

# Loud and Clear: making consumers voices heard





## Contents

Welcome from our Chair Anna Bradley 4

Summary from our Chief Executive Katherine Rake  
..... 7

About Healthwatch England ..... 10

Highlights of the year ..... 13

Getting people’s complaints taken seriously.. 15

Case study: Valuing complaints in Cambridgeshire 21

Case study: Mystery shopper in Camden GP surgeries  
brings results for local people ..... 23

Making people’s voices heard nationally ..... 25

Access to NHS dentists: identifying an issue that  
consumers want on the political agenda .... 27

Giving marginalised people a voice on improving  
discharge from care ..... 30

Shaping the media debate on the A&E ‘winter  
crisis’ ..... 33

Making people’s voices heard locally ..... 35



**Case study: Mothers have their say and help improve maternity services in Isle of Wight ..... 42**

**Case study: Responding to parents’ concerns about support for children on the autistic spectrum in Cornwall ..... 44**

**Case study: Reducing waiting times for A&E patients in Staffordshire and Derbyshire ..... 46**

**Case study: Putting people who use home care services at the heart of decisions in Reading . 48**

**Training local Healthwatch to use ‘Enter and View’ powers ..... 50**

**‘Enter and View’ case study: How our powers helped improve GP surgeries in Luton ..... 52**

**‘Enter and View’ case study: Carer and patient help change practice at a Wakefield care facility.. 54**

**‘Enter and View’ case study: Responding to feedback about care homes in Barnet ..... 57**

**‘Enter and View’ case study: Consulting patients about A&E Bradford ..... 59**

**Our plans for 2014/15: Giving people a more powerful voice within the health and social care system ..... 62**



**Our eight consumer principles..... 68**

**Thank you ..... 70**

**Endnotes ..... 72**



## Welcome from our Chair Anna Bradley

A year ago, in our first Annual Report to Parliament, we revealed the reality behind people's high satisfaction levels with health and social care services: a reality of being reluctant to criticise, and doubting whether we'll be listened to if we do.

We set a huge challenge for the health and social care system to listen and act on the feedback needed to make services better. And we decided to reflect this in two of our major priorities for 2013/14: championing the right of consumers to have their complaints taken seriously; and to have their voices heard. Our other priorities were supporting local Healthwatch to get up and running, as well as continuing to build our own organisation.

In this second Annual Report to Parliament we are able to tell the story of the Healthwatch network as a whole. It is a story of vigour, vitality, excitement and energy. I am proud to be able to talk not only about the impressive work done by Healthwatch England, but also about the achievements of local Healthwatch during their first twelve months.



This report describes the work we have been doing to help bring about change - building on the best and changing the rest.

We are a new network, but we are already demonstrating our effectiveness:

Getting people's complaints taken seriously we have helped keep the issue of complaints high on the agenda; showing just how complex and bewildering the current complaints systems are. We also exposed the fragmentation of the advocacy system in our evidence to the Health Select Committee's inquiry on complaints.

Making people's voices heard nationally we have turned up the volume, making sure people's voices are heard: for example securing a pause in the plans for NHS records sharing through the 'care.data' programme. To do this we have worked with local Healthwatch in many ways, building on what they have heard and testing what we have heard with them.

Making people's voices heard locally our support has helped local Healthwatch get established in their communities more quickly so they can speak out for local people.

And of course we have been listening. This year our



Committee and staff have travelled the country, listening for over 1,750 hours to people's expectations of health and social care and the way Healthwatch England can give voice to those views. We changed our draft strategy in response and the 'Consumer Rights Framework' we consulted on has become a set of eight principles that inform all our work.

It has been an exciting year, and it's clear that Healthwatch England is beginning to make a difference. I hope that once you have read this report you will feel you have heard the voice of the public, loud and clear.



## Summary from our Chief Executive Katherine Rake

It has been a privilege this year to travel around the country meeting local Healthwatch. From the Isles of Scilly to Northumberland I've been inspired by the passion and commitment of staff and volunteers to put people's experiences at the heart of improving health and social care services.

For our fledgling network these last twelve months have been about establishing our relationships as independent organisations joined together through common values and a shared mission; understanding what we can achieve alone and what we can do when we work together.

Local Healthwatch are working on a wide range of priorities - because people's concerns are different depending on where they live. We've helped them find out what their local communities want by supporting them to get up and running fast, providing a common brand, purpose and training. As grassroots organisations steeped in their communities, they ensure we always stay focused on what really matters to people and enable us, as the national body, to bring those voices to the heart of Government. For example, access to NHS dentists is not high on the Westminster or media





agendas, but the high number of local Healthwatch that raised this issue with us allowed Healthwatch England to raise the profile of what is clearly a very important issue for local communities.

I'm delighted that this year we also established a strong media profile, championing the voice of consumers nationally, with more than 175 pieces of national media coverage on issues from the A&E crisis to concerns about the 'care.data' programme. We also worked with the media to call for increased transparency when we identified a shortfall in the funding received by local Healthwatch and provided information to help network members negotiate with their local authority funders.

Strong, positive working relationships with the key national bodies are now in place. We've started work with the Care Quality Commission to develop a framework for engaging local Healthwatch in inspection regimes and established a joint work programme with NHS England on 'care.data'. Partnerships with voluntary sector organisations have included gathering evidence for our first special inquiry, which is focusing on improving people's experiences of being discharged from hospitals, care homes or mental health institutions.



It has been a year of incredible progress, building a network from scratch and testing our role as a consumer champion at the national level.

With many examples of improvements, from changes to local services to changing the way national organisations across health and social care handle complaints, we're proving the Healthwatch concept works. In 2014/15 we'll help people's voices get even stronger, so they can have yet more influence on the creation of health and social care services that are fit for the future.



## About Healthwatch England

Healthwatch England is the only statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. Established under the Health and Social Care Act 2012 as the consumer champion for health and social care, we have a range of statutory powers. We highlight the collective issues that matter most to people, advising the Secretary of State for Health, NHS England, the Care Quality Commission, Monitor and local authorities across England, among others, on where change is needed. Healthwatch England also leads, supports and guides the Healthwatch network which is made up of the national body and local Healthwatch across each of the 152 local authority areas in England.

### 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 the delivery of health and social care.



- Influence the services they receive personally.
- Hold services to account.

## Our mission

Healthwatch England is the consumer champion for health and social care. We achieve this by:

- Listening hard to people, especially those who are seldom heard, to understand their experiences and what matters most to them.
- Influencing those who have the power to change services so that they better meet people's needs now and into the future.
- Helping people to get the most from their health and social care services and encouraging other organisations to do the same.
- Working with local Healthwatch to improve services and support local people.

## Our Committee

Healthwatch England is 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 (from 2014), Andrew Barnett (from 2014), Pam Bradbury (from 2014), John Carvel, Paul Cuskin (from 2014), Alun Davies MBE, Deborah Fowler (from 2014), Michael Hughes, Christine Lenehan OBE, Jane Macfarlane (until 2014), Jane Mordue, David Rogers OBE (until 2014), Dag Saunders (until 2014), Liz Sayce OBE (from 2014), Dave Shields (until 2014), Patrick Vernon OBE and Christine Vigars (until 2014).

## Expenditure

- Our total expenditure for 2013/14 was £4.1 million.
- £3 million of this was core funding and £1.1 million was funding for one-off projects.



## Highlights of the year

### **We called for more action to improve the complaints system.**

We drew attention to the complexity of the system, highlighted the fragmentation of advocacy services and presented to Government people's experiences of complaining about health and social care. This helped lead to coordinated action from across the health and social care system, and increased recognition that the complaints system needs to change.

### **We launched our first special inquiry.**

Through the inquiry we will help marginalised people to tell their stories of unsafe discharge from hospitals and mental health institutions. Local Healthwatch identified this issue as an entrenched problem that needed to be addressed through a fresh approach.

### **We acted on people's concerns that were brought to us by local Healthwatch.**

When 40 local Healthwatch told us about the concerns they were hearing from the public, we took action and helped secure a delay to the roll-out of 'care.data' until patients have the answers they are looking for.



**We listened for 1,750 hours to people's views on health and social care, and changed our strategy based on their feedback.**

We also extended the conversation online to a potential audience of 684,000 via Twitter.

Overwhelming feedback about our proposed 'Consumer Rights Framework' was that it helped people understand what they can expect in health and social care. We have now translated this into eight consumer principles which underpin all our work.

**We provided training and support to help local Healthwatch to get off the ground.**

And we made the case nationally to ensure they have the resources they need to be an effective voice for the public. Our investigations uncovered that almost a quarter of money earmarked for local Healthwatch - £10 million - had failed to reach them.

**We made sure patients' voices were heard in the debate about the A&E winter crisis.**

Working with the media, we showed how lack of access to GPs was driving people to seek emergency care. In more than 175 pieces of national media coverage, we raised awareness of people's views on this, and a whole range of other issues.



## Getting people's complaints taken seriously

Sir Robert Francis QC's report into the crisis at Mid Staffordshire NHS Foundation Trust and the investigations into Winterbourne View show that listening to and acting on the concerns of patients and families is crucial. Valuing their insight more might have prevented neglect, enhanced wellbeing and saved lives. We have led work nationally and locally to identify why people's concerns aren't being heard. We have focused particularly on the need to simplify and clarify the often baffling health and social care complaints system.

## Speaking up for people like 'Mr & Mrs A'

It was the very first time Mrs A had been to hospital for chemotherapy. She was kept waiting for three hours, without any explanation or support.

“The treatment, which was eventually found to be harmful not beneficial, caused severe laryngospasm [when the muscles of the vocal cords seize up, restricting the flow of air into the lungs],” says Mr A. “Yet my wife was kicked out into a cold March afternoon even though the laryngospasm was known to be worsened by cold.”





Mr A decided to complain to the person named on the leaflet that the unit supplied because he wanted his wife to have better treatment and other patients to have a different experience on their first visit.

“I was bullied by the matron in charge for having the temerity to raise any complaint and received a written reply two months after the incident,” says Mr A. “No fault was admitted, no regret expressed and as far as I know, their practice remains unchanged.”

Over this year, we and local Healthwatch have spoken to many people like Mr A. They have told us about a litany of failings in their NHS treatment. For decades, people like Mr A have struggled to make a complaint, not knowing where to turn to and finding they are ignored, not taken seriously, or even bullied.

Last year, we promised to focus particularly on getting feedback and complaints systems working for consumers, so that where problems arise, they get a quick and fair resolution. This is underpinned by our consumer principle that people should have the right to be listened to.

It’s why, this year, our work on complaints has focused on four key areas:



- Highlighting the complexity of the complaints system. Our work mapping the complaints landscape found that there's a staggering 75 types of organisations in England which have a role in complaints handling and support in health and social care, from local councils and clinical commissioning groups to national regulators.<sup>i</sup> We've taken these findings to Government and have worked with the press to highlight the extent of the problem.
- Working with health and social care system partners to change the way complaints are dealt with. We used our statutory powers to ask NHS England, the Care Quality Commission and Monitor to commit to changing the complaints system. As part of system-wide efforts, our support is now helping the Department of Health improve the way NHS complaints data is analysed. We started working with the Parliamentary and Health Services Ombudsman and Local Government Ombudsman to make complaints handling more patient-centred. And we contributed to the Department of Health's new Complaints Programme Board, helping ensure key organisations pull together to coordinate change.



- Ensuring consumer perspectives were recognised by the Government. Our research shaped the Government's response to Sir Robert Francis QC's report, called 'Hard Truths', and the final report of the independent review into NHS hospital complaints from MP Ann Clwyd and Professor Tricia Hart. In their evidence to the Health Select Committee, Francis and Clwyd both recognised there was an important role for the Healthwatch network in improving the complaints system.

We worked with the Department for Education to make sure the new Children and Families Act included wider complaints reform for services affecting disabled children and those with special educational needs.

Following debates at our public Committee Meetings, we gave evidence to the Government about a legal duty of candour for health and social care providers. We proposed that all health and social care services should provide information about any harm patients might have experienced, whether or not a complaint has been made. Our evidence helped ensure more people will be told if something goes wrong when the new duty comes into force in October 2014.

- Making it easier for people to make a complaint.



We started work with Citizen's Advice to create online information and advice for people who want to raise a concern or complaint. We also committed to work with Citizen's Advice to produce new complaints resources to help local Healthwatch and advice workers better support people who want to raise a concern or complaint.

“The complexity and inconsistency of local complaints advocacy and support need resolving. We need a single integrated advocacy service across health and social care, with a brand that people recognise so they know where to go and are not lost on the internet trying to find who they can get help from.” Healthwatch England evidence to the Health Select Committee's inquiry ‘Complaints and Raising Concerns’

“Healthwatch England should continue to bring together patients and representative groups, and lead the Healthwatch network in the public campaign to improve complaints systems in health and social care.” ‘Clwyd Hart Report’, October 2013

Our research found that while one in five people in England were dissatisfied with their NHS or social care treatment or care, only half had raised a concern or made a complaint.



## Inspiring local Healthwatch work on complaints

Inspired by our work on complaints, more than three-quarters of local Healthwatch told us they had gathered information about people's experiences of complaints systems in their areas. For example:

- As a result of Healthwatch West Sussex's 'Can't Complain?' report, a local NHS trust has agreed to provide an explicit guarantee to patients that complainants' future treatment will not be affected.
- When Healthwatch Northumberland secured the contract to provide complaints advocacy services, they renamed categories under which complaints were recorded so that they can better share information with patient advice and liaison services.
- Healthwatch Leicester has been working with University Hospitals of Leicester to co-host a workshop with past complainants to discuss how the complaints process can be simplified.
- Through their contract to provide complaints advocacy support, Healthwatch Rotherham helped



three people to make complaints about inconsistency of care in the Rotherham NHS Foundation Trust Stroke Unit. As a result, the trust agreed to review staff rotas to ensure consistency of care throughout shifts.

## **Case study: Valuing complaints in Cambridgeshire**

Right from the launch of Healthwatch Cambridgeshire in July 2013, it was clear there was a problem with the local health and social care complaints system.

“From early on we were receiving calls from people who didn’t know how to report complaints about the care that they, or their relatives, had received,” explains Julie McNeill, Healthwatch Cambridgeshire Information Officer. Even those who managed to lodge a complaint found the process long and exasperating. “Some said it almost felt like they were being strung along until they gave up,” explains Julie.

Julie and her team looked at evidence from a Healthwatch England survey that found just under half of people believed complaints were not dealt with effectively. This helped them develop a major project to improve the system locally so that people feel they are listened to and taken seriously.



They developed visual maps for the Healthwatch Cambridgeshire website that signpost people to the right place to raise a concern or make a complaint. These maps were sent to hospital trusts, the clinical commissioning group and adult social care for their comments, as well as to Healthwatch Cambridgeshire's consultation network, which is made up of over 60 members of the public. "We've had great feedback which has enabled us to adapt the maps so they work better for everyone," says Julie.

The work has also involved alerting local trusts to out-of-date or misleading information on their websites, such as reference to the Primary Care Trust, which hasn't existed since April 2013. The project will continue with a survey about the experiences of people whose complaint case has recently closed.

"Our aim is to come up with recommendations for commissioners and providers that will make the complaints process more straightforward and ensure people feel their experiences are valued as an opportunity to improve services."



## Case study: Mystery shopper in Camden GP surgeries brings results for local people

After receiving a number of calls from people who had problems with their GPs but didn't know how to make a complaint, it became clear that Healthwatch Camden needed to act.

“Everyone had their unique story to tell,” says Frances Hasler, Director of Healthwatch Camden. “One person experienced a problem with the referral process between their GP and hospital. Others were finding it difficult to get a GP appointment at all. The thing they all had in common was that none of them knew how to report these issues.”

Healthwatch Camden responded by carrying out a mystery shopping exercise at all 39 GP practices in the borough to find out how easy it was to get information about complaints. Posing as someone who wanted to raise a concern, and asking for a copy of the practice's complaints procedure, the mystery shopper recorded how the reception staff handled the request.

“Responses were mostly really positive,” says Frances. “Only about a third of receptionists didn't know which forms to give and, in most of those cases, they were well trained to find someone who did. The really





significant issue was that few surgeries had anything up on the wall to draw attention to people's rights.”

The mystery shopper also conducted online research about the GP practices:

- Seven practices were very hard to find online.
- Three practices had no website at all.
- Of those that did have websites, some referred patients wanting to complain to the disbanded Primary Care Trust.

Healthwatch Camden presented its findings to GP practices and local commissioners. They have already begun to make positive changes on behalf of consumers. Eight out of the 39 practices have put up new information on their walls, updated their websites or trained receptionists on how to respond better in the future.

Meanwhile, the local clinical commissioning group discussed the findings at their Quality and Safety Committee. “This will form part of their overall quality improvement plan for general practice which will clearly benefit patients across the borough,” says Frances.



## **Making people's voices heard nationally**

We use our legal powers to raise the public's concerns with people who commission, regulate and provide health and social care services. Local Healthwatch are our 'eyes and ears' on the ground, providing information about people's experiences. We also analyse national data to identify issues that affect large numbers of the population, and carry out our own research to reach out to groups who are not often heard.

### **Challenging NHS England to respond to people's concerns about a shared records system**

In October 2013, Healthwatch Derbyshire used our formal 'escalation' procedure to raise concerns with us about new plans to share people's GP records with NHS and care services through the 'care.data' programme. NHS England proposed that information would be collected by the Health and Social Care Information Centre (HSCIC) and used to inform the improvement of treatment and care. But local people in Derbyshire were worried about anonymity and how data would be shared.

Then in January 2014, Healthwatch Herefordshire shared misgivings about the proposed roll-out of the



programme. Following this, we decided to consult other local Healthwatch and found that concerns were widespread, with one in four expressing worries about ‘care.data’.

- Healthwatch York said local people thought that NHS England flyers were ‘junk mail’ which were thrown out along with pizza menus and broadband leaflets.
- Healthwatch Ealing, Healthwatch Stoke and others reported that members of their local communities never received the flyers.
- Healthwatch Bradford raised concerns about the accessibility of NHS England’s information campaign conducted purely through print media.
- Healthwatch Cambridgeshire and various Healthwatch in the Northwest also told us that some GPs were opting their entire surgeries out of ‘care.data’, denying their patients the right to choose.

Armed with this evidence, in February 2014 we challenged NHS England and called for an immediate delay to the planned roll-out of ‘care.data’ until people had the information they needed to choose whether to



opt out. As a result, NHS England announced a six-month pause on the programme. Since then, we have continued to ask for more to be done so that the public understands the programme. We have:

- Raised further questions about the handling of other medical records already held by HSCIC.
- Joined the ‘care.data’ advisory group, providing guidance on ways to engage local Healthwatch so they can feed into the rollout of the programme - drawing on their understanding of public views and how to communicate with the public.
- Advised on the need to communicate better with the public to rebuild trust and make sure patients, as well as GPs, are included in plans for the programme.

### **Access to NHS dentists: identifying an issue that consumers want on the political agenda**

Local Healthwatch provide unique insight into people’s experiences of health and social care issues across the country, telling us what matters to their local communities. We use our national role to aggregate local information and identify emerging patterns. Through doing this, we were able to see that access to



NHS dental services is a major concern for people that isn't high enough on the political agenda.

Through evidence from local Healthwatch, we discovered that people are missing out on dental treatment because they can't get access to NHS services:

- Healthwatch Kirklees, Leicester and Lincolnshire found some areas have almost no dentists accepting new NHS patients. Patients have to join long waiting lists, travel for substantial distances, or are forced to pay for private treatment to find a dentist.
- When Healthwatch Bolton contacted local practices listed as accepting new patients on NHS Choices, some had long waiting lists, were closed or only accepting new patients if they had a relative already registered at the practice.
- People are being removed from practice registers without warning or inappropriately. One patient told Healthwatch Bolton she'd missed one dental appointment while she was experiencing domestic violence and the practice refused to see her again even though she produced police protection documents.



- Healthwatch Lincolnshire found that practices were asking patients for consultation fees of £40 to £80 before they could be seen as an NHS patient.

Information from local Healthwatch backed up NHS England research, which found that 13% of respondents had not had a dental appointment in two years because they thought they'd not be able to get an appointment with an NHS dentist. A further 5% had not had an NHS appointment because they thought it was too expensive. That's nearly a fifth of people experiencing difficulties accessing dental care.<sup>ii</sup>

In 2014, we took these and other concerns to the General Dental Council and the Chief Dental Officer at NHS England and have asked for Healthwatch to be able to participate in national reform of dentists' contracts. Through this we hope to improve access to dental services, and ensure dentists are more open and transparent about charging.



## Giving marginalised people a voice on improving discharge from care

Homeless people are discharged from hospital back on to the streets. Mental health patients are moved from mental health settings to supported accommodation too soon due to pressure on beds. Older people are sent home from hospital with no heating or food in the house.

These are stories that many people working in health and social care, and others, know well. This year, local Healthwatch told us that discharge from a range of health and social care settings was an entrenched problem - and that not enough had been done to change things.

We decided to use this information, and our statutory powers, to launch a special inquiry into what happens when people are discharged from a hospital, care home or secure mental health setting. The inquiry is being led by people who have experience of unsafe discharge because they have the potential to unlock solutions to stop it happening.

“To end the spiralling cycle of careless discharge, crisis and readmission, the professionals need to properly think through what their patients are going to do



when they leave their care.”

Paul Wilson, who is a member of our inquiry advisory group and has been homeless himself

As part of the inquiry, Healthwatch England, together with local Healthwatch, voluntary sector partners and our user-led advisory group, have collected experiences directly from those affected, as well as from providers and frontline workers.

We’ve found that tens of thousands of people are potentially being discharged from health and social care settings without proper support in place. It means people can be isolated and end up in a crisis that could have been prevented.

Our inquiry will be published in November 2014. We’ll use the inquiry and our statutory powers to:

- Bring those affected by unsafe discharge together with national policymakers and frontline workers to co-develop solutions.
- Advise the Secretary of State and relevant national bodies on recommended changes to policy, guidance or practice.





## Unsafe discharge: The facts

- In 2013, there were more than 1 million emergency readmissions (being readmitted to hospital within 28 days of being discharged), costing the NHS an estimated £2.4 billion. <sup>iii</sup>
- In the last decade, emergency readmissions have increased by over a quarter. <sup>iv</sup>
- Emergency readmissions for older people are highest, with 15.3% of those aged over 75 being readmitted to hospital within 28 days of discharge. <sup>v</sup>



## Shaping the media debate on the A&E ‘winter crisis’

Each winter, emergency care in the NHS sees a surge in demand. The public is often blamed for pushing the system to breaking point because we use it for the ‘wrong things’.

To understand what was really happening, we carried out our own research on the use of emergency NHS care. Our survey of 1,762 people showed that nearly one in five admitted to knowingly using A&E services for a non-emergency at some point in their lives. A lack of access to primary care was a key factor. A third of people said they would be likely to use A&E if their GP was closed, and a quarter would if they couldn’t get an appointment with their GP within a reasonable amount of time.<sup>vi</sup> Open all hours and guaranteeing to see patients within four hours, A&E has become seen as ‘NHS Express’.

Our findings put consumer voices at the heart of the media debate about this issue, featuring in news stories across BBC platforms, as well as in The Times and The Independent. The coverage also provided a platform for local Healthwatch to promote and carry out their own research, for example:

- Over a third of respondents to a survey by



Healthwatch Liverpool were unable to get an appointment with the doctor they wanted to see.<sup>vii</sup>

- Three-quarters of the public that Healthwatch Waltham Forest spoke to wanted GP surgeries to open longer and outside of normal working hours.<sup>viii</sup>
- Wheelchair users told Healthwatch Isle of Wight that accessible treatment areas were an issue and communication hatches were too high to communicate with receptionists.

In 2014/15, we'll work with people to come up with new solutions to get the advice they need from health professionals more quickly and easily.

“Last year I phoned my GP’s surgery on a Friday afternoon to ask for advice about an earache. The receptionist listened to me and decided to speak to a doctor. She came back and said to take paracetamol and if it was no better over the weekend then visit A&E. Exactly what I was trying to avoid!” Respondent to our strategy consultation



## Making people's voices heard locally

This year we supported local Healthwatch to get up and running so they could focus on getting out into their communities to listen to people and act on what they found out. At a national level, we made the case for local Healthwatch to have the resources they need to do the ambitious job they have been given. We also promoted good practice, and provided training and shared learning so that local Healthwatch could be effective at getting people's voices heard in their area.

## Getting local Healthwatch established

Setting up an organisation from scratch is a huge challenge. Setting up a network of organisations covering all 152 local authority areas in England is a massive task. This year we prioritised making it easier for local Healthwatch to get up and running by offering leadership, support and shared resources.

### *Understanding statutory powers*

Our briefings explained what was expected of local Healthwatch in terms of legislation and key statutory activities, like being part of the health and wellbeing



board. A training pack described local Healthwatch powers to visit health and social care services to hear from people and make suggestions for improvement. These visits are called 'Enter and Views'. Our best practice guide discussed how to build relationships locally and included guidance on working with clinical commissioning groups.

### ***Sharing learning***

We held 40 workshops with local Healthwatch where they shared expertise about how to improve local services. Our annual report guidance also helped local Healthwatch showcase what they had achieved in their first year.

### ***Online communications centre***

To date, 95% of local Healthwatch are signed up to our online communications centre which has helped them develop their brand and messaging. Around 600 people use our internal social media platform Yammer to share experience.

### ***On-going support***

Our weekly newsletter for local Healthwatch signposts them to guidance on issues from governance to health and social care policy. Local Healthwatch also have



access to a dedicated regional support team.

### ***Training for board members***

We've started to offer tailored sessions looking at setting priorities, building partnerships and managing relationships. These will help local Healthwatch be more strategic and do more for local people.

### ***Outcome and impact development tool***

We worked with the Local Government Association to develop a framework for local Healthwatch to measure the impact of their work. It is focused on how local Healthwatch can demonstrate their impact on local health and social care services, such as GPs. We also developed a 360 degree audit process so that local Healthwatch can assess their local relationships.

### ***Media training***

So far 60 local Healthwatch have received media training after local Healthwatch requested this from us in 2013. We'll continue to provide more opportunities for this kind of training which means more local spokespeople championing the voice of consumers in the NHS and social care.

Local Healthwatch cover each of the 152 local authority



areas in England. They are independent organisations commissioned directly by local authorities. Local Healthwatch and Healthwatch England together form the Healthwatch network.

The total income of the local Healthwatch network in 2013/14 was £33.5 million.



## Understanding local views, acting on community priorities

Our support getting local Healthwatch up and running enabled them to spend more time listening to local people. This year they have collected vital data on how and why people use health and social care services in their area, and used their statutory relationships on health and wellbeing boards, with local authorities, commissioners, providers and professionals, to change things for the better. Below are a few examples of how local Healthwatch have canvassed community views and responded to local concerns:

- Students told Healthwatch Blackburn with Darwen that they were unhappy with the service at their sexual health centre.<sup>ix</sup> With Healthwatch support, some of the 1,000 students who took part in the research presented the findings to key senior representatives from sexual health and health services.
- Russells Hall Hospital A&E and Dudley Walk-in Centre is introducing seven day opening hours, following Healthwatch Dudley's week-long survey of 1,000 people who use the service. There's now also extra support for children and adults with





mental health issues.

- Healthwatch Swindon's patient participation group forum brings together patient groups from various GP practices to share understanding of issues in their area and ideas on how to work effectively with their GP practices. Through this collaboration they are becoming more successful at influencing care and treatment for patients and carers.
- Recommendations from a Healthwatch Norfolk report<sup>x</sup> into how homeless people access health and social care services were presented to commissioners and providers at a summit meeting organised by Healthwatch Norfolk in March 2014. They called for more partnerships between the voluntary and community sector and NHS organisations.
- Patients at Northampton General Hospital are sleeping better following Healthwatch Northamptonshire's research. New hospital bins have been introduced with soft closing lids after patients said the previous ones were noisy.
- When Healthwatch Worcestershire discovered people were finding it difficult to see an out-of-hours dentist because the published telephone



number was wrong, they raised the concern with their local NHS England team. Subsequently, NHS 111 were commissioned to provide the out-of-hours emergency contact service from April 2014. Healthwatch Worcestershire have found that the new arrangements are successful so far.



## Case study: Mothers have their say and help improve maternity services in Isle of Wight

“My son was premature so he was tube fed in hospital. When I took him home he didn’t put on enough weight and I was told there was no alternative but to give him formula. I was desperate to breastfeed and wanted to do the best for my son, but wasn’t given the support I needed. I felt alone and frustrated. No one was listening.”

These are the words of Emma Porter. She is one of 187 mothers who took part in a Healthwatch Isle of Wight investigation into the state of maternity services. They launched the investigation after a number of parents said they’d had bad experiences during a community engagement session in a children’s centre.

Mothers filled in a survey about the care they received before, during and after the birth of their babies. They gave 200 pieces of feedback at 36 sessions held at children’s centres and independent mother and toddler groups. The majority said they were happy with the service, but some, like Emma, raised concerns. These ranged from complaints around lack of breastfeeding advice, to reports that midwives seemed rushed off their feet and anxiety about inconsistent antenatal



support for mothers who weren't first-time mums.

Healthwatch Isle of Wight presented its findings to local providers and commissioners who have welcomed the opportunity to address patient concerns. Of five key recommendations made in the report, two have already been adopted, and commissioners have committed to developing a long-term plan to action the remaining three.

According to Emma, who has become a breastfeeding peer supporter at her local children's centre, things are already improving for new mothers as a result of the investigation. "I know of a few instances recently where people have had premature babies who haven't been putting on weight and they have been given the right support, so I know it's changing," she says.

"I'm so glad Healthwatch asked me about my experience because I feel like I was a part of making that better. If you have a rough journey it's good to be able to share it so other people don't go through the same."



## **Case study: Responding to parents' concerns about support for children on the autistic spectrum in Cornwall**

When a concerned mother complained her daughter had been waiting for three months for an assessment of whether she was on the autistic spectrum, Healthwatch Cornwall began an investigation. It uncovered a major gap in services that meant hundreds of children who may be on the autism spectrum were going undiagnosed.

The mother said: “The lack of diagnosis was preventing my daughter from accessing support in school or through social services, and as a parent I couldn't get the help of a carer. Asperger's [an autism spectrum disorder] is a hidden disability and the gap in service was discriminatory to children and young people and their families.”

Healthwatch Cornwall talked to other distressed families who were in a similar position. In each case, the child was aged five or over and did not have an obvious mental health issue. They gathered robust evidence and presented it to local commissioners and the health and social care scrutiny committee. Within weeks, commissioners had written to all concerned



parents to explain what support was available.

The local commissioning group committed to following National Institute for Health and Care Excellence guidelines in relation to diagnosing children on the autistic spectrum. They have formed a multi-agency team, including a consultant psychiatrist, clinical psychologist, speech and language therapist and occupational therapist. In its first six months, 255 children from across Cornwall were referred to the service so they could start to receive the support they need.

“We are thrilled our work has helped to alleviate the worry for so many families,” says Debbie Pritchard, Healthwatch Cornwall Chief Executive. “This result, accomplished with no loss to other services, is testament to the positive change that can be achieved for people when they share their experiences through Healthwatch Cornwall.”



## Case study: Reducing waiting times for A&E patients in Staffordshire and Derbyshire

High patient numbers were causing long delays at Burton's Queen's Hospital A&E department, so the local commissioning group asked Healthwatch Staffordshire to find out why so many people were using the service. Working in partnership with Healthwatch Derbyshire, as the hospital serves both areas, they devised a survey to consult A&E patients.

“We spoke to 473 people over seven days,” explains Jan Sensier, Chief Executive at Healthwatch Staffordshire. “We were interested in whether people had considered using other services and whether they'd been referred to A&E by any other parts of the system. Astonishingly, we discovered that 40% had been referred by their GP.”

Healthwatch Staffordshire made a series of recommendations to the commissioning group and hospital, which resulted in the trust opening an acute assessment unit for people who've been referred by their GP. “The streamlined system works far more effectively because patients don't have to explain their symptoms twice,” says Jan. “It has reduced waiting times and improved performance in A&E. We've also had 100% positive feedback from patients using the



Acute Assessment Unit. It's great to be involved in a piece of work that puts patients at the heart."





## **Case study: Putting people who use home care services at the heart of decisions in Reading**

Calls to Healthwatch Reading from people concerned about the quality of care their relatives received has resulted in the experiences of home care users influencing the way services are commissioned and run.

Launched in partnership with the local council, the project involved in-depth interviews with 64 people who receive home care. “This isn’t something councils usually do,” says Rebecca Norris, Development Officer at Healthwatch Reading. “Usually monitoring consists of the care worker signing a sheet to say they arrived and left at a certain time and did their task. But these are some of the most vulnerable and potentially isolated people in society. Our idea was to spend time to really understand their views.”

Interviewees spoke of the vital role home care plays in their lives but said inconsistencies in quality severely affected their wellbeing. One woman, who has arthritis and cannot get out of bed without the assistance of a care worker and hoist, described feeling frustrated. She has to wait to be “rescued” from bed when her worker



is late.

Influenced by moving testimony from interviewees, Reading Borough Council signed the Ethical Care Charter, committing to buy home care only from providers who give workers enough time, training and a living wage. The council is using the project's findings to develop new, patient-centred targets for the next round of home care contracts. They've asked Healthwatch Reading to gather a group of home care users to be involved in selecting the providers who win contracts.

Rebecca is delighted that people who use home care services will now be at the heart of decisions about their care.

“I hope they now feel secure in the knowledge they will be treated with dignity, are receiving top quality care and are safe.”



## Training local Healthwatch to use ‘Enter and View’ powers

Local Healthwatch have been given a unique statutory power to enter premises where health or social care is being provided to gather the views of the people experiencing those services. It provides a unique opportunity to hear from groups of people who can otherwise be hard to reach.

Healthwatch England commissioned a review of how this power, called ‘Enter and View’, was being used, to inform the development of our training for local Healthwatch. Our findings revealed a lack of clarity of understanding, which had led to it being used in different ways. For example, ‘Enter and View’ was being used more frequently in health than social care settings, and some were more like inspections than ways to hear from people who use services.

We delivered training to 137 local Healthwatch based on the best practice we had found. More than 80% of those who attended the one-day or one-to-one sessions rated the training good or excellent, and it has since been cascaded by local Healthwatch to other staff and volunteers.



“It was well received by our volunteers and many said they had learnt something new.” Feedback from Healthwatch Rotherham

As part of the training, we provided guidance to local Healthwatch on how to share information gathered from ‘Enter and View’ activity with partners including the Care Quality Commission. In addition, we contributed to central Care Quality Commission guidance to their regional offices on how to work with local Healthwatch. We are delighted that this has led to effective collaborative working in a significant number of areas.



## **‘Enter and View’ case study: How our powers helped improve GP surgeries in Luton**

“My experience is very often that I leave thinking I didn’t really get what I wanted or I didn’t feel listened to,” says Beth Gregson. “I am Chair of Healthwatch Luton so if I leave feeling I didn’t get what I need then how on earth would somebody who doesn’t speak the language, or someone with a learning disability or dementia, or a young teenager, feel?”

Beth has a long-term chronic illness that affects her mobility and means she frequently uses her local GP service. Her concerns about GP services are not unique. Healthwatch Luton launched by asking the public what local healthcare improvements were most important to them. This led to a three-month consultation about GP services, endorsed by the Luton Commissioning Group and the local practice management group.

A team of volunteers conducted ‘Enter and View’ visits to every GP surgery in Luton and attended local events, carrying out around 1,000 interviews. In March 2014, the findings were published and each surgery received an individual report.

The main area of dissatisfaction was about physical



access to surgeries and the availability of translated documents and options for booking appointments. A total of 680 recommendations were made and within three months 292 of them had been adopted.

Healthwatch Luton is helping surgeries to implement the more substantial improvements and they're also helping colleagues around the country to develop their own consultations.

“Many patients may not have heard of us but if they find it easier to get into their building, or if an expensive 0845 number has become a local number or the receptionist now smiles at them then their experience has changed,” says Beth. “If our next National Patient Survey reports these improvements in Luton then we will know we have had an impact.”



## **‘Enter and View’ case study: Carer and patient help change practice at a Wakefield care facility**

Carol White was horrified when she found her 81-year-old father George lying on the floor beside his bed in Queen Elizabeth House. He was staying at the intermediate care facility in Wakefield to recuperate and receive physiotherapy after hip surgery. None of the staff had noticed he’d fallen. “I asked the nurses what had happened,” explains Carol. “They said, ‘Well, he has been shouting and we were going to come and see him...’”

Carol also noticed that George’s buzzer was out of reach, meaning he couldn’t contact staff when he needed to go to the toilet. Often his drinks would be placed too far away and the cups were dirty. The bathrooms had no blinds at the windows and the rooms were so unclean her clothes smelt of urine when she got home after visits.

Within just a week of being at Queen Elizabeth House, George had visibly begun to deteriorate. “Dad’s a proud Yorkshire man and not the kind of person to show feelings and emotion, but I was getting concerned because he didn’t want me to leave him at night,” says



Carol.

Carol made several complaints to the manager but they had no impact. Eventually she removed George from the facility after he developed hypothermia and contacted Healthwatch Wakefield to report her concerns. Within days, Healthwatch Wakefield organised an ‘Enter and View’ visit to speak to the facility’s staff, patients and relatives. They’d received another call from a woman who was concerned about her 95-year-old mother, so knew the problem was not unique to Carol and George.

Celia Bateson, Development Director at Healthwatch Wakefield, was traumatised by what she saw on the visit. “The majority of the patients were sat in the lounge and it seemed they couldn’t wait to speak to us - straight away we were alarmed,” she says. “Not one patient had anything good to say, they were all concerned about their care. Many didn’t know when they were going home. Some were concerned they had little physiotherapy, and had missed medication and hospital appointments. Others struggled to get to the nearest toilet as three were broken.”

Taking advice from social services, Healthwatch Wakefield immediately raised a safeguarding alert, and informed the hospital trust and clinical commissioning





group of what it had found. The following day, a new temporary unit manager had been put in place, the toilets were repaired and the planned refurbishment programme was set in motion.

Healthwatch Wakefield returned to Queen Elizabeth House once refurbishment was completed. “We were totally amazed at the transformation,” says Celia. “Patients spoke very highly about the nursing staff and said they were very well cared for. We saw nursing, physiotherapy and occupational therapy staff supporting patients, and patients had hand bells on their chairs to ring so that they didn’t have to search for a buzzer.”

Though George is now being cared for at home, Carol is glad to hear improvements at Queen Elizabeth House will mean nobody else will go through the trauma she and her father experienced. “It’s nice to know people like me can go somewhere and be listened to.”



## **‘Enter and View’ case study: Responding to feedback about care homes in Barnet**

“I have a strong desire to represent the views of people who don’t get heard. Luckily that’s what the government would like us to do through Healthwatch so I am able to help make a real difference,” says retired teacher Linda Jackson.

Linda is the lead volunteer of a project led by Healthwatch Barnet looking into the quality of care in residential homes. The project began after the Healthwatch was contacted by members of the public and it was quickly endorsed by the Care Quality Commission and local council.

To date, a team of 20 volunteers have visited 14 care homes, conducting interviews with staff, residents and relatives. “What we find varies,” says Linda. “One lady told me she’s looked after like a princess. Another man said he felt belittled by the choice of bingo as an activity.”

Residents were most dissatisfied with the poor range of activities and Healthwatch volunteers have made a number of recommendations. They include improving food, introducing staff name badges, creating better



relationships between staff and patients, and removing unpleasant smells.

Home managers fed back on the volunteers' reports, which were then shared on the Healthwatch Barnet website and with the local commissioning group, Care Quality Commission and relevant council teams. All of the 14 homes have implemented at least one of the recommendations and half have agreed to implement the majority of them. As the project continues, it will include revisits to the homes most in need of improvements.

“No other organisation in the sector goes out there to find out what an individual wants,” says Linda. “There are lots of surveys, the NHS is forever surveying, but that doesn't engage people. We make an effort to find out how people are.”



## **‘Enter and View’ case study: Consulting patients about A&E Bradford**

When the Independent Complaints Advocacy Team for Bradford got in touch about a pattern of complaints about Bradford Royal Infirmary, it was clear the local Healthwatch needed to find out more.

“They alerted us to a number of people who had been sent home from the accident and emergency department (A&E) with undiagnosed conditions,” says Andrew Jones, Manager of Healthwatch Bradford and District. “They included things like fractures and infections and resulted in people having to go back to hospital the following day.”

Healthwatch Bradford and District took its concerns to the hospital trust and arranged to spend an evening in the department to get a snapshot of staff and patient opinion. “I spent a long evening in A&E with a member of my team talking to staff, consultants, patients and carers about their experiences of being there,” says Andrew.

While some patients were satisfied with the care they received, others had negative experiences. “People didn’t feel they were treated with respect,” says



Andrew. “They talked about staffing levels and said they weren’t given sufficient information. Everyone knew about the four hour waiting limit, but one person told me they had just been told to, ‘Go and sit over there and we’ll see you in four hours’ time’.” Another issue was lack of privacy. Triage was taking place in busy corridors rather than in private rooms.

Shortly after the visit, the Care Quality Commission contacted Healthwatch Bradford and District to ask for patient feedback ahead of an unannounced inspection of the hospital. A&E was not on the Care Quality Commission’s list of departments to look at, but when Healthwatch revealed their findings, they changed their plans to include it.

The inspection resulted in the hospital trust failing four out of the five national standards and getting a formal warning in relation to staffing.

“Since then, the trust has made excellent progress in recruiting more nursing staff,” says Andrew. “They introduced training to improve the customer care aspects of the service and have got consultant cover from 8am until midnight, seven days a week, and senior medical cover throughout the night.”

Healthwatch Bradford and District will be returning to



the hospital later in the year to ensure changes continue to mean better experiences for patients.

“Through good, positive relationships with partners, changes are being made for patients and we’re delighted at that.”



## Our plans for 2014/15: Giving people a more powerful voice within the health and social care system

Everything we do is driven by users, patients and carers, their insight and what they want and need. In 2014/15 we will build on what we have learnt and work with local Healthwatch to make consumers' voices even stronger and ensure the public have even more influence on health and social care services.

In 2014/15, Healthwatch England will:

- Continue to make it easier for people to make a complaint about their experiences of health or social care services and have it acted on by:
  - Publishing a report into the state of the complaints system and advocacy services, and use our statutory powers to advise the Secretary of State on how things need to change.
  - Working with Citizens Advice to deliver online advice to help people navigate the complaints system, and resources to enable local Healthwatch to better support people wanting to make complaints.



- Give marginalised people a voice in improving the experience of discharge from hospitals, care homes and mental health institutions, preventing unnecessary deaths and emergency readmissions by:
  - Bringing people with direct experience of unsafe discharge together with senior decision makers and frontline professionals to find practical ways to tackle these entrenched problems, and supporting local Healthwatch to do the same.
  - Using our statutory powers to advise the Secretary of State of the changes that need to be made.
- Ensure future services meet people's needs and are shaped by those who use them by:
  - Encouraging communities to get involved in changes to local services.
  - Promoting the voices and views of those who often go unheard.
  - Supporting local Healthwatch to influence local decision making, and engage in major debates about changes to services.





- Supporting local Healthwatch to influence and inform delivery of the Better Care Fund, a joint NHS and local authority budget to bring together health and social care services.
- Make sure people's worries and concerns about services get heard in the health and social care system by:
  - Providing training and support to local Healthwatch so that risks and the concerns of consumers are reported to Healthwatch England.
  - Investigating national trends and areas of concern, including issues that have been escalated by local Healthwatch. We will particularly focus on lack of access to GP services, and issues around child and adolescent mental health services.
- Continue to develop the potential of the Healthwatch network by:
  - Enhancing the capability of local Healthwatch by offering tailored one-to-one support, training, sharing good practice, and policy and guidance with a particular focus on delivering



statutory responsibilities.

- Working with the network to identify shared priorities and take action together.
- Supporting local Healthwatch to engage with the Care Quality Commission's new inspection regime.
- Deepening our approach to diversity and inclusion, publishing our first diversity and inclusion plan.



## Top priorities from local Healthwatch for 2014/15

We asked local Healthwatch which priorities they had chosen for 2014/15. These were the most common issues:

1. Mental health services
2. GP services
3. Community health services
4. Hospital discharge
5. Residential care

## Encouraging people to demand quality health and social care

On the high street, we're quick to demand a replacement if we receive a faulty product. But in health and social care, we tend to be grateful for what we are given and put up with poor quality services.

This year, we consulted more than 500 people on our draft 'Consumer Rights Framework' and, following their feedback, have translated this into eight consumer



principles which will underpin everything we do. These consumer principles encompass a mix of people's rights in law, their expectations about services now and their aspirations for the future.

We'll use the findings to drive changes, ensuring services reflect people's needs and are responsive to them.

In 2015, we'll publish our first annual 'Consumer Index' based on these principles. By recording progress against the 'Consumer Index', we'll track people's changing experiences of their rights and entitlements in health and social care across England. And we'll use the findings to drive changes, ensuring services reflect people's needs and are responsive to them.

We'll also promote awareness of people's existing legal rights, as set out in the NHS Constitution, support them to exercise these rights, and challenge where there is a need to go further or where their rights are not being met.



## Our eight consumer principles

### *1. Essential services*

“ I want the right to a set of essential prevention, treatment and care services, provided to a high standard, which prevent me from being in crisis and lead to improvements in my health and care.”

### *2. Access*

“ 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.”

### *3. Safe, dignified and high quality service*

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

### *4. Information and education*

“ I want the right to clear and accurate information that I can use to make decisions about health and care treatment. I want the right to education about how to take care of myself and about what I am entitled to in



the health and social care system.”

### ***5. Choice***

“ I want the right to choose from a range of high quality services, products and providers within health and social care.”

### ***6. Being 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.”

### ***7. Being 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 my local community.”

### ***8. A healthy environment***

“ I want the right to live in an environment that promotes positive health and wellbeing.”



## Thank you

We are working towards a society in which people's health and social care needs are heard, understood and met. To do this, we work with a wide range of organisations and people.

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 with us.
- All of the generous volunteers across the Healthwatch network.
- Our special inquiry advisory group.
- The many voluntary organisations who contributed to our strategy consultation and special inquiry.
- Our colleagues in local Healthwatch.
- Healthwatch England staff.
- The Department of Health sponsorship team.
- NHS England, the Care Quality Commission,



Monitor, Public Health England, the Trust Development Authority, the Local Government Association and other statutory organisations who've worked with us this year.





## Endnotes

<sup>i</sup> Healthwatch England (2014) ‘Complaints system utterly bewildering people’

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<sup>ii</sup> NHS England (2014) ‘GP Patient Survey Dental Statistics’

<http://www.england.nhs.uk/statistics/2014/07/03/2346gppsw2201314/>

<sup>iii</sup> There were 5.3 million emergency admissions in 2012/13 which cost the NHS £12.5 billion, 19% were readmissions. For more information: National Audit Office (2013) ‘Emergency admissions to hospital: managing the demand’

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<http://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf>

<sup>vi</sup> Healthwatch England (2014) ‘Nearly a fifth knowingly using A&E for non-emergencies’

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<sup>vii</sup> Healthwatch Liverpool (2014: 38) ‘Improving access to GP services’

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<sup>x</sup> Healthwatch Norfolk (2014) ‘Homeless people’s access to health and social care services’

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