

Participation - the NHS working with people and communities

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Introduction

Participation can be used to describe various forms of activity that enable people and communities to interact with services in ways that influence service planning and delivery. It can include formal consultation focused on specific issues as well as informal interactions with no fixed agenda, and a range of other activities. At best, it leads to a situation where people's voices are heard and listened to, enabling them to have a visible impact. Importantly, people will know that they have been listened to and that their views are valued.

The [National Health Service Act 2006](#) (as amended) sets out legal requirements for the NHS to consult people who use services about the planning and delivery of those services. The NHS has a long track record of working effectively with people and communities, and will often go beyond the legal requirements, recognising the benefits of meaningful engagement.

The statutory guidance on [Working in partnership with people and communities](#), published in 2022, recognises that engagement needs to be seen as more than a legal requirement, and should run through all aspects of an organisation's work. 'Participation' and 'engagement' are not discrete processes, they are ways of working.

The legal requirement is important as it provides a standard against which NHS organisations (NHS England, Integrated Care Boards, trusts and foundation trusts) can be held to account - but that can lead to a transactional approach. Working with people and communities on an ongoing basis can be transformational, building a strong relationship of trust and better mutual understanding.

People regularly raise concerns about services and may have views about how they could be improved. While some issues will always need to be raised as formal complaints, ongoing engagement can enable people to raise issues constructively to support service improvement. Services should see this as a good opportunity to make sure services meet people's needs. This includes all sections of the community, and so it is important that participation works to reach everybody, including those who may not typically be involved.

The NHS supports a variety of ways that enable people to participate. At the most local level, Patient Participation Groups give people an opportunity to work with their local GP surgery. A crucial stage in the development of Integrated Care Boards was the production of engagement strategies setting out how the boards would work with people and communities locally.

Healthwatch

Healthwatch England and the network of local Healthwatch were set up by the Health and Social Care Act 2012. Each local Healthwatch is independent, enabling them to respond to local priorities. They act as a patient champion, making sure that the NHS and social care decision-makers hear people's voices and use that feedback to improve care.

Benefits of working with people and communities

The statutory guidance highlights eight benefits of working with people and communities. The following examples show how engagement and participation with people and communities can deliver real benefits to the health and care system. In reality, any project is likely to contribute to several of these benefits, and the process itself can be a positive one for those involved. These examples taken from Healthwatch across the country demonstrate the different ways people can participate with health services, and the benefits both to the people themselves and health services.

Improved health outcomes

By understanding local need, services may be better placed to provide what is needed in the way that best suits local people. Where there are variations, even within an area, the NHS should work to provide an equitable service.

When local people raised the issues of memory loss and dementia with them, Healthwatch Cornwall collaborated with the Cornwall Memory Café to find out more about the issues people with dementia and their families faced. [They got the views of 148 carers through a survey, spoke with 21 carers in focus groups and conducted 15 in-depth interviews.](#)

Experiences of diagnosis, accessing and receiving different kinds of memory loss and dementia services and support in Cornwall varied:

- across areas of Cornwall
- between carers, such as carers of spouses/partners and carers of parents - who were very often working carers
- by age of people living with dementia

Carers reported both positive and negative experiences, drawing on services provided by the NHS and the community and voluntary sector. The insight clearly showed that services were inconsistent. Based on this engagement, Healthwatch made recommendations about a clearer “pathway of diagnosis, services, and support, that is accessible and local to people”.

“The support can be really good. More recently as needs increased, but communication between different health disciplines does not always happen, I have had to liaise between the teams to get mum the treatment she needs.”

Healthwatch Cornwall

The recommendations will be used to underpin the development of local strategies and action plans across the county.

Value for money

Public services have to ensure that they provide value for money. This not only entails ensuring that services are provided efficiently but must also take into

account how people use services. One major challenge for the NHS is the number of missed appointments. Where the appointment is no longer needed, there is avoidable wastage, but where people miss appointments that are needed, this risks having a negative impact on their health.

The issue of missed appointments is frequently covered in the media, often blaming those who don't attend and suggesting fines for non-attendance. When [Healthwatch Brighton and Hove took a closer look at the issue and spoke to people using the Royal Sussex County Hospital Outpatients Department](#), they found a more complex picture - and one that services need to understand.

Although forgetfulness was a major factor, there were many other reasons. Some people, for example, received duplicate letters with conflicting information so were confused about when to attend. Checking details provided difficult as phone lines were often engaged. Busy phone lines also made it difficult for people to change or cancel appointments.

When Healthwatch Lincolnshire [surveyed people about a similar issue](#), it found that people with memory loss or other needs would benefit from reminders, but these were not available. Understanding the reasons why people may not attend is the first step to reducing the numbers, potentially leading to more appointments being used – providing financial benefits to the services, and health benefits to the patients.

Better decision-making

Healthwatch across the country collect a wide range of insight - from formal surveys and focus groups to unsolicited feedback about services. This insight can cover issues such as difficulty accessing services, communications, positive and negative experiences and practical issues such as transport and parking.

Not only Healthwatch, but many other organisations have useful insight from the public, patients and carers and others. At times, the difficulty for services is knowing what feedback is already available and how to access it – rather than starting a whole new stream of engagement that may duplicate previous work.

In the North East London Integrated Care System area, the eight Healthwatch (Barking and Dagenham, City of London, Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest) collaborated with the Integrated Care Board to develop the [North East London Community Insight System](#).

The Community Insight Centre holds over 300,000 separately coded issues, based on nearly 90,000 comments from residents. One of the main factors contributing to the success of the insight centre is the ability to access feedback and insight immediately. This is a great advantage for the Integrated Care Board which can use the insight to influence all aspects of its work. With such an extensive range of data, Healthwatch and the Integrated Care Board have been able to identify where they need to undertake further research.

In addition, the insight centre allows regular reports to be produced easily – for example, summary reports and dashboards – at Place-based Partnership level. The collation and easy access to the insight means that the Integrated Care Board can ensure that people's views and experience can influence decision-making, putting people at the heart of the work.

Improved quality

In considering quality, services need to consider how different people may have different experiences and whether improvement is needed to ensure that everybody receives the service to a similar, consistent standard.

Healthwatch Oxfordshire has developed an approach based on 'community researchers'. This methodology recruits researchers from within the community and develops their skills to create a research project based on the priorities of the community.

When looking at women's experience of maternity care, Healthwatch recruited a researcher through existing links with a local grassroots organisation with strong relationships within Oxford's diverse and multi-ethnic communities.

The researcher held a community event bringing women together from Black, Asian and Minority Ethnic communities to discuss their experiences. The women shared their stories and identified areas for improvement in maternity care. Their conversation was recorded on video.

The video conveys a powerful message and has been widely presented. As a result, the local maternity service is reviewing its translation services. As well as showing the video to students, the university is now planning to include sessions with women who have used maternity services in the midwifery course.

The community research programme highlights the benefit of enabling communities to set the agenda themselves. The focus on women's experiences provided insight that influenced a range of services from midwifery training through to maternity services.

“... everyone just started sharing. It was really, really powerful. And I was thinking, this is amazing. I thought, yes, there is no way you can't learn something from it. It teaches you ... where you can change and make things right. And that's exactly how I wanted it to be.”

Healthwatch Oxfordshire

Accountability and transparency

Engagement can come about in different ways. Often it will come from planned engagement around agreed priorities, but individual experiences can also be a catalyst for change. The willingness of people to speak up about their experiences can help make a difference for other people in the same position.

When Healthwatch Sunderland heard from Sandra, a Self-Advocate, about her disappointment that although her initial invitation to breast screening was in Easy Read, follow-up letters were not, they looked into how the system worked.

They found that, as Sandra had experienced, only the initial letter was available as Easy Read, and three recall letters were only available in the standard form.

Healthwatch worked with Public Health England, making the case that Easy Read was a reasonable adjustment for people like Sandra.

Although it took 15 months, [template letters are now available](#), ensuring that people like Sandra have access to clear information about their treatment in a way that is accessible and clear.

“When I received the letter to go to the hospital I didn’t know what it said, as it wasn’t in easy read. This made me nervous, but I spoke to Healthwatch and now I feel really good that we have been able to help so many women across the country who need easy read letters.”

Healthwatch Sunderland

Participating for health

Healthwatch have the legal power to ‘Enter and View’ premises to make comments and recommendations on the health and care services provided. These are not inspections, but an opportunity to give an independent view of the service through observation and, where appropriate, talking to people who use services and staff. Although Healthwatch staff are involved in planning of Enter and View visits, the visits themselves are conducted by ‘authorised representatives’ who have been trained, and these authorised representatives are often volunteers.

[Healthwatch Havering volunteers visited the local hospital](#) with a specific focus on catering services. Having made various recommendations, volunteers revisited the hospital the following year and the year after that to see what progress had been made.

The hospital produced an action log which showed how the hospital had responded to the recommendations; for example, by recruiting more volunteers to help at mealtimes and providing menus in different formats for people who have a sensory impairment.

The Healthwatch volunteers are highly valued, and the fact that they can see improvements as a result of their work is a great motivation.

I have undertaken E & V for a number of years till they were stopped by the Covid restrictions. I have found them useful and informative and they have given me insight over the running of care homes, the problems in hospitals, the frustrations of GP surgeries etc. It is quite rewarding to learn that sometimes our observations have led to improved service delivery, better management and a better understanding from both sides over the purpose of the visits.

Enter and View volunteer Authorised Representative, Healthwatch Havering

Meeting legal duties

Health services have a number of legal duties that are designed to ensure that people are able to use the services they need. The Accessible Information Standard, which first came in force in August 2016, sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

In 2022, Healthwatch England included the Accessible Information Standard as key focus of its *Your Care, Your Way* engagement programme. Healthwatch across the country collaborated on this, including engaging with local communities.

Healthwatch Lincolnshire consulted people about their experience and found a very mixed picture. Although some people reported understanding the information they were given, approximately one in six people said that they struggled. Approximately one in five people were unaware that they could ask for help, and so hadn't tried. A similar proportion reported being refused support to help them understand information when they asked for it. In some cases, the lack of support led to negative outcomes including missing appointments and problems with medication.

“I can understand if I'm well, I just can't speak due to severe symptoms flare, so I need help at that time. The biggest issue I have with medical information generally, is that Medics will often say one thing, but then write something else in the medical notes. I have to take someone with me now to every appointment, because of previous bad experiences.”

Healthwatch Lincolnshire

This insight can provide services with useful lines of enquiry when they are looking at their effectiveness. People may need support with communication for a variety of reasons, and these may not always be obvious. The findings of the Lincolnshire engagement should alert the local health and care system to the lack of knowledge of the Accessible Information Standard among patients, and the potential risks: for example, to patient safety if patients don't fully understand how to take their medication.

Addressing health inequalities

Various factors may contribute to why people have to deal with health inequalities. These include difficulties accessing services and differences in the way that services respond to different people and communities. Universal services may be designed around the needs of the population as a whole, but not taking account of individual needs can lead to avoidable health inequalities.

Services have to understand their communities if they are to meet everybody's needs. They not only need to understand the demography, but also any cultural or practical issues that may affect people's willingness or ability to use services.

Although services can gain insight through their regular work with patients, there are additional benefits from independent engagement.

Healthwatch Bolton identified use of screening services as a significant local issue.

Although it was higher than for some other screening services, the rate for cervical screening was declining and this was agreed as the priority. Healthwatch Bolton worked in partnership with Answer Cancer (a voluntary sector alliance providing the Greater Manchester Screening and Engagement Programme) and the Bolton GP Federation to get a better understanding of women's views, particularly those from Black, Asian and Minority Ethnic communities. This was focused on the Rumworth area.

The project spoke to 1,382 women through engagement events and an online survey, collecting both qualitative and quantitative insight. The responses confirmed many things that were already known, but also gave new insight which led to recommendations that helped change the way the service was provided.

As a result of this engagement, screening sessions were provided in community spaces where people could drop in for treatment or a simple conversation to find out more and allay any fears. This resulted in more women taking up the screening offer, as well as blood pressure checks and vaccinations.

"I have been putting off my test for a long time, I was very overdue. I did not plan to have my screening test done when I attended the pop-up clinic however, seeing how helpful the staff were, I decided to have my test done. I felt more comfortable and relaxed than going to my health centre"

Healthwatch Bolton

The Bolton GP Federation continued to collaborate with Healthwatch to adopt this approach across the town, working with local people to ensure that the final programme meets the needs of the communities who live there.

Cervical cancer is one of the most treatable forms of cancer, but hesitancy to undertake screening in some communities presents a real risk of increasing health inequalities. By working with Healthwatch and local people, the GP Federation made real progress in tackling barriers.

This project demonstrates how good engagement can provide transferable learning. This approach to the barriers to cervical screening can be extended to other issues in the same geography but can also be replicated in other areas.

Summary and conclusions

The terms 'participation' and 'engagement' cover a wide range of activity that works to ensure that people and communities are able to work with services so that their voices are heard, and decision-makers give proper weight to these views.

Participation with local people and communities can provide health and care services with useful insight about what is important to local people, as well as how they use services, and how they feel about their experience.

Health and care services will often undertake targeted consultation and engagement about specific issues, and that is an important part of the mix. However, through collaboration, they can find out even more about the people they serve.

Local Healthwatch, and other organisations that work closely with people and communities will receive a lot of unsolicited feedback, sometimes things that people would not want to say directly to a service because of a fear that it might affect their treatment. Using this feedback alongside other insight can provide helpful context as health and care services plan future work.

In many of the examples given, Healthwatch – and, sometimes, services as well – went out to where people already meet, so that people feel that they are on their own ground. Not only are people more likely to talk openly in community spaces, but they may also be more willing to access services.

The introduction of Integrated Care Boards has been a major change to the NHS landscape and, as our case studies show, there are many areas where the boards are working well with people and communities, and with Healthwatch. This reflects the excellent, often longstanding, relationships that exist in these areas.

The picture, however, is varied. Integrated Care Boards are still developing and the commitment to participation is decided at a local level. Some boards have a clear champion for engagement and participation, and it would be helpful if all Integrated Care Boards recognised the statutory role of Healthwatch and allocated a participant place at the board or in relevant committees where they have not already done so.

Healthwatch's core funding comes through the local authority. As the health and care landscape has changed, this has required additional work from Healthwatch, particularly in more complex areas, where coordination is necessary to ensure that Healthwatch can make sure that all views are represented, especially those of people who are most marginalised. Some Integrated Care Boards are already providing resources to local Healthwatch and to other voluntary sector partners, to support the engagement of local people, but this should be made a universal offer.

Participation and engagement cover a variety of types of activity which, done well, can make local people partners key in planning the future of health and care services. Different approaches may be used, and the work may be led by health services themselves, by Healthwatch and voluntary, community and social enterprise sector organisations or by the local community itself. As these examples from local Healthwatch show, communities hold valuable insight which can help services make sure that they are meeting the needs of all of their community, often contributing to improved services. Whether the catalyst is a large-scale programme or one person raising an issue that is important to them, good engagement will always rely on the ability, and willingness, of health services to work in partnership.

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