list-style-type: none"> • What criteria will be used to determine whether a patient should be discharged, whether they should revert back to the original pathway or whether the PIFU pathway should be extended? • Is automatic discharge appropriate? • If a patient experiences a related concern after being discharged, how will they contact the system and be managed?

Source: Adapted from NHS England implementation guidance.

Does PIFU work?

Our rapid review identified 17 studies published since 2015 that examined the effects of PIFU on service use (see Appendix for full study details). Of these studies, seven also reported on the costs of PIFU, and 14 on patient experience and/or clinical outcomes. We included studies across all specialties, clinical conditions and countries (see Table 4 on page 17). Most studies were randomised trials (12 out of 17) and single-site only (13 out of 17), and more than half (10 out of 17) were from countries outside the UK. Most studies compared PIFU with routine pre-planned or fixed-schedule appointments (as determined by specialty or national guidelines). However, in some studies, PIFU was compared with fixed follow-up alongside other service developments. For example, one study¹⁰ compared PIFU with an intervention that used routine patient questionnaires to determine the timing of follow-up, and another study¹⁴ compared PIFU with both consultant-led and nurse-led follow-up. In five studies,¹¹⁻¹⁵ PIFU was implemented alongside other service transformations, including psychological support/wellness programmes, joint care management with general practitioners (GPs) and teleconsultations.

Looking across studies, there is some promising evidence that PIFU might result in fewer overall outpatient appointments compared with fixed appointment schedules, although results are mixed. The impact of PIFU on wider health service use and costs is also unclear due to a lack of evidence. We rated most studies as being of low quality or demonstrating variable outcomes. PIFU appears to have little or no impact on patient quality of life or clinical outcomes but might have a small beneficial impact on patient satisfaction (see Table 4 on page 17 for more detail).

What is the impact of PIFU on outpatient activity?

Of the 15 studies assessing the impact of PIFU on outpatient activity, eight^{13, 16-22} showed that PIFU led to a statistically significant reduction in the number of outpatient appointments compared with fixed follow-up, with seven^{10, 11, 14, 23-26} showing no difference between approaches (see Appendix for full details). In one study,¹⁴ PIFU patients had fewer outpatient appointments compared with fixed follow-up care led by a consultant, but similar levels when compared to fixed follow-up care managed by a nurse specialist.

The effect size varied widely across studies. For example, a Danish study¹⁹ of rheumatology patients found that, after two years, PIFU patients had 31% fewer

outpatient specialist visits than patients with fixed follow-up appointments (2.6 ± 1.6 versus 3.5 ± 2.2 , $p < 0.0005$). Another UK-study¹⁸ found that a cohort of patients with low-risk endometrial cancer had an estimated 96% fewer follow-up appointments over five years compared with patients following a routine, fixed follow-up schedule (this is a mean of 0.95 appointments per patient as compared with 9.0 appointments per patient that would have been scheduled following routine clinical guidelines). Alongside variable results, understanding is limited and findings ungeneralisable due to variation in the outcomes evaluated. For example, in two studies,^{13, 19} a reduction in outpatient visits was replaced with an increase in phone contacts with the service – leaving overall impact on clinical capacity and costs unknown. Three studies^{11, 13, 17} reported that PIFU patients had fewer overall missed appointments/did not attend (DNAs) than patients with fixed follow-up.

What is the impact on wider health service use?

The seven studies that evaluated wider service use explored a range of outcomes – including primary care, hospital admissions and emergency department attendances – but results are mixed. Two of five studies looking specifically at how PIFU affected service use in primary care^{24, 25} saw a very slight reduction in numbers of GP visits (for example, 1.08 versus 1.84 monthly GP visits per patient in the previous year, and a median of zero GP visits versus one GP visit in the previous year). Two studies^{16, 20} saw no statistically significant effect. One Danish study¹⁴ of rheumatology patients found that PIFU led to an overall higher number of GP contacts compared with fixed follow-up, but this service model included PIFU alongside joint management/shared care with general practice, so is to be expected. The two studies^{10, 22} that explored the impact of PIFU on hospital services found no statistically significant impact on hospital admissions or contact, but one of these studies did find a small (non-significant) trend towards reduced Accident & Emergency (A&E) visits than patients with fixed appointments (mean difference = -0.11, 95% CI -0.21 to -0.01).¹⁰

Based on the variable results and limited number of studies, it is not possible to say definitively whether PIFU is associated with a reduction in primary care use or hospital service use more widely. Nor is it known whether outpatient activity shifts to other areas of the health system. Whether the PIFU approach leads to less use of primary care or wider hospital services will also likely vary by speciality and setting, and by health systems as countries differ in terms of how they design and operate health services.

What is the impact for health service costs?

Evidence of the impact of PIFU on health service costs is mixed and muddled by differences in study design, quality and length of follow-up. Some studies show a large reduction in costs while others show no impact or an increase in expenditure associated with PIFU.

Of the three randomised studies that explored cost, two^{14, 24} found no difference compared to standard fixed follow-ups, and another²⁵ found higher service costs attached to PIFU (£142.24 more per patient). In this study, the costs associated with training and remote monitoring of patients offset any cost savings obtained from the reduced number of appointments, although these results only apply to the first year after referral to PIFU and the scope for savings may increase over time.

Three studies^{12, 15, 18} found PIFU to be associated with a large reduction in costs (that is, over 90% estimated savings compared with fixed appointment schedules). However, these studies were non-randomised, observational and without a comparator group, and therefore PIFU costs were compared to estimated costs based on typical standards of care or national guidelines.

What is the impact for patient outcomes?

In general, the evidence shows that PIFU has no effect on clinical outcomes, patient satisfaction and patient quality of life. This suggests that PIFU might be able to reduce the number of outpatient appointments a patient has without any detrimental knock-on effects on quality, safety or wellbeing. At the same time, personalising follow-up may not improve patient experience, either. Of the 13 studies that looked at patient experience and quality of life, only five^{11, 13, 22, 24, 26} found that PIFU had a statistically significant beneficial impact for patients. These studies examined PIFU in patients with rheumatoid arthritis, hemifacial spasms, rectal cancer and type 1 diabetes. Experience with PIFU may vary by clinical condition, however. One study²⁰ on patients with endometrial cancer found that patients with personalised follow-up had greater fears of cancer recurrence and anxiety than patients following a fixed schedule.

Does experience with PIFU vary by patient demographic?

Most studies have not explored the impact of PIFU for different groups of patients – perhaps due to the limited size and scope of studies (most being single site). Only four studies^{10, 13, 22, 26} in our review included a sensitivity or subgroup analysis. Of those that did, one study¹³ reported no differences in clinical outcomes by age or gender but did find some gender differences in service use: men reduced their overall number of clinic visits and phone contacts by a larger degree than women. Another study¹⁰ found gender and literacy levels to have little impact on service use, yet found an association with age, with younger groups having slightly fewer telephone consultations and A&E visits than older groups (-0.67, 95% CI -1.29 to -0.04 and -0.21, 95% CI -0.38 to -0.03, respectively). Two studies^{22, 26} found that factors including patient activation (eg, patient’s knowledge, skills and confidence in self-managing their condition), age, gender and clinical factors were not related to the number of self-referrals or treatment received. Understanding how PIFU affects different population groups is crucial if we are to avoid any unintended consequences that could widen health inequalities if there are unwarranted differences in how patients engage with or experience PIFU and initiate care.

Evidence suggests that when patients are approached to take part in PIFU appointment systems, a considerable number decline. Nine studies^{11, 13, 15–17, 20, 22, 23, 26} reported the number of patients being offered and accepting PIFU, with the numbers declining ranging between 10% and 40%. Several studies have also found that patients who decline to take part in patient-initiated appointment systems might be different from those who accept. For example, one study¹³ looking at PIFU services for patients with diabetes found that older patients and those with a longer diabetes duration were more likely to decline PIFU. Other factors that affected acceptance rates included how the pathway was communicated to patients and study design elements (that is, randomisation). Further work is needed to understand the reasons why patients might decline or disengage from PIFU and how to best communicate PIFU to different patient groups.

How do the review findings compare with previous literature?

Our review findings are largely consistent with previously published work on personalised follow-up – generally showing mixed evidence relating to outpatient activity, while finding no harmful effects on clinical outcomes and the maintenance of patient satisfaction and quality of life.²⁹⁻³¹ Several systematic reviews of PIFU services have been undertaken. Table 2 below summarises these. Our analysis provides an update of the evidence in an area that is rapidly changing and goes beyond the available evidence by including observational as well as randomised studies, and synthesising evidence across a broader range of specialities and conditions (only five^{15, 17, 20, 23, 24} of the 17 studies in our review were included in the previously conducted reviews). We also provide further context by describing the range of models of PIFU that have been studied and the components that each involved, which may have influenced results.

Table 2: Systematic reviews of studies exploring the impact of PIFU

Author	Scope	Number of studies in the review	Conclusion
Whear and others (2013) ³⁰	Effects of PIFU on patient-reported outcomes, and patient and clinician satisfaction	7	<ul style="list-style-type: none"> • Similar psychological outcomes and quality of life between groups • Increased patient and clinician satisfaction with PIFU
Whear and others (2013) ³¹	Effects of PIFU on clinical effectiveness	8	<ul style="list-style-type: none"> • Similar clinical outcomes between groups and low risk of patient harm with PIFU • PIFU is associated with savings in time and resource use in some instances
Taneja and others (2014) ²⁸	Effects of PIFU on patients with chronic conditions managed in secondary care	6	<ul style="list-style-type: none"> • Fewer overall outpatient appointments with PIFU • No reduction in patient satisfaction, quality of life or clinical outcomes across a range of conditions
Whear and others (2020) ²⁹	Effects of PIFU on patients with chronic conditions managed in secondary care	17	<ul style="list-style-type: none"> • Little or no effect of PIFU on patient mental health or quality of life • No difference across groups in the number of outpatient appointments or contacts or wider service use • Unclear evidence on patient satisfaction and costs due to high risk of bias
Kershaw and others (2022) ³²	Effects of PIFU on gynaecology and obstetrics patients	8	<ul style="list-style-type: none"> • Increased patient satisfaction with PIFU, with no negative effect on health outcomes • PIFU shown to be cost-effective • Fewer overall appointments and reduced non-attendance with PIFU

Note: Reviews showing an overall positive effect of PIFU are coloured green, with reviews showing limited or mixed results coloured amber.

Is there any qualitative evidence related to PIFU?

While our review focused on quantitative evidence, there are a small number of qualitative studies that offer insights into patient experiences with PIFU and the factors that support effective implementation. These studies suggest that patients are generally satisfied with PIFU and experience the service positively, with patients reporting that it supports them to have more control over their health and fits better with routine management. Studies also report that PIFU has helped address patient needs when symptoms increase or do not respond to treatment.

There has been limited overall focus on clinician and staff experiences of PIFU. One study³³ found that clinicians supported this approach to follow-up, although had concerns for disengaged patients, and that it may increase fear and anxiety relating to recurrence, as well as delay the detection of recurrence. Qualitative studies have also highlighted the importance of certain components of the PIFU approach that can help to improve patient engagement and increase the chance of successful implementation (see Table 3).

Table 3: Key qualitative study findings

Theme/area	Study	Supporting factors
Organisational context	Kieft and others (2016) ³⁴	<ul style="list-style-type: none"> • Leadership buy-in • Staff and organisational capacity to deliver and absorb change • Trust among colleagues and teamwork
	Child and others (2015) ²⁷	<ul style="list-style-type: none"> • Clear communication and staff ownership over the change process
Patient experience	Bech and others (2020) ³⁵	<ul style="list-style-type: none"> • Sufficient training and education for patients to take on more ownership of their care
	Beaver and others (2020) ³⁶	<ul style="list-style-type: none"> • Having a clearly named person who patients can contact if problems arise or there are signs or symptoms of recurrence
	Rogers and others (2004) ³⁷	<ul style="list-style-type: none"> • Ensuring sufficient slack/clinical capacity to be responsive to patient requests, otherwise patients will be unlikely to accept the service over time
	Child and others (2015) ²⁷	<ul style="list-style-type: none"> • Patient confidence in using systems to request a medical review • Offered appointments being convenient and timely for both the patient and the clinician • Regular monitoring
Staff experience/acceptance	Loreno and others (2022) ³³	<ul style="list-style-type: none"> • Quick, reliable routes to recall patients back into clinic, particularly for disengaged patients • Careful monitoring of workload burden on nurses and allied health professionals (who may pick up displaced activity)

How confident are we in these results?

While the results for PIFU are promising, questions arise about the overall strength of the evidence. We rated most studies as being of low or moderate quality and the findings across studies are often mixed. Even when results are statistically significant, there are doubts about how important or clinically meaningful the observed differences are in practice. Although most of the PIFU studies are randomised, design issues are still common, meaning that the findings are highly context-specific. These issues include selection bias, single-site studies usually across one specialty or clinical condition and low patient numbers. Some studies include service models that involve PIFU as one component and delivered the intervention and/or usual care in conjunction with other service changes, making it difficult to isolate the impact of PIFU on its own. The nature of the intervention also means that blinding is not possible, which could further bias behaviour. The studies identified in our review involve only six specialties and have been conducted across three countries, further limiting generalisability. Clinical conditions, patient cohorts and contexts will affect the implementation of PIFU, and this has been previously highlighted as a challenge to developing a robust evidence base in this area.²⁸ Other study limitations relate to short follow-up duration, meaning that little is known about the impact of PIFU over time, and the inconsistency in outcomes across studies makes it difficult to synthesise the findings.

Table 4: Summary of the rapid review evidence

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
1. McBain and others (2016) ¹⁶	Rheumatology UK	<ul style="list-style-type: none"> ✓ Education ✓ Safety-net appointments ✓ Routine monitoring/ surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✓ Guaranteed appointment slot/ response time 	PIFU patients had significantly fewer visits to a specialist nurse compared with fixed follow-up	No significant differences were found between the PIFU group and the fixed follow-up group for the number of GP visits		No significant differences were found between the PIFU group and the fixed follow-up group for clinical outcomes	No significant differences were found between the PIFU group and the fixed follow-up group for psychosocial outcomes
2. Fredriksson and others (2016) ²³	Rheumatology Sweden	<ul style="list-style-type: none"> ✗ Education ✓ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✓ Guaranteed appointment slot/ response time 	Number of consultant appointments did not differ significantly across groups (PIFU versus fixed follow-up)			No significant differences were found in disease activity across groups (PIFU versus fixed follow-up)	No significant differences were found between groups (PIFU versus fixed follow-up) in terms of satisfaction and confidence in care
3. Goodwin and others (2016) ²⁴	Rheumatology UK	<ul style="list-style-type: none"> ✓ Education ✓ Safety-net appointments ✗ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✓ Guaranteed appointment slot 	<p>No significant differences were found in the number of in-person specialist consultations, although a smaller proportion of PIFU consultations were with a specialist compared with fixed follow-up</p> <p>PIFU patients made more telephone contacts than fixed follow-up appointment patients</p>	Self-reported visits to a GP were lower for the PIFU group than for the fixed follow-up group	Hospital costs did not differ significantly across groups (PIFU versus fixed follow-up)		PIFU had a small (significant) positive impact on some aspects of patient satisfaction, for example, ease of getting an appointment, ease of contacting a specialist nurse and overall satisfaction

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
4. Batehup and others (2017) ²⁵	Oncology and gastroenterology UK	<ul style="list-style-type: none"> ✓ Education ✓ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✗ Guaranteed appointment slot 	No significant differences were found in the use of community and hospital services between the PIFU + remote surveillance group and the fixed follow-up group	There were significantly fewer monthly GP visits among PIFU + remote surveillance patients than among fixed follow-up patients	PIFU + remote surveillance was more expensive than fixed follow-up in the first year (savings from reduced appointments were outweighed by patient training and remote surveillance)		Patients had high satisfaction with follow-up care regardless of model (PIFU + remote surveillance versus fixed follow-up)
5. Jeppesen and others (2018) ²⁰	Gynaecological oncology Denmark	<ul style="list-style-type: none"> ✓ Education ✗ Safety-net appointments ✗ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✓ Guaranteed appointment slot 	PIFU patients had significantly fewer in-person outpatient appointments than patients with a fixed appointment schedule (and similar numbers of telephone contacts with a specialist department)	No significant differences were found between groups (PIFU versus fixed follow-up) in the number of cancer-related GP visits or visits to a privately practising gynaecologist			Fear of cancer recurrence decreased significantly more for women receiving fixed follow-up compared with patients receiving PIFU
6. Khoury and others (2018) ¹⁷	Dermatology Denmark	<ul style="list-style-type: none"> ✓ Education ✓ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✗ Guaranteed appointment slot 	PIFU patients had significantly fewer specialist consultations than patients receiving fixed follow-up and fewer missed appointments				No significant differences between groups were found in patient satisfaction, quality of life, anxiety and depression

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
7. Schougaard and others (2019) ¹⁰	Neurology Denmark	<ul style="list-style-type: none"> ✗ Education ✓ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✓ Triage ✗ Guaranteed appointment slot 	No significant differences were found between groups in the number of teleconsultations or outpatient visits	Patients with PIFU had a very slightly (but significantly) lower number of A&E visits		No significant differences were found between groups for clinical outcomes (for example, mortality, number of seizures and side effects)	No difference between groups was found in patient confidence, safety, satisfaction or general health and wellbeing
				No significant differences were found between groups for hospital admissions			Patients receiving PIFU gave lower scores of wellbeing, although the difference was small and unlikely to be clinically significant
8. Sorensen and others (2015) ¹⁴	Rheumatology Denmark	<ul style="list-style-type: none"> ✓ Education ✓ Safety-net appointments ✗ Routine monitoring/ surveillance ✓ Designated hotline and/or patient portal ✓ Triage ✗ Guaranteed appointment slot ✓ Other intervention (shared-care model with GP) 	The PIFU/shared-care group had significantly fewer specialist consultations than the consultant-led fixed follow-up group, but similar numbers as the nurse-led fixed follow-up group	The average number of GP consultations was similar across all three groups, but the total number of GP services was highest in the PIFU/shared-care group	The PIFU/shared-care intervention cost less than consultant-led fixed follow-up patients, but was not significantly lower than the nurse-led fixed follow-up group	Disease activity and functional status for the PIFU/shared-care group improved (although not significantly) compared with fixed follow-up	Health-related quality of life after the first year deteriorated for the PIFU/shared-care group, although not significantly
9. Poggenborg and others (2021) ¹⁹	Rheumatology Denmark	<ul style="list-style-type: none"> ✓ Education ✗ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✗ Triage ✓ Guaranteed appointment slot 	PIFU patients had significantly fewer outpatient visits than the fixed follow-up group after two years			No statistically significant differences were found between groups in disease activity or progression, or adverse events	No statistically significant differences between groups were found in satisfaction with and confidence in their system of care
			PIFU patients made significantly more telephone contacts than fixed appointment patients after two years				

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
10. Luqman and others (2020) ¹⁸	Gynaecological oncology UK	<ul style="list-style-type: none"> X Education X Safety-net appointments (reminder letters only) X Routine monitoring/surveillance X Designated hotline and/or patient portal X Triage X Guaranteed appointment slot <p>(Models components not described)</p>	PIFU patients were estimated to have significantly fewer clinical appointments compared with patients with scheduled follow-up appointments		It was projected that PIFU could lead to a 94% reduction in costs based on the reduced number of appointments and telephone calls (based on standard fixed follow-up)		
11. Coleridge and Morrison (2020) ¹⁵	Gynaecological oncology UK	<ul style="list-style-type: none"> ✓ Education X Safety-net appointments X Routine monitoring/surveillance X Designated hotline and/or patient portal X Triage X Guaranteed appointment slot ✓ Other intervention (specialist psychological support, if required) 			There were reduced health service costs compared with the estimated costs of fixed follow-up (PIFU resulted in fewer appointments compared with fixed follow-up)		
12. Ryg and others (2021) ¹³	Endocrinology and diabetes Denmark	<ul style="list-style-type: none"> X Education ✓ Safety-net appointments X Routine monitoring/surveillance ✓ Designated hotline and/or patient portal X Triage ✓ Guaranteed appointment slot ✓ Other intervention (choice of provider for follow-ups, when initiated) 	<p>Patients in the PIFU group had significantly fewer outpatient visits than fixed follow-up patients, and fewer missed appointments</p> <p>Patients in the PIFU group made significantly more telephone calls to the clinic than fixed follow-up patients</p>			No significant changes in clinical outcomes were found for both groups	PIFU patients reported significantly increased benefit from the consultations and reported significantly fewer unnecessary visits

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
13. Johnson and Choy (2022) ¹²	Gynaecological oncology UK	<ul style="list-style-type: none"> ✓ Education ✗ Safety-net appointments ✗ Routine monitoring/surveillance ✓ Designated nurse hotline and/or portal ✓ Triage ✗ Guaranteed appointment slot ✓ Other intervention (exercise programme) 			There were estimated savings of approximately 97% with PIFU compared with fixed follow-up		
14. Jakobsens and others (2021) ²²	Gastroenterology and surgical oncology Denmark	<ul style="list-style-type: none"> ✓ Education ✗ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or patient portal ✓ Triage ✗ Guaranteed appointment slot 	PIFU patients and fixed follow-up patients had similar numbers of non-routine outpatient doctor appointments, nurse visits and telephone contacts	The total number of hospital contacts for the PIFU group did not differ significantly from the number for the standard-care group			Both groups rated satisfaction high, but the PIFU group was higher on all satisfaction items
			The total number of outpatient doctor visits was significantly lower in the PIFU group compared with the fixed follow-up group	More patients in the PIFU group had 15 or more hospital contacts than patients in the fixed follow-up group			
15. Balhorn and others (2022)	Gastroenterology and surgical oncology New Zealand	<ul style="list-style-type: none"> ✗ Education ✗ Safety-net appointments ✗ Routine monitoring/surveillance ✓ Designated hotline and/or portal ✓ Triage ✓ Guaranteed appointment slot 	There were significantly fewer follow-ups in the new clinic (PIFU group) compared to historical control			No significant differences in clinical outcomes (rate of colorectal malignancy) were found at five-year follow-up	

Study authors	Specialty and country	Key PIFU components	Outpatient specialist service use	Other health service use	Health service costs	Clinical outcomes	Patient satisfaction and quality of life
16. Laurberg and others (2022) ¹¹	Endocrinology and diabetes Denmark	<ul style="list-style-type: none"> ✗ Education ✓ Safety-net appointments ✓ Routine monitoring/surveillance ✓ Designated hotline and/or portal ✓ Triage ✗ Guaranteed appointment slot ✓ Other intervention (telemedicine) 	<p>Patients across both groups had a similar mean number of visits</p> <p>Did not attend (DNAs)/ missed appointments without cancellation occurred less frequently in the PIFU + telemedicine group than in the standard care group</p>			No significant changes in clinical outcomes were found for both groups	PIFU + telemedicine patients reported higher levels of mental wellbeing and lower diabetes-related emotional distress at the end of the study. At the end of the study, 54% of patients on standard care chose to switch to PIFU + telemedicine pathways, while 94% of intervention patients opted to continue with the PIFU + telemedicine pathway
17. Lawes-Wickwar and others (2022) ²⁶	Neurology Denmark	<ul style="list-style-type: none"> ✗ Education ✗ Safety-net appointments ✗ Routine monitoring/surveillance ✓ Designated hotline and/or portal ✓ Triage ✗ Guaranteed appointment slot 	Patients across both groups had a similar mean number of visits, treatments and days between clinic visits		<p>No significant differences were found in mean total costs of care per patient</p> <p>The costs of delivering primary and secondary care services did not differ significantly between groups</p> <p>The costs to patients also did not differ significantly between groups</p>	No significant differences between groups were found for disease severity or functional disability	<p>No significant differences between groups were found for depression, quality of life, satisfaction with care or confidence with the service</p> <p>Levels of anxiety differed significantly; the PIFU group reported a decrease and the control group reported an increase</p>

Notes: See Appendix for full details of the included studies. Studies are coded according to whether PIFU was associated with a positive, negative or no impact (green = positive impact; red = negative impact; orange = no impact [no statistical significance]). Reporting of significance refers to statistical significance and does not necessarily equate to clinical significance. The absence of a PIFU component does not necessarily mean that it did not feature as part of the service model, but that it was not described or referred to as part of the study intervention.

What models of PIFU were implemented?

PIFU was implemented in a variety of ways across the studies. These included different choices about:

- whether safety-netting or standard review appointments were offered
- whether education sessions were provided, and their length and content
- the processes through which patients initiated an outpatient consultation and whether and how appointment requests were prioritised or triaged
- the delivery of remote monitoring activities (for example, the reviewing of test results).

However, across the studies some common approaches emerged. For example, of the 17 models:

- 14 involved a designated nurse hotline and/or patient portal to log or check results
- 10 reported including an educational component
- 10 reported safety-netting or standard review appointments
- nine involved some type of routine monitoring or surveillance of the patient's condition (for example, test results)
- seven guaranteed an appointment slot within a certain timeframe after the patient requested one
- seven involved some form of triage to deal with the management and escalation of patient requests.

Patient selection for PIFU was often not clearly reported. However, several studies reported the inclusion of low-risk patients only, for example those with low disease activity or risk of recurrence, and excluded patients who were judged unable to initiate contact with the service.

The information that the studies give limits an understanding of the components of PIFU within the studies. However, Figure 3 below illustrates the range of design choices made in the different studies and in which specialties, to give a sense of the scope of options and how these might impact results. From the evidence available, we do not know which components of PIFU are associated with effectiveness, and how this varies by clinical speciality or patient population.

Figure 3: Key characteristics of PIFU from the literature

Safety-net appointments / patient monitoring		
< Less intensive input from services		More intensive input from services >
Patients prompted to complete questionnaire to monitor symptoms if enough time has elapsed (for example, neurology, endocrinology)	Annual clinical review with consultant for patients with no other contact (for example, rheumatology, gynaecology, oncology, endocrinology, dermatology)	Regular (for example, every two to three months) monitoring appointments with nurse (for example, dermatology, rheumatology)
Patient education / onboarding		
< Less intensive input from services		More intensive input from services >
Written material about the intervention and which symptoms to look out for / monitor, and how to make appointment if needed (for example, neurology)	One patient education session / needs assessment with nurse specialists on alarm symptoms and self-management (for example, rheumatology, oncology, dermatology)	Multidisciplinary course on self-management, symptom recurrence and treatment knowledge (for example, oncology, gynaecology, gastroenterology)
Patient access, triage and escalation		
< Less intensive forms of triage / prioritisation		More intensive forms of triage / prioritisation >
Patients with concerns access a dedicated nurse-led hotline or GP. Appointments are offered within a week, if needed (for example, gynaecology, dermatology, rheumatology)	Patients make contact through a patient portal, and complete a questionnaire on concerns / symptom changes. Clinicians respond to patient requests and book an appointment if needed (for example, neurology, endocrinology)	Patients make contact through a designated nurse-led hotline and a response / escalation for an appointment is triaged following standardised protocols / algorithms (for example, gastroenterology)

Where are there unknowns, and where is more research needed?

As PIFU is set to be scaled up in England, we know relatively little from published evaluations about what impact it is likely to have on patients, and whether it will help reduce unnecessary appointments and better match clinical capacity with patient need as intended. Only a small number of studies on a handful of specialties and clinical conditions have examined PIFU, of which we have rated only a small proportion as good quality. Among these, only a small proportion (six out of 17) have been studied in the NHS context. This makes further evaluation critical, to understand what effect PIFU has over the longer term, and when being implemented in the NHS context across multiple sites and conditions. We need to better understand the different models of PIFU, and its components, to evaluate which elements might be related to its effectiveness and to further explore contextual factors, including staff experiences, resource requirements and use of technology.

While some research has been focused on patient outcomes, given the rapid shift towards personalised follow-up it will also be important to monitor inequalities in access to and engagement with PIFU pathways. Most studies in the review limited participation to low-risk patients with higher levels of activation or agency to be able to initiate contact – but with few details on how these factors were assessed and determined, and whether results differed by ethnicity, race, gender or other demographic factors. As PIFU is scaled in the NHS, it will be important to understand which patients are being selected for personalised follow-up pathways and how their needs are being responded to or escalated, and whether there are any unwarranted differences by race, gender, age or other characteristics. It is also crucial to understand why patients might decline PIFU, how these patients might differ from those who accept the pathway, and how this might be affected by how the service is presented or introduced.

Finally, we need to better understand the wider impact of PIFU on other health services, including hospital, primary care and community services, to evaluate whether workload is being displaced to other roles or health services. It is unclear from the available evidence whether any cost savings achieved in studies from reducing outpatient appointments have been outweighed by activity elsewhere, such as educational sessions or increased support from nurse practitioners via patient hotlines. Costs are also likely to vary substantially depending on the PIFU model and clinical condition.

It is not uncommon for policy to be ahead of evidence, given the well-known delays in research and the time it takes to translate findings into practice. But without sufficient evidence, there is a risk that the shift towards PIFU could result in unintended consequences and it will be essential for the system to learn as it goes and adapt its approach as more evidence and learning surface.

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