

Patient Initiated Follow Up (PIFU) in Dudley

October 2025



A new approach to follow-up treatment

Patient Initiated Follow-Up (PIFU) is a national NHS approach that empowers patients to manage their own care: instead of receiving automatic, routine appointments after hospital treatment, patients arrange a follow-up only when and if they feel they need one.

This flexible, patient-centred model is a core strategy in NHS England's Elective Care Reform Plan. With the national elective care waiting list currently exceeding seven million people, PIFU aims to help manage this demand and reduce waiting times by freeing up unnecessary appointments.

Locally, The Dudley Group NHS Foundation Trust (DGFT) has already adopted PIFU in key areas, including orthopaedics and physiotherapy.

Listening to the community

DGFT commissioned us to gather local feedback on this new approach. Our role is to listen to people's experiences and share their concerns and ideas with decision makers, to ensure systems work for everyone.

Crucially, our past research has highlighted that some local residents face barriers to using digital tools for healthcare, which is why we must ensure the PIFU model is accessible and equitable for our entire community.

Our engagement was a short and focused piece of work. We aimed to capture a snapshot of local experiences and opinions, focusing on:

- What people like about PIFU
- What worries or concerns they have
- What could make it easier to use

To discover the potential benefits and challenges of PIFU, we spoke to local groups who may experience more barriers with the process. By speaking with these groups we captured feedback that may otherwise have gone unheard or unconsidered.

**Quotes within this report have been anonymised. Some quotes may have been amended for clarity and conciseness.*



Who we heard from

Group or charity	Seldom heard group	How we captured their feedback	How many people we heard from
Queens Cross Network Support centre for adults with disabilities, offering person centred, tailored support programmes. They also act as a supportive, safe environment to recharge and meet new friends.	Adults with disabilities	Group discussion	20
We Love Carers Provides support and guidance to unpaid carers in Dudley borough.	Carers	Group discussion at coffee morning	6
Beacon Ensures no one faces sight loss alone, supporting people no matter where they are in their journey.	People with sightloss	Group discussion	20
Dudley Voices for Choice Self-advocacy for people with learning disabilities and/or autism. They empower people to speak up for themselves and participate in community and strategic meetings.	Adults with learning disabilities and/or autism	Surveys	9
The What? Centre Provides holistic mental health and wellbeing support to people aged 9 to 25 years old.	LGBTQ+ group, gay men's group, and HIV support group.	Surveys	7
Total			62

Of the people who completed our survey:

- 50% of people who completed our survey said they have a disability.
- We heard from people from age 21 to 70+
- Ethnicity of survey respondents was: 56% White British / 19% Black British / 6% White Other / 6% Arab / 13% Prefer not to say

Dudley Stroke Association

Dudley Stroke Association (DSA) is a local independent charity that provides advice, support and information to people who have had a stroke and their families/friends. DSA staff asked if clients wanted to take part in this research. They opted not to do so, for various reasons, including:

- The research work not being consultation, as PIFU is already in place. They would have appreciated an opportunity to voice their concerns earlier in the process.
- They did raise concerns about using technology and being able to get through on telephone lines.
- Continued challenges in receiving care has contributed to them feeling disempowered and frustrated with the NHS.

We will be visiting DSA with NHS colleagues to listen to people's concerns and share their feedback with decision makers.

Opportunities and benefits

“Asking for an appointment makes me feel more in control and listened to, as though I am part of the process.”
-Survey respondent

“[If those who don’t need an appointment don’t book one it] leaves more space for those who need it.”

People see the potential benefits of PIFU. Namely in the potential to save time, provide appointments to those with the most need and give patients flexibility and choice in their care.

Prioritising those with the most need

People recognise the pressures on NHS services, and welcome a system that frees up appointments for those who need it most.

“Those who want an appointment can get one, and the people who don’t want one don’t have to remember to call and cancel it – leaving more appointments available for those who do want one.”
-Survey respondent

Taking control of health

We heard how people want the opportunity to have more control over their own health and care. By allowing patients to monitor their wellbeing and make a choice if and when they need a follow-up appointment, this provides them with more control.

“I would prefer not relying on someone else to manage my appointments. I missed an important appointment for my child, if I could have booked it myself it would have been easier.”
-We Love Carers

“I think it helps patients to be proactive about their care. Sometimes a follow-up appointment might not be needed because a patient might be feeling better.”
-Survey respondent

Flexibility

"PIFU may mean you have options around days and times to suit you."
-Survey respondent



**People hope
PIFU will offer
more flexibility.**

We heard that automatically scheduled follow-up appointments often occur at times that are unsuitable for patients. This typically means calling the hospital to rearrange, adding administrative time for both patients and the service.

"I get sent appointments automatically and have to call to rearrange."

-We Love Carers

People emphasised that existing processes lack necessary flexibility and control, especially for parents and carers:

"Appointments can mean my child misses school."

We Love Carers

People hope that Patient Initiated Follow Up (PIFU) will offer greater control and choice over appointment scheduling. The ability to choose the time and day is particularly valued by those whose work or caring schedules are unpredictable.

"It would be good to choose the time and day of an appointment."

-Survey respondent

"In my line of work I don't always have a predictable schedule and sometimes I can't rearrange things last moment."

-Survey respondent

Appointment type

63% of people prefer to have an appointment in-person as opposed to over the telephone or via video call.

However, we heard that people appreciate the convenience of a telephone appointment, if it is suitable.

This suggests appointments could be offered depending on a patient's personal circumstances, including communication preferences and the severity of their health condition or symptoms.

Trust

"It's a trust thing, people visit Queens Cross and they have someone here to help them, you've already built the trust, they can ask if they need help with something. Not everyone has this."

-Queens Cross

People expressed concerns about the confidence and ability of some patients to use PIFU, particularly for those who find it difficult to speak up for themselves.

"Some people may struggle to remember and go through with booking a follow-up.

Some people may disregard health problems due to not feeling 'serious' enough for a follow-up in their case."

-Beacon

This feeling had been witnessed by a student healthcare professional who was attending one of the patient groups.

"I've met patients and I've signposted them to somewhere. They say to us, 'can you call for me because they'll listen to someone in a uniform'."

-Student Healthcare Professional

People shared how they didn't have confidence in being heard by healthcare professionals.

"Not all of us feel comfortable speaking up to clinicians, they feel out of place."

-Survey respondent

This feeling was echoed by Dudley Stroke Association, who chose not to provide feedback on PIFU due to feelings that they sometimes feel unheard.



Falling through the cracks

We heard concerns about PIFU potentially leading to missed complications. People expressed that not everyone may have the capacity to identify complications. There was also concerns that some patients may find it difficult to advocate for themselves and ask for help.

“It might sound nice, but it could have a bad effect, as not everyone stays on top of their health. Some people wait until they get really bad. Things could be picked up at a routine follow up appointment and even though they think they're saving money it could mean more people going into the hospital”.

-Student Healthcare Professional

“Follow-up appointments can pick up anything that could lead to a life threatening condition. An automatic appointment saves you the time that would be needed to book one in PIFU.”

-Survey respondent

We discovered a feeling of anxiety regarding asking for support. This fear that some people may have regarding health services, may prevent them from attending needed appointments.

“People may not want to ask if they are vulnerable. I prefer to be invited automatically, otherwise it's more work for my carer.”

-Beacon



Communication

"Do staff have time to give people the information they need?"

Queens Cross



People highlighted the importance of identifying patient needs.

Receiving information on PIFU, understanding the ability to book follow-up appointments and empowering patients to receive effective care, hinges on effective communication.

"On the phone, some people might describe things differently."

-Beacon

For people who have additional communication needs, it is imperative that services communicate in a way that works for them.

"They use all these words that people like us don't understand – just put it in layman's terms."

-Queens Cross

Some people need more time to communicate and also to understand concepts, such as the PIFU process. and recognising complications. There were concerns from some people about the ability of clinicians to recognise if someone has additional needs and if they have the resources to address these needs.

"I need very clear and simple instructions."

-Survey

"My family help with reading letters."

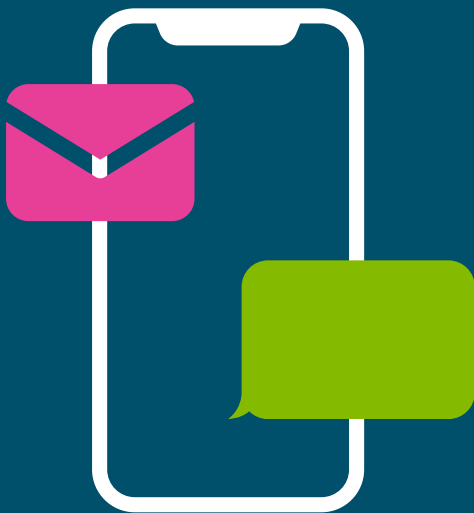
-Beacon

"My daughter has special educational needs and she has a passport that all her teachers have access to. It tells them what she needs, could we have something like that?"

-Beacon

Preferred ways to get information

"Easy read and pictures help some people."
Queens Cross



50%

of survey respondents prefer to get information by text or email

Our engagement found that there is no one-size-fits-all for receiving communication from and communicating with hospital services.

"It would be good to have reminders via text, email or NHS app on when to book follow-up appointments."
-Survey respondent

Communication differences

This digital communication allows people to view messages when convenient. However, for people with additional communication needs, they may require information in a different format.

"Telephone and video calls would be much easier."
-Beacon

"Have they got anything in Braille?"
-Queens Cross

When processing and understanding information some people may need it presented in a different way. This includes Easy Read, letters and face to face.

"I prefer a face-to-face appointment."

-Beacon

"I prefer to get letters."

-Queens Cross

For some people they would like the ability to discuss information to ensure they understand it.

"I need time to say things."
-Queens Cross

Digital access

"It's okay if you have a computer or smartphone. I am lucky I have my daughter who does it on her phone for me, I couldn't do it because of my sight loss. If I hadn't got my daughter it would be difficult. I would feel isolated and it would be practically impossible."
-Beacon



"Some people may not have a smartphone so they can't use phone for video calls."
-Queens Cross

Digital inequalities could present a barrier to some people being able to engage with PIFU.

Digital inequalities can arise from:

- Disabilities preventing use
- Digital skills and confidence
- Cost of devices and data

"I don't always get letters. I have to call to ask for one. I haven't got internet capability so I have to keep calling and it's annoying. They just sent me a text and a link, but I can't always get on the internet."
-Queens Cross

The PIFU system should have the flexibility to meet the differing needs of patients, particularly those with additional communication needs or barriers.

"I have received a call from a pharmacist for a review today. I didn't know anything about this as it was sent on the NHS app which I haven't used. No one asked me if it was okay to receive it that way."
-Queens Cross

"Some people would struggle with telephone or internet."
-Survey

"I hate booking online and trying to work the system. Sometimes it feels like after COVID this is the only way to get appointments."
-Survey

Real stories...

Traditional follow-up

People shared their experiences of the previous system of follow-up treatment. One person said that they waited so long for a follow-up appointment that previous test results were now out of date.

"I was meant to have a six month follow-up with rheumatology, but I waited over two years to be sent an appointment. By the time I was seen again my blood test results were too old so another set has to be done and I need to wait for another follow-up appointment."
-Survey respondent

Another person had concerns about a viral infection, they said they would have liked to have the power to book an appointment themselves.

"I had a virus and had to go to hospital. I would have liked to book a follow-up appointment to find out what the virus was but I was not given a follow-up appointment. If I could have booked my own I would have done that."
-Survey respondent

A survey respondent said they are on the waiting list for hospital treatment, they feel frustrated that they keep receiving communication asking if they wish to remain on the waiting list.

"I am unhappy with constantly getting text messages asking if I want to remain on waiting list for treatment."
-Survey respondent

These experiences paint a picture of a one-sided system that doesn't allow patients to take control of their health.

PIFU has the potential to allow people to take control of their own health, or have a contact so they may stay informed on their treatment and follow-up.

Real stories...

PIFU

We heard from a Dudley resident who used PIFU to follow-up on treatment for his son. He told us of difficulties faced when attempting to contact the right clinician. However, once through he received helpful information.

"I missed a call I was waiting for, concerning a follow up about my son's hand. The nurse left a voicemail with a number and department extension to call back. I called the number and was put through to the extension; the line just rang out and was not picked up. I tried calling again several minutes later and was transferred from reception to the required department. The receptionist told me I had to speak to a nurse. A nurse then answered and told me I had to speak to reception. After expressing my frustration with being passed from one department to another, the nurse then identified the colleague I needed to speak to.

I had the time and flexibility to persevere, somebody else may have given up and missed the important feedback and information. Telephone lines need to be well staffed and if you are provided with an extension, this should be the correct destination to talk to the appropriate clinician. When I did eventually speak to the right nurse, she was fantastic and very informative."

-Dudley resident

This experience highlights the importance of providing a well organised and structured system to allow PIFU to be successful. Staff should be trained on appropriately handling calls from patients and be able to direct them to the right clinician to provide information and guidance.

Suitability

"No way could my mum with dementia do it, I have to advocate for her."

-Beacon



"Hospital passports would mean people are in control as it includes your needs and preferences. It needs to be recognised more."

-Queens Cross

Identifying suitability

This research has demonstrated the importance of flexibility and considering individual patient desires and needs when implementing PIFU.

"Could it be an opt in service rather than opt out?"

-Beacon

We heard from people who were concerned about those who may not be suitable for PIFU. These concerns highlight how robust assessment is needed to determine those who are eligible for PIFU.

"I have carers who care for me, they help me with everything because I can't do it, I use a wheelchair."

-Beacon

Communication needs

Clinicians being able to understand patient needs is crucial. We heard from people who have previously used 'hospital passports', these documents set out a patients communication and access needs. Clinicians should seek this information before implementing PIFU.

"A communication passport for the hospital would be fantastic. It's a two way tool for the hospital. People say 'how many times do I have to tell my story?'"

-Queens Cross

Recommendations

PIFU provides an opportunity for people to manage their follow-up care, giving more choice and control while helping services to reduce waiting times.

There is a clear willingness among the people we heard from to engage with this model, however they recognise real barriers, particularly around communication and digital access.

We provide the following recommendations to consider when implementing PIFU in Dudley.



Clear information

- Provide a leaflet to patients upon discharge, clearly outlining the PIFU process and ways to arrange follow-up appointments if needed.
- Provide this information in different formats e.g. Easy Read, alternative languages.
- Ensure the information is easily accessible online.



Effective process

- Develop a flowchart, in consultation with clinical staff and patient groups, that explain the process.
- Include how to identify patients who are unsuitable for PIFU.
- Include checks that key information has been communicated to and understood by patients.
- Include a check for communication or access needs.



Clinical information

- Ensure any signs and symptoms patients have to look out for are explained clearly.
- Ensure the patient confirms they fully understand any clinical information.
- Provide this information in a suitable, written format for patients to refer to.



Communication

- Ensure phone systems are appropriately staffed to quickly and effectively direct patients to the correct department or clinician to arrange a follow-up appointment or to provide information.
- Identify and promote local services that can help reduce digital inequalities.

Thank you

Thank you to Helen Codd and staff at The Dudley Group NHS Foundation trust for reaching out and inviting Healthwatch Dudley to conduct some community conversations. A huge thank you to the voluntary groups and organisations for their responsiveness and agility when arranging the focus groups, namely: Beacon, Queens Cross Network, Dudley Voices for Choice, The What? Centre & Dudley Stroke Association. And thank you most of all, to the Dudley residents who took the time to engage in really informative conversations and shared their experiences with us, it's very much appreciated.

Further information

The Dudley Group NHS Foundation Trust – PIFU information

www.dgft.nhs.uk/

NHS England – Implementing Patient-Initiated Follow-Up guidance

www.england.nhs.uk/outpatient-transformation/patient-initiated-follow-up/

The What? Centre

Provides holistic mental health and wellbeing support to people aged 9 to 25 years old.

<https://www.thewhatcentre.co.uk/>

Queens Cross

Support centre for adults with disabilities, offering person centred, tailored support programmes. They also act as a supportive, safe environment to recharge and meet new friends.

<https://dudleyci.co.uk/services/queens-cross-network>

Beacon

Ensures no one faces sight loss alone, supporting people no matter where they are in their journey.

<https://beaconvision.org/>

Dudley Voices for Choice

Self-advocacy for people with learning disabilities and/or autism. They empower people to stand up for themselves and participate in community and strategic meetings.

<https://www.dudleyvoicesforchoice.org.uk/>

We Love Carers

Provides support and guidance to unpaid carers in Dudley borough.

<https://www.welovecarers.org/>

If you would like this report in another language or format please contact us.

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to quality**

Healthwatch Dudley is committed to providing a quality service, from how we collect data, to the information we provide. Every three years we perform an in-depth audit, in conjunction with Healthwatch England, to ensure we meet this high standard.