healthwatch

What people have told us about health and social care

A review of our evidence July – September 2018

Contents

Introduction

People want health and social care support that works for them – helping them stay well, get the best out of services and manage any conditions they face. Our job is to find out what matters to the public and to help make sure their views shape the support available.

17,172 people shared their experiences and views with us between July – September 2018. This briefing takes a deeper look at what people are saying, and how we're using this information to help shape health and social care policy and practice.

Our evidence includes data collected from 109 local Healthwatch publications and the views of 12,662 people. We also use an additional 4,510 individual pieces of feedback received directly through our digital systems.

What are people saying?

Primary care	
Emerging themes	More people are sharing feedback about: • Having trouble communicating with health professionals particularly around delays in their referrals to see a specialist. • Wanting a more empathetic approach from clinicians and staff when discussing issues such as medication. • Administrative issues in pharmacies resulting in wrong medication being dispensed or repeat prescriptions being stopped in error.
Ongoing themes	We continued to hear that people: • Have issues with GP appointments; this includes problems using telephone appointment systems and waiting too long for appointments. • Would like to know how to register with a GP when they move area or their GP closes or merges. • Struggle to find and access dental services as well as concerns over the cost of dental treatment services.
What are we doing?	• We currently sit on the GP Patient Survey Steering Group. We are working with IPSOS MORI and NHS England to help review and develop the survey in time for next year. We also want to understand how the new questions can be used to assist us with our work on underrepresented groups. • The scale of evidence we hold on this area, combined with the analysis we have done to date, has secured interest from the Care Quality Commission (CQC) for a piece of work about how people are experiencing variation in care. • We have used our intelligence process to date to look at 45,000 people's experiences of primary care. We have used this evidence to inform our operational planning and we have also shared this insight with those

Primary care	
	working on the Long Term Plan. • We have asked NHS England, when developing the Long Term Plan to consider what our insight means for: - How the NHS designs technical solutions that work with people - Patient experience of extended opening hours - What people mean by continuity of care - The growing issue of GP closures and mergers - Better use of pharmacy
External opportunities	• There is an opportunity for us to highlight the challenges faced by those not registered with a GP, e.g. homeless people. We have raised this as part of our evidence submission for the NHS Long Term Plan and we plan to release a publication on the challenges that homeless people, in particular, experience before the end of the year.
Internal next steps	• We will use the large volume of feedback we receive to identify regional variation in people's experiences of GP services, compared to our previous findings on Primary Care. We will also be looking at what works, highlighting initiatives that have generated positive experiences for patients. • We will review feedback on NHS111 to identify any geographical variation and correlation between providers of this service and incorporate it into our work on the NHS Long Term Plan.

Secondary care	
Emerging themes	More people are sharing feedback about: • Staff in A&E, GPs and on hospital wards have not given timely diagnoses of conditions such as cancer or broken bones. This has meant that people have had to attend more appointments than necessary to get the treatment they need. • Those attending A&E in crisis are not receiving adequate mental health support and are only being treated for physical symptoms. We have heard of two cases where patients in crisis overdosed on medication whilst in A&E. • Struggling to access interpreters for hospital appointments, which is made worse by responsibility for this being pushed back and forth.
Ongoing themes	We continued to hear that people: • Wait too long in A&E and for urgent care. However, - we are starting to receive more positive experiences of people receiving treatment within the four-hour target waiting time at A&E departments.

Secondary care	
	• Have positive feedback about their interaction with staff in urgent care and in A&E departments. They are feeling listened to and being given detailed explanations about their treatment. However, this is not the case in non-emergency hospital departments where we heard problems about communication between staff and patients. • Are continuing to wait long times for appointments with consultants or to have operations. We have heard some cases of patients facing multiple cancellations.
What are we doing?	• We have shared 6,500 people's experiences of A&E with NHS England to inform the Long Term Plan. This focused on the need for meaningful targets and systems, to help set expectations around waiting times and support patient choice. These targets would also tell a more sensitive story about demand management in the NHS. • We shared our early findings on this year's emergency readmissions data, at a roundtable discussion. Our findings will be published in October. We continue to work with the Department of Health and Social Care to ensure that it delivers its commitment to publishing this data on an ongoing basis.
External opportunities	• We want to develop insight on what people think about waiting times, using national research. This would build on our NHS Mandate recommendation that current waiting time targets don't tell the full story of what it is like to be a patient. • CQC has announced that it will undertake three new Local System Reviews and three repeat visits. We will continue to support this. We have suggested that there are ways in which our network could enable future activity to be undertaken more cost-effectively. This does not form part of CQC's immediate future plans, but we will continue to explore this over the next few months.
Internal next steps	• We will look at how the feedback about empathy towards patients across services has changed over time, as this is integral to good quality health and care service delivery. • We will also begin an annual tracker to chart any changes in feedback received about people's experiences of A&E waiting times.

Social care	
Emerging themes	We have not identified any new social care themes.

Ongoing themes	We continued to hear that people: • Have trouble finding consistent and accessible information about home care services. • Ask for information about equipment services and care assessments. • Find significant variation in the quality of care delivered across care homes, including hygiene and activities for residents
What are we doing?	• The Healthwatch England National Director is acting as an independent advisor on the Social Care Green Paper. As we move closer to publication a working group will manage our overall contribution. • We published 'What people want from social care' in September. In addition, we have analysed the experiences of 5,000 carers.
External Opportunities	The development and publication of the Social Care Green Paper presents multiple opportunities for us to make a difference. However, to be most effective, the Green Paper must answer these questions: • Is it understandable by the public and people who work in social care? • Will it support people to plan and make decisions about their care, will the public have access to high quality advice and information to help them make good decisions? • Does it facilitate quality and a wide range of choice in social care, do we have plans for a stable and varied social care provider market including care homes and support in the community, and will we have enough people with the right skills working in the sector? • Is the funding, charging and access thresholds fair, affordable and transparent? • Will it support families and carers? We will use this test to frame our next stage of policy work on social care.

Mental health	
Emerging themes	More people are sharing feedback about: • Those in crisis attending A&E are not receiving adequate mental health support and are only being treated for physical symptoms. As recorded in the secondary care section above, we have heard of two cases where patients in crisis overdosed on medication whilst in A&E.

Mental health	
Ongoing themes	We continued to hear that: • There is no straightforward pathway to access services for young people and that there is a lot of variation between areas. • Adults as well as children and young people are waiting for a long time between asking for help and getting it; meaning that some people are reaching a point of crisis with no support.
What are we doing?	• We have started working on two specific areas of mental health support, maternity, and mental health services for people transitioning from childhood to adulthood. • We have designed and released three surveys to gather the experiences of people, practitioners and stakeholders to formulate key questions for our network to ask their local communities. There has been with unprecedented take up. The next phase is to mobilise local Healthwatch to collect evidence on our behalf. • We have held a workshop to develop options for the Mental Health Programme Steering Group to consider our approach to researching some of the areas highlighted in our literature review. This will inform the next phases of work for the programme. • We have used 34,000 personal experiences to inform the development of the NHS Long Term Plan. This is helping the NHS understand services that need to be put in place – e.g. additional peer support – but also the targets used to measure performance.
External opportunities	• We understand there is significant new investment in maternal mental health, which aims to see new services implemented by March 2019. This provides a useful context for our findings to help highlight how effective these services are meeting people's needs. • Having reviewed the evidence gathered by local Healthwatch since January 2016 there are also opportunities to share content on a broader range of mental health topics. The focus here will be on sharing insights, which add something new to the mental health policy debate.
Internal next steps	• We are using criteria developed with the Healthwatch England Mental Health Programme Steering Group to prioritise further areas for work. In particular, we have done some work on suicide and have planned activity around prisons and homeless people.

People who find it hardest to be heard	
LGBT+ community	The following key themes have been identified about the challenges that people from the LGBT+ community face, particularly in relation to mental health: • People fear the stigma that often accompanies conversations about mental health and sexual orientation. • Health care professionals can sometimes lack awareness of the different types of support available for the LGBT+ community. • At times, GPs make assumptions about people's sexual orientation and gender identity, and can make homophobic remarks. • People experience long waits to access gender identity services
Prison population	We heard from 113 people about health and social care for those currently in prison or who have recently left prison. The following key themes have been identified in this feedback: • There are pockets of good practice in most of the prisons visited by local Healthwatch; however, these are balanced by poor access to appointments and treatment. • The biggest barriers to receiving treatment were lack of staff to enable prisoners to attend appointments, poor administration, and long waiting times.
External opportunities	• NHS England has made significant commitments to dealing with health inequalities and we know that our insight will be useful to inform the Long Term Plan. This can include general commentary on all health inequalities, as well as specific evidence such as our work on the experiences of homeless people, and those in prisons.
Internal next steps	• We have already published findings on LGBT+ issues. We will be looking at this community more closely as part of our mental health programme. • We will be undertaking development work to understand the experiences of prisoners and the impact that Healthwatch can have with this vulnerable population.

Where does our data come from?

We provide insight into people's views of health and social care services by using two key sources of information from our network.

1. Research reports produced and published by the local Healthwatch network;
2. Records of individual feedback collected by the network and passed to Healthwatch England through our digital systems.

Local Healthwatch reports

We received 109 publications from 47 local Healthwatch, involving more than 12,662 people. This is a significant fall of 50% compared to the previous quarter. This trend did not occur last year when we received 335 reports from our network during the same period. Further work is being undertaken to understand this apparent fall in reporting.

Over half (55%) of these reports were about visits to services, predominantly (48%) related to social care (visits to care homes).

Volume of insight collected between July - September 2018 (Q2) compared to April to June 2018 (Q1).

	No. of local Healthwatch reports Q2 2018/19*	% of local Healthwatch reports Q2 2018/19*	% of local Healthwatch reports Q1 2018/19	Number of individual feedback Q2 2018/19	% of individual feedback Q2 2018/19	% of individual feedback Q1 2018/19
Primary care	26	24%	25%	1831	41%	42%
Secondary care	30	28%	14%	1557	35%	31%
Social care	36	33%	34%	311	7%	11%
Mental health	7	6%	8%	260	6%	5%
Other care	18	17%	16%	551	12%	12%
Total	**109**	**100%**	-	**4,510**	**100%**	-

Please note: Some reports of feedback cross multiple service areas.

Individual pieces of feedback

Between July - September, we received 4,510 individual pieces of feedback from 43 local Healthwatch through our digital system, which is an increase of 5% compared to the previous quarter. At the same time last year we received 1,687 individual pieces of feedback which highlights the increase in information we receive from our network.

Around half (41%) of our feedback related to primary care services, the majority of which was about GP services. We continue to see an increase in feedback about secondary care reporting too.

A further 30% of individual feedback received was about secondary care, notably about hospital care outside of A&E and urgent care.

What are people asking us about?

Healthwatch received 603 requests for information, an increase of 13% compared to the previous quarter. This was identified through the individual feedback, collected by 35 Local Healthwatch and passed to Healthwatch England.[1] However, this data is skewed with almost a half (47%) of this information originating from Healthwatch Essex. As reported previously, the Intelligence and Digital Team are working with the network to understand how they are using our digital system to capture signposting and requests for information as part of our strategy.

Traditionally, most requests for information that we receive are about social care services. However, this quarter around half of the information requests related to primary care services, particularly GP services.

People have been asking about the GP services that are available in their area and how to register with or change GP practice.

What are people telling us about primary care?[2]

26 local Healthwatch reports covered primary care, and involved the views of 5,635 people. In addition, we received 1,831 individual pieces of feedback from members of the public about primary care through the Healthwatch network. This accounts for 41% of the all individual feedback received.

General practice

We received 20 reports from local Healthwatch, which included feedback from 4,635 people about GP services. In addition, we received 1,472 individual pieces of feedback about GP services, accounting for around a third (33%) of all individual feedback. The feedback tends to be divided, with people describing both positive and negative experiences about GP services.

Emerging theme – communication between GPs and patients

We have heard more about people experiencing poor communication around delays in their referrals to see a specialist. Others spoke about receiving little to no information on what to expect prior to receiving treatment. We also heard patients complaining about the lack of clarity around changes to the way they can collect their prescriptions. These concerns were also raised across other service areas.

Emerging theme – patients would like a more empathetic approach

Similarly, many people told us that they would like a more empathetic approach from staff and clinicians. We heard that people felt their GP did not listen to them, which on occasion resulted in needing multiple appointments to get their condition properly diagnosed. We heard of some

[1] This is based on data from 35 local Healthwatch that used the Healthwatch CRM to record signposting this quarter. A further 8 local Healthwatch provided feedback this quarter but this feedback did not relate to signposting.

[2] The following services are included in the primary care category; General Practice, Dentistry, Pharmacy, NHS 111 and Opticians. The majority (81%) of our primary care feedback relates to GP services.

cases where patients had difficulty discussing their medication with their GP. People also told us their concerns about the response they receive from receptionists.

"The GP was quite uninterested in patient input and disregarded reports of patient's experience. [The patient] was diagnosed with something not relevant and was dismissed. Receptionist was rude and unwelcoming. Patient care, call waiting time and standard of service could all be improved." **Healthwatch Haringey**

The following ongoing themes continue to occur:

- **People struggle to make appointments with a GP**
  Around 43% of those who spoke to us about GP services shared experiences about booking appointments. This includes trying to make regular appointment and arranging a home visit from the GP.
- **People want to know how to register with a GP**
  We continue to hear concerns about how to register with a GP for those who have recently moved to a new area or where GP practices have closed or merged.

Other primary care services

We received 7 reports from local Healthwatch about other primary care services notably dentistry and pharmacy, which involved feedback from around 636 people.

In addition, we received 296 individual pieces of feedback from members of the public through the Healthwatch network, the majority of which related to dental services. The feedback was largely (48%) positive.

Emerging theme – good advice but poor administration from pharmacies

We received 49 pieces of feedback about pharmacy services. People told us they are happy with the advice they are getting from pharmacists as it saves them time, but many people had administrative issues such as the wrong prescription being given, delays when collecting prescriptions, or repeat prescriptions suddenly being stopped.

"I am the care home manager ... we have a lovely lady resident who suffers with diabetes and has her insulin delivered by the local pharmacy. One of her carers noticed the medication running low and placed the order. This didn't arrive so the next day she rang and spoke to the lady behind the counter who was rude and told her she as a carer would have to come and pick this medication up, or the lady herself had to go in a taxi and get it. The carer said this was ridiculous and spoke to the nurse on duty here who also rang and said the lady needs this medication and they need to deliver it ASAP. After three telephone calls of the same abrupt nature the medication was delivered later that day. My issue here is this lady had three people to ring for her, what about all the people at home ill and on their own who don't have that." **Healthwatch Rochdale**

The following themes continue to occur:

- **Getting an appointment with a dentist**
  We continue to hear from people struggling to find and register with a dentist particularly those who take on NHS patients. Although we did hear more positive experiences of dentist treatment.

What are we doing?

We have submitted evidence drawn from over 45,000 people to inform the NHS Long Term Plan, with a specific request to consider:

1. How the NHS design technical solutions that work with people
2. Patient experience of extended opening hours
3. What people mean by continuity of care
4. The growing issue of GP closures and mergers
5. Better use of pharmacy

As part of our work with the GP Patient Survey Steering Group we are working with IPSOS MORI to help review and develop the survey in time for next year, We want to understand how the new questions can be used to assist us with our work on underrepresented groups.

The experience of these groups is not picked up by the GP patient survey as it currently only covers those registered. This is a gap in current system insight. We will be publishing a report on the experiences of homeless people in December 2018. The Department of Health and Social Care consider this to be a very timely intervention.

Digital primary care providers, who provide paid for consultations with a short waiting time, represent a growing market and are attracting more public attention. We have attended roundtable discussions with providers to look at costs and benefits of this emerging model if it becomes more prevalent within NHS services. There is scope going forward to look at how effective this service is in meeting people's needs, particularly looking at different demographic groups, ages and condition types, to compare outcomes.

What are people telling us about secondary care?[3]

We received 30 reports from local Healthwatch including feedback from 3,984 people about secondary care. This is an increase of 30% compared to the previous three months, despite an overall decrease in reports received from local Healthwatch.

In addition, we received 1557 individual pieces of feedback about secondary care accounting for around a third (35%) of all the individual feedback we received.

A&E and urgent care

Local Healthwatch have produced 11 reports about A&E and urgent care departments, involving the views of 2,893 people. We also received 224 pieces of individual feedback from members of the public relating to urgent care and A&E departments. This represents 5% of all the individual feedback we received.

Emerging theme – delays in getting the right diagnosis

We have heard from more people about problems with getting the right diagnosis. People have told us of missed opportunities for staff in A&E, GPs, and on hospital wards, to diagnosis ailments such as cancer or broken bones. We have heard of two cases where people have died following a delay in diagnosis and lack of treatment. We heard from 32 people who had to be seen by multiple services across secondary, emergency and primary care before getting the correct diagnosis. This is a trend that we have seen increase over the last three months.[4]

"[Caller's] mother had died the previous evening. [She] said that her mother had previously had cancer and should've been on a two referral pathway due to this when she found a lump in her stomach but the GP didn't refer her to hospital until it was long after this, by which time it was too late and she had cancer all inside her body. Caller came back from her two-week holiday and was shocked, as her mother could no longer speak, as the brain tumour was affecting this. She said her mother had 'a dreadful decline over her last few days and was in so much pain with no treatment or pain relief." **Healthwatch Essex**

Emerging theme – poor treatment for those in mental health crisis

We heard examples of some of the problems people face in receiving mental health support while attending A&E. People describe how A&E departments can repeatedly miss opportunities to support them during a mental health crisis.

We have specifically heard from a person who overdosed on medication whilst in A&E. We also heard that mental health crisis teams were unavailable in A&E departments, or only able to spend 10-15 minutes with patients due to busy caseloads, resulting in some people only being treated for physical symptoms.

[3] Secondary care services relate to A&E and urgent care services as well as hospital services such as maternity, ophthalmology, cancer services and cardiology.

[4] In Q1 we heard of 4 cases where there were delays in diagnosis led to serious consequences, whilst in this quarter we have seen 7 cases.

"A York resident attended A&E after attempting to take their own life. They were assessed by the Mental Health Liaison Team, and left in an assessment room alone. When a nurse came to see them, the individual told them that they didn't feel safe to go home. They thought that the nurse was going to tell the Mental Health Liaison Team, and perhaps another assessment would be done. A different nurse then brought the individual the medication that had previously been taken from them, and left them with it. The individual said they then took the medication, and thinks they passed out for a couple of hours, but wasn't sure how long as there was no clock in the room. When the individual came around, they went to the nurses' station to tell them what had happened, and that they didn't feel safe. The individual was told that someone would come and see them. The individual then rang their GP to tell them that they were still at A&E, and that they had overdosed. A nurse came and saw them, and told them they would do their observations, and then that they would be discharged. The individual reported that they left A&E, and walked to their GP surgery, where they waited as it was closed for a meeting. They saw their GP, who rang the Crisis team, who followed them up the same evening. The individual has subsequently been in touch with their GP regularly, and reported that they currently felt safe. The individual wanted advice on what they could do, as they felt the care they received wasn't supportive of their situation, or acceptable." **Healthwatch York**

The following ongoing themes continue to occur in the quarter:

- **Organisation and staffing is hit and miss**
  We heard generally positive comments relating to staff interaction with patients in urgent care and A&E departments. People have told us they felt that they were being listened to by staff and were provided detailed explanations about their treatment. However, we continue to hear about problems with organisation of staff particularly in relation to follow up after discharge.
- **More positive feedback about waiting in A&E**
  We have started to receive more positive feedback about waiting times in urgent and emergency care. Although we still hear occasions where people have had to wait over an hour for an ambulance, we have also heard some people have only waited around five minutes for an ambulance and treated in less than 3 hours.

Hospitals

We received 20 reports from the local Healthwatch network about hospitals involving the views of 1315 persons. In addition, we received 978 individual pieces of feedback, covering 50 hospital services, which made up a quarter (25.8%) of all feedback. So far, we've heard a total of 6005 views about secondary care.

We continue to receive feedback about a large variety of service types with references to over 60 different services.

Emerging theme – lack of British Sign Language (BSL) interpreters

We heard that people have struggled to access an interpreter for their hospital appointments. People told us that booking an interpreter can be a challenge, as the responsibility of booking is pushed back and forth between services to the individual.

"I was about 12 weeks pregnant when I started bleeding. Because it was my first pregnancy, I wasn't sure if this is normal so I called 111 through text relay as I am deaf. They advised me to go to A&E. When I arrived at A&E I asked the receptionist to provide a BSL interpreter. They said they would arrange this but I didn't feel very confident about this. I kept asking for the interpreter repeatedly but never got one. When I saw the doctor, we had to communicate through gestures, so I didn't really have any idea what was going on. There were lots of people coming and going but no one explained what was going on. They took lots of blood tests and then took me through many corridors in the hospital. I only knew we went to maternity ward as I saw the sign. I was then asked to open my legs and they did an examination. The doctor then told me that everything was fine, I should go home and rest and not to work tomorrow. I went home, but after a few weeks as I didn't feel right, I felt like the hospital had missed something. When I went to see my GP, the doctor looked at the computer screen and told me that I had had a miscarriage. I was in total shock as the hospital never said anything while I was there. Whilst I was in A&E I felt absolutely panicked as no one explained anything to me. They treated me like a ghost and called me the deaf person. They did not address me by my name. This whole experience left me very depressed and as a result I lost my job. I am now too scared to get pregnant again as this experience has traumatized me." **Healthwatch Birmingham**

The following ongoing themes continue to occur:

- **Quality of care hindered by poor communication between staff and patients**
  We continue to hear how important communication is when people are using hospital services. It can be a stressful experience for patients and their loved ones, so not having enough information about treatment, discharge or follow up care has a negative impact. Quality of care has been generally positive, but feedback about communication was predominantly (60%) negative.
- **Long waiting times for appointments and operations**
  Waiting times to see consultants or to have an operation continue to be a barrier to good service provision according to feedback we have received. We heard that people have waited longer than 18 weeks to have appointments and faced multiple cancellations before being seen.

What are we doing?

We have shared 6,500 people's experiences of A&E with NHS England to inform its Long Term Plan. We highlighted the need for meaningful targets and systems for people, to help set expectations around waiting times and support patient choice. These targets would also tell a more sensitive story about demand management in the NHS.

We have been asked by NHS England to assess people's experiences alongside its 18-week referral to treatment target, and to use patient insight to explore the effect of system pressures on people.

We will very shortly be publishing our findings on rates of emergency readmissions to hospital. Year-on-year numbers have increased significantly. We are looking to cross reference this data with council level data on delayed transfers of care.

What are people telling us about social care?[5]

We received 36 local Healthwatch reports relating to social care, capturing the views of 295 people. This included 33 reports about visits to care homes, which have been mostly positive.

However, we have received 34% fewer reports about visiting social care services compared to the previous three months. This contrasts with other service areas such as primary and secondary care, where we have received either the same or more reports about visits to services than in the previous quarter.[6]

We also received 311 pieces of individual feedback from members of the public through the Healthwatch network, representing 7% of our total individual feedback. This is 20% lower compared to the previous three months, and is the only service area where we have seen a fall in feedback.

Most of our feedback involves people talking to us about home care, followed by care homes and general questions about how to access social care and assessments. We have not identified any emerging themes.

The following ongoing themes continue to occur.

- **Increase in requests for information**
  We continue to hear requests for information about equipment including incontinence pads, wheelchairs and home adjustments. We have also received more requests for information about social care assessments, home care and finding a place in a care home.
- **Lack of consistent and accessible information about home care services**
  We continue to hear the most feedback about home care services. People still tell us they have trouble accessing the most appropriate home care services, with some needing help to set this up for themselves or a family member. They are unsure of who to complain to if care is inadequate.
- **Activities and hygiene – quality of care in care homes**
  As we reported last year in our work on Care Homes, many people experience variations of care in care homes.[7] People have told us about seeing residents looking unkempt or in hospital clothing while in care. Activities are an important feature to a care home, though people have said they don't always happen as advertised.

What are we doing?

Following our two reports on social care last summer, our National Director has been invited to act as one of a number of independent advisors to the Government's social care green paper.

We conducted two deliberative focus group sessions and some national polling activity to explore people's needs and wants around social care earlier in the year. We have shared our

[5] The following services are included in the social care category; care homes, home care, assisted living social care assessment and equipment services.

[6] We received 33 Enter and View reports on social Care services in Q2 compared to Q1; we received 13 Enter and View reports on Primary Care in Q1 and again in Q2; we received 14 Enter and View reports in Q2 compared to 7 in Q1.

[7] https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20171117_-_whats_it_like_to_live_in_a_care_home.pdf

insights from these events and from public polling we conducted with the Department of Health and Social Care, as well as a range of other stakeholders from across the sector.

We have highlighted the fact that lack of trusted information is often a barrier to effective planning, and we suggested that a consistent, independent and trustworthy information and advice service should be developed to support people to understand and make the right decisions about their social care.

The Green Paper was initially due for publication in the summer. However, the Department of Health and Social Care has since announced that publication will be delayed to align with the NHS Long Term Plan – likely to be December.

In September we published our research on 'what people want from social care', which we have shared widely with the Department and other external stakeholders. This research highlighted the need for improved information and advice services to help people understand and plan for social care.

In October, we published our research on carers' experiences of accessing support services, highlighting long-waiting times for assessments and services. It also showed that councils lack the data on carers in their area to effectively plan, commission or design support services for them. This report got widespread national media coverage and has been fed into the Social Care Green Paper development.

In addition to activity around the Green Paper we have also continued to pursue our long-term policy ask for better support for those wanting to complain about social care services.

What are people telling us about mental health?

We received 7 reports involving the views of 215 people on mental health services. This is half the number of reports that we received in the previous three months. However, traditionally mental health research that we receive from local Healthwatch is more detailed and complex than those in other service areas and as a result are likely to take longer to complete.

In addition, we have received 260 pieces of feedback about mental health, this is a 60% increase compared to the previous quarter. We have seen an increase in feedback about those attending A&E during a mental health crisis, which is discussed in the secondary care section above.

The following ongoing themes continue to occur:

- **People struggle to navigate the pathways of mental health support**
  We continue to hear about people struggling to access the right service for them. Some people have been to multiple services and haven't felt adequately supported while others are passed between services, including social care, assessment team, child and adolescent mental health services, community mental health teams and inpatient care. Many people have sought information on local services because practitioners were unable to point them in the direction of community services that could help. This was especially true for people with autistic spectrum disorders.
- **Long waits to receive mental health support**
  We have heard about long waiting times for both adult and children's mental health

services. Young people are waiting to be assessed before they can access treatment, which can sometimes mean that they are on two waiting lists. One young person reported waiting around two years before having an assessment for autism. Adults also face similar waits; this has been more common for people with complex cases as it makes finding the right service more difficult. Often when people reach out for help, they want it quickly and waiting has a detrimental effect on some.

"Still waiting for a CAMHS appointment - since August 2017. I ring them every few months. Receptionist keeps us informed...the school won't offer any support until he has been assessed. Despite the fact the school have completed paper work to support our application. My son has had severe anxiety and depression since 13 but is not a danger to himself - nothing has been done. No indication to let us know when we'll have an appointment, [we] speak to someone different every time." **Healthwatch Bucks**

What are we doing?

As part of our work on mental health we have started working on two specific areas, maternal mental health and transitioning from childhood to adulthood services.

We have designed and released three surveys to gather the experiences of people, practitioners and stakeholders to formulate key questions for our network to ask their local communities with unprecedented take up. The next phase is to mobilise local Healthwatch to collect further evidence.

We have held a workshop to develop options for the Mental Health Programme Steering Group to consider our approach to researching some of the areas highlighted in our literature review. This will inform the next phase of work for the programme.

We have shared 34,000 people's experiences to inform the NHS Long Term Plan. This will help the NHS understand what services need to be put in place – e.g. additional peer support – and the targets used to measure performance.

On maternal mental health, we understand there is significant new investment in this area which aims to see new services implemented by March 2019. This provides a useful context for our findings to help highlight how effectively these services are meeting people's needs.

The scope of the mental health programme and its focus on the experiences of different groups of people should enable us to spot those who are not having their negative experiences addressed by the mental health forward view.

What are people who find it difficult to be heard saying?

We received 26 local Healthwatch reports involving the views of 5685 people who find it difficult to be heard.

In addition, we received feedback from 1437 people which identified protected characteristics to varying extents or the feedback related to an underrepresented community. 43 pieces of this feedback related specifically to the latter.

We looked at two communities: LGBT+ and the prison population specifically in relation to Mental Health as part of our Mental Health Programme of Work.

LGBT+ community

There has been significant progress in equality of opportunity for members of the LGBT+ community in recent years which is reflected in legislation and national policy. However, evidence suggests that people identifying as LGBT+ are at greater risk of experiencing poor mental health, including depression, suicidal thoughts, self-harm and alcohol and substance misuse.[8] This can be attributed to a range of factors such as discrimination, bullying, rejection from family, isolation and homophobia.

Although we hear some positive examples of health professionals treating people with compassion, dignity and respect, others describe how they're made to feel different because of their sexual orientation and/or gender identity when engaging with health care services.

We've heard how:

- People fear the stigma that often accompanies conversations about mental health and sexual orientation, worried they'll be judged and discriminated.
- Health care professionals can sometimes lack awareness of the different types of support available for members of the LGBT+ community, and in some instances, an unwillingness among service providers to positively engage with them.
- At times, GPs make assumptions about peoples' sexual orientation and gender identity alongside making homophobic remarks. They can ask unnecessary and intrusive questioning or tests, be restrictive to treatment pathways or fail to use appropriate pronouns or names.
- People experience long waiting times to access gender identity services, sometimes up to a year, leading to those who can afford it to pay privately to receive support earlier.

Having poor access to information and support for LGBT+ related matters can be isolating. It can result in members of the LGBT+ community becoming less willing to access health care services through fear of discrimination and reducing their confidence and trust in health care services. This presents a significant barrier for members of the LGBT+ community to seek the right help at the right time, heightening their risk of developing poor mental health outcomes in the future.

[8] Cited by Mental Health Foundation; https://www.mentalhealth.org.uk/statistics/mental-health-statistics-lgbt-people

Prison population

We have heard from 113 people who've recently left prison or have friends and family who are in prison. 90 of these people were involved in projects completed by five Healthwatch with their local prisons. We've also heard individual feedback from 23 people who've recently left prison or have friends and family who are in prison.

Through our work on mental health, we identified prisoners and ex-offenders as being a group who are more likely to experience poor health compared to others. NHS England is responsible for providing an equivalent level of care as can be found in the general community for all prisoners. Healthwatch has engaged with 113 male prisoners and ex-offenders to understand their experiences of health and care services.

Services are widely varied across prisons, we've heard of pockets of good practice in most of the prisons visited however these are balanced by poor access to appointments and treatment. The biggest barriers to receiving treatment were lack of staff to attend appointments, poor administration, and long waiting times.

Many people who engaged with Healthwatch had experiences of poor mental health and needing to access support in prison. Out of five prisons only one had positive feedback about a particular mental health service. Some people felt prison staff lacked understanding of mental health conditions, and sometimes medication was withheld as punishment.

Services did not work together across prisons, nor between prisons, and services in the community. People who had been transferred between prisons described having to start the process of getting mental health support all over again. There were similar difficulties in transferring treatment from the community to prison and vice versa, as well as trouble sharing patient records.

What are we doing?

The Long Term Plan has made significant commitment to dealing with health inequalities and we know that any insight that can be shared on this will be well used. This can include either more general commentary on all health inequalities or indeed specific evidence such as the work we are conducting on the experiences of homeless people as well as planned work on prisons.

We have already published some of our findings about the LGBT+ community and we have undertaken work to understand the key issues facing the community as part of our Mental Health Work Programme.

We will be undertaking development work to understand experiences of prisoners and the impact that Healthwatch can have with this vulnerable population. We have a unique place in the health system where we can collect experiences while sharing important health information to vulnerable groups. We will also consider wider opportunities to share intelligence or influence service delivery.

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.

Contact us

Healthwatch England
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

www.healthwatch.co.uk
03000 683 000
enquiries@healthwatch.co.uk
@HealthwatchE
facebook.com/HealthwatchE