healthwatch

Working better across teams to improve health and care for all

April 2022-May 2023

Introduction

This briefing analyses patient experiences to support the development of a long-term vision for the NHS to work better, through collaboration and partnership working, to improve health and care for all.

Our evidence tells us that people expect and want collaborative working, not just between the NHS and external partners, but between people, departments and services within the NHS too.

To understand the impact partnership work has had on patients, and what 'better' could look like, we have analysed our evidence for insights into how the NHS is currently working to meet people's needs. This includes:

- How well different services join up and communicate with each other throughout the patient journey.
- How proactive different services are in offering people help, including signposting to other services.

Many of these themes were evaluated and addressed by the 2019 Long Term Plan, particularly the importance of service integration. This focus has since been accelerated by the introduction of Integrated Care Systems (ICS), which work to deliver the vision of meaningful partnerships between organisations, and service users.

"Integrated care systems are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area."

From *What are integrated care systems?*

Integration builds a framework for partnerships and collaboration and supports the aims of value-based health and care in two important ways:

- Good integration helps to create a more efficient and cost-effective system by preventing duplication, streamlining administration and communication processes, and facilitating the use of local and community resources.
- From the patient's perspective, collaboration supports the system to coordinate around their individual needs, which helps to deliver more personalised experiences and improve outcomes.

We often hear from patients about their positive experiences of clinical NHS care. However, we also hear about the importance of each part of the whole system working together in partnership to not only treat patients, but to assess, understand, navigate for, communicate with, and ultimately support them in a truly personalised way. This is where integration has the most to offer patients.

An example of this would be providing patients with support while they wait for hospital treatment. Until capacity can meet demand, long waits for elective care

services are to be expected for some time to come. While this is the case, the personalised interim support people receive while on waiting lists can be as important as the assessment, diagnostic test or surgery at their first outpatient appointment.

Providing the right support for individuals will be dependent on the joined-up work of primary care referral teams, secondary care admission teams, community pharmacies, physiotherapy and mental health teams, and voluntary organisations. These teams all need to be supported with access to the same information, so they can provide the necessary pain relief, mental health support, physiotherapy or signposting that people need.

Although in the data we analysed for this briefing, we did hear experiences about the importance of collaborative work with external partners, we also heard how there is more to be done to understand how NHS services currently join up around the patient, how well integration of these services is working for the benefit of patients, and what solutions could be put in place to support improvements.

Key findings from this research

By enabling collaborative, partnership-based working, integration provides good value to patients by:

1. **Supporting the health and care system to understand their needs as a whole person.**

   When everyone involved in a person's health and care journey is working together effectively, the system can respond holistically to patients' needs. We heard how patients want to be understood as whole people; this includes being **responsive** to personal circumstances, **supporting** them to live their lives as fully as possible, **considering** their medical history, and **sharing** this holistic information effectively between other professionals and teams.

2. **Making it easier for them to navigate the system.**

   When everyone in a local system is working collaboratively, health and care professionals have a better understanding of the whole system. This ensures they can better support people to navigate the system, helping patients to get the help they need from the right people. In turn, this reduces the time patients spend navigating a complex system alone. We heard about how patients value **accessibility**, ensuring that all people can access the system without barriers; **efficiency**, minimizing the time they spend navigating the health and care system; and both **proactive** and **two-way communication**, ensuring that they are kept up to date and can contact helpful people within the system.

3. **Signposting them to local and community resources.**

   When the health and care system nurtures positive working relationships with community partners, it can support people to access and use local resources. This helps people get the support, advice, prevention, and companionship they need. We heard how people **value effective signposting** from the health and care system to community organisations, how **people want to be empowered** to access helpful resources independently, and how people want to both **contribute to and establish** community resources.

4. **Supporting them to make efficient and cost-effective use of health and care resources.**

   Good integration helps the system to allocate resources, ensuring that people access health and care in an efficient and cost-effective way. Across the different themes, we heard how people value efficiency, including efficient administration, processing, navigation, and delivery.

   In 2019, we asked what people wanted from the next ten years of the NHS. We heard how people wanted to be seen as whole people, for carers to be more involved, better coordination around people's needs, and more collaborative working. Integration is delivering better patient experiences in areas of the system that have integrated successfully. We heard positive stories about how **integration has delivered better value** for patients, supporting them to get timely access to health and care in a way that suits them.

Methodology

How did we reach our conclusions?

Although the people that we hear from rarely use the language of partnerships, collaborative working, or integration, their stories often connect with these themes. For this briefing, we began with a piece of primary research using data that local Healthwatch had shared with us. We used a multi-stage approach to identify relevant stories from our local Healthwatch (CRM) data from the past year.

For the **first theme**, we focused on stories from carers and people with multiple health conditions, where the quality of coordination around their whole needs is likely to affect their experience. For the **second theme**, we searched for stories about communication, appointments, and referrals. For the **third theme**, we focused on stories about accessing and using community support organisations.

The project team met to establish search words that would help us to extract relevant stories from the local Healthwatch dataset. Using these keywords to search the data identified **14,646 stories**. We selected a random sample[1] of stories relevant to each theme for analysis.

The remaining stories from each dataset were then coded and analysed using an inductive thematic analysis approach. Items in the final three datasets were read by a team member, who added thematic codes, or tags, to the story based on its content. At the point where we no longer needed to add new codes to code stories, we stopped coding, as this indicates that we were approaching data saturation. In total, we analysed **193 stories** to generate the findings discussed below.

After we had completed the initial analysis, we triangulated our findings with those from local Healthwatch reports and two of our own research projects, one on GP referrals and an upcoming briefing on unmet needs in social care. We also used targeted advertising to encourage people with multiple conditions to submit their experiences getting joined-up care.

Selected quotes from these sources are used to supplement the main findings throughout the briefing, alongside demographic information where available.

This briefing is informed by:

- The experiences of **193 people**, shared with 51 local Healthwatch across England between April 2022 and March 2023, sampled from over 25,000 stories.
- Eight research reports from **local Healthwatch**. These reports represent the views of **2,325** people.
- **2,144** questionnaire responses about getting GP referrals and **18** depth interviews about unmet needs in social care.
- **128** people who submitted stories via our webform between 1st-12th May 2023.

4,808

[1] Stories were assigned a random number using the RAND() function in Excel. The data was sorted using the randomly assigned numbers from smallest to largest prior to coding, to ensure that a random selection was coded prior to data saturation.

Common issues across our feedback

Coordination around the whole person

When everyone involved in a person's health and care journey is working together effectively, the system can respond holistically to patients' needs. When people from different teams, services, and organisations collaborate, people can get the right help efficiently and without duplication.

When this works well…

We heard stories about the **positive impact** that coordination around the whole patient has on their health and care. These stories highlight times when the system has responded flexibly and holistically to people's individual needs to provide good care.

We heard how **teams can work together** to help people **live their lives more fully**. One person gave feedback on their husband's experiences with palliative care for advanced Parkinson's disease. Her husband was able to attend his daughter's wedding due to the support of the team around him. When he wanted to be treated at home, his wife was involved in all the decisions about his long-term care, and she was supplied with the equipment, supplies, and training to take care of her husband's nutrition via a peg tube. Her husband was able to stay at home to the very end of his life due to the help of the District Nurse service, carers, and his GP.

We also heard of examples of services **recognising the whole needs of a person**, including their medical history, and responding appropriately. In one example, a person suffering from acute gastritis told us about how their GP listened to their concerns, and then decided on a treatment plan based on their experiences, which included a referral for mental health support.

"He was absolutely amazing and exactly what I expect from a GP. He was very thorough and took plenty of time to discuss my condition. He gave me his full attention and as I've had this problem before decided together with me on the best treatment based on my previous experiences. I am extremely grateful for his help."

Healthwatch Norfolk

In another example, we heard from a person that has HIV and is from a low-income background, who had struggled to find an NHS dentist to treat their tooth pain. Together Dental recognised the importance of dental health to people with HIV and took them on as an NHS patient immediately, despite their long waiting list.

Understanding the person

In the small sample of stories we analysed, people told us about a lack of responsiveness on the part of healthcare professionals and community service providers to patients' personal circumstances. These stories often referenced system pressures alongside unmet needs or expectations, particularly around providing appropriate care and support for people with pre-existing conditions. Failure to respond to patients' personal circumstances leads to patients feeling misunderstood and ignored, and leaves patients with services that are inadequate or inappropriate for them. These findings are mirrored in a report by Healthwatch Lincolnshire, which found that patients want services to wrap around their needs.

We heard from people about the **lack of collaborative working**, and how this prevents their whole needs from being considered. This includes one person who told us how siloed working had affected their care.

"There is no coordinated care if you have multiple medical conditions. The doctor only deals with his speciality and doesn't want to know about any other medical problem, e.g., you have a heart problem of brady[cardia] and tachycardia and you see a heart consultant. He only wants to deal with the heart but not investigate the underlying medical condition that is causing the heart problem. He just wants to give heart tablets to treat the heart. In my case, it would have been fatal as it would have masked serious underlying infections and a thyroid problem." (White British woman aged 50-64, from Derbyshire)

We heard from people with **multiple health conditions and comorbidities** who told us about the additional challenges they face when their personal circumstances are not addressed. People told us they feel that only being able to talk about one issue per appointment at their GP prevents a holistic understanding of their health and can result in extra appointments.

"I have several medical conditions including hiatus hernia, IBS, type 2 diabetes, and erratic heartbeat. Only allowed to discuss one condition at one appointment, which is timed for 10 minutes. Ten minutes doesn't give enough time to discuss one symptom let alone four. Nothing is joined up." (White British woman aged 65–79, from Suffolk)

We heard both from **autistic people** and their parents, who told us about services not responding to their unique communication and sensory needs. This includes the parent of an autistic child who told us about their child's experience receiving surgery.

"I should have gone to PALs to talk about how things could be improved for children with autism, but we were exhausted, worried, and stressed and just wanted to come home and never go back. In fact, I dread the thought of us ever having to take him back in to a hospital. I think there should be a more holistic approach to care when dealing with an autistic child coming into the hospital environment."

Healthwatch Surrey

In other stories, people told us about how **system pressures** were affecting how personalised their care felt. We heard from people being offered inappropriate mental health support due to local demand; this includes one person that could only be offered group therapy, which the nature of their mental health condition prevents them from attending. We also heard about the effects of **staff shortages**, including the limited availability of trained care coordinators to help the system join up around the needs of the patient.

Informal carers

"I have been a carer for about 3 years now. I just don't feel like I'm getting anywhere. I'm so fed up with it. I am starting to really lack sympathy and empathy and I just feel angry now, which then makes me feel guilty for feeling that way."

Healthwatch Surrey

Carers told us that they feel their role, the effort they put in, and the impact that providing care has on their lives are often **ignored by health and care professionals**. This leaves them feeling frustrated and trapped, which can cause resentment. We heard how this detrimentally affects their mental health. Carers appreciate feeling included, and that their needs are being considered.

"The staff always enquire around my wellbeing. It makes a nice change as a carer we sometimes get forgotten." (White British woman aged 65-79)

Healthwatch Rochdale

Carers also told us about how **considering the patient as a whole person should extend to their carers** too. In one example, we heard from a family whose mother, due to a shortage of beds, was discharged without a care plan. The system had assumed the family would be responsible for their mother's care, despite working full-time and being unavailable throughout the day. Healthwatch Cumbria found that poor communication about discharge and not having the appropriate support in place at the point of discharge were common experiences.

In Healthwatch Suffolk's recent report about local people's experiences of dementia, they spoke about the importance of ensuring that families are invited to participate in multi-disciplinary meetings and be informed about how they can initiate these meetings, too. More broadly, this report highlights the importance of integration to the experiences of people with dementia and their carers.

In another example, a carer told us how they struggled to get to morning appointments due to the length of time it takes them to get the person they care for, who has dementia, out of the house. However, the clinic only offers morning appointments and is closed in the afternoon.

Feeling unheard

When all the parts of the health and care system are working together effectively, people should feel that their concerns are being listened to. If one part of the system can't provide help, it should be able to direct the patient to the part of the system that can. People should also feel that the system is working in collaboration with them, ensuring they can be involved in decisions about their care.

We heard from people who had been experiencing a range of symptoms that were affecting their day-to-day lives and had been unable to get the right help from the right people. These people often report a mismatch between the **impact that they feel the symptoms are having** on their lives and how seriously they are taken by health and care professionals.

"I struggled to make myself heard because no one was listening to me, they listened to me when my condition got much worse and intolerable for me..." (Woman aged 25-49)

Healthwatch Birmingham

We heard stories from people, particularly women, that feel their experiences of **physical pain are minimised** by health and care professionals. This includes one woman that had been to see her GP several times over a three-year period about pain, before seeing a private consultant who referred her with suspected advanced endometriosis. We also heard from people that have had formal diagnoses ignored or challenged by other health professionals.

Other stories we received from patients, family members, and **carers** told us they feel **excluded from decisions** made about their health and care or the health and care of their loved ones. This includes one person with a learning disability whose epilepsy medication was changed without adequate explanation. In another example, one family was unable to attend an appointment to discuss care funding but found it impossible to get through to someone over the phone to re-arrange the appointment.

Repeating their stories

One symptom of poor integration is that patients feel they have to **repeat themselves** to different health and care professionals. Having to repeat their story leaves people feeling frustrated and unheard. Our data highlights how this can be caused by issues of communication between services and within services.

In one example, a patient with skin cancer described how **seeing different GPs** at their surgery resulted in both having to repeat their story and resources being wasted through duplication. They told us that, as their test results weren't shared between health and care professionals, they had to repeat a range of x-rays and scans.

In another example, the carer of an autistic child described how they would always request to be seen by a senior GP, which ensured that they met with the same GP at each appointment. This reduced the amount of time the carer spent repeating the child's history, which also improved the carer's mental health.

Opportunities

There are opportunities to provide better, more joined-up care for patients and carers. Longer, coordinated appointment slots for those with multiple health conditions will enable a more holistic approach to their health, and improve the system's understanding of how to provide appropriate care. Involving carers in decision-making, and working to understand their needs, will also help to ensure that the system provides appropriate support.

As integration progresses, we need to ensure that it's working for patients and carers and improving experiences across the system. NHS England has developed a national integration index, and worked with The King's Fund, Picker, Healthwatch England and others to design a local approach to understanding integration. Following an initial launch in July 2021, a renewed focus on measuring the success of ICS and learning the right lessons will be key to the implementation of any longer-term vision for the NHS.

Navigating the system

One aim of integration is to make it easier and more efficient for people to get the right help. More interdisciplinary and collaborative working means that health and care professionals are better equipped to navigate the system on behalf of patients, making it easier to direct them to the person or service that they need. Good integration also means that people feel supported to navigate the health and care system themselves. This means that they're able to access the system to get the help they need; they know whom to contact about any questions or issues; and are kept up to date while waiting for help, treatment, and care. In some cases, this may include working in partnership with a care coordinator.

When this works well…

In the small sample of stories we analysed, we heard how **proactive communication** about their health and care journey helps people to feel supported, leaving them feeling more satisfied with the care they receive. This includes one person who spoke positively about the information they received regarding an operation, describing their care as excellent. One patient with an eye infection told us how they had been kept informed about their health and care journey from the first point of contact, and how this contributed to a positive experience.

"I have been ever so well treated. I have been coming here for a few weeks as I have an infection in my eye and have no complaints at all. I feel really well cared for, there's been good communications, excellent from my first point of contact. […] I have to come back in four weeks' time, they will send me a letter with an appointment on it."

Healthwatch Norfolk

A report by Healthwatch Greenwich to feed into the London Ambulance Service's forward strategy also links feeling informed about the next steps in a health and care journey to improved patient satisfaction and confidence in the treatment provided.

We also heard stories about people within the system taking some of the **burdens that come with navigating the system** away from the patient.

"It's a complex condition - my GP has been fantastic in offering support, and getting referrals sorted with all the other departments who need to be involved (and nudging/reminding them to crack on)." (Woman aged 25-49)

Healthwatch Warwickshire

In other stories, we heard how the patient experience was **streamlined**, reducing the time people spend arranging, attending, and navigating different appointments. This includes one story where the health system combined multiple appointments for different health conditions into one.

"Instead of attending various clinics at different times at the surgery for monitoring of long-term health conditions, they were now encompassing them all into one annual appointment to be reviewed in your birth month. […] Results were posted on my Patient Access account. I received a text 3 days later advising of cholesterol and diabetes reading with links to information and [the] Nurse at the surgery for further advice. It was a definite improvement on several different appointments."

Healthwatch Surrey

Navigation

In response to our call for stories from people with multiple health conditions about coordinated care, we heard a range of stories about the challenges they face navigating the health and care system. We heard how a lack of coordination and collaborative working means that these people **have to work harder** to get all the care they need. This includes spending time travelling to different appointments, managing prescriptions, and communicating across teams.

"You asked if my care was coordinated. I can only reply no. I see eight Consultants [in] three different NHS Trusts who are incapable of communicating with one another, the GP or me. Medication is changed randomly by any one of them. […] Nobody but me has oversight and I think I ought to be paid for the sheer amount of work I put in!! The GP frankly doesn't want to know." (White British woman aged 50–64, from St. Helens)

Our recent referrals research about the experiences of 2,144 people who didn't get referred and those that did detail the challenges people face trying to **navigate from primary to secondary care** and include stories about the impact that the lack of collaboration, coordination, and streamlining can have. We also heard about different parts of the system blaming each other for issues, leaving the patient without help.

"Different parts of the healthcare system don't seem to communicate well. When referrals don't go as expected, GP blames hospital… hospital blames GP… patient is caught in the middle. All the time, [their] health problem is worsening, patient feel[s] lost and helpless and not knowing who to go to or where to turn. Added stress and time making multiple phone calls, going round in circles. It seems each section of the healthcare system wants a different one to take responsibility for care of the patient. As a patient it is exhausting and exasperating." (Woman aged 25-49)

Healthwatch Herefordshire

In the data from local Healthwatch, we heard from people on waiting lists about the lack of information on the **progress of their referral**. In one example, a person phoned the department to find out information about their referral appointment, only to be told it had been cancelled without their knowledge and without explanation. Their appointment was rearranged at their request, but now came with a significant waiting time.

"I felt very much bounced between people who weren't listening to me, and now I've been left in the dark about whether the clinic will see me and how long the waiting list is" (Non-binary aged 18-24)

Healthwatch Hertfordshire

Other stories suggest that communication problems between services are barriers to proactive communication around to referrals.

"The GP submitted the referral without sufficient information and when I asked about updates on it, I was told it had been submitted. But in reality, it was rejected and only after 6 months of trying to get an answer [did] they check the status of the referral." (Man aged 25-49)

Healthwatch Devon

We also heard how people were **unable to reach someone in the system** to support their health and care journey. This includes one person who was trying to inform the hospital they could no longer attend an appointment, but the phone number on the referral letter was no longer in use. Similarly, another person told us that their consultant had asked them to make a follow-up appointment, but they couldn't get through to the number provided to book this. In a different story, we heard how one person was told to phone a number if they hadn't heard anything by a specific date. They phoned after not hearing back in the specified time, only to be told there was no point in ringing, and they'd just have to wait.

Other people told us about the challenges they faced in **working out where they should be going** for help. This includes one person who described how language and the use of acronyms were barriers to navigating the system.

"Is there anywhere in your toolkit a flowchart that describes the various pathways that a patient might be guided along, together with full names of various services and their [acronyms] (e.g., BBC = British Broadcasting Corporation)? I feel I am flying blind here and it is hampering my ability to help/care."

Healthwatch Bath & North East Somerset (BANES)

A report by Healthwatch Sheffield discusses the challenges people face trying to navigate the system, even when people have a good idea of where to start. They spoke to a range of community organisations who noted that people often don't know where to go for help.

Informal carers

We heard from **carers** about how they face similar barriers, which can be exacerbated when they are trying to navigate the system on behalf of someone else. We heard how carers struggled to contact people within the system to manage appointments and care, including getting care assessments booked.

We heard from one carer whose GP used to be that one point of contact, but that they're now too busy to provide this service. In another example, we heard how no one answered the phone when a daughter that cares for her mother wanted to check up on her. We also heard how, after hospital transport was delayed by over an hour, a carer tried to phone the department to inform them they would be late but was met with a recorded message asking them to call later. In a similar example, a carer tried to cancel care visits but was unable to contact anyone.

"ICS were supposed to provide two night-care visits per 24 hours for my 96-year-old father who is bed-bound at home. The service was minimal and provided no value to my father, so I tried to cancel it. It was extremely difficult to find out who to contact and, in the end, I left several emails and messages [with several] different departments." (White British man aged 80+)

Healthwatch Shropshire

We also heard from carers that were unaware of the support available to them, including one example where a carer wasn't told about continuing healthcare for the first five years of caring for her husband, despite being eligible.

Opportunities

There are opportunities to continue to improve patient communication through integration. Patient communication must be accessible, transparent, proactive, and two-way. For health services to provide truly personalised care, they have to consider and work around people's lives. This includes whether they have multiple conditions, access social care support, or have caring or work responsibilities.

As well as improving channels for the NHS to update patients about their care, patients must also have access to points of contact so they can give feedback about their condition. This could be while they wait for treatment, including whether they need to cancel or reschedule appointments, or quickly chase up a referral if they have not received information about its progress.

Using community resources

One aim of integration is to enable the health and care system to make better use of community resources to support the health of residents. This means that residents are aware of relevant support in their community, and patients are signposted to appropriate community organisations by health and care professionals.

When this works well…

Local organisations, groups, and facilities can provide essential support for people living with health conditions. Providing patients, service users, and their families with clear and concise information about available resources enables people to live healthier lives.

In the data we examined, we heard examples of local Healthwatch **signposting** people to community resources. One person was signposted by their local Healthwatch to VoiceAbility for advocacy when working with their mental health team. Another individual, who was experiencing financial hardship, was signposted to local charities and foodbanks. Several individuals were given information on social groups for elderly people, helping to reduce feelings of loneliness.

We heard stories about the **positive impact** that community organisations can have on people's lives. This includes a parent who received advice and signposting from a charity to help her receive support for her children:

"He has been the only person to listen and has gone above and beyond to support and listen to [the] needs of my children, treating them as the awesome and amazing children that they are! Without his input, we could have continued to struggle in silence, but as a result of his dedication, we are able to thrive." (Woman)

Healthwatch Sunderland

We heard from carers that had received vital support from community organisations, including carer support organisations, such as Action for Carers, and condition-specific organisations, such as Mind. This includes young carers that were able to attend carers meetings in schools, providing respite and a chance to socialise.

"I don't have a dementia navigator, but Sarah at Andover Mind has been excellent and so helpful and basically acts like a dementia navigator. […] I used Rare Dementia Support in London who were also excellent."

Healthwatch Surrey

We also heard from people that feel they have exhausted other avenues and are now turning to their community for support. Most of these stories in the small sample we examined related to mental health, and people that were looking for **community support while on waiting lists**. This includes one person that described a local mental health organisation, Anxious Minds, as a "lifesaver". Similarly, reports

from Healthwatch Stockton-on-Tees and Healthwatch York also recognise the important role of community-based mental health support.

Accessing community resources

We heard stories from patients that were **requesting information** about local services from their local Healthwatch, or that were contacting their local Healthwatch to talk about the **lack of signposting** or community support. These are often people that want to make use of community resources but haven't been effectively signposted by health and care professionals. In a report by Healthwatch Enfield, they suggest that urgent care could be enhanced by better signposting to community resources·

"I am confused about how I found out about local community services, I shouldn't have to have a problem to find out, I want to be proactive, not reactive."

Healthwatch Rochdale

We heard how people had **actively sought information** or advice about community organisations from primary care providers, but they had been unable to provide useful information. One person told us of their surprise at finding out that their local GP offered social prescribing, feeling that they didn't promote this service to those that could benefit from it. Another person spoke about how not being able to use a computer was a barrier to finding local organisations.

"Because of what I do with running my fibro groups, I have found some services that can help people with fibro, like the Lincolnshire wellbeing service and social prescribing, but I have found those out for myself, [no] one told me about these services. It is helpful to me to know about these services, as I then can recommend them to people in my group, as most people don't know these things are around or even know where to start to get any help and support."

Healthwatch Lincolnshire

Other stories spoke about **issues accessing local services**. These include local organisations not having the capacity to provide support to new people, support groups that people used to attend remaining closed after COVID, and support for children from community support organisations ending when they turn 18.

"[My son] used to be able to go to all kinds of different activities in the borough on the weekends. The Toy Library was great. They had lots of sensory toys for him. He used to go to weekly swimming 'Cascades' classes. I used to meet lots of other parents and carers in the same boat as me, so these activities were not just good for him, but for us as parents too but everything we used to do has either been closed down or he's not allowed because he's not considered to be a child anymore."

Healthwatch Greenwich

We also heard from a range of people that have identified **areas where community support doesn't exist**. These people made suggestions for new community organisations or spoke about opportunities for collaborative working between community organisations. These people had often turned to their local Healthwatch to ask for advice or support, as they lack the skills, knowledge, or expertise to take their ideas forward.

Informal carers

Carers told us about the extent they **rely on community organisations** to help manage being a carer, including support in completing the necessary paperwork and getting help to navigate the system. However, carers face similar challenges in making use of community resources. We heard from **carers that were unaware of the support** available to them, and that hadn't been able to make use of these valuable community resources. We also heard from carers about the reduced availability of support groups after COVID.

Opportunities

Many local organisations already provide expert signposting and information and advice to communities. Others provide services to help people with things like getting in touch with their hospital, carers breaks, physiotherapy, or with wellbeing groups.

Where good work is already happening to give people the help they need, organisations should be formally resourced and supported to enable them to continue and, where possible, scale up their work. Those that want to establish new community resources should be supported to do so.

There are also opportunities to make better use of Healthwatch. Local Healthwatch are independent and trusted by our communities, with Equality Diversity and Inclusion central to our values. Healthwatch are well placed to support relationships between the health and care system and community organisations, and to fulfill a role that goes beyond signposting.

Appendix i: Recommendations

Coordination around the whole person	Why is this change needed?	Who is responsible?
Offer longer appointment slots in general practice to those who need them.	Not all patients will need this, but for those who do, extra time during appointments would help give staff the space to assess patients holistically, and to share information about the referral process and where to go for help in the future. This would particularly help those with multiple long-term conditions and could potentially reduce the frequency of visits to general practice before onward referral. Only by understanding and managing demand can the NHS improve capacity at the right parts of the system.	NHSE, ICS, GP surgeries
Provide people on waiting lists with personalised support	Long waits for NHS treatment can impact people's mental health, their ability to work, to carry out household tasks, and the levels of pain they experience. While long waits for elective services remain an unfortunate inevitability for some time to come, the NHS must work to improve funding for and patient access to the support services they need while they wait. This includes different teams working in collaboration across the NHS and voluntary sector, including community physiotherapy, talking therapies, community pharmacy, and charities providing health and social care services.	NHSE, ICS
Formally re-launch the Integration Index	Following their development, it's now important for ICSs to understand where and how they are meeting the needs of their communities. NHS England has worked with Picker and the King's Fund on a national integration index, as well as Healthwatch England and others on a local integration index. These guides support ICSs to understand, monitor and measure how	NHS England

	well integration is working locally and how needs are being met. Following an initial launch in July 2021, a renewed focus on measuring the success of ICS and learning the right lessons will be key to the implementation of any longer-term vision for the NHS.	

Navigating the system	**Why is this change needed?**	**Who is responsible?**
Record people's communication preferences in e-RS or other care record systems.	Patient communications must be accessible. This not only ensures services meet people's needs under the Accessible Information Standard but can support people's understanding of and navigation through the health system. We have heard from people who have missed appointments and then either bounce back to general practice or go to A&E because of referral letters being sent in the wrong format. So, by ensuring all patients are communicated with via their preferred method, the NHS can reduce the likelihood of demand presenting in the wrong settings.	NHSE, ICS, GP surgeries
Improve the collection and sharing of patient data to ensure IT systems across different services can be interoperable.	Patient communications must be transparent. All parties should have access to the same centralised information, including what stage of the referral process patients have progressed to, when to expect their next appointment, whether they have caring responsibilities, or what communication preferences are recorded again them. This information should be accessible by patients as well as teams in primary, community, and secondary care. Progress is ongoing in this regard through updates to the NHS App, however, information should also be available and shared with patients via other communication methods, as not in their care record. This will support a future vision of one NHS, with no wrong door.	NHSE, ICS

Ensure that all NHS communication channels allow for two-way communication between services and patients.	Patient communications must be collaborative. For health services to provide truly personalised care, they have to consider and work around people's lives. This includes whether they have multiple conditions, access social care support, or have caring or work responsibilities. As well as improving channels for the NHS to update patients about their care, patients must also have access to points of contact so they can give feedback about their condition. This could be while they wait for treatment, including whether they need to cancel or reschedule appointments, or quickly chase up a referral if they have not received information about its progress. The NHS could ensure both-way communications through updates to the NHS app, as well as various single-points of contact in different services: • Care navigators in general practice • To support remote monitoring in primary care • To track referrals from primary to community and secondary care • To access interim support while on NHS waiting lists • To contact services following discharge from hospital • To manage regular visits for treatment using NEPTS	
Improve the online referrals tracker for patients.	The GP contract states that GP teams must use the NHS e-referral service. Where practices still do not have an electronic patient record system, transition should be supported by appropriate resource from NHS England. This will ensure that all referrals and appointment data is stored centrally, and is accessible to patients and the relevant services, minimising risk of referrals being lost or different professionals having contradictory	

	understanding of where someone is on the referral pathway. It will also support improvements to online tracking and booking systems. We've heard from patients who have received no information along with their referral, meaning they cannot book or manage appointments through the e-RS tracker. Some of these people have gone on to discover that the referral was never actually sent or received by specialist teams. This work would be supported via other recommendations throughout this briefing on interoperability and patient communications.	

Using community resources	**Why is this change needed?**	**Who is responsible?**
Fund interim support provided by the voluntary sector.	Many local organisations already provide expert signposting and information and advice to communities. Others provide services to help people with things like getting in touch with their hospital, carers breaks, physiotherapy, or with wellbeing groups. Where good work is already happening to give people the help they need, organisations should be formally resourced and supported to enable them to continue and, where possible, scale up their work.	DHSC, NHSE
Increase funding for Healthwatch	Providing core and sustainable funding for the Healthwatch network at local, regional and national level also means there is a strong infrastructure to call on should the NHS or DHSC need to carry out additional engagement work that goes above and beyond the network's standard workplan – the NHSE LTP engagement project is a good example of this. Without sufficient core funding, similar pieces of nationally commissioned work will simply not be possible in the future.	Government

Introduce a non-voting, independent role for Healthwatch on the ICS governance boards.	Healthwatch are independent and trusted by our communities, with Equality Diversity and Inclusion central to our values. Investing in Healthwatch to operate at all levels would be a relatively low-cost way of providing assistance to a sector that often struggles to show how it has engaged, even when it has done it well. With the right legal powers and data sharing agreements in place, Healthwatch would be able to provide additional analytical capacity to understand a whole variety of sources of user insight which the system currently collects but often doesn't have time or expertise to interrogate fully. For example, ICS or regional analysis of feedback left on NHS.UK or data from qualitative comments collected through the Friends and Family Test. If commissioned consistently, every ICS in the country would have ready access to our expertise to help support their engagement own activity. This is supported by our ability to reach and recruit people to support with co-production exercises.	Government, NHSE

Healthwatch England
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

www.healthwatch.co.uk
t: 03000 683 000
e: enquiries@healthwatch.co.uk
@HealthwatchE
Facebook.com/HealthwatchE

healthwatch