

# What matters most



Healthwatch England Annual Report 2017-18



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#### About us

Healthwatch is here to make care better.

We are the independent champion for people who use health and social care services. We're here to find out what matters to people, and help make sure their views shape the support they need.

There is a local Healthwatch in every area of England. We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that the Government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

Our sole purpose is to help make care better for people.

#### **Our strategy**

# Our vision is simple

Health and care that works for you.

People want health and social care support that works - helping them to stay well, get the best out of services and manage any conditions they face.



#### Our purpose

To find out what matters to you and to help make sure your views shape the support you need.

#### Our approach

People's views come first - especially those who find it hardest to be heard.

We champion what matters to you and work with others to find solutions. We are independent and committed to making the biggest difference to you.

#### Our aims

Over the next five years, we want to make the biggest difference by:

## Supporting you to have your say

We want more people to get the information they need to take control of their health and care, make informed decisions and shape the services that support them.

By 2023 we want over one million people to share their views or seek information from us each year.

# Providing a high quality service

We want everyone who shares an experience or seeks advice from us to get a high quality service and to understand the difference their views make.

By 2023 we want to be able to tell you the difference your views have made.



# Ensuring your views help improve health and care We want more services to use your views to shape the health and care support you need today and in the future.

By 2023 we want to see twice as many of our recommendations implemented by services.

#### A message from our Chair, Sir Robert Francis QC

Successive scandals in the NHS have shown the dangers that arise when services don't listen to patients.

With local services already going through rapid change, and further reforms - like the NHS Long Term Plan - to be implemented, it has never been more important for services to pay attention to the people they serve and what matters to them.

## More people share their views

The good news is that more people are coming forward to share their views with Healthwatch. When acted upon by health and social care staff, these experiences are translating into better, safer support.

Yet despite this progress, people's views are still seen as 'nice to have' by some professionals, rather than essential to preventing mistakes and developing the support that people want.

The NHS's aspiration to provide care that is close to home, joined-up and tailored to meet our individual



needs, is right. But, with a complicated system already fighting multiple battles, the journey to this goal will be even harder if citizens' voices are not heard.

# Spotting the gaps in care

Health and care targets used in isolation can prevent services from spotting problems. Services need to understand the perspective of those who use them. For example, a common issue people raise with us, and that we have reported to Parliament, is the impact of poor coordination between services when patients leave hospital. We heard harrowing stories about people being readmitted when support wasn't in place for them in the community, and decided to investigate further.

The NHS no longer collects readmissions data nationally, so we requested it ourselves and found that readmissions had risen by a fifth over five years. Thanks to the people who shared their experiences, the Government has now asked NHS England to address this issue, which may not otherwise have come to light.

The views that people share with us are also helping to identify gaps in policy. As part of the development of the social care green paper, we have highlighted the public's confusion when it comes to making decisions about social care.



Tens of thousands of people already contact Healthwatch every year because they don't know how to choose a care home, access funding or get the support they, or a loved one, needs to stay at home.

Our research has found that most people have given little thought to their future care needs and don't know where to turn for help. One of our key asks of the social care green paper is for people to be given a source of advice on social care that they can trust.

#### Investing in the public's voice

These examples show why listening to people matters and why using people's experience to inform decisions needs to become part of the DNA of health and social care.

The extraordinary staff who keep services running are not alone in this endeavour - we are here to help. Thanks to our growing band of volunteers, we have created an essential channel through which we can seek people's views on a vast range of issues and help others do the same.

Despite falling funding for Healthwatch services in some areas, demand for our help from both the NHS and the public has continued to increase. We are supporting more people and doing more to ensure their views make a difference. As the new Chair of



Healthwatch England, I want to see this trend accelerate.

Harnessing existing supporters and engaging new people, I want to create a movement that in five years will see the number of people having their say double. I also have ambitions to get more NHS and social care staff to understand and act on what people really want from care.

The Government's commitment to invest billions more in the NHS provides a rare opportunity. It is a chance for services to invest in a culture where, with a commitment from leaders, staff work in equal partnership with communities to shape support. It is a chance for us all to help deliver the NHS people want.

One thing is clear: for health and social care support to truly work, people must be at the heart of decision making. I look forward to leading Healthwatch as we play our part in helping to make this happen.

#### **Executive summary**

Our annual report for 2017-18 provides a summary of the experiences people have shared with Healthwatch and highlights the action we have taken in response. It also gives an overview of the support we give to local Healthwatch, and our future plans.



#### The year in numbers

The total funding local Healthwatch received to carry out their work fell by 7% year on year. Although this has resulted in fewer full-time staff to carry out our work, our volunteer numbers have increased. Despite having fewer resources, the number of people sharing their experiences with Healthwatch about health and care has risen by a fifth. The number of reports Healthwatch have published telling services the improvements people would like to see has also increased by a similar proportion.

#### Evidence into action

#### Common themes

No matter which service people use, the public commonly tell us they would like to see:

- + Better information to help them make the right choices
- + Easier access to services and less time spent waiting for support
- + Improved conversations with professionals
- + Services that are well-coordinated

#### Influencing current services

We have used these views to help improve the services of today. For example, by bringing attention to public concerns, our efforts have contributed to:



+ A sector-wide debate about emergency readmissions

The Government has asked NHS England to measure emergency readmissions after our findings showed that the number of people returning to hospital within 48 hours is still rising.

+ Improved dental support for residents in care homes

Oral health care will be a standard part of Care Quality Commission inspections after we highlighted that some care home residents struggle to see a dentist.

+ More people with a disability or sensory loss getting information they understand

NHS England will provide Easy Read and large print formats of its patient registration forms to GP practices across the country, because we highlighted a need for greater accessibility of information.

#### Informing future policy

We're bringing communities and policymakers together to help improve future services. For example, as part of our advisory role for the social care green paper, we highlighted people's confusion over how to plan for their care, and called on those in charge to provide people with better advice.



#### Supporting you to speak up

We want everyone to receive a high quality service from Healthwatch. To help deliver this, over the past year we have focused on:

## + Championing inclusion

We have put in place a new approach to help local Healthwatch understand who in the community is not being heard, so that we can reach out and amplify their experiences.

- + Raising awareness of our service
  - With the public keen to share their experiences, we supported the Healthwatch network to raise awareness of the difference people can make to care by sharing their stories.
- + Ensuring the right resources are in place
  We have continued to boost the skills of our people, providing the guidance and training they need to be effective. We've also worked to highlight and address where cuts in funding are putting a Healthwatch service at risk.

#### Our future focus

The evidence we gather from across England is already being used to help shape the future of NHS and social care. With a new Chair and strategy in place, we have big ambitions to go even further.



Over the next year we will concentrate on the changes needed to deliver our new ambitious aims:

+ Supporting more people to have their say

The launch of our nationwide research to find out
what mental health support people want is just

what mental health support people want is just one way we are testing new approaches to double the number of individuals Healthwatch engage with by 2023.

## + A high quality service

As well as making sure that local Healthwatch have sufficient resources to do their work, we will invest in the systems needed to help our staff and volunteers free up their time and demonstrate the impact they are making.

# + Making people's voices count

We can't achieve our ambitions alone. We will use opportunities like the NHS Long Term Plan to champion a health and care culture, where working in partnership with people to make decisions becomes the norm.



#### The year in numbers

Find out about the resources of the Healthwatch network and the ways we've engaged and supported more people over 2017-18.

- Our volunteer numbers grew by 7%. In total 5,053 people gave up their time to support our work.<sup>1</sup>
- Local Healthwatch employed 885 staff, 46% of whom are full time.<sup>2</sup>
- Our volunteer numbers grew by 7%. In total 5,053 people gave up their time to support our work. This is a decrease from the previous year where 72% of staff were full time.<sup>3</sup>
- Local Healthwatch received £27,230,687 in funding from local authorities in 2017-18 6.8% less than the previous year.<sup>4</sup>

<sup>&</sup>lt;sup>1</sup> An estimated 5,053 people volunteered for local Healthwatch in 2017-18, compared to 4,700 people in 2016-17.

<sup>&</sup>lt;sup>2</sup> An estimated 885 people were employed by local Healthwatch in 2017-18, compared to 790 in 2016-17.

<sup>&</sup>lt;sup>3</sup> An estimated 408 local Healthwatch staff members were employed as full-time equivalent in 2017-18, compared to 570 in 2016-17.

<sup>&</sup>lt;sup>4</sup> Local Healthwatch reportedly received £27,230,687 of funding from local authorities in 2017-18, compared to £29,213,966 in 2016-17.



#### Our work

- We reached 60% more people in this year's annual 'Speak up' campaign to get people to share their views of services.<sup>5</sup>
- 15% more people used our website to find their local Healthwatch.<sup>6</sup>
- 406,567 people shared their health and social care story with us, 19% more than last year.<sup>7</sup>
- 707,816 people accessed Healthwatch advice and information online or contacted us with questions about their local support.<sup>8</sup>
- We published 2,053 reports about the improvements people would like to see with their health and social care, 18% more than last year.<sup>9</sup>

<sup>&</sup>lt;sup>5</sup> Speak Up campaign gained a social reach of 1,018,463 in January 2018 compared to 636,098 in January 2017.

<sup>&</sup>lt;sup>6</sup> 65,888 unique visits to our 'Find your local Healthwatch' page in 2017-18 compared to 57,203 in 2016-17.

<sup>&</sup>lt;sup>7</sup> An estimated 406,567 people shared experiences of health and social care services with local Healthwatch in 2017-18 compared to 341,000 in 2016-17.

<sup>&</sup>lt;sup>8</sup> An estimated 707,816 people accessed advice and information from local Healthwatch in 2017-18 either face-to-face or online.

<sup>&</sup>lt;sup>9</sup> The Healthwatch network published an estimated 2,053 reports about people's experiences of health and care in 2017-18, compared to an estimated 1,745 reports in 2016-17.



## Change starts with you

Over the last four years, we've helped more than 1.4 million people have their say, from Lands End to Newcastle. We want to say a big thank you to everyone who has helped to inspire change by speaking up.

The more people share their ideas and experiences with us, the more the NHS and social care services can understand what works, what doesn't, and what people want from care in the future.

# People are at the heart of everything we do

We play an important role bringing communities and services together. Everything we do is shaped by what people tell us. Local Healthwatch staff and volunteers identify what matters most to people by:

- + Visiting services to see how they work
- + Running surveys and focus groups
- + Going out in the community and working with other organisations

Our main job is to raise people's concerns with health and care decision-makers so that they can improve support across the country. The evidence we gather also helps us recommend how policy and practice can change for the better.



#### The powerful impact just one voice can have

#### Tony makes it easier to find a care home

When Tony was searching for a care home on behalf of his mother, he found there wasn't enough information available to make an informed decision. Working with Healthwatch Durham he helped to improve the situation. Thanks to his dedication, the council will ensure all care homes provide up-to-date information online, so it's easier to find a care home.

#### Errol saves lives in Bristol

Since his friend died of prostate cancer, Errol has been working with Healthwatch Bristol to raise awareness about the disease in the African-Caribbean community. Thanks to Errol, lots of men have been screened for prostate cancer, and at least six were diagnosed early.

#### Evidence into action

People always want to have a good experience, no matter which health or care service they visit. But this doesn't always happen. Many people find getting the right support complex and confusing.

In this section, we highlight the changes that would make services easier for people to use. We also demonstrate what we've done to amplify people's voices, and how this has led to important national improvements.



In 2017-18 the collective work of the Healthwatch network was:

# • Informed by: 406,567 people's experiences and views.

#### • Resulted in:

2,053 local Healthwatch projects, which outline the improvements people want to see.

#### What changes to people want to see?

We identified four themes people commonly experience across all services.

# 1. Better information to make the right choices

With the right information, the public is not only empowered to make better decisions about their health and care, but they also know where to go for help when needed. However, this information isn't always available, and when it is, it can be too technical, confusing or difficult to find.

#### 2. Easier access to support

Quicker and easier access to health and care services is essential. Many experience delays at every step - getting an initial appointment, hanging around in waiting rooms, waiting to see a specialist - it can take a long time for people to get the support they need. Repeated cancellations also indicate that the NHS doesn't value people's time. Technology used correctly offers the



potential to alleviate these barriers and provides easier access to services, and to earlier diagnosis.

## 3. Improved conversations

We know people want to be involved in decisions about their treatment and care. Good communication between professionals and the public helps people to be more informed, understand their choices, and manage their expectations. This is particularly important for people with disabilities or people who don't speak English as a first language.

#### 4. Well coordinated services

Navigating health and social care can be complicated. People want a seamless experience across different services. When services work well together, it not only makes things easier for people, but also reduces the risk of serious issues being missed.

#### One way we've made a difference

# Helping people with a disability or sensory loss get information they understand

By law, NHS and adult social care organisations must communicate in a way that people with a disability, impairment or sensory loss can understand. To see whether this is working in practice, we looked at feedback from over 700 people and evidence from local Healthwatch visits to 50 services.



While progress has been made, there are still areas that are a struggle for people. British Sign Language (BSL) interpreters, accessible websites, registration forms, and signs all need to be available for everyone in a way they can use. When this support is missing, family members and carers often have to step in.

"One mum had to translate in sign language for her son. When the doctor broke the news of her son's diagnosis, she started to cry before she could tell her son. Both mum and son shared how distressing they found this." - Personal story, Healthwatch Bristol

The Care Quality Commission is using our findings during inspections to establish whether services are meeting people's communication needs. NHS England is also using our evidence to understand whether the Accessible Information Standard is working in practice.

# Your first line of support

GPs, dentists, pharmacists and other primary care professionals are usually the first point of contact when we need support with our health.

#### Changes you want to see

- + Make it easier to see a doctor or nurse quickly
- + Have a positive attitude and show empathy
- + Talk to them about what happens next



+ Give them information so they can make an informed decision

## In focus:

# Making it easier to see a doctor

While most people are happy with their GP practice, a 2018 NHS survey showed that over 121,000 people were not entirely satisfied. 10 We looked at people's feedback to help GP practices understand how they can make improvements.

The most common frustration we hear about is that people can't get a GP appointment soon enough. They struggle to get an appointment over the phone and online. Poor access has a knock-on effect. Long waits to be seen can prevent people from being diagnosed, treated and referred to specialist services.

Even though this goes against NHS guidelines, some surgeries don't let people register without proof of address. This particularly affects people who are homeless and could stop thousands from getting the care they require. To help tackle this issue, we supported the 'My rights to healthcare' initiative to raise awareness of what people can do when they are told they cannot register with a GP because they don't have a permanent address.

<sup>&</sup>lt;sup>10</sup> NHS England, GP patient survey, August 2018.



#### One way we've made a difference

# Helping people have their say about prescriptions

At first glance it may look like some items, such as eye drops and indigestion relief, shouldn't be available on prescription. But many people rely on these products. We helped over 600 people have their say when NHS England proposed to stop prescriptions for products that can be bought at pharmacies. Our responses made up a quarter of the total feedback NHS England received.

One in five respondents thought that these changes would have financial repercussions for themselves or a family member. People with chronic conditions were also worried they wouldn't be able to afford medication if it wasn't available on prescription. Ultimately, this could mean that minor issues left untreated might lead to complications, costing the NHS more in the long run.

"I have albinism where I have no melanin in my skin. I rely on prescription sunscreen as I'm at risk of skin cancer. I'm on a limited income so cannot afford factor 50 sun cream." - Survey respondent.

In response to our concerns, NHS England has confirmed that certain people will still be able to get their products on prescription, including those with long-term or complex conditions. GPs will also be able to prescribe based on individual need. This should



ensure millions of people continue to get the treatment they require.

#### What next?

#### Making sure technology works for you

People want to use technology to manage their health, just as they do in other parts of their lives, and the NHS is responding. Patient Online has already signed up 14 million users, and investment in technology, such as artificial intelligence, is likely to be an important part of future changes to the sector.

Our research shows that most people expect technology to be an integral part of future health and care. 78% of people we polled thought wearable technology will help to inform treatment options in the future, and 67% said it's likely that artificial intelligence will be used to diagnose conditions by 2050.<sup>11</sup>

To introduce technology that works, the NHS must work hand in hand with the public to invest in what they want. We will continue to share feedback with the NHS about digital services. By understanding what matters most, together we can ensure that technology is designed with people in mind.

<sup>&</sup>lt;sup>11</sup> Healthwatch England, Future of health and social care research, August 2018.



#### Getting treatment at hospital

Each year, millions of people are referred to hospital by their GP for treatment and tests. Millions more visit A&E for help in an emergency.

## Changes you want to see

Feedback about over 50 different types of hospital departments showed that people want services to:

- + Reduce waiting times for care
- + Improve administration so there are fewer missed appointments and people don't have to repeat the same information to different professionals
- + Provide good care all the time
- + Have a positive attitude and show empathy
- + Get hospital discharge right by having wellcoordinated services

## In focus:

## **Experiences in A&E**

We reviewed thousands of people's comments about using A&E in 11 areas across the country. Inconsistent care and poor staff attitudes are the main concerns people face time and time again. Many also feel that they're waiting too long to be seen for immediate care. In some cases, they're waiting beyond the NHS four-hour maximum waiting target.

However, we know that people are more likely to have a positive experience when there is good



communication. Being triaged quickly, knowing how long the wait will take, and getting regular updates on the situation, all help manage people's expectations.

We want NHS targets to take into consideration people's experiences in order to paint an accurate picture of A&E performance.

We also want the NHS to make better use of technology, so people can decide which service can help them best.

#### One way we've made a difference

# Our emergency readmission findings stimulate sector-wide debate

Over 2,000 people told us about their experiences of being sent home from hospital. When hospital discharge works, people can move on with their lives and recover safely. But when it doesn't, it can be distressing and see people return to hospital sooner than expected.

We wanted to examine national data to understand how widespread emergency readmissions are. However, no complete national data had been published on this topic since 2013, so we asked hospital trusts across England to share their data.

We found that emergency readmissions had risen by 22.8% over five years. One in five people affected returned to hospital within just 48 hours of leaving.



Although not every readmission is because of inadequate support, we have to ask whether it could have been prevented.

## Our findings have led to:

- + Organisations, including British Red Cross, National Audit Office and Quality Watch, focusing on the issue
- + The Government asking NHS England to reintroduce emergency readmissions as a measure of how well services are working together
- + The Parliamentary Public Accounts Committee reiterating that the NHS must improve its emergency readmissions data

Our findings have also helped the Care Quality Commission decide how to review care in 20 areas. The review looked at how older people move through the health and social care system, and if services can work better together.

#### What next?

## The importance of national data

One year on, emergency readmissions continue to rise. Despite its commitment, the NHS still isn't tracking why almost 500,000 patients are readmitted to hospital



each year. 12

Not every readmission can or should be avoided, but without national data it's difficult to say who is affected and why they are returning to hospital.

What we do know is that behind every number is a person. People continue to tell us about the difficulties they face, which could have been prevented with better communication, planning and support.

The NHS must fulfil its promise to provide better data, so that services can learn and fix these underlying issues.

#### Supporting you to live independently

Social care services play a vital role in supporting people to live independently. Our society faces challenges about how we can ensure this care is safe and affordable in the future.

#### Changes you want to see

Feedback about using care homes, home care and other social care services showed that people want services to:

- + Provide good quality care all the time
- + Meet their needs by planning care together

<sup>&</sup>lt;sup>12</sup> Healthwatch England, Emergency readmissions, November 2018.



+ Make information on social care assessments and funding widely available

#### In focus:

## What's it like to be cared for at home?

Over 600,000 people are supported by social care services to live independently in their own homes. <sup>13</sup> Care workers can help with basic tasks, such as washing and cooking.

People who receive care at home don't always get the opportunity to talk about their experiences. Our network proactively sought the views of 3,000 people, their families, and care workers, to help services understand what is working, and what isn't. We wanted to show providers that by seeking regular feedback, it can help to identify problems early and prevent minor issues from escalating into complaints.

Care works best when people are involved in planning it. But when people don't have a say, it can leave them feeling powerless in their own home. Without a care plan, people tell us they don't know if or when care workers will turn up, and in serious cases, some have missed their medication.

<sup>&</sup>lt;sup>13</sup> UK Home Care Association, An Overview of the Domiciliary Care Market, May 2016.



#### One way we've made a difference

#### A healthy smile for care home residents

Healthwatch visited almost 200 care homes to find out what daily life is like for its 3,500 residents. While most residents felt they received good quality care, too few homes got all the basics right. Not every home provided a good environment, choice of activities, and skilled staff.

"My laundry isn't always returned and is worn by others, though it does turn up eventually." Personal story, Healthwatch Wolverhampton.

In some parts of the country it can be difficult for care home residents to see a dentist or GP. This is particularly concerning for people who have poor mobility or dementia. In one care home, staff said dentists refused to do a home visit unless treatment was paid for privately.

As a result of our work, the Care Quality Commission has agreed to make oral health a standard part of care home inspections.

On a positive note, we've seen that the best care homes recognise that they are people's homes. These care homes:

+ Treat people as individuals, supporting them to make their own choices and maintain their independence. Some care homes go over and



above so that residents can visit pet rescue services and go on virtual sightseeing tours. One staff member held her wedding reception at the care home, so residents could join in.

+ Build a positive culture, actively seek feedback and use these views to make improvements.

#### What next?

## Government proposals must pass five key tests

There are big questions about how we plan and resource the care sector. To ensure future care is sustainable, the Government has committed to publishing a green paper on social care.

As part of our advisory role, we shared 14,000 views with the Government to ensure people are at the heart of these proposals. Our research showed that most adults haven't given much thought to their future care needs and believe it will be free when they need it.

Along with highlighting the need for better information and advice, we also want the social care green paper to answer five key questions:

- 1. Can the public and people who work in social care understand it?
- 2. Will it support people to plan and make decisions about their care, giving them access to high quality advice and information?



- 3. Does it provide a wide range of choice in social care? Do we have plans for a stable and varied provider market including care homes and support in the community? Will we have enough people with the right skills working in the sector?
- 4. Are the funding, charging and access thresholds fair, affordable and transparent?
- 5. Will it support families and carers?

#### Taking care of your mind

Each year approximately one in four adults in England will experience some form of mental health challenge.

#### Changes you want to see

Feedback about mental health support showed that people want services to:

- + Give clear information about the support available
- + Treat mental and physical health needs with the same importance
- + Provide good quality care all the time
- + Make it easier to see a specialist quickly
- + Train staff so they understand mental health issues
- + Involve them in decisions



#### In focus:

# Positive feedback about GP mental health support is on the rise

90% of adults with mental health conditions are supported solely by their GP or primary care service. <sup>14</sup> While we still hear negative feedback about GP support, positive feedback is on the rise.

Around half of the feedback we currently receive about GPs supporting people with anxiety and depression is positive. This change could be because initiatives, such as the GP Forward View and Mental Health Forward View, are starting to take effect. The plans injected billions of pounds worth of investment into primary care and created thousands of new roles to support mental health.

There are still areas where GP practices can improve. In particular, people want GPs to be able to diagnose and treat a wider range of mental health conditions. They also want to be treated with dignity and respect by all staff.

#### One way we've made a difference

## Improving young people's mental health

Mental health conditions can affect people of any age. It's vital that children and young people are supported

<sup>&</sup>lt;sup>14</sup> Royal College of General Practitioners, Mental health position statement, December 2017.



to stay well to prevent mental health conditions developing later in life.

According to an NHS survey, one in five children with a mental health condition wait over six months to see a specialist<sup>15</sup>. Based on our research, we know that long waits for mental health support are a huge concern for young people and their families.

Over the last two years, our network carried out over 80 projects on young people's mental health. The families we spoke to felt their child's condition had worsened because of long waits for support, causing additional stress, anxiety, and depression. They were also frustrated at the lack of communication from Children and Mental Health Services. Based on the views of 22,000 people, our evidence helped to inform a Care Quality Commission review of young people's mental health support. The review found that mental health services for young people are fragmented, so young people don't get timely and appropriate support.

The work, commissioned by the Government, recommended that local services should involve Healthwatch, which will ensure people are at the heart of future changes.

<sup>&</sup>lt;sup>15</sup> NHS Digital, Mental health of children and young people in England, November 2018.



Our insight has also led to the National Audit Office examining whether the Government is on track to meet its ambitions for improving children and young people's services.

#### What next?

## Investing wisely in what people want

We launched a new project to understand what mental health support people need at different stages of their lives. We reviewed over 34,000 people's views to understand the current gaps in support and identify solutions.

Our first step will be to look at the mental health support people want before and after birth. One area which people want to see prioritised is peer support. People value being able to access peer support services quickly, giving them the chance to hear and learn from others experiencing similar mental health challenges.

People recognise that the NHS is injecting more resources into mental health support. But they want policymakers to listen to their needs so that these investments are used in the right way.

# Helping you find answers

People don't always know how to get the information they need to make decisions about their own health and care. Healthwatch plays an important role in



providing advice and pointing people in the right direction. What do people ask us about?<sup>16</sup>

- 15% Hospitals
- 27% Social care
- 22% GP services
- 36% Other issues

#### Common questions people raise

#### Social care

Social care accounts for a quarter of the enquiries we receive.

Those who get in contact are often a relative or friend of someone who needs help. Most queries about support are for someone older (65-85 years old) and they sometimes have dementia.

The issues people ask for information about are:

- + Care homes: People want to know about the costs of care homes, what funding is available and the process of moving a relative into a care home or between homes.
- + Care at home: People want to know how to get extra help at home, including how to have their needs assessed, the costs of care and what

<sup>&</sup>lt;sup>16</sup> Analysis based on 1,532 records received by 56 Healthwatch from July 2016/17 - April Q4 17/18.



- services are available when someone is discharged from hospital.
- + Support for carers: Those caring for a friend or family member want to know how they can get support or financial help.

#### **GP** services

We regularly get asked about how to register with a GP.

People want to know what services are in their area, how they go about registering and how they can change GP when they are unhappy with the service they are receiving.

A small number of people ask us about services that are available out of hours, access to services for foreign nationals and how they can make a complaint about their GP.

#### Hospitals

The main questions we get asked are about:

- + Discharge from hospital: People want to know about the process of leaving hospital and the support that will be available to them while they recover.
- + Communication by services: People who have not received information from a hospital want to know when they should expect to hear about future



- appointments or treatment they have already received.
- + Choice of hospital: People want to know if they can choose which hospital they attend and the treatment they receive.

A small number of people ask us for information about waiting times, how to complain about poor treatment and what transport services are available to and from hospital.

## Supporting you to speak up

We want everyone to receive a high quality service from Healthwatch.

This is why we support almost 6,000 local Healthwatch staff and volunteers to reach out to every section of the community and encourage more people to speak up. We also help local Healthwatch to build their skills and make sure they have the resources they need.

Together, our work is resulting in big and small changes that are helping to make care better.

# Championing inclusion

Understanding who isn't being heard and supporting them to speak up.

By 2023, we want the Healthwatch network to support over a million people each year to share their views or find the information they need. To achieve this goal,



we need to understand which sections of the community are not having their say. Over the last year we have introduced a better approach to understand who Healthwatch are not reaching.

### Who are local Healthwatch engaging?

Understanding the experiences of different communities

Percentage of local Healthwatch who have undertaken specific work to understand people's experiences based on the following topics:

• Disability: 28%

• Age: 22%

• Pregnancy/maternity: 20%

• Homelessness: 14%

• Substance misuse: 12%

• Ethnicity: 11%

• Geographically isolated: 8%

• Veterans: 4%

Marital status: 1%

• Religion or belief: 1%

• Unemployed: 1%

• Stigmatised occupations: 1%

Understanding if life factors affect people's experience of care



Percentage of local Healthwatch who have looked at the following issues, as part of their general work to understand people's experiences of care:

• Age: 62%

• Disability: 55%

• Ethnicity: 53%

• Gender: 44%

• Geographically isolated: 34%

• Homeless: 31%

• Religion and brief: 29%

Sexual orientation: 27%

• Pregnancy/maternity: 22%

• Substance misuse: 22%

• Gender reassignment: 20%

• Unemployed: 16%

• Veterans: 14%

• Marital status: 13%

Stigmatised occupations: 6%

This knowledge will help us build on the great work local Healthwatch are doing to understand and amplify the experiences of different sections of the community.

### Tackling homeless healthcare barriers

NHS guidelines say that GP services cannot refuse to register someone because they don't have proof of address. But, all too often, people have told Healthwatch that they struggle to access support



because they don't have a permanent address, phone number or identification.

Over 600 people who have experienced homelessness shared their stories with Healthwatch. In response, we supported the charity Groundswell and Healthy London Partnership to raise awareness of people's rights when it comes to registering with a GP.

Distributed across the capital, the 'My right to healthcare' card has important information to help people register with a GP and provides our contact information if they face any issues.

In other parts of England, local Healthwatch have been shining a light on the other barriers that people without permanent accommodation can face.

In West Berkshire, which has high levels of rough sleeping, local Healthwatch interviewed rough sleepers who weren't accessing health services. People told them about the low trust they have in support services and the issues they can face accessing GPs, dentists and mental health support.

"Talking therapies said there isn't much they could do because I was homeless." Personal story, Healthwatch West Berkshire

Using these views, Healthwatch West Berkshire instigated major changes through the local Health and Wellbeing Board. A group, formed of key local



organisations, reviewed Healthwatch's recommendations and set up a plan for the winter.

The area has received £212,000 extra funding to help rough sleepers with complex needs and plans are being made to open a centre to support vulnerable people. As well as making a difference for people in the area, this work is being used by the NHS nationally to inform their health inequalities strategy.

### Helping you have your say

Encouraging more people to share their ideas

Three out of four adults in England would share their feedback to help improve health and social care services if given the opportunity.<sup>17</sup>

To make more people aware of how they can do this through their Healthwatch, we launched 'It Starts With You'. The campaign reached over a million people on social media and encouraged them to tell us what they think by sharing stories about how their views had made a difference.

We've seen the number of people sharing their views and experiences with Healthwatch rise by a fifth. Thanks to individuals speaking up, services across England have already made positive changes that benefit communities.

<sup>&</sup>lt;sup>17</sup> Healthwatch England, Public attitudes research, June 2017. 40



### Who has heard of Healthwatch?<sup>18</sup>

• Public awareness in 2016: 21%

• Public awareness in 2017: 33%

### Thank you Rosetta

Rosetta, who lives in sheltered housing, waited for hours for an ambulance after a fall. Anxious and in pain, she remained on the floor as safety protocols would not allow staff to lift her. Sharing her experience with Healthwatch has led to the NHS training sheltered housing staff on how to lift people after an accident.

### Providing a high quality service

Making sure our staff and volunteers have the skills and resource they need.

## Ensuring the right resources are in place

Our work is funded by the Government, which makes money available to local councils so they can commission an effective local Healthwatch.

While public demand for our help is rising and our evidence is increasingly being acted upon by professionals, investment in our work has fallen by over a third since the Healthwatch network was established.

<sup>&</sup>lt;sup>18</sup> Healthwatch England, Brand awareness research, December 2016 and August 2017.



72% of local Healthwatch were proactively contacted by local services asking for help in understanding people's views in 2017-18.

Falling funding is happening at a time when local services across England are being redesigned. It is important that communities are involved in the decisions that will affect them and their views are used to provide the health and care support they want.

We are concerned that without enough resources, local communities in some areas risk being denied an independent local Healthwatch champion to ensure their perspective is heard.

To make sure local Healthwatch have the resources they need, we are:

- + Supporting local authorities to commission an effective Healthwatch service
- + Putting in place better tools to monitor changes in quality and impact
- + Exercising our statutory powers when we believe a local Healthwatch is at risk

If the NHS wants to get health reforms right, it needs to invest more in understanding what people want.

Six ways we supported our network:

1. **Trained 435 staff and volunteers** to boost their skills in areas such as communication and research



- 2. **Welcomed 380 delegates** to our national conference for two days of learning
- 3. **Provided our digital system** to 100 local Healthwatch to help them manage their work
- 4. Shared 80 pieces of guidance on issues ranging from data protection to governance
- 5. **Sent 52 newsletters** to keep people up-to-date with developments
- 6. **Held 37 regional meetings** to help local Healthwatch leaders collaborate

### Using your views to improve support

Four ways people's experiences are shaping current and future care.

Each year, the Healthwatch network produces thousands of recommendations for services across England about how care and support could be improved.

Our evidence is helping NHS and social care staff and policymakers hear what matters most to people.

### Making care better today

NHS commits to making information more accessible With our support, the Healthwatch network has been making sure services provide information in a way that people with a disability or sensory loss can understand. Healthwatch Camden found that the patient registration form that NHS provides to GP practices



was not shared in a format that people with learning disabilities would understand easily. We worked with them to raise this issue with NHS England. Thanks to Camden residents speaking up, NHS England has committed to provide the patient registration form in Easy Read and large print formats to GP practices across the country.

Healthwatch Camden's work has also led to positive changes at GP practices in the area:

- + Patients can now register using large print or Easy Read forms
- + GP practices ask new patients about their communication support needs
- + Staff are given deaf awareness training to improve how they communicate with patients who have a hearing impairment

# £1 million investment for wheelchair service provision

To improve the experiences of young people using posture and mobility services, Healthwatch Calderdale and Healthwatch Kirklees asked wheelchair users, parents and carers what they thought.

One of the main issues was the long wait for a suitable wheelchair. This could take over 12 months, leaving young people without the right wheelchair, and sometimes in an uncomfortable seating position.



Healthwatch shared these views with the local Clinical Commissioning Group, which committed to investing over £1million in posture and mobility services. The money will be used to clear the backlog in demand for wheelchairs.

### Improving the services of tomorrow

### Helping the NHS to set its priorities

The evidence we gather plays an important role in helping the NHS to understand the issues people are talking to us about and the changes they would like to see.

Each year, the Government asks us for our views on what should be included in the annual aims that it sets for the NHS. Using people's feedback, we made a number of recommendations that were subsequently adopted.

The updated NHS Mandate for 2018-19 included a focus on the NHS doing more to demonstrate what it has learnt from complaints and feedback, and the need to evaluate the impact of mental health reforms.

Alongside this, the Prime Minister announced the intention to have NHS targets reviewed so that they incentivise the best care for patients.

Our network also tell us what they are working on, based on what people have told them. We shared these



issues with NHS England, which addressed them in their two-year plan for NHS services.<sup>19</sup>

### Championing your right to be involved

Across the country, services are being reformed to provide high quality and seamless support. People understand the need for these changes and want a say in decisions that will affect them.

NHS England has reminded services that the public need to be involved in these changes.<sup>20</sup> It also explained how Healthwatch can support services to engage with the public, and how our five-step guide should help communities have their say.<sup>21</sup>

We asked local Healthwatch whether the NHS is successfully involving communities in these plans. We also shared our findings for an inquiry on Sustainability Transformation Partnerships (STP) undertaken by the Health and Social Care Select Committee.

Although many Healthwatch felt the NHS was open to engaging others, only 23% thought it was effective. Our network felt services could improve public involvement by engaging communities at the start of reforms and

<sup>&</sup>lt;sup>19</sup> NHS England, Next Steps on the Five Year Forward View, March 2017.

<sup>&</sup>lt;sup>20</sup> NHS England, Next Steps on the Five Year Forward View, March 2017.

<sup>&</sup>lt;sup>21</sup> NHS England, Patient and public participation in commissioning health and care, April 2017.



communicating plans in a way everyone can understand.

"STPs are quite confusing to the public. (They) still shy away from an explicit conversation about service change and what it actually means for communities. The consultation is hurried and cursory." -Healthwatch Nottinghamshire

The Health and Social Care Select Committee recommended that the Government and NHS organisations should do more to explain the benefits of reforms. We'll continue to make sure that communities are involved as equal partners in decisions about how future care is provided.

## Our future focus by Imelda Redmond, CBE National Director

This year we celebrated five years of Healthwatch championing people's experiences of health and social care.

We have achieved a lot, but our staff and volunteers want to do much more. With NHS and social care services under pressure, a strong and independent Healthwatch is needed now more than ever to ensure the public voice is heard.

### A moment of change

This year the NHS celebrated its 70th anniversary. 2018 was also important for Healthwatch, with three key 47



moments that will help shape the next phase of our journey.

Firstly, Sir Robert Francis has joined us as our new Chair, bringing with him a wealth of experience when it comes to advocating people's rights at a national level.

Secondly, we launched our ambitious strategy. We want to put people's voices at the centre of health and social care changes, and our roadmap shows how we intend to get there in partnership with the public, professionals and other organisations.

In the first year of our strategy, our focus is on making sure that we have the right structures and systems in place; making the changes needed to deliver our vision and mission effectively.

Thirdly, the evidence we gather from all corners of England is being used by the Government to help shape the future of the NHS and social care. This has been shared with policymakers as they develop the social care green paper and the NHS as it formulates its new long term plan.

### Supporting more people to have their say

Although more individuals are coming forward to share their experiences of care with Healthwatch, I think this is just the tip of the iceberg. We need to do much



more to reach those not being heard and make it easy for them to have their say.

In the short term we're improving our understanding of our audiences and overhauling our digital channels. We've also launched our national campaign to get people to share their views about mental health. Working as one Healthwatch, we aim to find out about different people's experiences of care at different stages of life, to help services make the improvements the public would like to see.

In the long term, we're thinking about how we can bring about a much bigger transformation. We'll be looking at how, in partnership with others, we can create a social movement committed to making support better and helping everyone access the information they need to take control of their care.

## A high quality service

None of this will be achievable unless the public and local services are able to get support from a high quality Healthwatch service.

Local Healthwatch are already achieving so much, but we can do more. More to boost the skills of staff and volunteers, more investment in systems that can free up time to do their work, and more to demonstrate the difference we make together.



Above all, I want a work culture where innovation is celebrated, learning is shared and together, we make the greatest impact.

With investment by councils in our work under pressure in some parts of England, we're also focussed on making the case for sufficient resources, and if our service to the public is put at risk, we'll use our statutory powers to address this.

### Making people's voices count

We know that people won't share their valuable experiences with us unless they see the difference it makes to their health and care.

Not only are Healthwatch achieving positive changes to the support people receive today, our work is also influencing the future. For example, we've shared 84,000 people's views to help develop the NHS Long Term Plan.

But I want us to go much further, encouraging a culture in NHS and social care where working in partnership with those we serve is everyday business.

We can't to do this alone but we can provide the evidence that services can act on, and work with others to champion the benefits to quality and safety that listening to people brings.



### Our finances

To help us carry out our work, Healthwatch England is funded by the Department of Health and Social Care. In 2017-18 we spent £2.584 million.

The following section explains our funding breakdown and how we've used it.

### 2016/17

Total £2,647,872

• Non-pay: £680,271

• Pay: £1,987,601

### 2017/18

• Total: £2,584,032

Non-pay: £764,878

• Pay: £1,819,154

## How we used our funding to meet our priorities in 2017-18

• Total: 2,584,032

- Bringing the public's views to the heart of national decisions about the NHS and social care (research, intelligence, digital) £765,381
- To build and develop an effective learning and values-based Healthwatch England (core business, staff) £875,954
- To provide leadership support and advice to local Healthwatch to have greater influence and impact (Healthwatch network) £942,697



### Thank you

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

- + Members of the public who shared their experiences and views with us
- + All of our amazing volunteers across the Healthwatch network
- + The voluntary organisations who have contributed to our work
- + Our colleagues in local Healthwatch
- + Healthwatch England Committee members and staff
- + The Department of Health and Social Care sponsorship team,
- + Other colleagues across the Department of Health and Social Care, Care Quality Commission, NHS England, National Institute for Health and Care Excellence, NHS Digital, NHS Improvement, Association of Directors of Adult Social Care Services in England, the Local Government Association and other statutory organisations who have worked with us this year



### **Our Committee**

We are governed by a Committee who set our strategy, provide scrutiny and oversight, and approve policies and procedures that are needed for us to work effectively. They also spend time travelling around England to hear everyone's views and use this knowledge to inform our decision-making.

### **Our Committee members**

- + Sir Robert Francis QC (appointed October 2018)
- + Jane Mordue (until September 2018)
- + Lee Adams (appointed January 2018)
- + Jenny Baker (until May 2018)
- + Andrew Barnett
- + Pam Bradbury (until May 2018)
- + John Carvel (until October 2017)
- + Deborah Fowler (until May 2018)
- + Helen Horne
- + Philip Huggon (appointed January 2018)
- + Amy Kroviak (appointed January 2018)
- + Andrew McCulloch (appointed January 2018)
- + Danielle Oum (appointed January 2018)
- + Helen Parker (appointed January 2018)
- + Ruchir Rodrigues (appointed January 2018)
- + Liz Sayce OBE