

<b>MEETING</b>	<b>PUBLIC BOARD MEETING 17 July 2019</b>
<b>Agenda item and Paper Number</b>	<b>6 CM/07/19/06</b>
<b>Agenda Title</b>	<b>Healthwatch England Update</b>
<b>Sponsor</b>	<b>Sir Robert Francis – Chair of Healthwatch England and Non-Executive Board Member</b>
<b>Author</b>	<b>Imelda Redmond – National Director Healthwatch England</b>

### **PURPOSE OF PAPER:**

Actions required by the Board:

- For the Board to **NOTE** the update from Healthwatch England

#### **1. This report provides an update on the following:**

- NHS Long Term Plan
- Clinical Standards Review
- NHS Mandate
- Mental Health
- Social Care
- Reports Library
- Intelligence

#### **2. NHS Long Term Plan**

Since the last update to the CQC Board we have been focusing on supporting the network to carry out engagement on the NHS Long Term Plan in every local area in England. This activity has been designed to help shape local implementation of the national objectives set out by NHS England in the Long Term Plan document in January.

This work is being funded by a grant of **£504,000** from NHSE/I. The grant money was allocated across the network. 44 lead Healthwatch were appointed to coordinate activity across their respective STP/ICS footprints.

Healthwatch England has further supported the work by producing a range of resources, from supporting low-cost paid for advertising campaigns on social media to providing policy briefings on what the various elements of the Long Term Plan mean in practice. We are also providing research support to help ensure the work that local Healthwatch generate is of the highest quality.

Local Healthwatch engagement activity itself has also been progressing very well with all 44 lead Healthwatch meeting with their STP/ICS counterparts in March and early April to agree areas of focus for their engagement. Activity took place up to late May and staff and volunteers from all 151 Healthwatch ran over 500 focus groups.

Examples of the activities include

- Focus groups for people with learning disabilities in Cheshire and Merseyside STP.
- Facilitating an 'ask the panel event' in Northumberland, Tyne and Wear and North Durham STP where young people with mental health challenges were able to ask questions of local system leaders.
- Getting out and about across Gloucestershire and Somerset in the consultation campervan to hear from rural communities.

We have had over 30,000 responses to the Healthwatch England template survey:

- These survey templates were used by Healthwatch covering around half of the ICS/STP footprints. A further quarter of local Healthwatch have been running modified versions of the survey and the final quarter have been running their own surveys. This data will give a deeper insight into how people wish to engage with health and care services but also how they experience using services for specific medical conditions.

We are on schedule to deliver against the programme timelines as agreed with NHSE. Only two areas did not finish their engagement before June and this was due to the request of local STP/ICS partners and had been agreed with NHSE.

### 3. Clinical Standards Review

In the Summer of 2018, NHS England announced plans to conduct a review of some of the core performance targets including 4 hour A&E, 18 week referrals, cancer waiting times and mental health.

Healthwatch originally called for such a review back in our Mandate submission in Jan 2018 and we have continued to support NHS England's work in this area.

To coincide with the publication of NHS England's [interim report](#) in March, we published a [summary of Healthwatch evidence](#) that we have contributed to. This primarily focused on people's experiences of A&E drawing on two main sources of evidence:

- Feedback gathered by the Healthwatch network from almost **6,500 people** between January 2016 and September 2018, covering A&E departments in 25 different local areas. This showed that:
  - o The most common reason for patient dissatisfaction with A&E was the quality of the care/treatment they received.
  - o Poor staff attitudes and issues with communication came second. This is possibly linked to the pressure on staff leaving them with less capacity to deliver the sort of care people have come to expect from the NHS. (This issue of a growing lack of empathy was highlighted more broadly in [Healthwatch England's Quarter 3 Intelligence Report](#))
  - o Waiting times come up less often but are still an area of concern.
- National polling of a representative group of **2,000 adults** from across the country on what they think matters most when visiting A&E. (Conducted in January 2019).

- The polling corroborated the qualitative findings, showing that waiting times are important but when compared with other factors their relative importance is significantly lower.
- For example, 35% of people said waiting times in A&E were very important compared to 85% who said the same about ensuring everyone gets high quality treatment.

NHS England's review drew significantly on our research and has put proposals in place for testing proposed new targets in A&E based on the speed of initial assessment and faster treatment times for the most urgent cases. Importantly, the review also commits to NHS England properly evaluating the impact of the changes on patient experience of care.

We are currently working with NHS England to explore how Healthwatch can support with the testing phase, which will be carried out over the next few months across the following hospitals:

- Cambridge University Hospitals
- Chelsea and Westminster Hospital
- Frimley Health
- Imperial College Healthcare
- Kettering General Hospital
- Luton and Dunstable University Hospital
- Mid Yorkshire Hospitals
- North Tees and Hartlepool
- Nottingham University Hospitals
- Plymouth Hospitals
- Poole Hospital
- Portsmouth Hospitals
- Rotherham
- West Suffolk.

#### 4. NHS Mandate

In March we made our formal submission to Department of Health and Social Care (DHSC) on the NHS Mandate. This follows discussions over the last six months, with the team feeding in evidence about the issues that matter most to people and how the Mandate can help ensure the NHS focuses on these.

DHSC published the Mandate in the form of Accountability Framework in May 2019 the document extended this year to cover both NHS England and NHS Improvement.

This year's framework sets out priorities for the next twelve months, with the main focus on putting in place the necessary foundations for the success of the NHS Long Term Plan. Our submission included a number of recommendations where we feel NHS plans could be further developed to ensure that they address the issues people have raised with Healthwatch. We also highlighted areas from the previous Mandate which we felt are important not to lose.

We called for the Joint Accountability Framework to:

- **Send a strong message about involving people in NHS decision-making**  
Healthwatch brought 85,000 people's experiences to the table during the development of the Long Term Plan, but this level of involvement needs to become part of the DNA of the NHS, helping to shape plans and to track progress.

- **Make NHS targets more meaningful for people** We urge the DHSC to back the work of the Clinical Standards Review and outline a clear expectation that new performance measures will need to be fully tested with service users to ensure they improve people's experiences of care.
- **Reassert the focus on the NHS being the world's largest learning organisation** Whilst we support the alignment of the joint accountability framework with the NHS Long Term Plan, it is vital that we do not lose important direction set by the existing Mandate about the importance of learning from feedback and complaints.
- **Building public confidence in new technologies** We fully support the Long Term Plan's commitments to grow the use of technology across the NHS, and this is very much in line with what people want. To ensure these initiatives have the trust of the public and achieve the maximum impact in improving care for everyone, they need to be fully user tested. They must also be continually refined in response to user feedback. There is significant opportunity to develop this approach by ensuring public engagement is put at the heart of the way NHSX will operate.
- **Listen to what people want from the future of the NHS workforce**  
As the NHS finalises the workforce strategy, we encourage the Department to ensure those in charge take on feedback from people about the different types of professionals and peer support services they would like to access. This will be important if the health service is to address people's concerns about continuity of care and the level of empathy services are able to offer.

In May we received a response from Stephen Hammond, Minister of State for Health, acknowledging the value of our input and setting out how they have considered our comments for 2019-20. Full contents of the letter can be found on <https://www.healthwatch.co.uk/response/2019-05-21/government-recognises-contribution-you-have-made-shaping-long-term-plan>.

## 5. Mental Health

In Q4 we completed our fieldwork on maternity and mental health. In total we have gathered 3,408 responses from new parents about their experiences of mental health, supported by a further 107 responses from stakeholder organisations and professionals. Our five local Healthwatch projects on this topic was also completed. All the evidence is currently being analysed for reporting in Q1.

During Q4 we also carried out the first stage of deliberative research finding out what a good mental health services looks like for children and young people. We have attached a summary of the research in the **Appendix B** but key themes were:

1. A strong view that medical professionals are often 'too scientific' when approaching mental health concerns, and that people want more access to people who had been through similar experiences.
2. This led to conversations about the positive power of social media in facilitating peer-to-peer conversations.
3. They talked about wanting more regular mental health check-ups, similar to when people go to the dentist and greater awareness of mental health first aid.

4. They discussed wanting more mental health awareness campaigns (such as sports relief) which could help raise awareness and normalise mental health challenges.
5. They also wanted greater focus on mental wellbeing in the school curriculum and from a primary school age onwards.

In addition to the deliberative research we have also analysed the 17 local Healthwatch reports completed on CYP mental health issues in 2018/19, bringing together another 15,000 views, to create a firm foundation for the development of the next phase of the mental health programme.

At our network policy forum event we created an opportunity for NHS England colleagues to engage with the network as part of the development of new targets in crisis support for mental health.

## 6. Social Care

The publication of the Government's Social Care Green Paper continues to be delayed with Government now stating that it will be published "at the earliest opportunity". However, there has been significant speculation in the press outlining potential options for the future of the sector:

- According to a number of reports, the Secretary of State supports a new system of insurance to fund care for older people which could operate in a similar way to the auto-enrollment pension scheme. This would see money taken directly from people's pay packets to cover future care costs.
- Former Government Minister, Damien Green MP, has called for the introduction of a flat-rate entitlement, of perhaps £2,000 a month for residential care, or £2,500 a month for nursing care, funded through taxation of the winter fuel allowance and a possible 1% national insurance surcharge for the over-50s.
- The charity, Independent Age, has also published a report on ways in which 'free personal care' could be funded in England. This would entitle everyone to free personal care support, either in their own homes or in a care home, similar to the system currently operating in Scotland. However, so called 'hotel costs' would still be covered by individuals.

To help develop Healthwatch's position further on this matter, in Q4 we carried out some public polling to understand the reaction to the various proposals being mentioned in the media. We asked a representative sample of 2000 adults in England which of the following funding options they preferred:

- Increased general taxation: 42%
- Compulsory insurance: 20%
- Optional insurance: 9%
- Pay at the point of use if you have assets/savings: 8%
- An additional pay as you earn pension scheme: 2%
- Don't know: 18%
- Other: 1%

This new research, combined with our existing work on social care, has been shared with the Department of Health and Social Care (Appendix C) as well as a range of interested stakeholders, including the Lords Economic Affairs Committee, which recently published its report into social care funding. We shared our insight with a new cross sector campaign called 'Health for Care' which is a coalition of 15 health sector organisations led by the NHS Confederation. The aim of the campaign is to provide a united voice on behalf of the health sector calling for a long term solution to the challenges facing social care.

## **7. Communications with the Public and a No Deal Brexit**

As we move into July there is a considerable amount of uncertainty about the impact this will have on the provision of health and social care services. We have had a number of meetings with representatives from the DHSC to get clarity. Given that Healthwatch plays an important role at national and local level to inform the public, we have been pushing for some answers.

The DHSC is undertaking a significant amount of contingency planning particularly around the supply of medication. Information is gradually going into the public domain and we are helping to share this with a wider audience. We will continue to press for greater clarity and will issue responses when we have enough accurate information to do so.

## **8. Reports Library**

All local Healthwatch reports from 2019 are now loaded onto the Reports Library giving a voice to 213,085 people. We have seconded staff from the network to work through the archive and expect all reports prior to 2019 to be available on the Library by the end of December 2019.

## **9. Intelligence**

Overview of what we heard January to March 2019:

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.

Between January 2019 and March 2019, Healthwatch England received reports of 22,513 people's views and experiences of health and social care from our network. Each quarter we share what we've heard and what it tells us about what people think of services.

### **What did people speak to Healthwatch about this quarter?**

Below is a summary of the issues - new and established - that we identified this quarter. We share more detail about what people told us later in the report.

### **GPs, dentists, pharmacists, and other primary care support**

#### **What's new this quarter?**

- GPs aren't always equipped to provide support for mental health conditions or challenges.
- People are not always referred to secondary services in a timely manner and many end up chasing up appointments themselves.

#### **What we continue to hear:**

- People often find it difficult to get an appointment with a GP.

- People would prefer to keep seeing the same GP but struggle to.
- GPs don't always communicate clearly with patients.
- GPs sometimes show a lack empathy towards patients.
- Patients experience delays collecting prescriptions, and sometimes find prescriptions have been stopped without notice.
- It can be challenging to register with a dentist, particularly ones offering NHS services.
- Patients often aren't clear about payments for dental care, especially when they need further treatment.

### **Hospital care including urgent and emergency care**

#### **What's new this quarter:**

- Correspondence concerning people's medical results, diagnosis and prognosis is not always sent to the patient or relevant health professional.

#### **What we continue to hear:**

- People are waiting too long for appointments and operations, sometimes facing multiple cancellations.
- Quality of care can be affected by poor communication between hospital staff and patients.
- When people are discharged from hospital, they do not always get clear and timely communication about their ongoing care and the support available.
- People attending A&E during a mental health crisis do not always get the mental health support they need.
- People have difficulty accessing interpreters for hospital appointments, and it can be unclear whose responsibility it is to arrange them.

### **Social care**

#### **What's new this quarter?**

- Some dental surgeries don't support visits to care homes to provide checkups and treatment.
- Dental surgeries are sometimes unequipped to serve people with dementia or other disabilities.
- People in care homes want more personalized care, and to be able to make choices about things such as their clothes and meals.

#### **What we continue to hear:**

- People want easy access to information about how they can access social care support for themselves or a relative.
- People aren't always clear what a social care assessment is or how it can support them or the person they care for.
- People have trouble accessing home care support or finding an appropriate care home for themselves or a relative.
- People want more consistency when being cared for at home. The time care workers and the standard of care offered all vary too much.

- There is also variation in the quality of care for residents living in care homes, especially when it comes to cleanliness and the activities on offer.
- There are mixed levels of training and awareness among care home staff, notably concerning dementia.
- People don't have clear information about care home costs, particularly 'living costs'.
- It can be difficult for families to have their relatives' care packages reviewed when their care needs appear unmet.

## **Mental health**

### **What's new this quarter?**

- People seeking mental health support sometimes find the professionals who are there to help them dismissive and uninterested in their needs.
- Families and friends want to be more involved with their loved ones' care and for professionals to take their views into account.

### **What we continue to hear:**

- There rarely appears to be a straightforward route to mental health support.
- Adults and young people often wait a long time for formal assessments and follow-up treatment.
- Waiting times can be longer for people with multiple mental health diagnoses, a severe mental health condition/s, or for people who don't speak English.
- People who are waiting for a diagnosis or treatment don't always get enough support and information in the meantime, and many end up chasing services themselves.
- Carers for people with mental health challenges can struggle to coordinate care when they are given contradictory advice by different mental health support teams.
- People have difficulty contacting mental health crisis services by phone.
- Healthcare professionals do not all have a strong understanding of mental health conditions and the services available to people.

### **Where does our data come from?**

Our evidence this quarter contains data from 150 publications collected from 51 Healthwatch and includes the views of at least 18,963 people.

Our insight is also informed by an additional 3550 individual pieces of feedback received directly from the public. These include views people shared with 42 Healthwatch at engagement events, or shared over the phone, online or in person. The amount of feedback we are receiving continues to increase.

### **What do people tell us about primary care?<sup>1</sup>**

Over the quarter 30 Healthwatch reports were published about primary care. They incorporated the views of 3863 people.

In addition, we received 1492 individual pieces of feedback from members of the public about primary care through the Healthwatch network. As usual this represents the largest category of feedback received, comprising 39% of our total dataset.

## GP surgeries

19 of the 30 reports Healthwatch shared included feedback from more than 2353 people about GP surgeries\*. We also received 1207 individual pieces of feedback about GP surgeries which accounted for 81% of overall feedback regarding primary care. This represents over a third (34%) of the overall individual feedback we've received this quarter, which reflects our average trend for data of this type.

### What's new this quarter?

- A lack of knowledge about mental health conditions and challenges amongst GPs

We've heard before from people concerned about a lack of awareness amongst GPs about mental health. We've also heard more positive feedback about the way in which doctors have dealt with people who have presented with mental health challenges or concerns.

This quarter the balance has tipped once again with some people saying that their GPs have been unsupportive and unable to provide the right support, and that they do not listen to them when they talk about their mental health conditions.

People also said that they felt their mental health condition can act as a barrier to a diagnosis for a physical health problem, as GPs consider their symptoms to be related to their mental health condition. People have said they want a more caring, understanding service from GPs and receptionists, which links to our focus last quarter on the role empathy plays in providing quality care.

---

## Personal stories: Confusing physical and mental health

---

**“Someone with a learning disability reported [...] that they were unhappy with a diagnosis they had received from their GP. They experienced physical pain and were prescribed pain killers but were told that the cause was anxiety. The physical pain continued and they visited A&E for it. But they were referred to a mental health service [...] by the GP (practice unknown) which they do not think is an appropriate step as they are still experiencing pain.”**

### Healthwatch Lambeth

**“I am writing to raise a concern I am having with my GP, I have been seeing her for around four years. Always if I go there with any physical problems she refers it to my mental health and being a very stressed person. I don't have the impression she actually checks any other symptoms or excludes any physical conditions.”**

### Healthwatch Birmingham

---

- **A lack of timely communication between GPs and hospitals:** We heard from 22 people this quarter that they have had issues with delayed referrals from GPs to hospitals and specialists. They told us they had no communication from their GP during the waiting period so they had to get in touch to ensure the referral was submitted.

### What we continue to hear:

- **Difficulty getting appointments:** We have continued to hear about people struggling to get GP appointments. Not everybody can access online booking systems, so appointments get taken by those who can.

---

### Personal story: Limited access to appointments

---

“Surgery only releasing 2 weeks of appointments in a block. If you aren't at the surgery at 8.00am on the morning they release them, all the appointments are gone and you have to wait another 2 weeks. Not everyone can get there at that time.”

### Healthwatch York

---

- **Continuity of care and accessing the GP you want to see:** People struggle to see the same doctor each time, which means they have to repeat their medical history to each GP at each visit.
- **GPs can lack empathy towards their patients:** People have told us they have often felt that their GP can be dismissive of their worries. People want a more empathetic approach and to feel listened to by their GP.
- **People are unclear about what happens next after leaving their GP appointment:** People have told us that they sometimes leave appointments feeling confused because their issue or treatment plan was not discussed properly. They've been left unsure who to contact after their GP appointment and say they would like more information and guidance.

### Healthwatch in practice

**Healthwatch Redbridge conducted 45 Enter and View visits to GP practices across Redbridge to investigate whether the Accessible Information Standard (AIS) had been implemented effectively across the borough. They collected feedback from 88 members of staff and 134 patients using questionnaires and semi-structured interviews.**

Only 41% of practices had provided staff members with training about communicating with people with communication impairments. Less than half of the GP practices had trained staff to use the hearing loops that enable people with hearing aids to receive clearer information. Additionally, 91% of GP practices have a computer system that identifies when a patient presents with a communication impairment, however, only 53% used the system. Nevertheless, although the findings varied across GP practices, the report highlighted good practice, such as GP surgeries displaying information posters, and practices frequently assessing staff members' knowledge of AIS.

Healthwatch Redbridge made several recommendations as a result of their work and some practices have now introduced a Communication Book to make it easier for patients with a sensory impairment to communicate with staff. There has also been a 35% increase in the number of GPs who are providing necessary information in accessible formats.

### Other primary care services

The other Healthwatch reports we received this quarter which discussed people's experiences of primary care included feedback about dentistry (4) and pharmacy (5), incorporating feedback

from 1503 people. We also received 285 individual pieces of feedback from members of the public through the Healthwatch network, the majority of which (68%) related to dental services.

### What's new this quarter?

- **Dental surgeries inaccessible for people with disabilities:** This quarter we have heard that some dental surgeries are not accessible for people with disabilities. People have spoken about dental surgeries refusing to provide British Sign Language (BSL) interpreters for people who are deaf or who have communication difficulties. This has led to people who require a BSL interpreter either not being able to have a dental appointment or having to cover the costs themselves.
- **Lack of privacy in pharmacies:** People have told us that staff have discussed sensitive issues, medication and personal details loudly in areas of the pharmacy that could be overheard by others. In a report from Healthwatch Hartlepool people suggested the use of a queue barrier to retain some privacy, as they have been made to feel uncomfortable when confidentiality has been breached.

### What we continue to hear:

- **No available local NHS dentist:** Our feedback on dental services talks about how people struggle to find local NHS dentists taking new patients. As a result, people are forced to get private treatment or wait excessively to gain access to an NHS dentist. Some NHS dentists have changed to only offer private treatment without informing their patients, which leads to confusion when people are asked to pay for their treatment.

---

### Personal story: Trouble accessing local care

---

**“The patient is unable to find an NHS dentist in Cornwall. They had a problem with a tooth and decided to go private but still had to wait more than 3 weeks in considerable pain for a private appointment. Approximately 9 months ago they made four 10-hour round trips to a dentist out of county who treated them before they moved to Cornwall.”**

### Healthwatch Cornwall

---

- **Cancellation of dental appointments:** People have told us that when they do eventually get an appointment, it's sometimes then cancelled. Furthermore, some people have been told their dentist will no longer treat them on the NHS because they haven't had an appointment within the practice's time limit, even though this has happened due to cancellations the patient did not bring about.

---

### Personal story: The impact of cancellations

---

**“Patient's follow up appointment was cancelled by their dentist and another was not rebooked. When they rang to book a checkup, they were told they'd been taken off the books as they hadn't been seen there for 6 months, even though it was the dentist that cancelled the appointment. They contacted at least a dozen dentists at the time and none were taking on NHS patients. Consequently, the patient and their spouse have not had a**

dentist for approximately 2 years resulting in emergency dental appointments and gum problems and loss of teeth.”

Healthwatch Cornwall

---

- Pharmacies not delivering medication on time, if at all, and prescribing the wrong medication: We have heard that people are still having problems receiving their medication in a timely manner from their pharmacy. Some people have found that when it does eventually arrive, their medication is incorrect. In other cases, people have had their repeat prescription stopped without notice.
- 

**Patient story: Waiting for medicine**

---

“Ten days wait for a prescription to be authorised and when it was finally sent electronically to the chemist next door, they only had one of the five items in stock!”

Healthwatch Bucks

---

### What are people asking us about primary care?

This quarter we reviewed 175 questions people asked us about primary care services. These are the most common questions Healthwatch are asked about primary care:

- How to find a GP.
- How to register with a practice.
- How to change to a new practice.
- How to complain about their GP.
- How to access a relative’s medical records.
- How to find mental health-friendly GP services.

### What are people telling us about secondary care?<sup>2</sup>

As usual, we heard a lot of feedback this quarter about people’s experiences of going to hospital and other specialist facilities. We received 26 reports from Healthwatch which included feedback from at least 689 people.

We also received 1220 individual pieces of feedback in this area. This accounted for 34.4% of all the feedback we received, making it the second most common area people commented on.

### Urgent and emergency care

Healthwatch have produced five reports this quarter about urgent and emergency care services, informed by at least 22 people’s experiences. We also received 148 pieces of individual feedback

---

about these topics, representing 12.1% of secondary care feedback. People shared their experiences of ambulance services (23%), A&E (51%), NHS 111 (12%), and urgent care services (11.5%).

#### What's new this quarter?

- **Ineffective communication between services:** Correspondence concerning people's medical results, diagnosis and prognosis is not always communicated effectively to people or to the relevant health professional. For example, people have reported that the results from medical examinations, tests and scans conducted in A&E have not been sent to them, their GP or their care homes (4%). This means that people are left to chase up their results, delaying subsequent treatment for their conditions.

---

#### Personal story: Poor communication

---

“Client visited A&E in Kent on a Saturday as felt unwell. She has a long-term neurological condition and had more scans completed via A&E. There were then delays in communication with London Hospital where the results had been sent for specialist advice from a consultant at XXX's. Still no response by the evening so client went home without any treatment.

Delays in accessing specialist advice from the neurological department who received the scans from hospital in Kent. Client waited by the phone throughout Sunday, no telephone contact from the hospital. Monday morning client rang consultant's secretary, and this secured a response from the consultant. Advised she needed to be admitted for treatment at Southampton hospital asap. Client drove herself there same day.”

Healthwatch Kent

#### What we continue to hear:

- **Staff attitudes:** 7% of the individual feedback we received in Q4 shows people have felt that health professionals don't always show the level of empathy they expect. This is a theme that recurs across the urgent care services, including A&E ambulance services and NHS 111. For example, people have felt that their problems are not considered serious enough to be treated in A&E and are left feeling belittled.

---

#### Personal story: Lack of empathy

“I attended A&E in March 2019. The receptionist was incredibly rude, abrupt, had a poor attitude, lacked any professionalism and customer service, very dismissive...The nurses in A&E that I encountered were very, very dismissive, lacked any empathy or patient interpersonal skills whatsoever. No one that we approached was willing to help with our enquiries or concerns, not due to being busy, but through lack of care. You are treated as irritants to their shift. One nurse (1st point after reception) had a bad attitude and wrongly misinterpreted my concern for my own health as being rude. The person in question then raised their voice and verbally tried to silence me.”

Healthwatch Hillingdon

---

- **Long waits in A&E:** Some of the feedback we receive states that people felt they have waited too long to be seen for an assessment in A&E. We have heard from individuals with dementia who find this wait for an initial assessment particularly difficult as this can be a confusing and distressing time.
- **Poor communication and information sharing:** People have reported that some staff in urgent care services, including A&E, communicate information ineffectively to patients who are waiting for assessments and treatment. People are often left confused about waiting times and next steps, with many having to chase staff for information.
- **Inadequate mental health care in A&E:** People attending A&E in a mental health crisis often struggle to get the support they need. We received reports that mental health crisis teams were regularly unavailable in A&E departments or too busy to spend more than 10 minutes with patients. This can lead to only physical symptoms being treated, which further contributes to the inequality of care between mental and physical health.

## Hospitals

We received 21 reports from Healthwatch this quarter, which shared at least 667 people's experiences of hospitals. We also received 1073 individual pieces of feedback, covering 54 hospital services. This represents 88% of individual feedback received about secondary care.

### What's new this quarter?

- We identified no new themes in the intelligence we received this quarter, as most of the feedback we received related to issues that have been raised before.

### What we continue to hear:

- **Waiting times for appointments:** People are waiting too long for outpatient appointments and operations, sometimes facing multiple cancellations beforehand. We have heard that people have waited longer than 18 weeks to have an appointment. This could be due to the notifications about appointments not being sent in a timely manner and missing referral notes and patient records. People have told us they have received letters on the day of their appointment or have arrived at hospital to be told that their appointment or operation has been cancelled.
- **Poor communication:** Quality of care can be hindered by poor communication between hospital staff and people. This includes information about treatment, especially for aftercare and surgery. Additionally, communication and information sharing after a patient is discharged from hospital and returned to their community can be delayed, vague and limited.
- **Access to interpreters:** People have difficulty accessing interpreters and they have reported that services put the responsibility on them to get an interpreter. This information is sometimes only given to people when they arrive at hospital.
- **Difficulties parking:** People have told us they struggle to find a parking space, particularly disabled bays, when they attend hospital appointments. It has also been mentioned that the cost of parking has increased with complicated parking machines and procedures requiring different technological capabilities.

## Healthwatch in practice

Healthwatch Kent conducted three investigations into how easy it would be to attend a hospital appointment with a visual impairment, dementia and learning disabilities.

They worked with relevant organisations and charities to involve people who could identify the areas in which hospitals were lacking awareness and support for disabilities. They recommended that staff be trained to support patients with additional needs and the Accessible Information Standard (AIS). They also suggested a fast-track appointments system to reduce stress and anxiety caused by waiting times. Service providers have developed action plans to address these issues, and follow-up investigations are scheduled in the next year to evaluate the impact this report has had.

### **What are people asking us about hospitals, urgent and emergency care?**

This quarter we reviewed questions that 90 people asked us about hospitals and urgent and emergency care. These are some of the questions Healthwatch have been asked:

- How do I access support for long term conditions outside of hospital?
- What do I do if I have been waiting a long time for a referral or operation?
- What are the contact details for local hospital services?
- How do I make a complaint about hospital services?
- What type of support is available following discharge from hospital?
- What support is available for expectant mothers?
- How do I get information about dementia support?
- How do I get medical treatment without going to A&E?

### **What are people telling us about social care?<sup>3</sup>**

We received 61 reports relating to social care, capturing the views of at least 828 people. This included 55 reports about visits to care homes. We also received 220 pieces of individual feedback from members of the public about social care. Most of our feedback in this area is about either care homes (27%) or care provided in people's own homes (29.5%).

### **What's new this quarter?**

- **Reluctance from dental surgeries to treat people with disabilities and dementia:**  
We have continued to hear throughout the year that people generally have struggled to access dental services. In relation to social care this quarter we received feedback that some dental surgeries do not have the appropriate facilities for people with disabilities and dementia and therefore to treat residents in care homes. Seven Enter & View reports identified difficulties getting dentists to visit care homes to provide treatment and check-ups. In addition, a report from Healthwatch Dorset investigating NHS dental services in care homes found that 49% of care homes said dentists were not willing/able to treat residents with disabilities and 45% weren't willing/able to treat residents with dementia.

---

### **Personal Story: Inaccessible dentists**

**“Our residents struggle to access any of our local dentists. The one they prefer to go to has a significant number of steps that they find very difficult to ascend and descend. There are no travelling services which would make a big difference to our residents and families. We also struggle to get appointments that work around our staff getting residents.”**

**Healthwatch Dorset**

- **A lack of ‘home from home’ experience in care homes:** In the Enter & View reports we received this quarter, people from 16 care homes had issues with residents being dressed in the wrong clothes, despite their own clothes being clearly labelled. They state that residents have a lack of meal choices at dinner times, which detracts from the ‘home from home’ experience.

#### What we continue to hear:

- **A lack of timely and consistent home care:** We continue to hear about a lack of consistency in care agency staff and issues with punctuality and the timing of visits. This includes care agency staff visiting people’s homes late, changing visiting times without notice, and failing to administer medication during visits.

These issues can cause disputes between families and care agencies and lead to families changing care provider altogether. This causes additional stress and places further pressures on unpaid carers to fill the gaps in care. It also delays people receiving the crucial support they need to help them live independently at home for longer.

People want to know that the care delivered in their home will be consistent - especially those who are vulnerable - and that their basic care needs will be routinely met, particularly in relation to washing and dressing.

---

#### Personal story: Impact of inconsistency

---

“Last night I had no care. I was supposed to have someone give me a bath, help me go to the toilet and put me to bed. No one came. At 11.15 I rang XXX. They didn’t even answer the phone. I haven’t been to the loo since 5 o’clock yesterday.”

Healthwatch Islington

---

- **Quality of care and engagement in care homes:** We continue to hear about the lack of planned activities and stimulation for care home residents, and that things don’t always happen as advertised. People also continue to speak to Healthwatch about a mixed level of training and awareness among care home staff, particularly in relation to dementia.
- **Social care costs and care plans:** People spoke to us about the lack of transparency when it comes to care home costs, with continuing healthcare and ‘lifestyle payments’ being unclear to many. We also heard from families struggling to get care home packages reviewed when their personal care needs are not being met.

#### Healthwatch in practice - Enter & View

Healthwatch Doncaster reported on good practice in care homes, where the independence of residents was promoted by providing them with the option to eat their meals in their rooms or in the lounge or dining room. This contributed to giving residents a ‘home from home’ experience as they can be in control of their day to day activities.

Healthwatch Halton and Healthwatch Rochdale have highlighted cases of good practice in their Enter & View reports, where care home staff have trained to become Oral Health Champions. This allows staff to put processes in place so that oral health care plans are followed, leading to better oral care for care home residents.

Healthwatch Derbyshire successfully encouraged care home staff to develop a training course to cover several care subjects. This included oral hygiene care to allow staff to keep a record of their residents' teeth status.

### What are people asking us about social care?

This quarter we reviewed questions that 79 people asked us about social care support. These are the most common areas Healthwatch are asked about:

- How to access home care services.
- How to choose the right care home.
- How to get equipment installed or repaired in the home.
- How family carers can access respite care.
- How to get information about care packages.
- How to access supported accommodation.
- How to get a social care assessment.

### What are people telling us about mental health?

This quarter we received 12 reports including at least 12,893 people's views on a range of mental health services. We received 185 individual pieces of feedback about mental health, which represents 4.2% of our overall feedback received.

### What's new this quarter?

- **Family involvement:** We have received feedback about relatives wanting to be more involved in mental health care for their loved ones (3%). This theme recurred across most mental health services, including child and adolescent mental health services (CAMHS) and community mental health services. Parents of children accessing CAMHS were often not consulted during assessments and felt that clinicians did not consider relatives' or teachers' experiences. Furthermore, relatives of older adults felt that health professionals did not consult with them about diagnoses and ignored relatives' concerns over medication levels, despite them witnessing the side effects daily.
- **Empathy is key to good quality care:** We have heard that some people feel that mental health professionals lack empathy (10%). This has been spoken about across multiple mental health services, including Psychiatry, Crisis Services, Learning Disabilities Services, Community Mental Health Teams and CAMHS. People feel that they are not taken seriously and that clinicians do not understand the issues they face.

Some people said that their health professionals made them feel that they were 'attention seeking,' which made them feel belittled, not listened to and that their issues were not important enough to warrant help.

### What we continue to hear

- **Rarely a straightforward route to support:** People have found accessing mental health services difficult due to complicated pathways and problems navigating them. There have

been reports that young people are experiencing problems with their diagnosis and subsequent support due to this. People told us that being passed between services means they end up waiting a long time to get the mental health support they need.

- **Long waiting times:** Adults and young people often wait a long time for both a formal assessment and for follow-up treatment, with little or no interim information or support. We have continued to hear that long waiting times have led people to seek alternative support, such as private mental health treatment. Having complex mental health needs or not being able to speak English often makes it difficult to find the right service that offers the appropriate support.
- **Limited and inconsistent advice and guidance:** People have told us that healthcare professionals don't always have a strong knowledge of their mental health conditions or of the support available. Furthermore, carers for people with mental health conditions have reported that they struggle to coordinate care as they are given contradictory advice by different mental health support teams and professionals. This highlights that there is a lack of integration between services and limited communication between support teams.
- **Access to crisis services:** Throughout the year we have heard that people have difficulty accessing mental health crisis services. People have found contacting crisis services over the phone increasingly difficult, leaving people in desperate need without support.

### Healthwatch in practice

Healthwatch Darlington has spoken to people with a history of substance misuse about their experiences of accessing mental health services. People said it's particularly difficult to get help when you have complex needs, that they are often passed around services, and that they feel hopeless and unsupported during long waiting periods. They also said they don't feel listened to by health professionals and that they are treated differently.

As a result of these findings, Healthwatch Darlington has worked with Tees, Esk and Wear Valleys NHS Foundation Trust and NECA to involve service users in the development of a new information pack containing details about complaint procedures, care plans, keeping well plans and more. Healthwatch Darlington are also sharing information about service user opportunities to attend the Dual-diagnosis network and to be a volunteer peer mentor, to help make sure people with complex needs get the right support.

### **What are people asking us about mental health?**

This quarter we reviewed the questions that 38 people asked us about mental health care. Here are some of the most common questions Healthwatch are asked:

- How can I get help to understand the pathway for mental health support?
- How do I find out about CAMHS?
- How do I get an early diagnosis for an eating disorder?
- How do I access non-medical support for mental health conditions?
- What support is available for veterans and victims of trauma, including bereavement and sexual abuse?
- How do I complain about mental health services?
- How do I access befriending services?
- How do I get support in my own language?

### **In focus: Patient transport**

Whilst compiling our Q3 report, we noticed that lots of people have been speaking to Healthwatch about the difficulties they face travelling to and from healthcare appointments. Since then, we have analysed this in more detail. Here we share what we have heard so far about this issue.

#### **What people have told us**

Whilst people often have positive things to say about the quality of care they receive from the NHS and social care services, they're often far less positive about how easy it is to access care in the first place.

We've heard many times before that poor communication combined with complicated administrative systems make accessing appointments difficult. But more and more we're also hearing that physically travelling to services presents a challenge for people too.

Issues people have raised with us include:

- Poor parking facilities.
- Lack of public transport options for those who don't have access to their own car.
- Poor awareness of the support the NHS offers with transport.
- The quality of support from patient transport services (PTS).
- Particular challenges for rural communities.

#### **Getting to and from healthcare appointments**

It's vital that people have access to accessible, efficient and affordable transport to and from health and social care services.

It encourages people to stay healthy by making it easier for them to go to routine appointments at local clinics or GP practices, and to collect prescriptions from pharmacies. It also helps

alleviate stress for people who need to travel for specific treatment or support for an ongoing condition.

Although there are services and support available - such as Patient Transport Services and the Healthcare Travel Costs Scheme - we've heard that there is not enough clear information shared with people about their options.

We've heard from people who go to enormous efforts to visit various healthcare settings, often on a regular basis, for treatment such as blood tests, radiotherapy or chemotherapy. This is exacerbated when services make people attend multiple appointments which could have been grouped together into a single visit.

This is not just about convenience for patients. Some of the people we've heard from simply cannot get to appointments without help. We've heard that:

- Some people with disabilities, a medical condition or frailty, cannot get to services by themselves. This is a particular problem for people who live on their own.
- Although the NHS is free at the point of use, getting there is not. People have told us about the difficulties they face paying for transport to get to appointments.
- People living in rural areas face all the same challenges outlined above but they're made worse by the distances they need to travel, frequency of public transport services and the reduced range of transport options available.

#### **Difficulties using public and private transport**

Affordability can play a big role in people's decisions about which transport they'll take to get to and from an appointment. Research by the Health Foundation shows that people on the lowest incomes take nearly three times as many bus trips as those in the highest income group<sup>4</sup>. We've seen in our feedback that it is often people who rely heavily on public transport who are the most likely to report difficulties relating to the frequency, reliability and convenience of services.

We've also heard from people who've felt vulnerable and confused after leaving hospital without any help to get home. This is worse for people who can't afford a private taxi but are discharged late at night or early in the morning when public transport services aren't operating or are running less frequently.

We've consistently raised this issue for the past few years in our work on hospital discharge processes<sup>5</sup>. We've highlighted the connection between poor discharge support and emergency readmissions (people returning to hospital for further unplanned treatment within 30 days of leaving). There has been significant and positive focus on getting people out of hospital quickly, which is good, but we need to see as much emphasis on making sure they get home safely, and this includes transport support.

Meanwhile, people who can travel to hospital by car say they face problems too. In our Q3 report we included some of the concerns we've heard about parking at hospitals and other healthcare settings. We often hear complaints from people about struggling to find a parking space, including disabled bays, which can lead to stress, annoyance and late arrival to appointments.

---

<sup>4</sup> The Health Foundation, Transport and health: <https://www.health.org.uk/infographic/transport-and-health>

<sup>5</sup> Healthwatch England, Safely home:

[https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/final\\_report\\_healthwatch\\_special\\_inquiry\\_2015\\_1.pdf](https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/final_report_healthwatch_special_inquiry_2015_1.pdf)

Issues with hospital parking are often greater for people needing regular treatment because what people consider to be ‘high parking charges’ present a significant cost burden. Others, such as people visiting A&E, have told us they’ve worried whilst waiting for treatment about whether they’ve put enough money on the parking meter. We’ve also heard from people who find new parking payment systems complicated and that it presents a problem when they don’t accept cash.

### **Poor communication and awareness about the support services available**

People do not always have enough information about Patient Transport Services (PTS) when they need them. People have told us they would benefit from having proper information from the very beginning about what to expect when travelling to and from different healthcare services and how they could receive travel assistance if they ever needed it.

We’ve also heard about poor communication about the Healthcare Travel Costs Scheme, which entitles people to claim back health related transport costs if they’re in receipt of income-based benefits, although visits to GP surgeries and dentists for routine care and check-ups and most A&E attendances are not included<sup>6</sup>.

Greater awareness of the Healthcare Travel Costs Scheme is vital. When people aren’t aware of the support they’re entitled to, they may end up missing appointments because they can’t afford to get there. Likewise, we’ve heard about the burden travel costs present to family members and friends who accompany people who can’t travel alone to their appointments. Although these people may be eligible to receive a reimbursement for their travel costs, it is dependent on the eligibility of those they’re accompanying. Again, clarity regarding entitlements is essential.

### **Issues using the Patient Transport Service**

One of the biggest issues people have raised with us about using PTS is having to wait too long to be taken to and from appointments.

Healthwatch Coventry found that while actual travelling times were usually acceptable and that staff were kind and helpful, many people found themselves waiting well beyond their arranged collection time - up to two hours in some cases. This meant that people weren’t just late to their appointments but sometimes they missed them altogether. Similarly, Healthwatch Brighton and Hove heard from people about inconsistencies in PTS pick up and drop off times and failures to keep people updated about changes.

Regardless of how well healthcare services operate, it is important that people can travel to and from them safely and in a timely manner, irrespective of their health condition/s or where they live.

---

### **Personal stories**

**“I have no immediate family close by which makes life very difficult at times, and accessing hospitals is very hard as I live in a rural community.”**

**Healthwatch Suffolk**

**“Last year I was having chemo and radio therapy. Every day for about 2 to 3 months and visits to the doctors etc. But since then I have to attend Papworth and Addenbrookes to see**

---

<sup>6</sup> NHS, Healthcare Travel Costs Scheme: <https://www.nhs.uk/using-the-nhs/help-with-health-costs/healthcare-travel-costs-scheme-htcs/> & Help with travel costs: <https://www.qvh.nhs.uk/wp-content/uploads/2015/09/Help-with-travel-costs-all-areas.pdf>

doctors and have scans. My daughter and son have arranged to take me, but if I find it difficult, I have to get the bus. I can't always get there and need help."

Healthwatch Suffolk

"The cost of parking at the [name of hospital] is disgraceful and the new way of paying is complicated and relies on patients remembering their number plate. Technology is too complex for some people."

Healthwatch Cheshire West

### **The policy context: Improvements must have people at their heart**

The NHS is recognised as offering some of the best healthcare in the world, with access to high-tech equipment, the latest medications, and cutting-edge clinical expertise. But in cases where people still need to physically access a building to benefit from them, these advancements are only of benefit if people can get there.

This is important to note, as the NHS and social care sector is going through a major period of change, with a clear policy aspiration to provide more services where people are, rather than making them travel to access care. This will mean more services being delivered in people's homes and in their local communities, supported by efforts to create a more digitally-enabled NHS.

However, even with more care delivered outside of hospital, the issues people have raised about transport will continue to affect people unless they are addressed. Take, for example, the development of the new Primary Care Networks (PCNs), which are designed to ensure a whole range of enhanced primary and community services can be delivered at scale across communities. This means surgeries will increasingly be sharing services across multiple sites which may well require patients to travel to different areas to access care. Engaging with local communities will help PCNs work out how best to deliver services across their areas in ways that make best use of the existing transport infrastructure. Likewise, Integrated Care Systems will also need to consider such challenges but across a broader geographical area.

The growing improvements in data sharing and analysis across the NHS and social care sector provide interesting opportunities for improvements. For example, by understanding where a patient lives in relation to services, and factoring in data about their transport options, there is the potential to create smarter appointment booking systems. These systems could use the data to identify slots that are most convenient for people, both in terms of time and costs involved, and that they're therefore more likely to be able to attend. This could help reduce the number of missed appointments, and the need for people to spend time rearranging timings that don't work for them.

Although not drawn from the evidence we have gathered this quarter, this example from Healthwatch North Yorkshire's report on hospital transport illustrates why this would be helpful:

**"One of the key areas for concern in terms of hospitals is Upper Wharfedale. The only reasonable window over 4 hours for access to a hospital is the Royal Lancaster. While this does provide potential for appointments between 10.35am and 3.45 pm even this would require a 12-hour round trip leaving at 7am in the morning. All other hospitals were only accessible within a 2-4-hour window. It should also be of interest to commissioners that for wards in this area it seems apparent that, via public transport at least, facilities such as the Royal Lancaster that are geographically further away are more easily accessible than those such as Skipton and Castleberg which may appear closer."**

Healthwatch North Yorkshire report 2017.

Finally, we need to collectively start considering transport and its links with the prevention and public health agenda. Good transport enables people to function freely within society, whether it is used to collect food shopping, socialise with family or friends, or to access greater job prospects. These are all a vital part of helping people to live independent, fulfilling and healthy lives and can help reduce burdens on costly health and social care services. The Government is currently developing a Green Paper regarding prevention and it will be important to see how this is considered.

To support further understanding of people's experiences of transport in relation to health and care, Healthwatch England is conducting additional research and will be publishing a fuller briefing in 2019.