healthwatch

The NHS Long Term Plan

Healthwatch Evidence Summary

To support the early development of the Long Term Plan, Healthwatch committed to providing NHS England with a series of briefings on current user experience of the NHS.

These were developed using the wealth of existing insight gathered by our network and in total compiled views and experiences of well over 85,000 people including:

- **45,000 people's views on primary care services including GPs, dentists and community pharmacies** *(pages 4 - 8)*
    - Improving access
    - Continuity of care
    - Technological solutions that work for people
- **34,000 people's views on mental health services and support** *(pages 9 -12)*
    - Top three priorities for mental health and the Long Term Plan
    - Further gaps that need addressing
- **6,500 people's views on A&E** *(pages 13 - 15)*
    - What feedback can tell us about the 4-hour target
    - Why do people choose A&E in the first place?
- **766 homeless people's experiences of the NHS** *(pages 16 - 19)*
    - Primary care - particularly problems registering
    - Hospitals
    - Mental health
- **A summary of views on hospital services including waiting lists for surgery and the process of being discharged from hospital** *(page 20)*
    - What feedback can tell us about experience of the 18-week referral to treatment target
    - Emergency readmissions
- **People's views on social care - including 5,500 carers and 9,000 care users and members of the public.** *(page 21)*
    - Information and advice needs

Healthwatch has shared the findings of this research with NHS England colleagues throughout the development phase both directly with the relevant policy teams and through our seat on two of the workstreams - on engagement and on clinical standards.

This document brings together the top lines of each of these briefings to support the Committee in its upcoming evidence sessions on the NHS Long Term Plan.

Overview

Broadly speaking, our work with the public and those who use services suggests that health planning is moving in the direction that people want it to go in.

People want to see a greater focus on prevention, with the health service doing more to help people stay well – both physically and mentally.

People with long-term conditions want to be empowered to manage their conditions as independently as possible, drawing easily upon the right support and advice when needed, and want to be equal partners in making decisions about their care.

People are ready to embrace greater use of technology and broadly understand how this can support the shift of services away from hospitals towards more community-based care.

However, it is vital to the success of the Long Term Plan that NHS England and NHS Improvement engage with people on an ongoing basis to ensure things are developing as intended and to enable services to adjust things as they go.

Three key themes:

Three key themes have emerged from the briefings which we believe have particular relevance for the NHS as it develops and implements its plans for the next decade.

- **Engaging with people and listening to their experiences helps identify where policy is right but isn't working as planned**

  Feedback can highlight where different policy initiatives clash rather than complement; for example, online booking for GP appointments and the drive to diversify the primary care workforce. Both policies are providing what people want but are being implemented independently. This means the online systems only enable people to book a slot with their GP and not the practice nurse or pharmacist, exacerbating the burdens on family doctors.

- **Current performance measures don't focus on what really matters to people**

  Whilst existing metrics, such as the 4-hour A&E target and 18-week referral to treatment, are of use to the NHS, people are often unware of them or place more importance on other aspects of their treatment. Developing metrics around patient experience would still enable services to be benchmarked against each other but would also help people understand more about what to expect from the NHS beyond simply how long they may have to wait.

  With an additional £20 billion of taxpayers' money being invested in the NHS, there is a real opportunity to develop performance measures which make more sense to people.

- **The need to think differently about the workforce**

  It is clear that people are open to seeing a whole range of different professionals as long as they are the right person, with the right skills, for the job. In particular, our work has found a real appetite to make much greater use of peer support, calling on those who have been through an experience to support new and future patients.

Engaging communities in the implementation

Healthwatch has been commissioned by NHS England and NHS Improvement to support public engagement in the development and implementation of the Long Term Plan at a regional and local level.

Between January and June, we will be working with our network of 152 local Healthwatch, supported by their 5,000 volunteers, to conduct local surveys, focus groups and discussion events with communities up and down the country.

These will explore how local commissioners and providers can create services that work for local people as well as delivering the national level priorities.

Whilst engagement will happen at a community level, 42 local Healthwatch will also produce an engagement report for each of the STP/ICS areas, covering a number of communities.

Overall, this programme aims to create the foundation for ongoing engagement with communities over the lifetime of the plan.

To ensure all have a voice in shaping implementation, we will ensure particular focus on reaching out to groups who sometimes have less engagement with services, collaborating with the voluntary and community sector to do so.

Primary Care - 45,000 people's views

Scale of the insight gathered by Healthwatch:

- Around 40% of the feedback we gather each year relates to primary care.
- The vast majority of primary care feedback is about GPs, but it also includes pharmacy and dentistry.
- Roughly 40% of what we receive about GP services is negative, with the remaining 60% either positive, neutral or mixed.
- 409 local reports relating to primary care services produced since 2016.
- 64 of the 152 local Healthwatch are doing further work on primary care in 2019.

Key themes since January 2016:

The following points are based on analysis of feedback from **45,735 people** (mostly patients and public, but also some staff) gathered during visits to over **1,000 GP surgeries** across England. People told us about:

- Problems making contact to book appointments – particularly when trying to book over the phone.
- Too few appointments being available for an early date.
- Telephone triage systems perceived as intrusive.
- Issues with staff attitudes and communication with patients – with particular issues around an emerging perceived lack of empathy (possibly as a result of the pressures on the workforce).
- Lack of coordination with other services, which can lead to avoidable mistakes – particularly around timeliness and accuracy of prescriptions.
- GP surgeries closing or merging with little warning and with limited support to make alternative arrangements for care.
- Issues registering with GP practices for specific groups and in specific locations (see section on homelessness).

Many of the above will be familiar to those working in health and social care, as many of them are the same concerns which the GP Forward View set out to fix.

The fact that these themes are still coming through should not be taken as an indication that the GP Forward View has failed. On the contrary, many of the new initiatives such as Patient Online and the greater use of pharmacy have been welcomed by patients.

However, listening to people's experiences highlights a number of improvements that could be made to ensure that these sorts of initiatives have the intended effect.

1. Improving Access

One of the key initiatives to improve access has been to extend practice opening hours, either individually or over a group of practices. This is positive, yet in some places uptake has been low. This may be down to how the new hours are being communicated.

For example, *Healthwatch Manchester* noticed that the volume of complaints about not being able to get a GP appointment had not changed despite a new initiative to increase opening hours of local surgeries. A mystery shopper exercise conducted by volunteers revealed that only two out of every five GP surgeries were actively promoting the new evening and weekend appointments. Healthwatch Manchester's findings led to a major marketing drive by the local CCG, which has seen the number of concerns about access raised with the local Healthwatch fall dramatically.

As well as extending opening hours, we have also seen examples where surgeries have changed the sorts of appointments on offer at different times of day, to cater for different needs. For example, *Healthwatch Reading* identified a number of local practices offering short appointments in the early mornings and evenings and offering longer appointments during the day.

One idea raised with us by people was that certain patients could be allowed to register at more than one practice, such as working age patients who commute long distances. Enabling these patients to register at two surgeries would make it easier to access support around work commitments, helping people to concentrate on maintaining good health rather than waiting until they are sick to see someone. However, this would have substantial implications for the GP contract and how practices are funded.

2. Continuity of care

The policy narrative around continuity of care has concentrated on ensuring people have access to the same GP, helping to build trusting relationships and limiting the number of times patients have to repeat their story. This is very sensible but is practically very difficult, particularly given the pressures around recruitment and retention of GPs. It therefore helps to understand in more detail what people mean when they say they want better continuity of care.

Our conversations with patients, combined with our deliberative research, suggest that continuity is most important for those with an ongoing issue or chronic condition. These people report a more positive experience when they know that one person is helping them to manage their concerns, even if other professionals are involved.

However, people have been clear with us that this doesn't always have to be the GP. People tend to use the term GP as shorthand for the practice as a whole. They are mostly concerned with seeing the most suitably-qualified professional for the job. For diabetes patients, for example, that may mean seeing a specialist diabetes nurse as their main contact, with quick referrals to the GP if there are serious changes. People often report that seeing such specialised members of the primary care team gives them confidence that they are up to date on all the latest research.

Knowing people have a named GP is still important in a general sense, but patients also recognise it is unrealistic to expect that their GP will always be available. For many experiencing a new concern or requiring a one-off intervention the more important factor is getting to see someone quickly. Routinely offering people the choice of waiting

longer to see their usual doctor or another professional sooner would be a very pragmatic and practical way of allowing individuals to choose.

Making better use of pharmacy

Research conducted by Healthwatch has consistently shown a great willingness amongst patients to make better use of community pharmacy, with 3 in 4 saying they would be happy to go to the pharmacy with a minor illness.

Indeed, people have heard the message from the NHS, particularly during winter time, that they should seek help first from their pharmacist. This has been supported by the introduction of consultation booths in pharmacies, which have been welcomed by patients

However, people are still uncertain precisely what a pharmacist can help with. To provide reassurance to people that their trip to the pharmacist is not a wasted journey, the interaction could be factored in to the triage process should they need to see a GP.

The key to successfully diversifying the primary care workforce is to ensure patients are confident that whoever they see has access to information about their care. This is important to relieve the common frustration around patients having to go over their case each time, but also provides reassurance that things aren't missed simply because patients end up seeing someone different. The increased sharing of records and introduction of smarter computer systems should support this but it will be vital to communicate this change effectively to patients.

3. Technological solutions that work for people

The proactive research we have undertaken has consistently shown broad support for more technological solutions like Patient Online. People have come to expect these sorts of interactions in other areas of life and are often happy to undertake a range of admin activities online, including booking appointments, ordering repeat prescriptions and checking results. Used effectively, these systems could significantly reduce pressure on the system. People's interest in using such services is clear with 14 million people (more than 1 in 4 adults in England) already signed up.

With so many signed up, we would have expected to see a change in the feedback we receive, particularly around getting an appointment. Yet the level of feedback we are receiving about online services remains low. What we do hear continues to be negative. This suggests that current initiatives have not yet had the effects we might have expected.

It would be useful, particularly as the NHS looks to expand the digital offer, to dig underneath the headline statistics regarding Patient Online and use people's feedback to explore how and why they are or aren't using it.

Common points raised about GPs and technology include:

- **Having to physically go in to the GP practice to sign-up to online services**. This is a barrier people do not face with other online services. To increase sign-up, and use, it would perhaps be more effective to concentrate on removing this barrier, including through the NHS app, and enable people to sign-up at the point

when they are most motivated to do so – such as when they are trying to get a GP appointment.

- **Lack of available appointment slots.**
  People report that the number of slots available for online booking are often limited, resulting in them having to call or physically queue. This may be down to how individual surgeries manage their appointments or because of limited capacity generally, but if there are never any slots available online this will result in use of online services dropping. Solutions people have suggested to us include the ability to add your name to an online waiting list and automatic alerts when slots become available.

- **Poor traditional communication reducing the effectiveness of digital solutions.**
  A number of patients reported to us how they had ordered repeat prescriptions online only to find the GP had not communicated effectively with the pharmacist, in some cases leaving people without important medication.

- **A missed opportunity to promote alternatives.**
  Online systems could also be used more effectively to signpost to alternatives such as local pharmacies, walk-in centres, NHS 111 and even other surgeries in the area which may have capacity. People are used to similar interactions in other sectors, such as using websites to check which is the next nearest branch of a shop that has a desired item in stock or using SatNav to plan different routes to avoid traffic.

- **Only being able to book appointments with GPs.**
  People like the idea of being able to see a greater range of health professionals via their GP practice, particularly where this offers greater continuity of care and the potential for direct referral to specialists in supporting things like diabetes or mental health conditions. Yet current feedback suggests online booking systems are only working if you want to see a GP, actively working against a key policy change to increase the range of professionals making up the primary care workforce.

- **Avoid making assumptions about targeting new technology at younger users.**
  Our deliberative research has consistently challenged the view that younger users are more likely to use new technologies to access healthcare. They can, for example, be more likely to have concerns about data sharing. In order to promote the effective use of new technology, the focus should be on those people who may benefit most; for example, by making it easier for people who need regular appointments to schedule them at times that suit them or by using technology to help people to self-manage their conditions.

- **Digital exclusion**
  Whilst the risk of digital exclusion of certain groups, in particular older people, should never be used as reason for not pursuing the roll-out of new technology, it is still a very real challenge. There is a particular issue around patient perception, and a need to reassure and support those who are not able to use, or do not feel comfortable using, new technology that they will not miss out on these services they need.

“Lady been a patient of Unity Health for 60 years; very worried that the practice appears to no longer want older patients. When trying to make an appointment she was told she had to go online to do so. She explained she wasn't confident to do this so she was then grudgingly taken through a question and answer process to be told a triage nurse would ring back in the next 24 hours. The appointment was for her husband and she feels if she hadn't been able to do this on his behalf he wouldn't go to the doctor's again.”

Patient story shared by Healthwatch York, June 2017

Mental Health – 34,000 people's views

For the past three years mental health has been the top priority issue for the Healthwatch network.[1] During this time, we have heard from over **34,000 people** about their experiences of receiving mental health care and support, as well as more general views on what help should be offered to those experiencing mental health conditions and challenges.

Whilst mental health is not the most common issue people talk to us about, it stands out from other areas of health and care because most of the feedback we receive is negative.

We recognise and commend the efforts, both in policy and in practice, that have been made in recent years to invest in mental health services and to put it on an equal footing with physical health. We also know that it will take time for these initiatives to drive large scale improvement in people's experiences of receiving mental health support.

However, given the nature of the feedback we receive about mental health we think it is useful for NHS England and others to check in regularly and see what people's experiences can tell us about the level of progress being made.

Even if the NHS managed to meet all the top-level targets set out under the Mental Health Forward View, it would be difficult to see the true impact this has had on people. This is because the current targets are framed around communicating the increased level of activity rather than capturing and evaluating people's experiences of support.

Summary of Healthwatch insight

The majority of the feedback we receive on mental health covers four main service areas:

- Primary care
- Crisis care
- Community care
- Children and young people's services

The six most common issues people report are:

- Struggling to find information about the support available
- Mental and physical health needs being treated in isolation
- Not always getting the same level of service, with variation between services and between areas
- Waiting too long to access mental health services and receive diagnosis
- Professionals who are not specialists in mental health not always having the awareness, information or training they need to recognise and respond to people's mental health challenges
- Not feeling listened to or involved in decisions that affect them.

[1] Local Healthwatch prioritise their work based on what their local communities want them to work on. This does not mean they automatically work on the most common issues, rather they work with their communities and their independent governing boards to set priorities that address issues judged to be of most concern.

Our top priorities for the NHS Long Term Plan on mental health

Refocus the way improvement is tracked

Rather than focusing on any specific service or user group, the main priority for NHS England should be to refocus the way improvement is being tracked, including how targets are being set.

For example, we know at the moment that 9,000 additional new mothers have received specialist mental health support in the past year as a result of the changes and extra investment. This a positive development and a significant step to reaching the target of supporting an additional 30,000 new mothers each year by 2021. However, the way performance is currently monitored makes it very difficult at a national level to know:

- Who are these mothers and are there any groups missing out?
- Did their partners require any support and if so was it made available?
- Did the parent/parents get the support they wanted/needed?
- What would people receiving support have wanted to be done differently?
- What is the remaining gap between provision and demand, and what alternative support is being made available to bridge this gap?

At a local level there is likely to be more detail to answer these questions. But without capturing this consistently at a national level it is impossible to know whether or not the changes being implemented are driving the sort of improvements we all want to see.

Learn from the user-led approach

We know from the work of local Healthwatch across the country that listening to people's views on mental health can lead to important changes in how services are managed – from actively *gathering the experiences of veterans in Norfolk* to *involving teenagers in the commissioning process in Bristol*.

Engaging in this way enables services to focus on treating people as individuals, building a culture where understanding an individual's needs and involving them in shaping the support they receive is at the core of their care plan. We want to see a much greater spread of this approach with services sharing their learning with each other.

We also want to see a growing use of the concept of recovery in mental health, as defined by users, which focuses on helping people discover a life that is fulfilling after a diagnosis of a mental health condition. The UK's 70 'recovery colleges' are a good example of this, where professionals and people with experience of living with a mental health condition design and deliver courses, as equal partners, on issues from managing the effects of medication to dealing with stigma and discrimination.

Continue efforts to improve children and young people's mental health

We support the continued focus on developing and improving support for young people with mental health challenges and conditions. Maintaining the mental health and wellbeing of young people is vital to preventing mental health conditions developing in later life.

However, we would stress the need for even greater ambition to ensure that no child is left without support, and that interim help is always provided for those on waiting lists for more intensive support.

What gaps or problems need to be addressed?

As outlined above, the most effective way of identifying gaps in support is to ask those who are seeking support about their experience. Some examples identified by Healthwatch include:

- **Peer support services**

  People's experiences of accessing mental health support through GPs have improved over the last year according to the feedback we have received. This is a positive impact of the commitments and investment made under both the GP Forward View and the Mental Health Forward View. Yet when we talk to people in more detail about what they want, it raises important questions about the current approach.
  Rather than going to the GP as an individual professional, it is the ability to seek mental health support through the security of the practice that appeals. We know the NHS has already started moving in this direction by creating more primary care mental health specialist positions, but from what people tell us it is clear they want this to go further. In particular, they want to see much greater focus on provision of accredited peer support services so they can speak to people who have faced similar challenges and are managing them effectively. This is not a replacement for clinical interventions, but it provides something different that could help meet people's needs and relieve pressure on waiting times for clinical services.

- **Double waiting**

  Feedback from some users suggests incorrect referrals are having an additional impact on waiting times. For example, some patients who are referred to an Improving Access to Psychological Therapies (IAPT) service are being told they are not suitable and need support from the Community Mental Health Team (CMHT) instead. However, they are only being told this once they have reached the front of the queue for IAPT and then have to go to the back of the queue for the CMHT. This effectively means some people are double waiting to access support, during which time their condition could be getting worse. Whilst this approach may not be taken everywhere, steps needs to be taken to ensure that where this is the case, it is looked at again to avoid unnecessarily exacerbating matters.

- **Psychosis targets**

  We support the introduction of the new two-week target for treating the first instance of psychosis. The target, similarly to those in other parts of the NHS, is focusing on performance and ensuring those in with the most acute needs are seen quickly. However, the narrow focus does create potential problems. What is happening to people who experience repeated psychotic episodes or people who have been managing their condition effectively but suffer an unexpected deterioration in their condition later on?

  This should hold a broader lesson as headline targets are set for mental health (part of the plan's mental health workstream and the clinical standards review workstream). The NHS should aim to avoid introducing targets that only measure one part of the patient journey as this can provide a skewed picture of performance. It would be sensible to look at creating a composite target based on measuring performance across pathways. One of the simplest ways of doing this

would be to ground the target in user experience and whether they feel they got the support they needed.

- **CAMHS waiting times and the prescription of medication**

  One of the main points raised with us about Child and Adolescent Mental Health Services (CAMHS), by both young people and their parents/carers, is the long waiting lists. This is both in terms of waits for referrals and waits for a diagnosis.

  Recent figures suggest a growing prevalence of mental health challenges and conditions amongst children, and whether this is because we are just talking more openly about it or cases are genuinely on the rise, the net impact is potentially even longer waiting lists.

  At the same time there has been an increase in the number of prescriptions for anti-depressants for younger people. We believe it would be worth looking at this issue in more detail to see if there is a link between the two. Are young people being prescribed medication as an interim measure whilst they wait for further support? This may be clinically appropriate, but given the potential impact of the medications involved it would perhaps be worth looking at what other interim support arrangements could be put in place.

  The issue of medicating whilst people wait may be a particular issue for those transferring between children's and adults' services. This is something we will seek to explore in the next phase of our own mental health research programme.

- **Tackling inequalities**

  There are a number of well-known and significant inequalities in how people from different groups access and experience mental health services.

  To tackle this, providers, commissioners and regulators need to make much better use of the mass quantitative data collected by NHS Digital and map it against the qualitative data collected by user-led organisations and Healthwatch.

  It might also be useful to learn from the 'case tracking' methodology employed by the CQC in their recent local systems reviews. This could be adapted to check to see if certain groups of individuals are getting the standard of care we should all be able to expect. This provides a way of assessing inequalities without having to track outcomes for every single patient.

  It is also important to look beyond just those covered by the protected characteristics and ensure that the right data is being captured. For example, the current NHS data dictionary definitions means that data about health outcomes for Gypsies and Travellers is not routinely collected.

  Finally, we would stress the need to go past understanding access to and experiences of services. For groups of individuals for whom the current system isn't working, it is even more important to explore what support they actually want. This could be shaped by a number of factors. Unless these groups are involved in shaping the solutions then the likelihood of them having the necessary impact will be limited.

A&E – 6,500 people's views

The pressures on A&E are well documented, with hospitals across England consistently unable to meet the 4-hour target for some time.

Whilst this tells us something about system performance, and can be an indicator of problems, breaches of the 4-hour target tell us far less about the quality of care people receive and their experiences. This is a point we raised in our *submission* to the NHS Mandate refresh for 2018/19.

This briefing will not go over the extensive existing analysis of the 4-hour target that has been done by NHS England and others. It will instead look to set out what people are telling Healthwatch about their experiences of A&E and how this might be used to develop a new and more useful way of monitoring performance.

It draws on feedback from almost **6,500 people** since January 2016 covering A&E departments in 25 different local areas around the country.

Key findings:

- The most common issue is dissatisfaction with the quality of care and treatment.
- Poor staff attitudes and issues with communication comes second – possibly linked to the empathy point made in the primary care section, that staff under pressure are less able to offer the sort of care people have come to expect from the NHS.
- Waiting times come up less often but are still an area of concern.

Interestingly, despite increasing pressures on A&E, we have not seen a significant rise in negative feedback over the last two years. This doesn't mean people are completely happy with the service - not least because other research suggests that people may be making adjustments in expectations of the NHS because they recognise the pressure the service is under. However, it does suggest we need a more sensitive measure of performance for A&E.

1. What feedback tells us about the current 4-hour target

How long are people actually waiting?

Over the last two years we have heard from a number of people who report having waited between five and 12 hours in A&E. This is not surprising given the national performance figures and the increased likelihood of people leaving feedback when they have a negative experience.

However, for the majority of feedback we receive it is difficult to say how long people are waiting because people tend not to recount their experiences in this way.

People are more likely to express either having been seen in an appropriate amount of time or having waited a long time, regardless of whether they were seen within the 4-hour target or not. Much of this is characterised by the quality of communication, the quality of care they or their loved one received and the attitude of the staff looking after them.

What affects how people feel about their wait?

This way people feel about their wait in A&E is affected by a number of factors:

- How they were triaged
  - Those who are triaged on arrival and have the next steps explained to them are more positive, even if they face a long wait. This also applies to those who are redirected to onsite GP services for less urgent cases where this service exists.
  - Those who have to wait a long time for triage and then wait again for treatment are more likely to feel negatively about the experience. Often one of the main things people are looking for when they visit A&E is being triaged quickly, providing reassurance that the severity of their condition has been assessed by a trained medical professional and they will be seen in a medically appropriate timeframe.
- Whether or not they were then told how long they might have to wait
  - Local Healthwatch work suggests anywhere between a third and two-thirds of those attending A&E are not given any indication of how long they may have to wait. This causes understandable frustration.
- Whether they were kept updated if things changed due to other circumstances – e.g. more urgent cases arriving
  - Those who are kept informed are usually understanding of the constantly shifting priorities in A&E.
- The support they received whilst they waited – e.g. what was the waiting environment like, did they have access to pain relief etc
- Whether they were satisfied with the treatment they eventually received
  - For example, those who wait over five hours are often negative, but they leave even more negative feedback if they felt treatment at the end was 'short'.

We also know that people's view of A&E is affected by their experiences of other services. For example, people who have been left frustrated by the lack of support from primary care or those who have experienced a long wait for an ambulance (sometimes up to 6 hours) are more likely to register negative feedback about A&E.

2. Why do people choose A&E in the first place?

Whilst inappropriate use of A&E is rare, when it does occur is not good for either the NHS or those seeking help. To tackle this, it's important the NHS understands why people make the choices they do. The feedback gathered by Healthwatch can help shed light on this.

Key findings:

- Most people Healthwatch speak to in A&E departments are attending for appropriate clinical reasons. It is important to recognise this when communicating with people.
- However, not all people are seeking help elsewhere before going to A&E and many could have been seen elsewhere more efficiently for both them and the NHS.
- Often this is because they are unaware of alternatives, with current NHS marketing campaigns having limited impact.

- However, awareness of alternatives is not necessarily helping to reduce attendances, with people often reporting difficulty in accessing them when they need them. In some cases the alternatives being promoted nationally are simply not available in all local areas.
- In other instances people do seek help elsewhere, often through NHS 111, but find themselves being instructed to go to A&E anyway.
- There are some people who attend A&E because they believe it is the most convenient option for them as it offers easier access into health care than other services that require patients to register beforehand or remain within a catchment area.
- There are also those who continue to take loved ones as they think it is the best course of action – parents with young children are group unlikely to change this without significant investment in creating more attractive alternatives.

Designing solutions:

As in primary care, we know that people are open to seeing a range of different health professionals depending on their needs at a given point in time.

It is also not in anyone's interest to have people waiting 4 hours or longer in A&E when they could have been treated elsewhere.

What is needed is better signposting for patients, better information for the public generally and improved alternative services which offer faster help and support.

Ideas that have been shared by people that might help include:

- Greater freedom and encouragement for ambulance services to provide on the spot support and not make unnecessary admissions.
- Build public trust in the clinical training of NHS 111 call handlers – this will need to be backed up by experience that means cases are not always referred to A&E.
- Live data on signposting sites telling people waiting times for different services to help them choose between the different options.
- Triaging patients via online or telephone systems before they arrive at A&E to reduce waiting times upon arrival and help hospitals plan ahead. Patients with legitimate but less urgent needs could be supported to wait at home.
- Education for those in A&E on what other options they could have chosen which might have been better for them if they have future needs.
- Reassurance that those who seek treatment elsewhere first won't have to start at the back of the queue once they reach A&E.

Homelessness – 766 people's views

This section draws on the work of 16 local Healthwatch over the last two years engaging with homeless and vulnerably-housed people. In total they have worked with **766 people** affected by homelessness.

Whilst the points below relate to homelessness there are common messages here for how the NHS works with groups of people who are less able to engage with formal structures and systems.

Key themes

From this insight two key themes emerge:

- A lack of access to services
- A lack of holistic support

Generally, the insight showed that access to health services is impeded by solvable bureaucratic factors around homelessness such as:

- Lack of address
- Lack of identification
- Lack of phone credit

These issues are then compounded by the often chaotic lifestyles of people who are homeless which can make it hard to attend appointments or follow health advice.

Overall there was a strong sense that services, and the professionals running them, lacked a true understanding of the holistic support people need when they don't have a home.

Primary Care

Dentists

We heard that access to dentistry was a significant problem for many people, as they were unable to afford treatments offered by dentists. One person said that when they had arrived at a dentist to make an appointment, the surgery de-registered them because they were homeless. Whilst we understand that it is not technically possible to be de-registered from a dentist as dentists don't use registers anymore, the reality of this situation was that a homeless person was denied treatment for administrative reasons.

We also heard that dentists were not very understanding of people's fear or anxiety of having treatment. In some instances people said they pulled out their own teeth rather than attend a dentist.

Registering with a GP

Registering for a GP can be very hard when you are homeless as some practices ask for proof of address or photo identification which people cannot always provide. NHS England has confirmed that a person does not need proof of address to register but we hear about cases where this guidance is not followed, meaning that homeless people are prevented from accessing the care they need.

Healthwatch West Berkshire found that rough sleepers who had been able to remain with their previous GP had better experiences than people who tried to register with a GP after they had become rough sleepers.

People told us that they thought being homeless not only led to them being de-registered, but it also meant that they were not informed of this at the time. As a result, they may only have become aware of being de-registered when they needed to access services.

Four Healthwatch have conducted mystery shopping exercises to review how many GP practices will register people who do not have a fixed address. In total 182 GP practices in Buckinghamshire, Greenwich, Barnet, and Stoke on Trent were reviewed and Healthwatch found that 58% of these required documentation for registration. GPs in Buckinghamshire were most helpful, and gave good advice even if they couldn't register the person themselves. This suggests there is variation in how GP practices approach registration of people without a fixed address.

Local Healthwatch have run campaigns to help GP surgeries understand how they should be approaching this challenge, however we continue to have concerns about the impact this issue is having on homeless people nationwide.

Getting an appointment

For people who were registered, we heard that booking an appointment was difficult when people did not have phone credit or found it hard to call first thing in the morning.

People felt stigmatised because they were homeless - they didn't feel like they had been listened to, and felt rushed in and out of surgeries. In some cases, people did not want to be in waiting rooms long because of people staring at them.

Continuity of care was an issue for many, as they were often unable to see the same doctor and felt a lot of time was wasted going through history.

Access to medication

Access to prescription medication was difficult due to not being able to get an appointment. One person said they'd been refused pain medication as they lived in a hostel and it could attract people with substance misuse.

In Croydon, a number of people got in touch with Healthwatch after being *refused registration at GP surgeries*. Here they felt that GPs "explain away" people's concerns by taking all issues to be related to substance abuse and sending individuals to the drug and alcohol team. Adults with complex mental health needs were found to be the most affected in that they struggled the most to get registered and book appointments with GPs.

Specialist health centres that offer services tailored to vulnerably-housed people received positive feedback. Staff treated people respectfully and had a better understanding of challenges that face people without accommodation. However, these services are not widely available.

In some cases, we've heard positive feedback about GPs or walk-in centre staff when they are sympathetic to people's situation and try to accommodate their needs as much as possible.

"I am registered with the walk-in centre and I can go straight in come out and I am happy. I have explained to them beforehand that I'm homeless and I get anxious around crowds

of people so I've explained that to them so they are a bit more sympathetic to me and they don't start judging me because (a) I'm homeless and (b) I got issues."

Patient story shared with Healthwatch Reading, July 2017

Hospitals

Overall, people told us that they had a hard time accessing specialist appointments and were often discharged without accommodation. For example, a young man who had been stabbed while rough sleeping was discharged to a hostel for three days before going back to the street and struggled to sleep due to pain for weeks as a result.

Access to appointments can be slowed down due to cancellations, poor communication and poor access to referrals. *Healthwatch Reading* heard from two people who had only been told of a cancellation when they arrived at hospital. For someone who is homeless, this can be especially frustrating as the journey to the hospital can be costly.

Stigma negatively affected care for some people, as they felt they were actively treated differently by hospital staff when they found out they were homeless. There was double stigma if someone had substance misuse problems as well, which sometimes meant people were not given any pain relief medication.

A&E

Homeless and temporarily housed people have told us they attend A&E to support their mental and physical health when they are having an issue. It can be more convenient to access as you do not need to register, and sometimes the condition can be treated quickly – such as a sprained ankle.

There were mixed views on how helpful staff were. Some people found the setting to be inappropriate while in a mental health crisis but didn't know where else to get support.

Mental Health

Earlier this year *Healthwatch Hackney* worked with single homeless people with mental health needs and found the homeless application process and support from housing officers to be lacking full understanding. One person said it took them being sectioned before the council really listened and helped sort out housing.

For people with complex concerns, we heard that being homeless often means poor or no access to the support you need to help manage your condition. Further to that, not having a stable environment can contribute to poor mental health.

When asked about accessing mental health support, most people felt it was difficult to access mental health services with long waiting lists and fixed appointment times. Many people said that A&E was their only option to get mental health support, although it cannot provide the ongoing support that is needed.

We heard that services need to be better equipped to treat people holistically – for example *treating someone's alcoholism and depression whilst helping them find accommodation* – and the only way this can happen is by services working together.

There are also higher rates of substance misuse in the homeless population, with some people saying drugs and/or alcohol are the only coping mechanism they have. At the same time, being a known substance misuser can be a barrier to accessing other types of treatment. Stigma attached to addiction can mean people are treated differently, not

given medication, and unable to access other types of support until they have recovered from their addiction.

"Why does everything have to be about accommodation? Full time job? Help with mental health? Can't get that because I'm not in full time accommodation, I can't get accommodation because I'm not in a full-time job. It is always back and forth. And I've got to the point where I'm like what's the point?"

Patient story shared with Healthwatch West Berkshire, Feb 2018

Hospital Services

Our input on people's current experience of hospital services focused around two key issues Healthwatch has identified over the previous year.

18-week referral to treatment (RTT) target

As with the 4-hour A&E target, the fact that the NHS is failing to consistently meet the 18-week RTT tells us something about the performance of individual hospitals and of the broader system in local areas.

However, as raised in the section of this briefing on people's experiences of A&E and in our *submission* to the NHS Mandate refresh for 2018/19, it tells us far less about the quality of care people receive.

We analysed feedback gathered from site visits to over 30 inpatient wards and the direct experiences shared with us over the last six months from 477 people. This identified a number of factors that people said were important to them:

- Challenges getting referrals in the first place
- Lack of clarity over the process after referral and 'when the clock starts'
- Lack of choice about when or where to have their procedure
- Their conditions worsening whilst waiting but having no way of raising this
- Cancellations – both in terms of repeat cancellations and last-minute cancellations.

  A cancer patient awaiting gall bladder surgery reported waiting over six months having experienced repeated cancellations. At the time of giving her feedback she reported that she was still waiting and had received no new communication from the hospital despite having sent three letters to her oncologist. She reported that the delay was affecting her cancer treatment. However, she was reluctant to complain as she had always received excellent support and care from the NHS prior to this.

Emergency readmissions

In November 2018 we published our latest *briefing on emergency readmissions* –Whilst the number of cases has continued to rise, our concern is over the lack of understanding as to why.

NHS England suggested that the increase is down to the introduction of initiatives such as ambulatory care. Yet we also know from the testimony from patients and relatives that people feel they are having to return to hospital for unplanned care which could have been avoided.

NHS England has committed to looking at this further and providing better data but it is now important that they follow through on this commitment. This should also provide a broader opportunity for the NHS to think about what data can tell us about patient experience and use this as the basis for future performance indicators for the NHS.

Social Care -14,000 people's views

Through 2018 Healthwatch fed in to the Government's plans for the future of social care, with our National Director acting as an independent advisor on the Green Paper.

To inform our contribution, we analysed feedback from over **14,000 people** including members of the public, carers and users of care services.

From this research we identified a number of key themes:

1. Many people don't know how care is funded and expect it will be free at the point of use
2. Most people have given 'little thought' to their future care needs
3. Individuals want to know if a care service is safe, will meet their needs and the comparative cost
4. Many people don't know where to go for information to help them plan
5. People want a reliable and trustworthy source for advice on social care

Whilst it is important the NHS take note of our research in its entirety, we have stressed a particular need to think about the lack of information out there about social care.

Under legislation it is local authorities who have the duty to provide information and advice about social care services.

The reality is that most people see their GP as the most trusted and first port of call for information and advice on social care. This is because they want independent support rather than going to the council.

The net result of this is that additional burden is being placed on already stretched GPs to provide this additional support. It is also worth noting that whilst GPs want to be helpful, they don't always have all the relevant information to provide the best possible advice.

However, at Healthwatch we don't think the answer lies in GPs simply re-directing people to their council. The Long Term Plan should look to address this issue by exploring options for NHS and council services to work more effectively together to address people's information and advice needs. For example, council-managed advice services could be hosted in local GP surgeries. For more, see our *research* on social care.

Spotting gaps between health and social care

Healthwatch evidence gathered on social care in recent years has also helped to spot gaps in NHS provision. Take for example our November *2016 Dentistry Report* and our *2017 Care Homes* report, which both highlighted the challenge care home residents and people receiving home care support were experiencing when trying to access an NHS dentist. This problem is being exacerbated by poor levels of training and awareness among care staff about how to support people with their oral health needs. This needs to be addressed by the NHS to help reduce avoidable admissions to hospital which can occur following oral health issues, such as poor nutrition due to people not being able to eat or conditions not being spotted earlier such as mouth cancers or heart disease.

About us

We are the independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

A local Healthwatch exists in every area of England. We support them to find out what people want from health and care services and to advocate for services that work for local communities. Local Healthwatch also act as our eyes and ears on the ground, telling us what people think about local health and social care services. We use the information the network shares with us and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.

Contact us.

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

www.healthwatch.co.uk

t: 03000 683 000

e: mailto:enquiries@healthwatch.co.uk