healthwatch

People as partners

Healthwatch England Annual Report 2014-2015

Healthwatch England
Annual Report 2014-2015

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of the Health and Social Care Act 2008 as inserted
by the Health and Social Care Act 2012.

Healthwatch England is the national consumer champion in health and care.

Any enquiries regarding this publication should be sent to us at enquiries@healthwatch.co.uk

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Our vision

We are working towards a society in which people's health and social care needs are heard, understood and met. Achieving this vision will mean that:

+People shape health and social care delivery

+People influence the services they receive personally

+People hold services to account

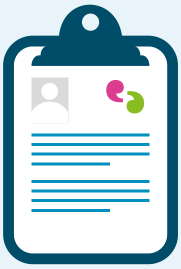
We have statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.

Local Healthwatch across England provide unique insight into people's experiences of health and social care issues. They act as our eyes and ears on the ground, telling us what matters to their local communities.

The year at a glance

The focus of our activities was informed by the **300,000** experiences gathered this year by the **800** staff and **5,400** volunteers who make up local Healthwatch.

We compiled and shared findings from 55 local Healthwatch who had spoken to **11,000** people about their experiences of primary care services.



We collated **3,230** stories about people's experiences of leaving hospitals and mental health settings for our special inquiry.

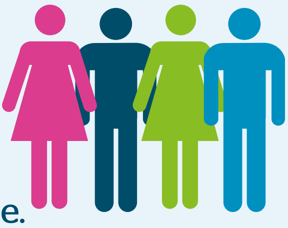
We ran our second annual conference, attended by **380** people from across the Healthwatch network.

24% of people are now aware of

healthwatch

based on the perceptions of **1,775** respondents given through a YouGov poll carried out in September 2015.

Thanks to the work of **77** local Healthwatch, we brought the views and experiences of more than **2,000** people to the national Children and Young People's Mental Health and Wellbeing Taskforce.



Foreword from our Chair, Anna Bradley

This is our third annual report to Parliament and it is the year in which we and the Healthwatch network have found our voice.

A year in which insight from hundreds of thousands of users of health and care services has been gathered by the thousands of volunteers and staff supporting local Healthwatch across the country. It is this unique insight which has enabled us to highlight what matters most to people and effect change, together with our statutory partners. We have worked throughout the year in partnership with the Healthwatch network – using local insight to tackle the issues of biggest concern at a national level, and providing support to local Healthwatch so that they can be powerful advocates for better services.

Some of the issues we have addressed have the potential to affect every one of us. For example the inadequacy of the complaints system and the importance of confidentiality of personal data. Much of our work has focused on issues which particularly affect those who are rarely heard, for example people who use child and adolescent mental health services; homeless people, those with mental health conditions and older people when they are discharged; and people waiting for gender reassignment consultation and surgery.

Occasionally the experience of one or two individuals shines a light on something which could affect so many more – our work on orthotics, for example, was the result of one courageous mother pursuing her case with Healthwatch Staffordshire, and the work on deaths in secure mental health settings was initiated by Healthwatch Northamptonshire.

Armed with these experiences, Healthwatch England seeks to bring about change at a national level. We are working with the Department of Health on improving the hospital discharge process and child and adolescent mental health services, and NHS England on confidentiality of data, specialist commissioning, and access to primary care and dentistry.

All of this work is shaped by people's experiences, so that every time Healthwatch England goes into a room, we take people's voices and the work of local Healthwatch with us. It is this evidence that makes our case for us.

So what of the future? We know that health and social care has substantial financial and delivery challenges. As always, we have started by finding out what people's expectations are for the future.

Our research has found that people are realistic and understand the challenges of delivering modern health and wellbeing services. People want to contribute by managing their own wellbeing and helping to build something better for the future.

People ask for information and services that support good health and wellbeing, rather than just treating illnesses, that all needs are taken into account, not just some, and the power to be an equal partner regarding immediate care, as well as decisions that will be taken about future services.

The NHS Five Year Forward View sets out how health services need to change to meet people's needs in the long term. It aspires to deliver many of the things that people want from health and care. It aims to make care more focused on the individual, to make navigating services easier, and to enable services to work better together to support all needs, not just single health or care issues.

The challenge for Healthwatch, nationally and locally, will be to bring people's voices into all those places where the future is being shaped and advise those making the decisions to involve people in the process in meaningful ways. We need to do everything we can to encourage decision makers to capitalise on the desire of consumers to engage, and to work with people as partners for change.

Anna Bradley

Five building blocks that help us achieve change

There are many organisations representing the views of specific groups of health and social care users. This is why we have to be clear about what Healthwatch England and local Healthwatch can contribute.

1. Our mandate:
We speak for everyone using or in need of any service across health and social care, from birth until death.

2. Our reach:
We are present in every area of England, engaging hundreds of thousands of people every year.

3. Our insight:
The human intelligence we gather helps ensure that changes made to services focus on the most important things for users.

4. Our collective force:
We work together as a network, all striving for the same goal.

5. Our statutory position:
We have the right to be heard and responded to.

People's expectations of health and social care

We exist to give people a voice in health and social care to help ensure that health and social care services meet people's needs and expectations. When we started out in 2012, we spoke to people about what those expectations were. These resulting eight consumer principles are the expectations we promote on behalf of people through all our work.

The eight consumer principles

During the last year, the majority of our work has been around four of the consumer principles, with particular focus on issues affecting the level to which people have been listened to, given the safe, dignified and good quality service that they expect, had access to services, and been involved in decisions affecting their health and care. Examples of each of these are explored over the next few pages.

People expect to be listened to

> **“I want the right to have my concerns and views listened to and acted upon. I want the right to be supported in taking action if I am not satisfied with the service I have received.”**

Calling for reform to the complaints system

It is crucial that people are able to register concerns about health and social care services, that they do not fear repercussions of speaking up, and that action is taken to resolve and learn from each incident.

The health and social care sector has recognised the need to improve the complaints process as an issue requiring action, with the Government bringing a number of agencies together to address it. We wanted to use our position to bring people’s experiences of the complaints system to light and to inform recommendations for what needs to change. In 2014, in partnership with local Healthwatch, we undertook an investigation to find out about people’s experiences of the complaints system.

What we found

We heard that people want their views and experiences to inform improvements to services so that other people will receive better care in the future.

We heard about the ways in which the complaints process is not working, and what people want to be done differently. People want:

+ **To have easy access to information about how to complain**
  + We heard that members of staff are not able to provide people with the information they need to raise their concerns formally.
+ **To have reassurance that complaining will not affect their care**
  + People told us that they want to be confident that coming forward to complain will not jeopardise the quality of care they receive.
+ **To be listened to, for something to be done to address their concerns, and for someone to say sorry to them**
  + In many cases, people just want an apology, an explanation or a simple change, but instead they get pulled into a complex system which does not meet their needs.
+ **The complaints system to be easy to understand**
  + We heard that people find the system utterly bewildering, time-consuming and exhausting to navigate.
+ **To be supported so that their voices can be heard**
  + When people are unwell or in crisis, they sometimes need more than just information about how to complain; they need somebody to help them raise their concern.
+ **Health and social care services to learn from complaints**
  + We heard that the main reason people complain is because they want to make sure health and social care improves for the future.

People expect to be listened to

What we did

- Since publishing our report **Suffering in Silence – Listening to Consumer Experiences of the Health and Social Care Complaint System** we have been working at a national and local level to bring people's experiences to light and to contribute to change. We have met with a range of people and organisations that are in a position to improve the complaints process and influence change, and shared the unique insights we gathered about people's experiences of the current complaints system.

"There has been no outcome to my complaint; simply more distress, inconvenience, injury and injustice."

National progress

- **Complaints and Raising Concerns** – the Health Select Committee's report on health and social care complaints, released in January 2015 – echoed many of the recommendations we made in **Suffering in Silence**. It highlighted the need for greater improvement and culture change in the way that people's complaints and concerns are handled. The report also identified the need to simplify the confusing complaints system by creating a single gateway for both health and social care complaints.
- The House of Commons Public Administration Select Committee's (PASC) report into **Investigating Clinical Incidents in the NHS** reflected our findings and recommendations.
- We worked with the Parliamentary and Health Service Ombudsman (PHSO) and the Local Government Ombudsman (LGO) to develop **My Expectations for Raising Concerns and Complaints, a Consumer-Led Vision of Good Complaints Handling**, which is being used by the Care Quality Commission (CQC) as part of its key lines of inquiry for inspection, and all inspection reports will include a complaints section.
- We wrote to Health Secretary Jeremy Hunt to advise use of the seven point plan for reform that we developed, setting out ways to create an effective and compassionate complaints system that both gives patients what they need and ensures the NHS and social care services can learn continuously from mistakes.

“I now understand why people are reluctant to make a complaint. The devastating effect it has had on me is unbelievable.”

Local support

- We worked with Citizens Advice to develop a series of tools for use with the public to help them navigate the complaints system, and made these available to local Healthwatch.
- On publication of **Suffering in Silence**, we provided local Healthwatch with resources to enable them to raise awareness of this issue in their areas and drive local change.
- We developed a set of standards that provide a vision for what a good complaints advocacy service should look like, from the perspective of service users, and shared them with local Healthwatch.

“I had no support to challenge complaints decisions. At a meeting with the head nurse, the head nurse was accompanied and I was alone.”

What next?

Our work has helped shape the ongoing debate about how to secure a complaints system which is truly focused on people, and which empowers them to come forward to speak up about their experiences. We will continue to use our position to encourage health and social care leaders to enable the public to play their part in developing a complaints system which ensures that complaints are dealt with compassionately and learnt from. At a local level, we will help the Healthwatch network to monitor the quality of local complaints handling systems and work in partnership with local providers to secure improvements. We will support those local Healthwatch that provide advocacy services to deliver to a quality standard. We will also promote good standards across the advocacy sector as a whole.

People expect a safe, dignified and good quality service

> **“I want the right to high quality, safe, confidential services that treat me with dignity, compassion and respect.”**

Highlighting failings in the discharge process

When we heard from local Healthwatch that people were leaving hospitals and mental health settings feeling badly prepared for their departure, we decided to investigate further. We worked together to gather 3,230 people’s experiences of the discharge process.

Whilst a significant amount was already known about the financial cost of this issue – emergency readmissions are thought to cost the NHS more than £2 billion every year – little was known about the human cost. Our unique role enabled us to gain a true understanding of the impact of this issue on people.

Throughout the inquiry we focused on the experiences of older people, homeless people and people with mental health conditions – three groups for whom the consequences of a failed discharge process were particularly detrimental.

> **“Some people are just left to exist rather than getting support to pick up the reins of their lives.”**
>
> **Anne Beales,** Special Inquiry Advisory Group

What we found

Our findings confirm that people want a safe, dignified and good quality service. But this is not being delivered to all. We found that people want to be involved in making sure change happens, and for their experiences to inform improvements to services.

The problems with the discharge process are not new. Although there is no simple solution, during our research we did see and hear about lots of great and inspiring efforts to make the discharge process work better for people. Unfortunately this good practice is simply not widespread enough to resolve the issues.

Good practice in action

RAID

Based at Birmingham City Hospital, this initiative follows the patient’s journey through rapid assessment, interface and discharge (RAID), 24 hours a day, seven days a week.

The team sees any hospital patients who might be suffering from mental health problems, provides assessment, support and advice and, if appropriate, will arrange support in the community after discharge, communicating with GPs.

The RAID service has seen a dramatic reduction in admissions, leading to a decrease in bed use of 44 beds per day, and has reduced discharge of older people to institutional care by 50%, saving local authorities an estimated £3 million per year.

People expect a safe, dignified and good quality service

This inquiry has highlighted five core reasons people feel their departure from care was not handled properly:

1. **People are experiencing delays and a lack of co-ordination between different services**
   - We heard numerous stories about services not talking to each other, leaving people stranded in hospital, and people having to go from service to service themselves, trying to get the medicines and equipment they need to recover.
2. **People are feeling left without the services and support they need after discharge**
   - We heard from hundreds of people verging on crisis as a result of not being able to access community support and services after being discharged, often leading to another admission.
3. **People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances**
   - All three groups felt that stigma affected the way they were treated by staff.
4. **People feel they are not involved in decisions about their care or given the information they need**
   - We heard that people were not listened to, that they were not given the information they needed about their conditions, and that people were left feeling confused and abandoned by the health system.
5. **People feel that their full range of needs is not considered**
   - We heard people's frustrations that their full range of needs – including their physical and mental health, housing, care responsibilities and financial situation – were not all taken into consideration at the point of discharge.

Across all groups, we found that people expect some simple things from the discharge process:

- To be treated with dignity, compassion and respect
- For their needs and circumstances to be considered as a whole – not just their presenting symptoms
- To be involved in decisions about their treatment and discharge
- To move smoothly from hospital to onward support available in the community
- To know where they could go for help once discharged

Calling for local change

We have provided the network with tools and resources to enable them to call for change in their local area.

Healthwatch Brighton and Hove published its own report **Leaving Royal Sussex County Hospital** which revealed patients' views on their experiences of being sent home from the local hospital and made recommendations for changes needed. Since the report's publication, a number of improvements have been made:

+ extra staff have been recruited to help speed up completion of assessments and to allow for more rehabilitative therapy to be completed before people leave hospital;
+ a new leaflet dispenser and notice boards have been purchased to display a greater range of information to help people when they are back at home, including self-help groups, community services, and general advice;
+ medications are now prepared 24 hours before a patient leaves hospital.

Case study

My father has vascular dementia and was admitted with a urine infection.

He had lots of tests and was in for three and a half weeks, during which time he had a fall and hit his head, had several differing diagnoses, two transfusions, and three ward moves. He was confused and scared, and I found him naked and falling sideways in his hospital bed covered in his own excrement. On moving him from one ward to another they had lost his teeth.

Dad's mobility was better when they discharged him. We were told that Occupational Therapy (OT) would follow his ambulance home and ensure everything was in place for him. This never happened and his mobility went downhill rapidly. He couldn't even stand. He had got to the toilet but due to the lack of grab rails he couldn't get up again. Someone was supposed to fit them before he was discharged.

Within four days my dad was readmitted with hospital-acquired pneumonia and still had the urine infection.

What next?

This issue is not new and we know that there are people and organisations across the country already working to try to improve discharge on a local level. However, these initiatives are not sufficiently widespread to resolve the problems that exist at a national level. We will work with the Department of Health to encourage agencies to work together to tackle this long-standing problem.

Focus on: **mental health**

Concerns about risks to people with mental health conditions

After hearing concerns about the quality of care at St Andrew's – one of the largest secure mental health institutions in the UK – Healthwatch Northamptonshire decided to look into the issue to make sure that people's voices were being heard.

Their concerns were reinforced by information about four unexpected deaths which happened on the same ward within an eight month period, between 2010 and 2011.

Following a visit to the hospital with the charity Together for Mental Wellbeing, Healthwatch Northamptonshire spoke to patients and identified issues with safety, patient involvement in care plans, staffing levels, and the quality of the environment, which they shared with the hospital, the lead commissioner at NHS England and CQC.

We contacted the Chief Executive of NHS England regarding the delayed review into what was learnt from the four deaths, and Healthwatch Northamptonshire gave evidence to the Equality and Human Rights Commission inquiry into deaths in custody.

We continued to work with NHS England to ensure that the review report addressed the full range of concerns. We are pleased that NHS England has now agreed that, in addition to publishing a public summary of the report, the full findings will also be made available. This case has also flagged concerns about how deaths in some services are investigated and whether the current system is capable of answering fully and transparently families' concerns. We will be exploring this issue and doing what we can to ensure that families' needs are met at this very difficult time.

Focus on: **unregulated care**

Calling for better treatment for social care users

Jane was shocked to discover that her son, who has schizophrenia, was living in squalid conditions, despite having an agency employed to support him to live independently and maintain his home.

She tried to raise this issue with CQC but was told that no action could be taken as neither her son's residence nor the agency that provides his home support were subject to regulatory inspection or supervision.

This is just one of the stories shared with local Healthwatch about how some of the most vulnerable people in society are being left to live in appalling environments and receiving poor care. These services are often not subject to regulation and, at the moment, local authorities can only intervene if there is a formal 'safeguarding' issue.

We wrote to the Department of Health and in his response, the Director General (Social Care, Local Government and Care Partnerships), outlined work that the Department is leading to address these concerns. We are pleased that the CQC is now reviewing how it inspects and regulates the care that people who live in supported living environments receive. We will contribute to the CQC's work in this area.

We are encouraging local Healthwatch to contact their local authority to ask if this is a problem in their area, and also working closely with ADASS to gather more intelligence on this issue. We will use this insight to help drive change at a national level.

People expect to have access to services

> **“I want the right to access services on an equal basis with others, without fear of prejudice or discrimination, when I need them and in a way that works for me and my family.”**

Making people’s views on GP, dentistry and other primary care services heard

The local Healthwatch network has spoken to more than 11,000 people this year about community healthcare services. Local Healthwatch have also visited over 550 GP surgeries and other services, such as pharmacies and opticians.

We reviewed the range of issues that people raised, identified common themes, and used our national position to bring people’s concerns to light.

> **“I’m a 65 year old pensioner, I called up my dentist for new dentures. I was told I was “no longer on our computer”. They advised me to call them every month to check if they were taking NHS patients, but they were only taking on private patients. In the end I had to go private and pay £760 for new dentures and I am on pension credits.**
>
> **Paul,** Yorkshire.

What we found

People who have access to services express high levels of patient satisfaction. But local Healthwatch found that many people face trouble accessing care in the first place.

We found that people experience ten common problems and that they want to use their experiences to help make sure services improve:

+ People struggle to access primary care services
  + Disabled people spoke about their difficulties accessing services, from physically being unable to enter buildings to inflexible on-the-day booking systems making it difficult to arrange carer support for appointments.
+ People struggle to register with a GP or dentist
  + People struggle to find an NHS dentist, with as few as one in five surgeries in some areas accepting new patients. There were also reports of patients being denied appointments at their usual surgeries due to funding or capacity issues, or because a previous appointment had been missed.
+ People can’t get a GP appointment so go to A&E instead
  + Patients experience frustration when booking appointments. We found that one in five patients faced with long waiting times to see their GP are going to A&E instead.

People expect to have access to services

+ **People struggle to communicate with their doctor because of poor translation services**
  + Changes to the way translation services are funded have left many deaf people and those who speak English as a second language struggling to communicate with their doctor.
+ **People cannot get appointments with their preferred GP**
  + The NHS constitution gives people the right to see the GP of their choice, and calls on practices to comply where possible; however what we heard suggests patients' preferences are not always met.
+ **People don't know which healthcare service to use**
  + Patients don't always feel they have enough information to know which healthcare service to visit, as out-of-hours services, community pharmacists and walk-in centres are not sufficiently promoted.
+ **People feel rushed in their appointments and need more time**
  + Patients reported feeling rushed through fixed length appointments and struggling to make themselves heard, particularly if they have multiple health problems.
+ **People don't know how to complain about their care**
  + We know from our **Suffering in Silence** report that the complaints system is utterly bewildering for people. This is made even harder by a lack of information about how to complain.
+ **People don't think staff are as compassionate as they should be**
  + Patients reported sometimes finding staff, particularly GP receptionists, to be nosy, abrupt and rude.
+ **People need more information to make the right choices about their care**
  + People do not have access to clear information to inform decisions about their care. They want better signposting and greater use of plain English.

What we did

We published a report setting out the main barriers to accessing primary care services in March 2015, collating the views and experiences gathered by local Healthwatch. We shared this with a number of key stakeholders, including the NHS England Board, the Royal College of General Practitioners, the Treasury, the National Audit Office and the British Medical Association, and highlighted a number of concerns with existing practice and areas for action..

What next?

We will build on the evidence we have gathered to date by speaking to more people across the country about their experiences. This will enable us to develop a more detailed understanding of what specific groups of patients want to change about existing services to provide fair, equal access for all. We will also be working closely with the public to develop a clear understanding of what it will take for services to meet their needs in the long term and sharing what we hear with those developing the services of tomorrow.

Focus on: **dentistry**

Highlighting gaps in access to dentistry

Simply accessing an NHS dentist has caused people huge frustrations this year. We heard from local Healthwatch about people having to travel miles to find a dentist that would accept them as a patient, and about others being struck off lists for missing check-ups, despite extenuating circumstances.

One patient said this happened to her when she missed her appointment because she had to care for her husband whilst he received treatment for cancer. We also heard from people concerned that they would get a poorer quality service on the NHS opting for private treatment instead.

We carried out a spot check of 300 surgeries and found that in some areas as few as one in five practices were willing to take on new NHS patients, with Yorkshire and Humberside the worst affected region.

Our findings sparked an ongoing conversation about disparities in access to dentist services.

We also worked with the CQC and other dental regulators to inform future regulation. We will continue to work with NHS England and the Department of Health to address patient concerns through their reform of the dental contractual system.

We will also support local Healthwatch in their research into specific gaps in dentistry, such as Healthwatch Bolton and Healthwatch Kirklees which published their research into oral healthcare in residential care homes, identifying major gaps in provision for elderly people – an issue which is now being addressed locally.

Focus on: **young people**

Taking action to improve mental health services for children and young people

People spoke to their local Healthwatch about long waits for access to mental health services, having to be in crisis in order to get a referral, and poor transitions from services for children and young people to adult psychiatric services. Some also said that health professionals' attitudes are not what patients would expect and that families do not feel listened to or supported.

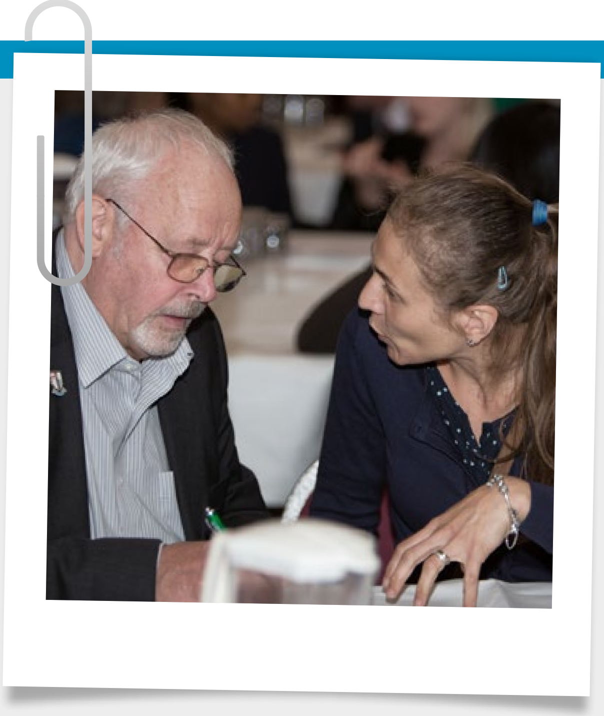
People shared concerns about the lack of prevention services available, and the need to tackle stigma and raise mental health awareness among children, young people, health and social care professionals, parents and teachers.

By gathering local Healthwatch findings and working closely with a group of ten local Healthwatch, we advised national decision makers and external stakeholders through our seat on the Children and Young People's Mental Health Taskforce.

As a result, the concerns raised by local Healthwatch are reflected in the Taskforce's final report **Future in Mind: Promoting, Protecting and Improving our Children and Young People's Mental Health and Wellbeing.**

We are now supporting the implementation of the recommendations in the report. Using local Healthwatch unique insights, we want to help national and local decision makers develop a better understanding of the level to which local people have been engaged with suggested changes to local services and to encourage more effective engagement where needed.

Focus on: **commissioning**



Calling for changes to commissioning

When people's experiences highlight fundamental problems with the way in which services are commissioned, we contact those with the power to make changes.

Issues often occur because the people responsible for commissioning services on patients' behalf do not know enough about their needs or experiences of the service.

For example, local Healthwatch told us that a high proportion of people in England waiting for gender reassignment are subject to excessive delays for consultation and surgery. They heard that there are not enough specialist consultants, and that there is a lack of clear and timely communication to patients, causing additional frustration and distress.

We raised this with NHS England which following an investigation, has committed to additional investment in 2015/16 to address waiting times for surgery. It has also committed to developing a communication plan to support patients waiting to access services.

Orthotic devices can help improve patients' mobility, independence and help with pain relief. We called for changes to orthotics services after Healthwatch Staffordshire, working with a local mother who gathered patient stories from around the country, told us about the significant effect that a lack of access to these vital services can have.

We heard about one fifteen year-old boy who has required orthotic care since he could stand. When he was nine, his orthopaedic surgeon recommended serial casting to set his foot straight. He should have had an ankle foot orthosis to wear immediately afterwards to keep his foot and ankle straight. However, it took 17 weeks and within days he had lost all his mobility, and later had to undergo complex surgery. The personal cost to his development, education and emotional wellbeing was severe. These delays also generated significant and unnecessary costs to the NHS.

We contacted NHS England to highlight this issue and, in response, NHS England commissioned the NHS Quality Observatory to review data on the quality of orthotics services. It also hosted an event at Salford University to explore how the quality of orthotics services in England should be improved.

We understand that NHS England will be publishing a report in 2015-16 setting out the case for change, people's experiences, workforce issues, commissioning tips and recommended actions for key stakeholders.

People expect to be involved

> **“I want to be an equal partner in determining my own health and wellbeing. I want the right to be involved in decisions that affect my life and those affecting services in my local community.”**

Getting people’s voices heard about use of their data

When the Care.data programme was first announced, a quarter of the local Healthwatch network raised concerns about the way in which the programme was being explained to the public. Following feedback shared by us and other partners, the programme was paused.

The Care.data programme aims to make better use of patient information to improve care for the future. However, we heard that the way in which it was being articulated to the public made people feel nervous about how their information would be used, and concerned that their data would not be safe.

What we found

From our own research, we know that while many adults would be happy to donate their personal health data to help research, they want it to be anonymous. People want to be confident about how their personal information will be recorded and used.

What we did

When we brought people’s concerns to the Care.data programme they were listened to, and both Healthwatch England and local Healthwatch have continued to take the opportunity to share people’s views as the programme has developed.

We have developed a set of principles for collecting and sharing personal health and care data, to help inform the programme. These are based on what we have heard from people about what they need to know to be confident about the collection and use of their data.

10 principles for good information sharing

1. People should be able to access their own health and social care data and records to see what the system has collected and who they are sharing it with.
2. Data should be collected and shared in a manner that does not unjustifiably compromise people's anonymity, safety or treatment.
3. Collecting and sharing data should not be used to justify treating people on an unequal basis with others.
4. Data collection and sharing should not have an impact on a person's wellbeing by, for example, causing them additional anxiety or distress.
5. People should be provided with all the information they require about Care.data or any other data sharing initiative, to make an informed choice about whether they want to opt in or out.
6. Frontline professionals should be upfront and honest about the benefits and disbenefits of opting in or out of Care.data or any other similar programme.
7. If an opt-out is offered, it should be a genuine option (i.e. not overly burdensome) and people must be informed about the restrictions and limitations of this option.
8. If someone raises a concern or makes a complaint about the collection or sharing of their records, this should be taken seriously and staff should take immediate action to address the concern and, if it relates to a breach of confidentiality, put safeguards in place to restore the person's anonymity.
9. People should be able to opt out of Care.data later if they change their mind about the programme in future.
10. People should be offered an opportunity to get involved in local decisions at their GP surgeries about whether or not records are shared with the Care.data programme.

These principles have been shared with the local Healthwatch in the four Care.data programme 'pathfinder' project areas, and with NHS England.

What next?

We will continue to monitor the progress of this issue to help people make an informed decision about whether to opt out of sharing their data. We will also support local Healthwatch in the four Care.data programme 'pathfinder' project areas to test the clarity of communications with patients.

A stronger local voice

We have provided the network with a range of support, training and guidance this year, all designed to enable them to deliver the best possible service for the public.

Influence

We have helped connect local Healthwatch with those leading major changes to the way that services are run, and made sure that they have a seat at the table when decisions are being made so that people's voices are represented.

- When NHS England told us that commissioning for GP services was to be delegated to clinical commissioning groups, we advised that local Healthwatch should be on relevant committees so that local people would be represented. This has enabled the network to share the primary care needs of the public and help shape decisions.
- The Government set up the £5.3 billion Better Care Fund to help make health and social care services work more effectively together. Health and social care providers across the country have been given the chance to bid for their share of the money, and we have worked to ensure that local Healthwatch are involved with that process, and that the people who use services are enabled to share their opinion.
- We have been working closely with local Healthwatch in the North West to establish their role following the decision for Greater Manchester to control a combined NHS and social care budget of £6 billion from April 2016. We have been working with national and local stakeholders to involve local people in decisions about how health and social care services will be delivered in the area, and this support will continue in the year ahead.

Leadership

We provide guidance for local Healthwatch on how to lead effective organisations. This year, that has focused particularly on assisting them with their relationships – both with external stakeholders and within their own organisations.

+ To give everyone a clear, shared understanding of the role local Healthwatch is here to play, we have started a project to enable the network to develop a series of statements to set out what it means to operate as a good local Healthwatch, and what people can expect from them. We have secured support from Leeds Beckett University to co-develop these statements with the network. We will also ask local Healthwatch to test how they work in practice before developing a final set for use across the network.
+ We gave the network guidance on how to articulate its role and purpose to commissioners to ensure they are adequately funded to deliver their statutory responsibilities.
+ We have supported numerous local Healthwatch with matters relating to their governance in order to help them meet their statutory requirements. This involves support for local Healthwatch boards and wider organisational development.
+ We worked closely with the CQC and local Healthwatch to strengthen collaboration between the organisations, which has resulted in improved working relationships.
+ To help the network develop productive relationships with their local MPs, we provided tools and guidance, as well as engagement opportunities, such as the parliamentary reception we held to launch **Suffering in Silence** and our annual 2013-14 report. We also gave local Healthwatch extensive guidance ahead of the General Election on how to maintain impartiality during this period.

Learning and sharing opportunities

We run a number of networking and training events to enable local Healthwatch to learn new skills, connect with one another, and raise awareness of the issues of greatest importance to local people.

+ We held media training, giving 65 people from 55 local Healthwatch an understanding of how to raise public awareness of their work.
+ We ran case study training, showing the network how to demonstrate their impact through storytelling.

- 380 people attended our second annual conference, which gave us all the chance to explore the impact we can make together. We delivered training on topics such as complaints handling, income generation, and working with CQC inspectors, with many sessions led in partnership with local Healthwatch colleagues. We also celebrated the achievements of local Healthwatch with the first Healthwatch Network Awards.
- We ran sessions throughout the year to enable local Healthwatch to develop their relationships with our teams and with one another, and to identify the strengths and development needs of each organisation. These included network meetings, as well as one-to-one face-to-face meetings with local Healthwatch officers and Chairs. We provide information, support and advice on a day-to-day basis covering all aspects of running an effective local Healthwatch, working together with the network to troubleshoot and develop solutions.

Tools and resources

We listen to what the network needs and develop tools and resources to support their work.

- Introducing the social networking site Yammer has seen local Healthwatch seeking answers to their questions online, finding contacts to work with on projects, and connecting more effectively with one another. Our success was recognised with the Digital Impact Award 2014 for 'Best Intranet'.
- We developed a Customer Relationship Management (CRM) system so that we can all manage contacts, interactions and correspondence on one system. This was designed with local Healthwatch to ensure that it meets their needs. We will use it to form an understanding of people's experiences of health and care, and to identify trends and common concerns raised by the public. The system has been piloted and tested with 32 local Healthwatch, and will be rolled out further in 2015-16.
- To support local Healthwatch in completing their annual reports and ensuring that they meet their statutory requirements, we developed a set of detailed guidance, including a template report. This was put together in partnership with the network to make sure it would meet its needs.

Driving change in 2015-16

Summary from our Chief Executive, Katherine Rake

We have a unique role at Healthwatch England. Our sole focus is on making health and social care work for people – on listening to their experiences, and sharing their views with those with the power to make change happen.

Speaking with local Healthwatch and with the public this year has deepened our understanding of what people want from health and social care services.

In the next 12 months, we will use people's experiences to advise decision makers about how to better design services that meet people's expectations, now and into the future.

Our potential scope is all of health and social care so we have carefully prioritised our work for the year ahead.

Firstly, we will **amplify people's voices to help improve health and social care.** It is our job to give a voice to people who may not otherwise be heard so that they get the health and social care that they deserve. This will involve pursuing the changes needed to the discharge process and making sure marginalized groups, such as the elderly, homeless people, and people with mental health conditions, are listened to, as well as exploring other concerns that people raise with their local Healthwatch.

We will work to **inform the future design of services so that they are shaped by the people who use them.** This will involve listening to people across the country about what they think of their local primary care services to identify the changes needed. We will make people's voices heard regarding reforms to health and social care service delivery. Our work has shown that the public doesn't just want to be consulted but to play an active role in shaping more efficient and sustainable services.

With local Healthwatch providing the 'eyes and ears' on the ground, at a national level we will act as a critical friend, calling for services to be designed based on people's needs and experiences.

Developing the effectiveness of the Healthwatch network will remain a major priority for 2015-16. As the national body, we support local Healthwatch to be strong, sustainable organisations, providing a high quality service to the public. We will work with the Healthwatch network and commissioners to provide everybody with a clear understanding of the value that local Healthwatch can add. We will provide local Healthwatch with training, development and networking opportunities so that they can work together to give people a powerful voice in health and social care.

Lastly, we will **ensure that we are an effective, efficient organisation and a well-governed public body**. As we move into our third year, we are excited to start developing our next strategy for 2016-21, setting out what we will focus on in the years ahead to make the greatest difference to people.

Katherine Rake

Thank you

Thank you to everyone who is helping us put people at the centre of health and social care, including:

+ Members of the public who shared their views and experiences with us
+ All of the generous volunteers across the Healthwatch network
+ Our Special Inquiry Advisory Group
+ The many voluntary organisations who have contributed to our work this year
+ Our colleagues in local Healthwatch
+ Healthwatch England Committee Members and staff
+ The Department of Health sponsorship team
+ Other colleagues across the Department of Health, NHS England, CQC, Monitor, Public Health England, the Trust Development Authority, the Local Government Association and other statutory organisations who've worked with us this year

Our Committee Members

We are governed by a Committee who set our strategy, provide scrutiny and oversight, and approve policies and procedures that are needed for us to work effectively. They also spend considerable time travelling around England to hear people's views – holding meetings in public, visiting local Healthwatch, and deliberately seeking out people who are seldom heard. The Committee then brings those voices back to inform our decision-making.

Our Committee Members: Jenny Baker OBE, Andrew Barnett, Pam Bradbury, John Carvel, Paul Cuskin, Alun Davis MBE, Deborah Fowler, Michael Hughes, Christine Lenehan OBE, Jane Mordue, Liz Sayce OBE and Patrick Vernon OBE.

To find out about the governance and financial arrangements of Healthwatch England, please read the Healthwatch England Annual Governance Statement 2014/15, which accompanies this report online at **www.healthwatch.co.uk**

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