

Healthwatch England Annual Report 2012/13



Healthwatch England

Annual Report 2012/13

Presented to Parliament pursuant to section 45 C (2) of the Health and Social Care Act 2008 as inserted by the Health and Social Care Act 2012.

© **Healthwatch England 2013**

The text of this document (this excludes, where present, the Royal Arms and all departmental and agency logos) may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not in a misleading context.

The material must be acknowledged as Healthwatch England copyright and the document title specified. Where third party material has been identified, permission from the respective copyright holder must be sought.

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

You can download this publication from www.healthwatch.co.uk

Contents



Setting the scene and summary

Foreword	6
Executive summary	8

The current context and our research findings

The world we work in	10
The hidden story of health and social care	18

About us and what we've done so far

Consumer rights in health and social care	20
Our vision for rights in health and social care	24
Healthwatch England - a unique role	34
Local Healthwatch	46

What we will do in the coming year

Next steps	52
------------	----

Foreword



Welcome to Healthwatch England's first Annual Report to Parliament. We are the new consumer champion for health and social care. To fulfil this role, we will always start with people; with your experience.

By talking to people, we have found that the public are reluctant to criticise health and social care services; you understand the pressure services are under, and are grateful for what you get. As a result, satisfaction levels are high. But our research also shows that if one looks a little deeper, a different picture emerges. The actual experience of consumers, users and their carers is not as positive and the vast majority of people believe change is needed.

Listening to people who use services and acting upon what you say will help to make those services better; this is a lesson that has been learnt across the public and private sectors, and in many different industries. Involving people in service planning and delivery can help to maintain focus on what is important and ensure people get what they need.

The health and social care system is not so good at listening. That is the lesson of Mid Staffs, Winterbourne View and Morecambe Bay. It is why the consumer or user is now being put centre stage and why Healthwatch has been created. It is time to do things differently.

Healthwatch want to put the voice of the public at the heart of health and social care, by adopting a new approach built around rights. We have been working with the public to develop a clear set of rights suitable for health and social care. This report presents a working draft of those rights for discussion and refinement. We also want to start a conversation about responsibilities, because consumers have told us very clearly that with rights come responsibilities. Rights and responsibilities in health and social care will help all of us to know what to expect as consumers, users and carers.

The NHS Constitution was the first time rights were discussed in health. Our rights comfortably encompass the NHS constitution, but they extend beyond it. They are broader, and perhaps most importantly, they apply to all types of health and social care. We are already working with Department of Health to bring the two approaches together and establish greater awareness of rights.

We are living in economically constrained times where we all need to do more with less. Budgets are stretched, the population is ageing and treatments are increasingly expensive. Health and social care needs to change in response. Rights and responsibilities will help those who plan and deliver services to know what really matters to the public when they plan for the future. But if the system is to deliver more for us with less resource, we will also need to be involved in the future shaping of those services. Healthwatch is in a unique position to help do this.

Local Healthwatch will be key to discussions about changing services, ensuring the changes reflect what local people say is most needed. The roots provided by 152 local Healthwatch combined with the strong national place of Healthwatch England will ensure a strong consumer voice in discussions about the future of health and social care.

'Consumer' is an uncomfortable word for some people in health and social care. People in our research described themselves as many things: patients, clients, users, carers, even a few consumers. But we have found that the term consumer helps everyone to think differently; to ask new questions. This is why, we think borrowing from the consumer world will be helpful.

It is early days for Healthwatch but I hope you will see from this report that we are bringing something new to the discussions about the future of health and social care. We have a challenging task, a huge ambition and a big programme of work ahead of us this year. We are confident that by continuing to build the Healthwatch network, and by working closely with national players in health and social care and the third sector, we will be well placed to ensure consumers are given a powerful voice in making health and social care services better in the future.

We look forward to working with you all to achieve this.



Anna Bradley - Chair



Executive summary



This is the first Annual Report from Healthwatch England, the national consumer champion for health and social care in England.

Our first report outlines two fundamental parts of our work so far. They are:

- an overview of the current state of health and social care in England. We commissioned research including a survey and a face to face deliberative event, so we could understand what people really think about the care they receive
- an explanation of the role of Healthwatch England and local Healthwatch, as well as reporting on our activity for the first six months of our life, from 1 October 2012 to 31 March 2013.

Health and social care is fundamental to the people in this country. They are best able to articulate what they want from their care. That is why all of our work starts with the consumers' point of view.

We have been working with members of the public and this report contains quotes from them throughout.

Our survey found that 72% of the public say they get good quality care. This is heartening. It might, at first sight, seem surprising that almost 94% of us think NHS and social care services could be improved.

The reason for this quickly becomes clear when you dig a bit deeper. A shocking 1 in 3 people say they are worried about basic levels of safety, with someone they know having experienced a serious mistake, abuse or preventable illness or death.

Taken together, these findings demonstrate the need for a fundamental change that puts the user at the heart of the service. To help drive this change, we think a set of rights in health and social care can help people become more empowered and engaged and help service providers and commissioners focus on the things that matter most to users and their carers.

The concept of consumer rights is a familiar one in many areas of our lives. Nowhere more so than on the high street. We thought it could help people get what they want and need in health and social care. Our research shows that the public agree and they have helped us to develop a set of consumer rights that they think work in health and social care.

I hope Healthwatch will be created as a robust independent organisation that is taken seriously by those in the health service and more widely.

David Cameron, Prime Minister

Healthwatch England is uniquely placed to work with consumers to define a set of rights that can help them get what they need from health and social care. This is because our role is to champion the rights of all people: children, young people and adults, from birth to death. And we have a particular responsibility for championing the needs of those who are often not heard. We have a dual role to champion the needs of users of health and social care, as well as holding the system to account for how they successfully engage the public.

We have a national perspective on the things that affect people.

However, we do not work alone. We form part of the Healthwatch network. Along with ourselves, the network is made up of Healthwatch across 152 localities. These organisations are our eyes and ears on the ground. Since our launch, we have been busy developing the network, building our organisation and working with key partners to have an impact on the things that matter most to people.

This report provides a summary of our work so far and lays out our mandate for future work.

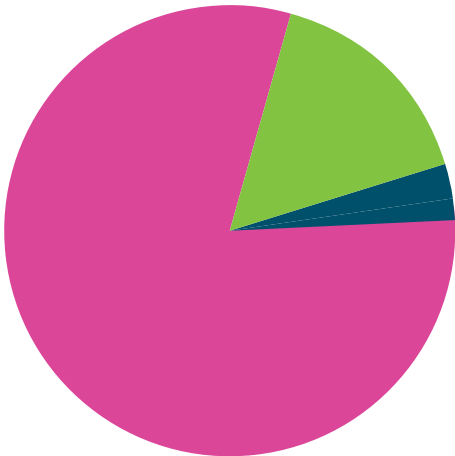
Over the coming year, we will continue to refine our work on rights, in conversation with the public, stakeholders and partners. In our next Annual Report, we will lay out the complete set of rights that people expect when using

health and social care. We think this will help consumers and users to understand their personal rights. Importantly, this should help to give them the confidence to speak up about what works and what doesn't and give them reassurance that they will be taken seriously. It will also help Healthwatch England to work with commissioners, providers, regulators and policy makers to challenge them to improve health and care services to meet consumer expectations.

By listening long and hard to the public's voice, together we can make sure our health and social care services are focussed and responsive to people's needs.



The current context and our research findings



We spend around £129 billion a year on the NHS and social care, with about £109 billion going on health and £20 billion on social care.

Of the £20 billion, around £7.5 billion of that is spent on residential care and £7.7 billion on home, day and domiciliary care for adults and older people. Councils spend around £3 billion on care and support for children and young people.

We spend 16% of the country's annual budget on the NHS and 2.5% on social care for adults and 0.4% for children and young people.

The NHS sees **over a million patients every 36 hours**



That's **over 27,000 patients every hour**

Over a million disabled and older people receive care and support from their local council...

...and **67,000 children and young people**

The world we work in



Health and social care matters

Health and social care are vital parts of many people's day to day lives. Many are passionate about the NHS and social care because they, or a loved one, are using a service right now. Even those who don't know anyone using health and social care services now know it is important to our future and those of the ones we love.

Health and social care

At some point in everyone's lives, they need support or treatment. With so many more people living with lifelong,² chronic and age-acquired conditions,³ people need to know what they can expect from health and social care so they can stay as healthy and independent as possible.

Each month in hospitals:⁴

- nearly 1.5 million patients see a consultant
- 900,000 are admitted for treatment
- almost half a million are just there for the day
- 400,000 patients come because of an emergency.

In the community, people see their GP, on average, three times a year.⁵ If you counted all the times people went to see a GP, a nurse or another health professional, it would amount to over 300 million consultations each year. Also pharmacies give out over 860 million prescriptions each year.⁶

Similarly, many people in the community need care and support to live their everyday lives. Over 360,000 people receive council or NHS funding to live in a care home⁷ and over a million get council funding to get support in their own home or to enable them to get around their local community.⁸

For most people, NHS services are free at the point of use, but some people have to pay to get NHS prescriptions, dental and optical check-ups and treatment.

By contrast, social care is means-tested. Nearly half a million older people pay for their own care and over £1 billion is spent every year by people who have to self-fund their home or community support.⁹ Many more rely on money from their family and friends to pay towards the cost.¹⁰

The current context and our research findings



Nearly 95% of people think their health is ok or good



Every year in England:

150,000

people have a stroke

20,000

people die from lung disease

130,000

people die from cancer

11,000

people die from liver disease

70,000

people die from heart disease

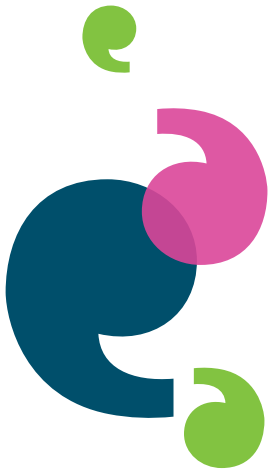
Men are now expected to live to an average age of nearly **79 years** and women nearly **83 years**



27,350

children and young people are in care arranged by their council

The current context and our research findings



The importance of carers and unpaid care

Much care goes on outside the formal health and social care systems. Around 800,000 older people¹¹ and at least one in six disabled adults,¹² are unable to get any formal support for health or social care. Those without support are left to the goodwill of family, friends and neighbours to help them with their day to day care needs.

Over 5 million adults provide unpaid health and social care to older and disabled family or friends, and over a third give more than 20 hours a week of care.¹³ Many older workers, predominantly women, are balancing working lives with providing childcare for grandchildren and care for their older or disabled relatives.¹⁴

The number of young carers has risen by 20% over the last decade, with most of them providing up to 19 hours of unpaid care. Around 10% provide 50 hours or more each week. Providing care without adequate support can significantly affect the health and wellbeing of carers.¹⁵

As a nation we spend just under £2 billion a year on financial support for carers.¹⁶ Yet the estimated economic value of all unpaid care is £119 billion per year.¹⁷

Health and social care is changing

The Health and Social Care Act 2012 radically changes the way services are bought and provided.¹⁸ Clinical Commissioning Groups now buy services for their local communities and Health and Wellbeing Boards oversee the local delivery of services. NHS England oversees the commissioning.

The new system is complex and the public remain puzzled by these changes. Almost 70% of people still feel like they don't know enough about the changes that are taking place and how they will be affected by them.¹⁹ Over half the public didn't have enough information to make an educated guess about the cost of social care and over half of those who did give an estimate gave amounts much lower than the going rate.²⁰

The Government has also recently introduced ambitious plans in a new Care Bill.²¹ The aim of this new law is to consolidate decades of legislation, regulation, policy and guidance on social care. The ambition is to make it easier for people to understand what their rights and entitlements are.



The Act has paved the way for bringing together health and social care services to centre around the person. At the last Spending Review,²² the Government invested £3.8 billion to allow local health and social care commissioners, and local Healthwatch, to come together to find solutions that are based on people's overall needs. The aim is to improve their experiences, the quality of services and outcomes.²³

Personalised healthcare and treatment may enable people to receive medicine and interventions better tailored to their individual needs. Advances in medicine and modern technology gives people the opportunity to take more control of managing their own health. This is strengthened by a greater focus on prevention and helping people to manage their needs at an early stage.

Around 609,000 people are currently self-directing their care and support and over 150,000 are receiving a direct payment²⁴ to buy the care and support they need²⁵ and are eligible for. Similar direct payments to pay for services in residential care are currently being piloted by the Government.²⁶

Scale of funding challenge in health and social care

The NHS is under a huge amount of financial pressure. Along with the changing needs of the population which place a financial pressure on services, £20 billion of efficiency savings are needed between 2011 and 2014 to make it sustainable for the future.²⁷

Similarly, councils have to make savings because their budgets reduced by around 30% between 2010 and 2015,²⁸ and it has been suggested that since 2010 around £2.68 billion savings have been made by adult social care - or 20% of all the money councils spend.²⁹



The current context and our research findings

Almost 1 in 4 (23%) say that professionals aren't really interested in what they have to say or do not actively seek or listen to their views or those of their loved ones



24% of people felt they were not involved in decisions affecting their health

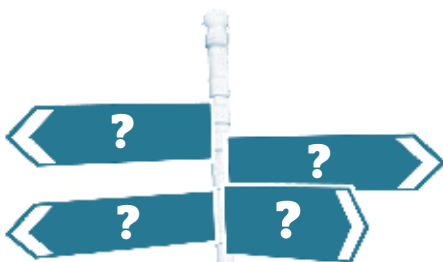
An overwhelming majority of the public (94%) think NHS and social care services could be improved



Almost **9 in 10** think the healthcare system needs to change



Nearly 3 in 5 (61%) did not feel they had a clear way of providing feedback on a service. Where concerns are raised, many people are not confident that action would be taken



Many of us don't know where to go if we have a problem or concern to raise



The hidden story of health and social care



Given the scale of change in health and social care, understanding what people want from the new health and social care system is critical. We asked the public for their experiences of using health and social care services and their ideas about the future.

In general, people are very positive about their experiences of health and social care. Seven in 10 of the public get a good quality service³⁰ from the NHS or local care services, and most of us say we are satisfied with the treatment (61%)³¹ and care (90%) we get.³²

While this is heartening, dig a little deeper and the level of concern about services emerges strongly.

An overwhelming majority of the public (94%) think NHS and social care services could be improved³³ and almost 9 in 10 think that the health care system needs to change.³⁴

At first sight this seems contradictory - overall, people are happy with the quality of the services they receive and yet almost all of us think there is room for improvement in services.

Yet it quickly emerges that there is good reason for people thinking reform is needed.

Worries about basic levels of safety abound. A staggering third of people surveyed said they knew someone who they thought had experienced a serious mistake, abuse or a preventable illness or death in a health or social care service.³⁵

Issues of dignity and respect remain a significant worry for many, with around half the public thinking that NHS (49%) and social care (48%) staff should treat people who use these services with greater dignity and respect.

There is a major concern about how far professionals actively listen to and involve the people using their services:

- Almost 1 in 4 (23%) say that professionals aren't really interested in what they have to say or do not actively seek or listen to their views or those of their loved ones.
- The same proportion (24%) of people felt they were not involved in decisions affecting their health.
- Many of us don't know where to go if we have a problem or concern to raise.
- Nearly 3 in 5 (61%) did not feel they had a clear way of providing feedback on a service. Where concerns are raised, many people are not confident that action would be taken.³⁶

This results in half of the public who had a problem with a health or social care service in the last three years doing nothing to report it, primarily because they did not have any confidence that their complaints would actually be dealt with.³⁷

These opinions provide a strong mandate for change.

Consumer rights in health and social care



Why do we need rights and why now?

The Government is committed to putting the voice of patients and people at the heart of the health and social care reform.³⁸ But report after report has found a systematic failure to listen to, and act upon, the concerns of patients, carers and families. These failures have resulted in neglect, poor quality care and even death.

People tend to use health and social care services when they are in crisis, when they feel vulnerable or over long periods of their life to meet their everyday need.

People have told us that they are grateful for the support they get (even if it is not up to scratch) because they know the NHS is largely free, health and social care staff are stretched and the system is under financial pressure.

However, as our research shows, behind the high satisfaction rates and a nation of grateful citizens lies a very different story. At the moment, people are reluctant to say anything when things go wrong, and yet the vast majority of the population think services need to improve. We know that the future provision of health and social care services will be increasingly difficult:

- dealing with the challenges of an ageing population
- providing better yet often more expensive services and treatments
- handling increasingly stretched budgets
- managing significant system reform.

To manage these pressures effectively, we need a different approach.

You have to know your rights to get them.

**Participant, Healthwatch England
deliberative event, July 2013**

Modern health and social care services should be designed around people's needs. This can be done only by working with people, by truly involving and engaging them in policy, commissioning and service delivery. Despite best intentions, those running the health and social care system have often engaged people in a very tokenistic way. Feedback is not actively encouraged and engagement is patchy - some very effective, some not. Truly involving people in developing services ensures their insights and experiences help services improve. It also helps them understand the tough decisions that have to be made.

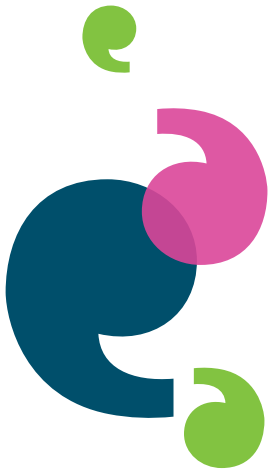
If we are going to have a sustainable and affordable health and social care system that is responsive to people's needs, we need a different relationship between the people who control services and those who use them, with a move towards people playing an active part in decisions about their care and treatment. It means giving people the information they need to manage their own care. It means helping people be actively involved in decisions about the future of services. In other words, a move from grateful patients to empowered citizens and consumers.

Developing a framework of rights, based on the things the public say, helps in this journey. Rights tell people what to expect from the services they receive. Rights empower people to assert what they need, when they need it. They help people to take an active part in decisions that affect their lives. They also help those in charge of providing services to stay focused on the things that really matter to those using services and they provide a framework within which we can measure what is delivered and see the extent to which it is meeting public expectations.

When we looked for data to see how well the current system was doing at delivering the rights people have defined, we found there was little information available. Even in an area as obvious as complaints, there is no national data set that tells us the number and nature of complaints across health and social care.



About us and what we've done so far



How we developed our framework of rights

We have been working with the public to develop a new framework of rights for health and social care.

Crucially there is a well-established and globally recognised framework for consumer rights, developed and refined over the last fifty years. We thought it would provide a strong foundation to build our work in health and social care.

These rights are based on international guidelines³⁹ adopted by the United Nations in 1985, and expanded in 1999. Governments around the world use these guidelines to help shape people's rights. They have inspired people and organisations around the world and in the UK to get better quality services and ensure their voice is heard.

We took these eight international consumer rights and tested them with representatives from local Healthwatch⁴⁰ and the public, drawing on their own experiences of the health and social care system. People helped us to develop the rights at a deliberative workshop,⁴¹ reflections after the event that we captured on video,⁴² and through nearly two thousand interviews⁴³ during the summer of 2013. We also spoke to academics and researchers about the rights⁴⁴ and explored different international and domestic models⁴⁵ to make sure we hadn't missed anything.

What do people want from a set of rights?

At the beginning, the people we spoke to didn't frame their discussion in terms of rights. They didn't want to demand too much from the health and social care services, which they thought were already stretched. Notwithstanding, as they began to describe the things they thought they should be able to expect, they had clear views.

People have told us that they want to manage their own condition and are more conscious of what they should be doing to live a healthy life. They want more choice over the kind of treatment available to them and want to decide how their care is provided. Many are buying care via Direct Payments or Personal Health Budgets.

People want high quality services that offer value for money and deliver better outcomes for patients and greater independent living for people using care services. They tell us that they feel they have a stake in the NHS and local care services through their National Insurance and tax contributions.

People want agencies to work collaboratively and deliver high quality services across service boundaries; they want continuity of support between different providers. They don't want different professionals arguing over who has responsibility to fund their care or to know the intricacies of how the NHS or council care is funded. They just want a good and joined up experience.

Despite not talking about rights spontaneously, when we presented them with the framework, people quickly got excited. The public found the international rights to be a useful starting point, but wanted to improve and develop them and make them easier to understand. They wanted to introduce some concerns arising from their own experiences of health and social care services.

Importantly they also wanted to see how these rights could be complemented by responsibilities to ensure people use health and social care services properly. We were struck by how keen and quickly people moved into a conversation about individual responsibilities, understanding that making health and social care services better is not simply a one-way process.

By the end of our conversations, the people we spoke to saw real value in adopting a rights approach, suggesting that it could introduce a greater level of accountability and ensure health and social care systems are more focused on the people they are serving.

We brought all of this work together into our new rights framework.



Our vision for rights in health and social care

With the public, we developed eight consumer rights for health and social care. We asked people to draw on their own experiences of using health and social care services to help us better understand what these rights might look like in reality. We have captured some of these below.

1. The right to essential services

Everyone has the right to a set of basic and essential treatment and care services at a defined standard.

People we spoke to felt this is the starting point for thinking about rights. It represents the way that as a society we ensure every one of us has access to a core set of services.

It's at the centre of everything - the minimum - the things that you can expect across the whole spectrum.

Given the pressures on funding in health and social care, this right could become even more important in the future.

What this could mean in practice

- You have the right to be seen by a cancer specialist within a maximum of two weeks from GP referral for urgent referrals where cancer is suspected.
- If you are a child at risk of abuse, harm or neglect, your council or health professional should work together with the relevant authorities to make sure your needs are met in a sensitive and supportive manner.
- If you are a resident in a care home, you have the right to be adequately fed and given help with eating at mealtimes if you need it.





2. The right to access

I have the right to access services on an equal basis with others, when I need them and in a way that works for me and my family.

People should be able to access the treatment and services they need, irrespective of where they live or who they are and have a clear sense of what they are entitled to. People felt that easy and timely access to GPs is particularly important as they are often the gatekeeper for access to other medical services.

Getting appointments at GP surgeries is a joke. They forget we all have jobs. There are no loopholes or ways round it. You just cannot get an appointment.

What this could mean in practice

- If you need to see a GP, you should be able to choose and register with a local practice, and ask to see a particular GP, especially if you want to see one of the same gender.
- If you need to use a health service, the health professional should not deny you access, provide you with a lower quality service or discriminate against you because you are disabled or because of your age, religion, ethnicity, sexuality or gender.
- If you need social care and are moving from one council area to another, the councils should ensure you have a continuity of support before, during and after you move.

About us and what we've done so far

3. The right to a safe, dignified and quality service



I have the right to high quality, safe services that treat me with dignity, compassion and respect.

This right is about how services are delivered. When people are ill or need care, they should expect high quality services that are safe, will help make them better or make their lives easier. They should also expect to be treated like a human being, being looked after by people who are compassionate. People we spoke to felt very strongly about this, pointing out the good and the bad:

I had an excellent service when I had my daughter two years ago. The midwife was very professional and knew what she was doing. I experienced some complications and it was handled very professionally.

My Nan's 87, she paid into the system all her life. She's been out and worked. It's a basic human right. She needs her toenails cut. You wouldn't leave a dog in pain. You shouldn't leave a human

What this could mean in practice

- If you are in a care home and can't go to the toilet alone, staff should offer support in a timely fashion and give you the privacy you want. You should not be left to wet your bed or strain your body while you try to hold it in.
- If you have a learning disability and are undergoing surgery, you should expect the specialist to talk to you (if you want them to) about it. They should tell you what the benefits might be and any possible side effects. They should do this using language you will understand. They should not withhold any information if you want to know more.
- If you receive a health or social care service, you should expect the building to be well maintained, cleaned regularly and contain the equipment needed to support the people using it.



4. The right to information and education

I have the right to information and education about how to take care of myself and what I am entitled to within the health and social care system.

People are often keen to manage their own needs and conditions as much as possible. They should have access to the information and education they need to do this. They should also be told from the outset about the rights they have and be given information about the services they are entitled to receive.

Pharmacists are very good. The pharmacist will correct the GP or tell you to go to A&E if you should do. My pharmacist does talk to my GP to talk about the prescription to check its ok.

What this could mean in practice

- If you have diabetes, you should be able to find out how nutrition affects your condition and you should be given advice on how to manage your diet effectively.
- If your dad wants to go into a care home, you should be able to find out about the support he could get from his council, the quality of the services available and what he would be expected to pay for himself.
- If the NHS collects any confidential information about you, it should be kept safe and secure. You should be told how information about you might be used and you should be able to request that your confidential information is not used beyond your own care and treatment.



5. The right to choose

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

Wherever possible, people should have the right to make choices about how and where their treatment or care is provided. They should be given a meaningful choice, including the necessary information to support proper choice.

Where there are additional paid-for options, people should be told about them. Not everyone wants to choose. Some people have told us they prefer if the choice is made on their behalf, but all of us should be given the option of choice.

Just to be able to know what the options are. You know, 'this is what's going to happen'. A lot of the time people get treatment but then they realise they could have done something else.

What this could mean in practice

- If your council has said you are eligible for social care, you should be given the option of choosing different ways of being supported in your own home, rather than being pressured to go into a nursing home.
- If you go to your dentist to have a filling replaced, you should expect a high quality service, but you should also be offered paid-for options such as white fillings, even if you will have to pay for this yourself.
- If you have been assessed as needing therapy to help you manage your anxiety condition, you should be able to choose who provides this support and what type of therapy you get.



6. The right to be listened to



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

You should have the right to have complaints and feedback taken seriously and acted upon when things go wrong. People don't want to have to complain - they would prefer things are right first time. But when they do complain, they need a system that works and is easy to use.

When my husband became ill, I knew straight away he wasn't right. But because it was me speaking on his behalf, I just got brushed off. I had to get him sectioned and then get help from the crisis team, they were amazing. But I had to fight.

What this could mean in practice

- If your mum is in a care home and you notice that she did not eat any of her food before it was taken away, you would report this to the home manager. You should expect the manager to put things right. The next time food is brought over to your mum, you should be able to see the difference your feedback has made.
- If you suspect someone is being mistreated in a residential home where your sister also lives, you should be able to register your concerns and have them investigated appropriately. You should not have to worry that your sister's care will in any way be altered as a result of your complaint.

7. The right to be involved



I am an equal partner in determining my own health and wellbeing. I have the right to be involved in decisions that affect my life and those affecting services in my local community.

There are two elements to the right to be involved. Often people are experts in their own condition or the condition of people they care for. Their views must be taken seriously by professionals as they can have valuable insight to add.

People are also citizens and part of the wider community. They should have the right to be consulted and involved about decisions that affect health and social care services in their area.

With my direct payment, I am in control of my care and my life. I chose who comes into my home and what they do to support me.

What this could mean in practice

- If you are a young person with a mental health condition, your ideas, opinions and concerns should be treated on an equal basis with the professionals when planning how you will be supported in the future.
- If you are at the end of your life, your family and your doctors should listen to your wishes and make sure you have the support and care you need to die at home, if you want to.
- If your council is closing a community centre for older people in your area, they should ask your opinions about the future of the service and keep you updated on what is happening and how your views have affected their decisions.



8. The right to live in a healthy environment

I have the right to live in an environment that promotes positive health and wellbeing.

We live in a society where our health and wellbeing is connected to a wider set of economic, social and environmental factors. People should have the right to live in an environment that protects their basic wellbeing as well as promotes and encourages good health.

If you go to my pharmacy, there's no information about how not to become sick, you just get medication when you're ill.

At my child's school, they tell parents what to put in lunch boxes but never explain to kids the reason behind it.

What this could mean in practice

- If you are an older person being discharged from hospital, the council and health services should work together to make sure your home is safe and suitable for your needs, making sure any alterations are made before you leave hospital.
- If you are a child carer, your council should make sure you have opportunities to have a break from your caring responsibilities, have fun and socialise with other children of your own age.
- If you want to give up smoking you should find it easy to get the support and information you need to help quit.

About us and what we've done so far



Bringing this to life

This is just the beginning of our work on consumer rights in health and social care. Our work to date has raised a number of questions that we need to resolve as we bring these rights to life and make sure that they can be used not only by people but by providers, commissioners and regulators to help design and evaluate services.

People felt that whilst these rights were distinct, they were also closely interrelated. For example, the right to choose depends on a degree of knowledge and information to make an informed choice, yet the right to information and education is not only about choice, it also makes it possible for people to be involved and take responsibility for their own care, for example.

It was also clear that everyone might apply a different interpretation to the meaning of the rights. This is particularly the case in relation to the right to essential services. The people we spoke to thought it probably included urgent medical treatment, adequate nutrition in any care setting, help with managing a long term health condition and home or personal care to live as independently as possible.

Developing a shared view of essential services is complicated by the issue of funding. People are used to having some services provided free of charge such as accident and emergency services, or seeing a GP.

Other health services like dentistry or physiotherapy may have charges. The situation in social care is changing rapidly, with many more people paying for more of the basic services they need. Finding a common understanding of essential services may be increasingly important with increasing pressure on funding.

In our deliberative work, people also quickly pointed out that where they exercised rights, they were acutely aware that they had a set of responsibilities to use health and social care as good citizens and to safeguard their own health as much as possible. Developing a complementary set of responsibilities is something we particularly want your views about and this will be one focus for our ongoing conversation with the public.

We are also aware from all our work across the health and social care system that there are a number of frameworks already in existence - the NHS Constitution, the Care Quality Commission's fundamental standards and the Think Local, Act Personal "T" statements to name just a few. We will continue to work to ensure we develop a shared understanding of how the rights framework sits alongside and complements these existing frameworks.

This adds up to a requirement for more work in developing a shared sense of what these rights mean in action.



When we submit our next Annual Report to Parliament in a year's time, we will have finalised our set of consumer rights, having had conversations with the public, stakeholders and partners to refine them. This report starts our conversation with you, and will include a formal consultation process. We will:

- launch a dedicated area on our website to discuss consumer rights, where you can leave comments
- start a conversation with the public, people who use services and people who advocate for them, to talk with them about these rights and start getting people to use them in their everyday lives
- ask people to share their experiences of these rights with the Healthwatch network to make sure local and national decision makers listen to, and act on, their experiences
- do more work to check whether the right laws, policies and practices are in place to ensure people can assert these rights and use our statutory powers to challenge local services and advise the Government where rights are being ignored or undermined
- collaborate with people who use mental health services and children and young people to understand better what these rights mean for them.

We also plan to develop and test a new index for health and social care that will help us know whether we are getting better, worse or standing still on each of the rights. This will help us to identify areas for improvement for discussion with the public, providers, regulators, commissioners and the Government.

We are keen to start a discussion with you. Please get in touch with us by:

Email: rights@healthwatch.co.uk

Twitter: [#HealthwatchE](https://twitter.com/HealthwatchE) [#thinkrights](https://twitter.com/thinkrights)

Phone: **03000 683000**

Address: **Healthwatch England, Citygate, Gallowgate, Newcastle upon Tyne NE1 4PA**

About us and what we've done so far



The one thing people respect is being kept informed, whether it's good news or bad.

Participant, Healthwatch England
deliberative event, July 2013

Healthwatch England - a unique role



Healthwatch England was born at a time of great change in the way health and social care services are provided.

The Health and Social Care Act 2012 created Healthwatch England with a powerful ambition of putting those who use services at the centre of health and social care.

We have a unique role to be the independent consumer champion in health and social care. We have been given significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who control health and social care services.

Health and social care is a critical lifeline to many millions of people every year. It can be a bewildering environment that we often interact with when we are vulnerable, fearful and more dependent than usual. It can be difficult to speak up and when we do, we are not always heard. A strong consumer champion can help to make sure these voices, especially those who are vulnerable and speak more quietly, are heard.

Interpreting our role

As with any new organisation, we have spent time interpreting what our role means, and testing this out with stakeholders across the health and social care world.

Understanding where we add most value has been important - we are a relatively small player in a complex and vast system. Our aim is to focus on those areas where we can make most difference. We need to set the agenda rather than just respond to what others are doing. However, we can only set the agenda if we have the right priorities and partnerships to argue powerfully and credibly for change.

There are a number of unique aspects to our role.

We have been established as a consumer champion

This means we always start with the needs of the consumer (or patient or service user or client). We understand the issues that matter most to people and lobby for change on their behalf. Often this means representing and amplifying the voice and concerns of those who use services.

However, it also means we have to argue for what is in the overall consumer interest - taking an overview of what will benefit consumers most, particularly in relation to the future.

About us and what we've done so far



We have to ask the awkward questions, see things from a different point of view. Above all, we are focused on achieving results for consumers. We will be ambitious - our role is to say where change is most needed. But we will be realistic and provide solutions that improve services for consumers.

Our remit covers children, young people and adults

We have a particular responsibility for those in greatest need and those who sometimes struggle to be heard. We have a responsibility to champion the needs of children, young people and adults. We seek out evidence and views about what matters to everyone who uses health and social care services. If we can make it better for these most vulnerable people in our society, we will all benefit.

Our remit covers health and social care

The world of health and social care is not always people-friendly. Too often it categorises people into a variety of ailments or conditions, with disparate clinical, emotional, social and physical needs, each met by a different part of the system. However, as consumers, we do not divide our own experience in this way because we are individuals with a series of needs, some very complex.

Many people, before they are in contact with health and social care services, assume all their needs will be met by a joined up service.

We know that this expectation is simply not met in reality. Even within the health service, people share with us their frustration that different groups of professions appear not to communicate with each other and fail to act in a co-ordinated way. Even more frustrating is the interface between health and social care systems, with many people reporting being passed from pillar to post as they try to get their needs met. And yet it is this group of people with multiple needs who are often the most vulnerable and least likely to be heard.

For Healthwatch England, our starting point is always the person, someone with a range of health and social care needs. Our work is based on their experiences, needs and preferences.

We have a national perspective

We develop an informed view of the issues and trends affecting people at a national level. We can draw together the evidence and experiences of service users and experts in the third sector and from local Healthwatch to establish a holistic national picture of what works and what doesn't - regardless of location, who pays the bill or what part of the health and social care system is involved.

We have strong statutory powers

The Health and Social Care Act formalises the relationship between Healthwatch England, the Secretary of State, NHS England, Care Quality Commission, Monitor and local authorities. We have a unique power to advise this formidable range of organisations. Our ultimate recourse is to the Secretary of State.

We have the power not only to report on the key issues that affect people who use services, but to expect that those in control respond to us. They don't need to agree, but they have to publicly tell us what they are going to do to respond to our advice.

Our role is to say where change is most needed. Sometimes we will give advice formally, using our powers to raise issues of concern or where we feel we, or any local Healthwatch, are not getting an adequate response. Often, we will work together with partners to influence their thinking at an early stage and to help them get it right from the start by designing services around consumers' needs.



About us and what we've done so far



How we work

We have a lot to do. To deliver, we need to work effectively with colleagues at a national and local level and across different sectors. We do not want to replicate work already being done by others, nor do we want to recreate expertise others already have, for example, the third sector organisations who know so much about particular groups of service users.


Our formal partners

Over the first six months, we established formal strategic arrangements with all of our key partners including statutory partners, the Local Government Association and the Department of Health.

Our arrangement with the Care Quality Commission had special attention early on. We were aware of the concerns about our creation as a committee of the Care Quality Commission and the impact that some thought this would have on our independence to speak and act. We have developed and agreed a very robust approach to guarantee our independence and our relationship to date has been co-operative and productive.

Our work with our statutory partners has also been productive. The question we ask them is simple: are they putting people at the centre of what they do? We challenge them to be focussed on people's needs when they plan, commission, deliver and evaluate services. There are many new organisations involved in health and social care services with new responsibilities to put consumers at the heart of their work. It is not our job to engage the public for them. It is our job to challenge and hold them to account to do that public engagement well.

The NHS Constitution brings together the principles, values, rights and responsibilities that underpin the NHS to empower patients, staff and the public. But it is little known by the public. We have been challenging the Department of Health to make the Constitution useful for everyone using services. They are now looking into how the public understands the Constitution and how individuals could use it to enforce the rights and pledges made. We are hoping to bring this together with our work on consumer rights in due course.



In these first few months, we have been raising the concerns of people using health and social care services in the corridors of power. We have been particularly pleased to have our role acknowledged through invitations to advise and respond to major inquiries and consultations. A large part of our work has been to explain to people what Healthwatch is and how we want to work with them.

Establishing a new organisation and a new concept takes time. We have developed a new structure and been building our staff team, as well as developing our remit and ways of working.

During the first few months of our existence, major reports have been commissioned or published which raised deep and troubling concerns about patient safety in our hospitals. For example, we were part of the National Steering Group for the Keogh Review into the quality of care and treatment in NHS hospitals.⁴⁶ We advised the Review on how to ensure patients' views were captured when the 14 hospitals were inspected. The Review found that gathering patients in a room and asking the simple question "how is it for you?" gave powerful insight into how hospitals were working. When the Review was published, we worked to ensure that local Healthwatch organisations understood what it meant for their local hospital service.

About us and what we've done so far



The Healthwatch network

We lead, support and oversee the work of the Healthwatch network across the country. It is our task to make sure that the whole is greater than the sum of the parts.

As the network grows, we will have eyes and ears in every region of England telling us what matters to users of health and social care. A strong network will mean that local issues can be raised at national level. Local Healthwatch can draw on the best national evidence and Healthwatch organisations can learn from each other, share best practice and focus their resources to make the most impact.

Our network campaigns will ensure that together, we influence decisions taken at a local and national level and challenge local providers and national bodies to make the changes needed to improve services.

We also support the Healthwatch network to ensure people get the best from the health and social care system that currently exists. In every area, local Healthwatch will signpost people to where they can get the services they need, and help people navigate a large and complex health and social care system. Together, we help people understand what to expect when they receive services and what to do when things go wrong or they have a problem with the services they receive.

Building an effective network has been an early priority. In all of this work, we have taken advantage of new technologies. Our launch event, which has been nominated for a sustainable event award, consisted of five simultaneous events across the country. The morning events were led and run by a local Healthwatch and at lunchtime all locations linked up to London to hear Jeremy Hunt, Secretary of State for Health, celebrate the birth of the network.

Since meeting face-to-face is often expensive and time-consuming, we have developed a virtual, cloud-based space for Healthwatch to meet. We call this online space the Hub and it is where the Healthwatch network can get in touch with each other, share ideas, store and share information, build evidence and simply come for a chat with other Healthwatch across the country.

If we're going to crack these really big challenges, the only way to do it is to think about the issue from the patient's point of view. We need to take the person's point of view, and not the needs of the institution, the hospital or the system.

Rt Hon Jeremy Hunt MP
Secretary of State of Health at the
Healthwatch network launch

We have made good progress in ensuring that the network works well with those who commission, run and regulate services across the country. In time, this will help ensure that the Healthwatch network:

- 1 knows how local health and social care services work and the changes coming down the line that will affect their local communities
- 2 ensures the local community is properly informed and engaged in decisions affecting services
- 3 can flag issues of concern immediately
- 4 knows when an announced Care Quality Commission inspection is taking place and can feed in issues raised by the public.

However the Healthwatch network needs to collaborate widely with all those who have an interest in improving health and social care services. England has a long history of patient and public engagement in health and social care. Each arrangement has broken new ground, building on its predecessors. Healthwatch can also break new ground, but only by working with others.

We know, and have met, many outstanding third sector organisations and charities. They are already delivering for some of the hardest to reach communities and have a deep understanding of their communities' needs - much more than we could ever know. We want to work with those organisations to ensure we have the best possible evidence and the widest possible views to help influence the national agenda.

Many charities have helped us raise awareness of Healthwatch with their communities and are keen to work with us co-operatively, so that the best interests of people who use services are met. Over the next year, we will continue to meet and learn from each about where we can add the most value to each other's work.

Professional associations such as the Royal College of Nurses and the Royal College of GPs have, without exception, opened the door to us. They have helped us to raise awareness of the role of Healthwatch, and helped reinforce the message that professionals have to understand and respond to the needs of patients and users of services.

About us and what we've done so far

Who we are

Since our launch, we created an independent committee, whose remit is to determine the direction of the organisation, maximising the benefits we can bring to users of health and social care at a national and local level.



Chair - Anna Bradley

"It is time to put consumers, users and patients at the heart of health and social care; time to create people-shaped systems that suit all of our varied needs. Healthwatch England is central to achieving the change - we are here to speak up on behalf of consumers and constantly challenge the system to be different and better"



Michael Paul Hughes

"Healthwatch England will speak to the public, to government, and the people who manage and deliver health and care services. Through our own work, and the work of the thousands of people involved in local Healthwatch, we will make sure that the consumers' views count in our health and social care services"



John Carvel

"The biggest change I would like to see in health and social care is that they become properly integrated. Lots of people have healthcare needs and social care needs. They shouldn't have to get a master's degree in public administration to work out how to get the NHS and local authority social care services to cooperate"



Christine Lenehan

"Healthwatch is a real chance to make the voices of people who use health and social care services matter, that this also includes children and families is fantastic"



Alun Davies MBE

"I believe passionately that those who use services must have a genuine say in and influence on what they do and how they do it. I believe the Healthwatch network and Healthwatch England have a vital and key role to play in moving a long way to achieve this long-cherished goal. Nothing about us without us"



Jane Macfarlane

"For me Healthwatch provides a well assembled and balanced structure for people to have their say and for those collective voices to be taken notice of in all the right places"

The work...the wider Healthwatch network is doing will be key to creating and delivering a successful health and care system for local communities across the country.

Norman Lamb MP
Minister of State for Care and Support



Jane Mordue

"I passionately believe that Healthwatch, with its focus on the voice of real people, can make a difference for all who use health and social services. I joined because this feels like the best chance for a generation to do so - our statutory powers give us the tools to do the job. Now we must use all this evidence to persuade policy makers to listen and act to improve services"



Dave Shields

"Healthwatch is well placed to make a real difference to users of health and social care, both at a national level - influencing those in power - and at a local level - helping those in the local community. I'm proud to be part of that difference"



Patrick Vernon OBE

"Healthwatch is a new approach and ethos in advocating and representing the views and experiences of consumers, service users, patients and carers that access health and social care. What is exciting about local Healthwatch in particular is that they will engage with local stakeholders as a real player of influence and change in improving local services"



Cllr David Rogers OBE

"Healthwatch England is a real opportunity to put individuals and their experiences at the heart of the complex web of health and care services"



Dag Saunders

"For me, Healthwatch England represents the opportunity to bring together consumer experiences across the health and social care sector and share local experiences at national level. This allows us to bring about changes where they are needed"



Christine Vigars

"Healthwatch is uniquely placed at both national and local level to improve patient experience of health and social care services. Local Healthwatch is now established across the country and working with voluntary organisations and user groups to give local people a voice and to begin to close the gap between rhetoric and reality in local services"

About us and what we've done so far

[Healthwatch has...] got to be here for the long term. I make that commitment. We don't want any reinvention now of the patient voice or public involvement. Let's make this system work. You will have my full backing in doing just that.

Rt Hon Andy Burnham MP
Shadow Secretary of State for Health



Dr Katherine Rake OBE
- Chief Executive

"It is a privilege to have been tasked to build this unique organisation from scratch. I have been impressed by the energy and commitment I have seen with local Healthwatch. This, combined with the access we have already been given to influential organisations, gives a sense of the power of Healthwatch"



Dr Marc Bush
- Director of Policy and Intelligence

"Healthwatch has the power to build from people's experiences, opinions and ideas and influence the priorities and decisions of policy makers. I look forward to witnessing the moment when policy makers realise people who use services, and the wider public, must have an equal say in the future of health and social care"



Claire Pimm
- Director of Communications and Engagement

"I am excited to support local Healthwatch up and down the country as they get established and build relationships with the public and professionals. With Healthwatch, there is an opportunity to create a trusted and powerful nationwide brand that can deliver a real difference to people that use health and social care services"



Sarah Armstrong
- Head of Operations

"Healthwatch means the opportunity to make a difference to people when it most matters - when something has gone wrong, or when someone needs advice or a listening ear, and sometimes when they are feeling vulnerable, Healthwatch is a safe place to share and be heard"

How we work

We have taken an open, transparent and accessible approach to the Committee's work. Our committee meetings have been held all around the country, from Gateshead to Plymouth. At every meeting, we have heard from the experiences of local Healthwatch and the partners they work with. The meetings are webcast live to ensure everyone can see the Committee at work and the meetings can be viewed after the event. The public can also get involved on the day with a question and answer session or through questions submitted on-line. We will continue to look at new ways to generate public interaction and engagement with our work.

We also recognise that our task is enormous and to make a difference, we need to focus our resources. That is why we have been working hard to make sure we choose the issues that matter most to consumers and where we can make a clear difference. In our first year, we have chosen to focus our resources on a few key areas. These are:

- improving the complaints system in health and social care
- ensuring people's voices are heard across the health and social care system
- supporting local Healthwatch
- building an effective organisation.



Local Healthwatch



Local Healthwatch was launched across the country from 1 April 2013, but many councils had established one in shadow form before this date. These early trailblazers tested and showed what the Healthwatch network might achieve once it was officially up and running.

In their first few months, local Healthwatch have been appointing dedicated staff and committees with an impressive range of skills and experience. They have held successful launches, often with standing room only, and have shown early signs of imaginative engagement with local communities.

Local Healthwatch organisations have three roles:

- They help local people get the best out of their local health and social care services by providing information, advice and support about services.
- They gather the views and experiences of local people on services, so that they can influence how they are designed and delivered locally via the Health and Wellbeing Board.
- They pass information and recommendations to other local Healthwatch organisations, Healthwatch England and the Care Quality Commission.

Local Healthwatch organisations were commissioned by councils, according to local needs and priorities and as a result they are diverse in their size, form and set up, as the map shows.

Some were commissioned with plenty of lead-in time, some were active in shadow form well ahead of their official launch and others were commissioned much closer to the deadline.

Despite the diversity, all local Healthwatch organisations shared similar challenges: how to establish a new organisation quickly, with a new remit, in a new health and social care landscape.

Local Healthwatch development route July 2013

● Transition from Local Involvement Network	(23)
● Voluntary sector collaboration	(96)
● Consortium approach	(16)
● Independent social enterprise	(11)
● Not known	(6)



About us and what we've done so far



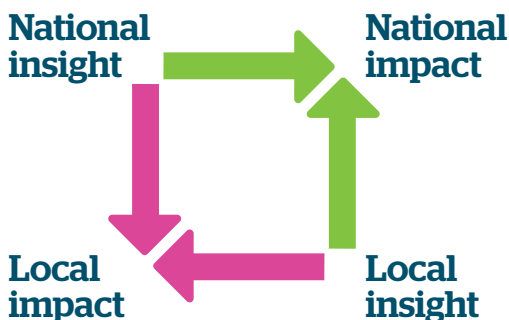
Supporting local Healthwatch

Our explicit focus in the first six months was to offer as much support as possible to emerging local Healthwatch and to begin to develop the Healthwatch network.

Like many of the early Healthwatch, we were also a start-up organisation. Finding our feet and collaborating with them at this time helped us to understand what support they might need from Healthwatch England in the future. Our main aim during this period was to show 'what good looks like' and to offer some centrally-produced guidance, products and services to save time, money and duplication.

We believe we can add value to the network in two ways:

- When we join up their experiences and amplify their voice across the country, so local experiences lead to national impact.
- When we share the information and intelligence we hear at a national level so that national experiences lead to local impact.



We recruited a Development Team to offer advice and assistance to local Healthwatch organisations to help them carry out their work effectively. There is a named officer for every local Healthwatch and the team also runs a helpline, produces regular newsletters, runs training on the statutory powers and supports regional Healthwatch networking.

The team also works closely with the Local Government Association, which offers advice and assistance to councils as they commission and monitor local Healthwatch organisations.

A network speaking with one voice

Lots of work happened in the build up to the network launch to prepare Healthwatch and to ensure it could start to have as big an impact as soon as possible. This work was delivered by the Department of Health and the Care Quality Commission, working with the Healthwatch programme board, advisory group and task and finish groups. We would like to thank all of those involved in the planning and creation of Healthwatch for all the hard work and for laying the foundations for success.



During the set up phase, we developed a unifying brand to promote awareness of Healthwatch nationally and locally and to provide a recognised 'symbol of trust' for the public. We engaged widely when developing the brand to make sure we captured and understood what people wanted from Healthwatch. Each local Healthwatch uses the brand and it translates well online, in print and on social media, where its presence grows daily.

We have developed an online communications centre - only the second example of this in the country. This offers advice on use of the brand and shares very simple methods of producing high quality, locally-branded materials for every local Healthwatch. This means local Healthwatch can look highly professional and unique, but are still clearly part of the Healthwatch family.

We built a free website and content management system for each local Healthwatch to customise and use. We were able to do this very cheaply compared to the many hundreds of thousands of pounds it would have cost the Healthwatch network overall, if each local organisation had commissioned their own.

We have also produced a range of tools, including key messages, a communication toolkit, a digital communications guide and a series of films including an advert explaining the role of Healthwatch. All of these are designed to help local Healthwatch communicate professionally and easily.

Guidance to the network

We have published lots of guidance notes, briefings, policies and templates to support the development and operation of local Healthwatch organisations. These include guidance on maximising influence, a toolkit on how to create a children and young person-friendly Healthwatch, guidance on complaints policy and sample templates and an escalation and whistleblowing framework.

Local Healthwatch in practice



The Healthwatch network is already delivering for people in local communities. We are continuing to share this best practice around the network and have worked with the Local Government Association on a new tool to help local Healthwatch and council commissioners measure the impact and outcomes of their activities.

Healthwatch Solihull

has created 'Service Watch', a survey that gathers opinions from service users on health and social care.

Healthwatch Torbay

has been on the road with its "consultation caravan". The caravan has caught the attention of local people in Brixham, Paignton and Torquay. They also have a number of ways of involving young people, including a new young people's forum called 'Torbay Youth Power', and training a team of Young Inspectors.

Healthwatch Cornwall

has uncovered a major gap in the services meant to deliver a diagnosis for autism for children aged five and over. This was causing distress to a number of families and Healthwatch Cornwall's work resulted in new solutions at no loss to other services in the area.

For more detail about the work of local Healthwatch, please go to www.healthwatch.co.uk

Healthwatch Sefton

has developed Community Champions to gather experiences and views from the local residents across Sefton.

Healthwatch Kingston upon Hull

has been working to make sure that local people know more about dementia, by running training sessions for health and social care professionals, carers, representatives from local voluntary and community sector organisations and members of the public.

Healthwatch Staffordshire

has been monitoring services through patient appeals and unannounced ward visits and has produced a series of local service directories to ensure local residents have the information they need about local services.

Healthwatch Peterborough

has focused on those in prison to ensure they get support on health-related issues. They will shortly produce guidance to help all local Healthwatch engage with their local prison and prisoners.

Healthwatch Sutton

has been working to improve the experience of patients admitted to the local hospital. They published an action plan and follow up visits showed how the recommendations had improved patient care. The work has been recognised with a Quality and Value award.

Healthwatch Essex

has focused on how health and social care providers bring together their services so that the citizens of Essex get services that work better together.

Healthwatch Surrey

has used its powers to enter and view local establishments and produced a report to help improve stroke services.

Healthwatch West Sussex

has conducted a survey of GP surgeries and patients, and had responses from over 50% of the practice managers across the county. They have fed back results to each practice manager highlighting their respective areas of concern and good practice.

Healthwatch Dorset

has formed in partnership with the county's most prominent football club, recently promoted AFC Bournemouth, and will be running a community project to promote diversity and fight inequalities - focusing on working with children, young people and their families in specific neighbourhoods across Bournemouth.

Next steps



Our journey in developing and promoting consumer rights for health and social care has only just started. We want to become a powerful champion both nationally and locally, connected to what matters to people and what makes change happen at the highest level.

Being independent

Over the year to come, we will use the independence and the powers we have been given by the law, to challenge others to put people at the heart of what they do. Where we spot problems, we will give them a voice and ask the appropriate body to take action. This year, we will focus particularly on how we get feedback and complaints systems working for consumers, so that where problems arise, they get a quick and fair resolution.

We will be campaigning to:

- influence the direction of national policy to ensure that concerns and complaints systems are designed with people's needs in mind
- improve local complaints procedures and demonstrate what a good complaints system looks like
- help people navigate their way through the complaints system and ensure they know what kind of service to expect when they make a complaint.

Being trusted

We are committed to raise awareness of Healthwatch nationally and across local communities. It is critical that those who need our services know where to find us and we will work together to become a recognised name, taking full advantage of innovative and new technologies. We will continue our commitment to openness and transparency by, for example, holding our Committee meetings around the country and in public.

We are committed to making the Healthwatch network more than the sum of its parts. Realising the potential of the network will require us to link national and local together to form one strong voice. We want to gather local insight to influence national policy. And, we want to ensure that the best national evidence informs local services. Armed with the evidence, we will support improvement now and shape the future.

With the Local Government Association, we are developing support for local Healthwatch to achieve good standards of service across the whole Healthwatch network.

Our support will help local Healthwatch focus their resources on making a difference locally. We will ensure that local Healthwatch know what to do when there are problems or worrying events in their local services and ensure they get a swift response from providers and regulators.

We recognise the unique importance of the input of children and young people, particularly those with long term health conditions. That's why over the next year we will be working closely with children and young people and organisations, building on the work we have already done with Brook, the sexual health charity for young people, and the children's toolkit we produced for local Healthwatch.⁴⁷

Giving a voice

We recognise that individuals can feel lonely and vulnerable when they are using health and social care and may not be able to voice their personal concerns. We will make sure that we provide a powerful collective voice to the issues that matter most and bring the concerns of people locally to a national stage, where they are able to have influence. We will pay particular attention to those that find it hardest to be heard. If we get it right for them, we will get it right for everyone. But, we recognise that for voice to be heard everywhere within health and social care, it needs to be everyone's responsibility to do this well.

Our job is not to do public engagement for health and social care services but to demonstrate how best these services listen and respond to public views. We will be looking within health and social care, and more broadly, to identify how best to gather the public's views, how to engage them in the decisions that affect them and their local communities and how to involve them as equal partners in their care.

Here for the long term

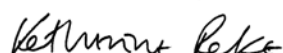
We are here for the long term and are delighted that in the early days we have secured explicit cross party support. We are conscious of making best use of our limited resources and will need to focus our work on clear priorities. This way will build our profile, credibility and influence. In developing these priorities, we will consult and engage consumers to ensure that we are working on what matters most to them. Next year, we will report back our further development of the rights framework presented here and our evidence of how, as a nation, we are making progress to realising these rights.

Together we can make a difference

We know that there are bodies with deep understanding and expertise in specific issues. It would be pointless for us to attempt to replicate this. Rather, we will always seek partnerships with others to make change happen, ensuring that we get the most value from our limited resources. We will connect with these influential bodies - be they charities or professional associations - at a national level and support local Healthwatch to do the same.

With eyes and ears in 152 parts of the country, we will have an unprecedented insight into what is happening and what matters most to communities across England. We will use this to ensure that we highlight problems and hold others to account in putting them right. But dealing with the here and now is only part of the solution. We will work together to help shape the future design and delivery of services and support local Healthwatch to use their local networks to ensure that services are designed with communities in mind.

As a new body, we know that we have to prove the value that we add to a complex and changing environment. To do this, we are involving people in the planning of how we work into the future. After all, the ultimate test of our success will be the difference that we have made to people's experience of health and social care.



Dr Katherine Rake OBE - Chief Executive

References



- ¹ NatCen (2013) British Social Attitudes 30: <http://www.bsa-30.natcen.ac.uk>
- ² Centre for Disability Research / Department of Health (2009) Estimating future numbers of adults with profound multiple learning disabilities in England: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103200.pdf
- ³ For a comprehensive discussion of the pressures of our aging population see Select Committee on Public Service and Demographic Change (2013) Ready for Ageing?: <http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf>
- ⁴ Health and Social Care Information Centre (2013) Provisional Monthly Hospital Episode Statistics for Admitted Patient Care, Outpatients and Accident and Emergency Data: <http://www.hscic.gov.uk/catalogue/PUB11550/prov-mont-hes-admi-outp-ae-apr-may-13-14-inp-tab.xls>
- ⁵ Health and Social Care Information Centre (2013) Community Care Statistics, Social Services Activity: England 2012-13, Provisional Release: https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-stats-soc-serv-act-12-13-prov/comm_care_stat_eng_2012-13_soc_serv_act_reppdf
- ⁶ Health and Social Care Information Centre (2009) Trends in Consultation Rates in General Practice 1995 to 2008: Analysis of the QResearch® database: <https://catalogue.ic.nhs.uk/publications/primary-care/general-practice/tren-cons-rate-gene-prac-95-09/tren-cons-rate-gene-prac-95-09-95-08-reppdf>
- ⁷ Health and Social Care Information Centre (2013) Community Care Statistics, Social Services Activity: England 2012-13, Provisional Release: https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-stats-soc-serv-act-12-13-prov/comm_care_stat_eng_2012-13_soc_serv_act_reppdf
- ⁸ Health and Social Care Information Centre (2013) Community Care Statistics, Social Services Activity: England 2012-13, Provisional Release: https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-stats-soc-serv-act-12-13-prov/comm_care_stat_eng_2012-13_soc_serv_act_reppdf
- ⁹ Laing & Buisson (2013) Care of Elderly People UK Market Survey 2012/13: <http://www.laingbuisson.co.uk/MarketReports/MarketReportsHome/tabid/570/ProductID/548/Default.aspx>
- ¹⁰ Independent Age (2012) The Real Cost of Care: Five ways our care home funding system penalises the average older person and their family: http://www.independentage.org/media/207665/the_real_cost_of_care_2012.pdf
- Institute of Public Care / Melanie Henwood Associates (2011): People who pay for care: quantitative and qualitative analysis of self-funders in the social care market: http://ipc.brookes.ac.uk/publications/pdf/People_who_pay_for_care_-_report_12_11_final.pdf
- ¹¹ Age UK (2013) Care in Crisis: Seven building blocks for reform: http://www.ageuk.org.uk/documents/en-gb/campaigns/care_in_crisis_report_2012_propdf?dtrk=true
- ¹² Scope, National Autistic Society, Mencap, Sense, Leonard Cheshire Disability (2013) The Other Care Crisis: Making social care funding work for disabled adults in England: http://www.scope.org.uk/sites/default/files/The_Other_Care_Crisis.pdf
- ¹³ Office for National Statistics (2013) Inequality in the provision of unpaid care in England and Wales: <http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/sty-unpaid-care.html>
- ¹⁴ Carers UK / Employers for Carers (2012) Sandwich Caring: Combining childcare with caring for older or disabled relatives: http://www.carersuk.org/media/k2/attachments/UK4054_Sandwich_Caring_Nov_2012.pdf
- ¹⁵ Office for National Statistics (2013) Inequality in the provision of unpaid care in England and Wales: <http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/sty-unpaid-care.html>
- ¹⁶ Based on estimated spend on Carer's Allowance 2012/13. For more detail see Department for Work & Pensions (2013) Medium-term forecast for all DWP benefits: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/222845/expenditure_tables_Budget_2013.xls
- ¹⁷ Carers UK / University of Leeds (2011) Valuing Carers 2011: Calculating the value of carers and their work: http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011__Carers_UK.pdf




- ¹⁸ Health & Social Care Act [2012]: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>
- ¹⁹ Ipsos MORI (2012) Public Perceptions of the NHS (Tracker Survey): Spring 2012 wave report: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213052/Public-Perceptions-of-the-NHS-Tracker-Spring-2012-Report-FINAL-v1.pdf
- ²⁰ The Strategic Society Centre (2013) Right Care, Right Price: A discussion paper exploring the way in which the price of care is determined and its implications for social care policy: http://www.anchor.org.uk/sites/default/files/news_articles/documents/Anchor-Right-Care-Right-Price-Report-Sept-2013.pdf
- ²¹ Care Bill [2013/14]: <http://www.publications.parliament.uk/pa/bills/lbill/2013-2014/0045/140045.pdf>
- ²² HM Treasury (2013) Spending Review 2013: <https://www.gov.uk/government/publications/spending-round-2013-documents>
- ²³ Local Government Association / NHS England (2013) Statement on the health and social care Integration Transformation Fund: http://www.local.gov.uk/c/document_library/get_file?uuid=b20e023f-fabb-4f46-b881-31bbe92e74a4&groupId=10180
- ²⁴ Health and Social Care Information Centre (2013) Community Care Statistics, Social Services Activity: England 2012-13, Provisional Release: https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-stats-soc-serv-acti-12-13-prov/comm_care_stat_eng_2012-13_soci_serv_act_reppdf
- ²⁵ Community Care (Direct Payments) Act [1996]: <http://www.legislation.gov.uk/ukpga/1996/30>
- ²⁶ Department of Health (2012) Developing the use of direct payments in residential care: <https://www.gov.uk/government/publications/developing-the-use-of-direct-payments-in-residential-care>
- ²⁷ Health Select Committee (2012) Public Expenditure: Thirteenth Report of Session 2010-12: <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1499/1499.pdf>
- ²⁸ See HM Treasury (2010) Comprehensive Spending Review: http://www.hm-treasury.gov.uk/sr2010_completereport.pdf and 5 HM Treasury (2012) Autumn Statement: http://www.hm-treasury.gov.uk/as2012_documents.htm
- ²⁹ Estimation of the Association of Directors of Adult Social Services (2013) Social care funding: a bleak outlook is getting bleaker: http://www.adass.org.uk/index.php?option=com_content&id=914&Itemid=489
- ³⁰ YouGov Health & Social Care Survey for Healthwatch England 2013. The survey of 2286 adults was undertaken online between 28th-30th August 2013 and has been weighted to be representative of all GB adults (aged 18+).
- ³¹ For details of satisfaction with the NHS see: NatCen (2013) British Social Attitudes 30: <http://www.bsa-30.natcen.ac.uk/> and social care see: Health & Social Care Information Centre (2013) Measures from the Adult Social Care Outcomes Framework 2012-13: <https://catalogue.ic.nhs.uk/publications/social-care/vulnerable-adults/meas-from-asc-of-eng-1213-prov/meas-from-asc-of-eng-1213-prov-rpt.pdf>
- ³² Health & Social Care Information Centre (2013) Personal Social Services Adult Social Care Survey, England 2012-13, Provisional Release: <https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2012-13-prv/per-soc-ser-adu-soc-car-sur-eng-2012-13-prv-rep.pdf>
- ³³ YouGov August 2013
- ³⁴ NatCen (2013) British Social Attitudes 30: <http://www.bsa-30.natcen.ac.uk>
- ³⁵ YouGov August 2013
- ³⁶ Ipsos Mori Health & Social Care rights survey for Healthwatch England - August 2013
- ³⁷ YouGov Health & Social Care Complaints survey for Healthwatch England - March 2013
- ³⁸ Department of Health (2010) Equity and Excellence: Liberating the NHS: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf
- HM Government (2012) Caring for Our Future: reforming care and support: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136422/White-Paper-Caring-for-our-future-reforming-care-and-support-PDF-158OK.pdf

References

- ³⁹To read the current version of the United Nations Guidelines for Consumer Protection visit: http://www.un.org/esa/sustdev/publications/consumption_en.pdf. The latest version is currently under review by United Nations Conference on Trade and Development and is likely to be updated in 2014.
- ⁴⁰We spoke to local Healthwatch about a consumer rights approach at our annual conference on 20th June 2013 held at Aston Villa Football Club, Birmingham.
- ⁴¹The deliberative event was facilitated by Ipsos Mori for Healthwatch England at the Coin Street Neighbourhood Centre, central London on 20th July 2013; however participants travelled from across the country to attend and contribute to it.
- ⁴²These videos were recorded and edited by Channel 2020 for Healthwatch England 2013.
- ⁴³The 1975 telephone interviews were conducted between 2nd and 8th August 2013 as part of the Ipsos Mori Omnibus. The interviews were based on a nationally representative sample across Great Britain and data presented here has been weighted to the known population.
- ⁴⁴The academic interviews were conducted by Ipsos Mori between 23rd July and 7th August 2013 and lasted around 30 minutes. Interviewees included Professor Martin Knapp (LSE), Ruth Thorby (Nuffield Trust), Dr Veena Raleigh and Dr Jocelyn Cornwell (The King's Fund and Point of Care Foundation), and Patricia Kearney (Social Care Institute for Excellence).
- ⁴⁶NHS England (2013) Review into the quality of care and treatment provided by 14 hospital trusts in England (Keogh Review): <http://www.nhs.uk/NHSEngland/bruce-keogh-review/Documents/outcomes/keogh-review-final-report.pdf>
- ⁴⁷This will contribute to our pledges under Improving Children and Young People's Health Outcomes policy. For more details see: <https://www.gov.uk/government/publications/national-pledge-to-improve-children-s-healthand-reduce-child-deaths>







The one thing people respect is being kept informed, whether it's good news or bad.



Healthwatch England

Citygate, Gallowgate

Newcastle upon Tyne NE1 4PA

Tel 03000 68 3000

Fax 01132 204 650

enquiries@healthwatch.co.uk

www.healthwatch.co.uk