the patients association

NHS ENGLAND OUTPATIENT STRATEGY
PATIENTS ASSOCIATION PATIENT PANEL

Report on feedback in Patient Panel Two

Access and future models of care

June 2023

Acknowledgments

We would like to thank the patients who took part in the discussion and shared their experiences of outpatients' services.

Contents

Table of Contents

Executive summary

NHS England and the Royal College of Physicians (RCP) are working together on the development of a new NHS outpatient strategy; the Patients Association is providing support with patient engagement which includes facilitating three patient panel focus groups and supporting patient involvement in four summits.

This report provides feedback from the second patient panel focus group, which was held on 7th June 2023 and facilitated by the Patients Association. The patient panel was comprised of ten patients who had recently had experience of outpatient services, including two additional younger patient members from NHS Youth Forum who joined for this panel. Some of these patients had attended the recent summit meeting in Liverpool on 25th May 2023. Three patients could not attend the panel so were interviewed separately to ensure their views were included in this feedback report.

The panel was asked to discuss what could be improved and what works well in the outpatient system regarding access to outpatient services, diagnostics and specialist support. The patient panel members provided personal and family experiences of being an outpatient and accessing services.

In this session the participants were able to give positive and negative examples of what access means to them. The patient panel were also invited to comment on some proposed new models being suggested and what the pros and cons of these might be for patients and carers. These models were: Patient Initiated Follow Up (PIFU), Asynchronous consultations, One stop shop, and Group appointments – all of which had been defined on slides provided by NHS England and Royal College of Physicians.

Whilst these new approaches were welcomed there was some caveats pointed out by the patient panel to ensure they didn't add to health inequalities. It was emphasised that patients should always have a clear and informed choice in how they are communicated with and that not all patients are able to self-manage; follow-ups and proactive contact from NHS staff should not be lost. By being left to totally fend for themselves, some disadvantaged patients and carers could be falling through the net or left vulnerable.

Main themes where improvements are needed around access:

- Communication and public awareness
- Flexibility to meet individual needs
- Openness and transparency
- Staffing and attitudes
- Speed and efficiency
- Health inequalities- barriers and discrimination
- Use of jargon and acronyms.

Patients felt the current approach to co-production and involving patients in the design of a transformed outpatient service is at present very encouraging. Those patients that attended the last summit in May felt they were listened to and were able to make a positive contribution and are looking forward to the next summit on 21st June 2023. They would encourage more networking as a group of patients and better understanding of who is who in the room. One big plea is that use of jargon is minimised, especially when new proposals are being put forward to patients in language that is unfamiliar and unnecessarily complicated.

Recommendations

Recommendation 1: Patients and carers need to know how to access outpatient services, what is available and what their rights are regarding choice of appointment time, location, staff member, preferred method of communication and with a focus on shared decision making.

Recommendation 2: Ensure staff are trained to communicate well with patients and carers using good interpersonal skills, a customer care approach, compassion and empathy; enable patients and carers to be kept well informed throughout the process.

Recommendation 3: Ensure access to services is flexible and adaptable to individual needs and to those of the carer.

Recommendation 4: Ensure the service is open and transparent with patients and carers so they are told where they are on waiting list, roughly how long the wait will be and what support is available while they wait if their health is deteriorating.

Recommendation 5: Referrals to be made to the right clinician/speciality so that the patient sees the right person at the right time. Discussion to be had between GP and specialist beforehand if clarification is needed.

Recommendation 6: Reduce unnecessary waits, ensure referrals and appointments are set up as efficiently and timely as possible, whilst also making sure patients and carers are given adequate notice.

Recommendation 7: Introduce standards and criteria to ensure no discrimination or exclusion towards patients and carers because of circumstances that can play into inequalities of access. These include age, financial hardship, disability, gender, mental health, ethnicity, religion, homelessness or other aspects.

Recommendation 8: Avoid use of jargon and acronyms especially when new proposals are being put forward so that patients do not have to struggle with language that is unfamiliar and unnecessarily complicated.

Introduction

NHS England is working with the Royal College of Physicians (RCP) to develop an outpatient strategy. The strategy will look at digital technology, patient experience, behavioural insights, and health inequalities. NHSE and the RCP have commissioned the Patients Association to set up a patient panel to support the gathering of initial information and line of enquiry for the strategy. The strategy will look at pre-specialist, referrals, diagnostics, hospital settings, follow-ups, discharge, and ongoing care.

NHS England is keen to gather diverse patient views from patients with long term complex needs and/or on multiple pathways. Two members of the Patients Association have attended and participated in the project steering group for this outpatient strategy. Seven patients attended the summit on 25th May 2023 in Liverpool. The summit enabled at least one patient or carer to be present on each discussion table and showed a short video of three patient stories from members of the patient panel, which the Patients Association had produced for the summit. This provided a patient perspective in all the discussions and co-production approach to planning the new outpatient strategy.

NHS England anticipates working with the Patients Association in a longer-term programme of patient engagement to support this work.

Objectives

1) To set up a panel of diverse patients/ carers to feed into the steering group meeting. Patient members will include people with long term complex conditions and those who experience lower levels of engagement as outpatients. The panel will consist of eight core members including one NHS England patient representative and one from the RCP. There will be a need for additional participants, depending on the criteria and topics discussed for future sessions.

2) To provide patient insight from this focus group at summit meetings in 2023 as part of the development of the outpatient strategy.

3) To support NHS England patient representation on the outpatient strategy steering group (to act as a feedback lead for the panel on the steering group).

Overview of the second patient panel focus group

A virtual focus group was held on 7th June 2023 to continue the process of co-producing the development of the NHS outpatients' strategy. This focus group consisted of a panel of ten patients including two new younger members from NHS Youth Forum.

The two-hour focus group was held on Zoom. Representatives from the Patients Association were Project Manager Heather Eardley and Head of Patient Partnership, Sarah Tilsed who chaired and co-facilitated the groups. Representatives from NHS England and the RCP did not attend the meeting but provided some slides with an overview of new models of care being considered.

Session one: patient experience of access

The first session, which was split into two breakout groups, focussed on what patients want in order to access the outpatient system, with group members discussing their experiences of accessing outpatient services using a series of prepared questions that had been agreed with NHSE and RCP. Session two focused on providing patient views on the new models of care presented and is described later in the report.

Meaning of access in three words

The panel members were asked to describe in just three words what access meant to them. This ensured we got a snapshot of their experience, without each patient having to provide a lengthy description. There was a mixture of adjectives about their experience and highlighted what was important to patients about accessing services:

What choice have you had when you have been referred?

Choice was a big issue in terms of accessing services and most patients said they hadn't had any choice. This applied to choice of location, specialist staff and time. A few patients had been given a degree of choice on occasions, such as location or time and when this happened their experience was perceived as much better.

Choice of appointment time is particularly important and can save wasted cancellations, rearranging appointments, and unnecessary stress as patients are busy people too. Caring responsibilities, travel arrangements, distance and cost all have to be considered. Choice of consultant and location was also cited as important for patients.

"A lot of people don't know they have a right to choose and I only found this out recently when I attended a conference on outpatient services."

"You don't get a choice of hospital or consultant and it would be good to have a list of their qualifications etc."

"I've never been given a choice (or advice) of specialist and then when you get there it's not the person specified (normally someone fairly minor) – this is unsatisfactory."

Did you understand the process and why you were referred?

Most people did not understand the process and felt it was far too bureaucratic and complicated. Those that did understand had been through the process many times before, and so were familiar with it. The problems did not seem to be with the clinicians who were very highly praised by patients when they were eventually seen. It was more a problem with complicated systems and requirements with convoluted ways in which it takes to get to see the person required. Examples included a GP referring and then the specialist saying they were not sure why they had been referred, which seemed to happen fairly frequently and seems to be a waste of both patients and clinicians time.

"No, I was directed to a department but not explained why. Don't get it in writing. There are notes on you on their system but they can't give them to you (as a printout or email them to someone), so you don't have access to your own notes."

Did you know where you were on the waiting list?

Most people are not told where they are on the waiting list even when they have been on it for 18 months or more. One person had been referred to a transgender service where they were told it was a five year waiting list. One patient panel member had worked as an administrative assistant in a speech and language therapy team; she was directed not to give any information to patients about where they were on the waiting list in case it caused distress. All patients in the focus group felt this holding back of information created more stress. If patients know roughly how long they will have to wait, it enables them to get on with their lives or plan accordingly without raising expectations.

"In the case of transgender services there is a high suicide rate as people have to wait so long without any support and that is a big issue – the impact on your health both physical and mental when you are waiting."

"You never know – it's left up to you to sort it out and find out who to speak to. It's all a mess at the moment. If it was a business appointment you would have all the information – who, where and when, and wouldn't keep you waiting."

If you needed to see a specialist again, could you get back in contact?

Most people said they could not get directly in contact with the specialist. In some situations it was possible to phone the secretary, but this usually involved going through a lengthy hospital telephone system before they could get put through to the right medical secretary. One patient said the secretary had told her she could never have direct contact with the consultant so messages had to be passed between them, resulting in the issuing of a new appointment when the query could have been dealt with by phone or by email.

"I had to see four specialists/ departments – see a locum, have to chase up, then get a letter from the main consultant who was not the person you visited."

"The letter you receive from a person is not the person you have seen – it's normally a different consultant. They all say different things."

"Chase secretary or GP – start all over again. Why can't we just see the same person again? Like a lottery if you see them again".

How did the specialist communicate to you (letter/email/text/other)?

In all cases the patients said the specialist had communicated by letter even though this wasn't the best method for the patient.

"It took a month to get a letter with an appointment date the day after the letter was received!"

"I've never had an email, text or phone call from the hospital. "

What is most important for you about access e.g. speed, convenience, place, time, staff or other?

There were varied answers to this question:

- Seeing the right person and feeling listened to
- Efficiency of time - both staff and the patient
- Speed - the time it takes from initial symptom to diagnosis and treatment
- Flexibility – the potential to choose an appointment time and location.

Are there issues around health inequalities in accessing services?

All participants felt there were issues around health inequalities and accessing outpatient services. There shouldn't be a "one size fits all" approach as there are so many different types of patents and circumstances.

"What if you don't have a phone, address, internet, deprived areas – how do you get an appointment? "

"What if you can't understand English?"

There were concerns about a postcode lottery, with so many variations and inconsistencies and the need to spread services more evenly. There were also concerns about gatekeeping by GPs and ageism affecting whether or not someone accessed a service or treatment. People with disabilities such as autism, learning disabilities, and mental health conditions, or who are transgender, were cited as particularly excluded. If people have their own funds, they also have more choice and better access to range of services, as well as speed.

How can services be more easily accessed by ALL patients?

- Less discrimination and gatekeeping
- Services spread more easily
- More investment and funding

“There is sometimes a negligence of carers yet we are the ones who arrange the transport, bring the patient along to appointments and know the patient well.”

What three things would you change to make access better for patients?

Each patient gave their three suggestions of what needs to change to improve access:

- Communication
- Options / flexibility
- Make it simple
- Staffing - see who you are supposed to see / have the right attitude
- Have test results available at your appointment
- Tell patients where they are on the waiting list and provide regular updates
- Letters are not always the best way to communicate, and can miss vital information
- Email reminders to patients
- Text messages not always clear / lack sufficient information
- Choice of dates for appointments
- Information clearly given about date, department, time, location, who patient is seeing
- Openness and transparency
- Funding
- Accessibility
- Think about carers.

“Don’t send a reminder on a Friday night as can’t contact them as no-one answers on the weekend.”

“NHS make patients ill because they are not accessible – phone numbers that don’t work, too many appointments at once, can’t process it all.”

Think about services that can directly refer someone to a hospital specialist, rather than going via a GP (opticians, physiotherapists, dentists etc.) Is this a good idea for other services?

Everyone felt this was a good idea and could be expanded to other services, such as dermatology. It could even follow a consultation with a pharmacist who could suggest the appropriate specialist needed to be seen, or via NHS 111 which could go through an algorithm. If there is no need to go via the GP - who often doesn’t know the patient - it would make it much more efficient and streamlined for the patient.

Session two: proposed future models

A short presentation of slides produced by NHSE/RCP was given by the Patients Association facilitator, outlining different models and an explanation for each. These included Patient Initiated Follow Up (PIFU); asynchronous consultations; one stop shop; and group appointments.

Feedback was given on each initiative. All panel members disliked the jargonish terms but generally liked the concepts with some caveats.

Patient Initiated Follow Up (PIFU)

All felt this was very good idea, gave a lot of flexibility to the patients, and prevented time-wasting of unnecessary appointments. However there were some concerns expressed particularly around health inequalities and the lack of ability by some patients to be able to take the initiative to do this. It was suggested that there should be a defined time period relevant to the condition rather than one size fits all, and then follow up with the patient before discharging. The time period needs to include a bit of leeway to pick up any outliers, so it is realistic and flexible.

There was concern expressed about symptoms or complications that the patient may not know about or understand in terms of surgery or treatment, so there needs to be some additional checks by staff in preparing patients for this and also if they hadn't heard from the patient for some time.

If patients had problems getting through to ask for an appointment or some advice, this could be very frustrating and upsetting; and it was questioned whether this will work with complex conditions. For example if the patient has more than one illness and the symptoms are not clearly related to one thing, where and who would the patient contact?

"I like this - It enables a conversation with a specialist."

"Some criteria and time limits need to be put in place."

Asynchronous consultations

This seemed a complicated term for a simple idea. The opportunity to email or text directly with a consultant or GP and for them to be in communication with each other seems eminently sensible and would work well if the patient is familiar with the use of text and email. However for those who find it difficult to communicate using digital methods this could be quite daunting, especially if someone has a learning disability or dyslexia. There could also be age related or other factors preventing access to a phone or computer and sometimes face to face or a phone call suit some patients better. Patients need to be given the option for communicating this way by asking about their preferred method of communication at the outset and having this on their notes.

“My immediate thought is will this way affect my entitlement to have a face to face appointment. A 1:1 consultation on an email can be very impersonal, but if this follows that initial consultation then it could be very good and improve communication.”

One stop shop

The majority of patient panel members felt this would be a positive benefit for many patients, preventing the need to return the hospital several times and waiting for test results. Nevertheless this may not suit everyone, especially frail or elderly patients, or people with disabilities who find long appointments exhausting and overwhelming, especially if they rarely leave their home. Choice and preferences need to be taken into consideration with patients and presented with options and honesty about timescales.

“I would want to do this but my elderly father wouldn’t be able to manage this all in one day.“

Group appointments

In general this was seen as a useful option but with an element of caution. Timing would be important as well as the mix of patients. Some people do not like groups; some people can be very negative which could affect other patients in the group and would need to be carefully facilitated. This option should not be used to reveal test results or a first diagnosis, or to the exclusion of a face to face meeting with the specialist on a 1:1 basis.

Group sessions may be better suited to some conditions rather than others, as with some methods of communication. This will also depend on people’s cognitive abilities, age, and digital access.

Patients felt there could be positive benefits in hearing the experiences of other patients and ideas for coping mechanisms, but there will also be times when it could be inappropriate or embarrassing to share personal information.

Some patients had already experienced groups sessions for conditions such as diabetes - listening to a talk and hearing information in a group about diet and the Desmond course with specialist staff available have proved useful.

What are the most important points to raise to NHS England and the Royal College of Physicians from today?

1. Use existing systems and resources in the most efficient way

2. Don’t forget carers: consider the impact of appointment times and changes to them, which can impact the carer and are often very inconvenient. If someone has no transport, they may be relying on family carers to bring them to the appointment
3. Inequalities play a part – it is so difficult for some people to access health services. To ensure there is no discrimination, this should not be overlooked
4. Make access to digital means easier e.g. pods in GP surgeries; support accessing computers, such as in libraries
5. Meet individualised needs, rather than a standard process
6. Raise awareness of, and publicise, the different access routes and choices in different formats
7. Importance of staff attitude – compassion, empathy and respect
8. Use of jargon – even the word ‘access’ was not seen as a useful, commonly used or understandable term for most patients. The new models described in the slides were also given very jargonistic terms with some acronyms which patients felt were unnecessary and unhelpful.

Key themes on access to outpatients

When discussing their experiences and what patient panel members would like to change, the examples given were interwoven across all the themes raised in our first report that was based on general experiences of outpatient services.

The focus of this report is access and whilst the themes described in our first report still apply here, there is a slightly different emphasis for access, so we have identified seven distinct themes from this focus group.

Communication

Recommendation 1: Patients need to know how to access outpatient services, what is available and what their rights are regarding choice of appointment time, location, staff member, preferred method of communication and a focus on shared decision making.

Recommendation 2: Ensure staff are trained to communicate well with patients and carers using good interpersonal skills, a customer care approach, compassion and empathy; enabling patients and carers to be kept well informed throughout the process.

Flexibility

Recommendation 3: Ensure access to services is flexible and adaptable to individual needs and to those of the carer.

Openness

Recommendation 4: Ensure the service is open and transparent with patients and they are told where they are on waiting list, roughly how long the wait will be and what support is available while they wait if their health is deteriorating.

Staffing

Recommendation 5: Referrals to be made to the right clinician/speciality so that the patient sees the right person at the right time. Discussion to be had between GP and specialist beforehand if clarification is needed.

Speed /Efficiency

Recommendation 6: To reduce unnecessary waits, ensure referrals and appointments are set up as efficiently and timely as possible, whilst also making sure patients and carers are given adequate notice.

Barriers and discrimination

Recommendation 7: introduce standards and criteria to ensure no discrimination or exclusion towards patients because of circumstances that can play into inequalities of access. These include age, financial hardship, disability, gender, mental health, ethnicity, religion, homelessness or other aspects.

Use of jargon and acronyms

Recommendation 8: Avoid use of jargon and acronyms especially when new proposals are being put forward so that patients do not have to struggle with language that is unfamiliar and unnecessarily complicated. Even the word 'access' was not seen as a useful, commonly used or understandable term for most patients. The new models described in the slides were also given very jargonistic terms and made up of acronyms, which patients felt were unnecessary and unhelpful.

Conclusion

The patient panel of ten patients including two new youth forum members provided a lot of personal and family experiences of being an outpatient and accessing services. In this focus group the participants were able to give positive and negative examples of what access means to them. The focus group looked at the pros and cons of proposed new models for patients and carers. Whilst these new approaches were welcomed, there were some caveats pointed out by the patients to ensure they the models did not add to health inequalities. Patients need choice and follow up, rather than being left to fend for themselves with a danger of falling through the net or being left vulnerable.

The main areas that NHSE and RCP should focus on to improve access to outpatients are communication and public awareness; flexibility to meet individual needs; openness and transparency; staffing and attitudes; health inequalities and discrimination.

Patients felt the current approach to co-production and involving patients in the design of a transformed outpatient service is at present very encouraging. Those patients that attended the last summit in May felt they were listened to and were able to make a positive contribution and are looking forward to the next summit in June 2023.

There is a universal plea that the use of jargon is minimised, especially when new proposals are being put forward to patients in a language that is unfamiliar and unnecessarily complicated.

Recommendations

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