Quarterly Intelligence and Policy Report - Q1 18/19

What we have heard in the last quarter

26,814 peoples view have been received by Healthwatch England and reviewed in Q1 18/19. This includes 168 publications involving the views of 23,167 people and an additional 3,647 individual pieces of feedback.

Primary care	
Emerging themes	In Q1 we received increased levels of feedback on the following areas: • People who have long-term conditions who need to take regular medication are having issues with their medication not being ready on time, or have issues booking a regular appointment for medication review due to the limitations of the appointment system. • Significant variation in the level of service provided by NHS 111. In some regions we are hearing people attending A&E services after failing to receive any practical advice from NHS111.
Ongoing themes	In Q1 we continued to hear that people: • Have issues with GP appointments; this includes problems using telephone appointment systems and waiting too long for appointments. • Have difficulties registering to a GP. • Struggle to find and access dental services as well as concerns over the cost of dental treatment services.
What are we doing?	• We currently sit on the GP Patient Survey Steering Group. We will be working with IPSO Mori to promote the findings and use of the survey due for publication in early Aug 2018. • Due to the volume of feedback we receive on this area, we're undertaking more in-depth analysis at a local and regional level.
External opportunities	• One of the main aims of the GP Forward View is to increase the number of appointments made available to patients at evening and weekends as part of general drive towards 7 day services. It also sets a clear ambition to increase the use of online booking systems to make things more convenient. • However, our evidence suggests that two years in to the GP Forward view these initiatives are not yet substantially changing the feedback we receive from people about their experiences of accessing the GP.

Primary care	
	• There is therefore an opportunity to map the evidence we gather against the national statistics on access to help provide a more detailed view on progress from the patient perspective. • There is an opportunity to raise this analysis directly with NHS England and also the Regulation of General Practice Programme Board which has prioritised 'access' as a key issue for 2018/19. • There is also an opportunity for us to raise the profile of challenges faced by those not registered with a GP – e.g. homeless people, migrants, students. The experience of these groups is not picked up by the GP patient survey as this only covers those registered. Therefore this is a gap in current system insight.
Internal next steps	• We will be using the large volume of feedback we receive to identify regional variation in people's experiences of GP services comparing against our previous findings on Primary Care. We will also be looking at what works highlighting initiatives that have generated positive experiences for patients. • We will review feedback on NHS111 to identify any geographical variation and correlation between providers of the NHS111 service.

Secondary care	
Emerging themes	In Q1 we received increased levels of feedback on the following area: • Access to British Sign Language (BSL) interpreters. People told us that services put the responsibility on the patient to get an interpreter. This information is sometimes only given to patients when they arrive for appointments.
Ongoing themes	In Q1 we continued to hear that people: • Wait over 4 hours in A&E before receiving any urgent care or treatment and wait up to 11 months to receive non-urgent hospital appointments. • Generally recognise that hospital staff are very busy but could show more empathy towards patients.
What are we doing?	• Insight on A&E shared with DHSC cross system insight group – multiple references to our findings made in final report in understanding pressures on system. • Emergency readmissions work resulted in DHSC/NHSE agreeing to publish this data again. Since this agreement the National Audit Office, the Public Accounts Committee and Quality Watch (joint initiative by the Health Foundation and Nuffield Trust) have all referenced our work and the need to address the data issue as a priority. A roundtable has now been called with key players for July.

Secondary care	
External opportunities	• Develop insight on people's views on waiting times. This would enable us to build on our suggestion in the NHS Mandate that current waiting time targets don't tell the full story of what it is like to be a patient. • This insight should be developed ahead of the winter period to enable the organisation to engage effectively in the winter pressures debate and focus attention on what matters most to people. • The CQC's Local System Review has been supported and promoted by Healthwatch over the last 12 months to encourage a move away from focus on DTOC and for whole systems to look more at patient flow to review performance. The final report was published in July but the CQC is looking to extend. We will continue to work with local Healthwatch to support the development of this approach.
Internal next steps	• We will be looking at how the feedback about empathy towards patients in hospitals has changed over time.

Social care	
Emerging themes	In Q1 we received increased levels of feedback on the following area: • Requests for information about social care services, particularly questions about assessments, access to care at home, care home entry and equipment services.[1]
Ongoing themes	In Q1 we continued to hear that people: • Have issues accessing appropriate home care services that are reliable and where adequate time is allowed. • Find significant variation in the quality of care delivered across care home.

[1] This comparison is between financial year 2017/18 and 2016/17; the data used for 2016/17 is from Jun 2016. However, proportionality has been considered.

Social care	
What are we doing?	• Healthwatch England National Director is acting as an independent advisor on the Social Care Green Paper. • Meeting with Minister of State for Care, Caroline Dinenage MP highlighting the poor level of information available when seeking care. • Conducted primary research to explore people's needs and wants around social care and shared with DHSC and other key stakeholders. • We have provided feedback to the CMA on their guidance around care homes. We were broadly supportive of the guidance and our comments focused on implementation and consistency of application. • On schedule to publish the 'single complaints statement' for social care developed in partnership with the LGO. This is part of the Quality Matters Initiative.
External opportunities	• The Green Paper has been moved back from July to align with the publication of the NHS long term plan, likely to be November. This means we may well need to factor in additional research activity on the proposals for Q3 and Q4. • Continue to work with DHSC to discuss their upcoming feedback strategy for health and social care. Our contribution to include review of current provision of complaints advocacy in social care and the extent to which the social care system is learning from complaints.
Internal next steps	• As part of the wider strategy we are continuing to look at what types of information people are requesting to help improve our signposting services.

Mental health	
Emerging themes	In Q1 we received increased levels of feedback on the following area: • IAPT service and predominantly about the limited number of sessions offered. People felt this was not enough and had to start the whole referral process again to get further support.
Ongoing themes	In Q1 we continued to hear that: • Children and young persons are still facing problems gaining access to timely support from Child and Adolescent Mental Health Services (CAMHS). • Adults also face long waiting times to access help and are seeking alternative support mechanisms whilst they wait.
Policy context	• On CAMHS specifically the role local Healthwatch can play in providing insight on user experience to inform decision making was highlighted by the CQC in their recent report.

Mental health	
What are we doing?	• We have conducted a scoping of the patient experience we have received, literature review and focus groups to determine the areas we want to work on as part of the Mental Health Work Programme. • We plan to publish content on this initial phase of work in the forthcoming months. • We have started working on two specific areas of mental health support, maternity and mental health and support for people transitioning from childhood to adulthood.
External opportunities	• Stakeholders are increasingly interested in using user feedback to inform service change in this area, in particular to test out whether or not the Mental Health Forward View is achieving the outcomes intended. • On maternity and mental health we understand there is significant new investment in this area which aims to see new services implemented by March 2019. This provides a useful context for our findings to help highlight how effective these services are meeting people's needs. • On CAMHS specifically the CQC is launching a campaign in October to push for young people to share their experiences with services to help them improve. This could provide an opportunity for us to join forces and support the wider work around transition. • Having reviewed the evidence gathered by local Healthwatch since January 2016 (engagement with over 35,000 people) there are also opportunities to share content on a broader range of mental health topics. The focus here will be on sharing insights which add something new to the mental health policy debate.
Internal next steps	• We are using criteria developed with the Healthwatch England Mental Health Programme Steering Group to prioritise further areas for work as part of this work programme.

Protected characteristics – Dementia in older people	
Key themes	4% of our feedback over the last two years has related to support for those with dementia. The following key themes have been identified in this feedback: • Access to information remains a key concern for carers looking after those with dementia with carers frequently enquiring about the support available. • Care pathways for those with dementia can sometimes feel unclear, confusing and unrealistic. • Greater awareness is need of how to keep those with dementia active in the community for as long as possible.

Protected characteristics – Dementia in older people	
Internal next steps	• We will review the feedback we have received to update on the state of dementia care and awareness following on from the report released in Jan 2017.

Under represented groups - Homelessness	
Homelessness	In the last quarter we have heard from 543 persons about health and social care support for the homeless community. The following key themes have been identified in this feedback: • Access to health services is impeded by factors around homelessness such as lack of address, lack of identification and chaotic lifestyle • The homeless population face particular challenges registering with a GP. • Services do not understand challenges of being homeless and were unable to give holistic support.
Internal next Steps	• We will be work to understand experiences of vulnerably-housed and homeless people using health and care services with an initial focus on primary care.

Where does our data come from?

Healthwatch England is able to provide insight into people's views of health and social care using two key sources of information from the local Healthwatch network:

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

In Q1, we received 168 publications from 68 local Healthwatch involving 23,167 people. A third of these reports (34%) relate to social care, all were about 'Enter and View' visits to Care Homes.

Volume of insight collected in Q1 2018/19 compared to 2017/18 averages

	No. of local Healthwatch reports	% of local Healthwatch reports	% local Healthwatch reports Q1 17/18	Number of individual feedback	% of individual feedback	% of individual feedback Q1 17/18
Primary Care	41	25%	12%	1537	42%	37%
Secondary Care	23	14%	13%	1131	31%	27%
Social Care	55	34%	40%	388	11%	10%
Mental Health	13	8%	8%	166	5%	3%
Other Care	26	16%	26%	425	12%	5%

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

We received 3,647 individual pieces of feedback from 48 local Healthwatch. The same quarter last year we received 1,092 individual pieces of feedback. This is the most feedback we have received through the CRM for any quarter. This increase appears to be a result of the 48 Healthwatch using the CRM more regularly to capture feedback.

Overall, almost half (42%) of our feedback related to primary care services, the majority of which was specifically about GP services. A further 30% of individual feedback received related to secondary care, notably about hospital care outside of A&E and urgent care.

What are people asking us about?

In Q1, Healthwatch received 532 requests for information as identified through the individual feedback collected by 36 Local Healthwatch and passed to Healthwatch England. However, this data is skewed with almost two thirds (57.7%) of this information originating from Healthwatch Essex. For this reason, the Intelligence and Digital Team are working with the network to understand how they are using the CRM to capture signposting and requests for information as part of the Healthwatch strategy.

Over a quarter (26.5%) of the requests relate to social care, in particular:

A third of these requests were made on behalf of a relative, friend or person cared for and over a quarter (26.5%) of the requests relates to social care, in particular:

1. The process for moving into a care home
2. Transitioning from residential to nursing homes

3. Costs and funding availability

Many queries (13.5%) related to care at home specifically:

4. How to get care/help at home
5. How to get needs assessments and equipment
6. What services are available once discharged from hospital

A further quarter (24%) of requests was about GP services. The majority of people were asking about how to register to or change to a GP practice and what GP services are available in their local area (see GP section for further information).

What are people telling us about Primary Care?[2]

During the last quarter, 41 local Healthwatch reports were published covering primary care involving the views of 10,070 people. In addition, we received 1,537 individual pieces of feedback from members of the public about primary care through the Healthwatch network. This accounts for 42% of the all individual feedback received.

Over the last year we have seen an increase in the proportion of our feedback relating to primary care. During the same quarter last year (Q1 17/18), primary care accounted for 32% of all individual feedback received.

General Practice

We have received 38 reports from local Healthwatch including feedback from 7,138 people about GP services. In addition, we received 1,250 individual pieces of feedback about GP services which accounts for around a third (34.3%) of our individual feedback received by Healthwatch England.

The following emerging theme has been identified across this feedback:

Emerging theme - medication issues

This quarter we have started to hear more about people who are having issues with prescriptions of medication from their GP. Particularly people who have long-term conditions and need to take regular medication are having issues with their repeat prescriptions not being on time. Others have raised issues with doctors changing the medication they are prescribed or refusing to prescribe them a particular medication.

The following ongoing themes have been identified across this feedback:

- **People struggle to make appointments with a GP**
  In Q1, we have continued to hear about the difficulties in being able to get a GP appointment. Over a half of the negative feedback we receive relating to GPs is around issues with booking appointments, particularly via the telephone appointment system.

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

- **People want to know how to register to a GP**
  Almost a quarter of feedback we receive relating to GPs are concerns about how to register with a GP for those who have recently moved to a new area. Other people have told us they have difficulties due to not meeting catchment area regulations, or in some cases due to practices merging which requires people to re-register.
- **People want to see the same GP**
  We have continued to hear that people see a different doctor every time they visit their GP surgery. People feel it's important to see the same GP to build up patient/doctor relationship.

"Rang the surgery recently, line was engaged. Can't even get through to the waiting queue. Finally got through and was told would get a call back. Two hours later called back but have had to wait 5 hours once for an urgent appointment. Did get an appointment for same day but never get to see same doctor - always have to explain situation and sometimes see the nurse who then has to see doctor. Need more doctors and staff to manage ever-growing population."
Healthwatch Cornwall

Other Primary Care Services

In the quarter, we received 8 reports from local Healthwatch about other primary care services notably dentistry and pharmacy, which involved feedback from around 3,718 people.

In addition, we received 287 individual pieces of feedback from members of the public through the Healthwatch network, the majority of which related to dental services. The feedback was largely (43%) positive, relating to the excellent service received, especially at opticians. We identified the following themes from this feedback:

The following emerging theme has been identified across this feedback:

Emerging theme - people turn back to A&E after an unhelpful NHS 111 experience

Whilst some people reported good experiences of the NHS 111 service, many people have told us that NHS 111 can be an unhelpful and sometimes unnecessary process, with long waits for a call back to speak to a doctor or to get an appointment somewhere. People want to avoid using urgent and emergency services or GP services when they recognise it may not be necessary however, NHS 111 is not consistently meeting people's needs so people end up using these services in the end.

"NHS 111 - Not very impressed if I am being honest. I fell at home and hurt myself so I phoned 111. But to be honest they weren't very helpful at all. Ended up having to phone 999 and get paramedics out in the end. They, by the way were fantastic and very helpful and got me to A&E quickly, safely and they treated me very well indeed."

Healthwatch Wakefield

The following ongoing themes have been identified across this feedback:

- **Getting an appointment with a dentist**
  We continue to hear from people struggling to find and register with a dentist particularly

those who take on NHS patients. People also told us they can't always find a dentist that can offer them immediate dental treatment in emergencies.

- **Disputes and confusion over the cost of dental treatment**
  Much of our negative feedback about dental services relates to the lack of clarity around payments for treatments and whether treatment is covered on the NHS or not. People feel that their dentist could be clearer when explaining dental costs, especially if they need further treatment.

What are we doing?

As of March 2018, we now have a seat on the GP Patient Survey Steering Group – attended by the Head of Intelligence. We will be working with IPSOS Mori to promote the findings and use of the survey due for publication in early Aug 2018.

There is also an opportunity for us to raise the profile of challenges faced by those not registered with a GP – e.g. homeless people, migrants, students. The experience of these groups is not picked up by the GP patient survey as this only covers those registered. Therefore this is a gap in current system insight.

There is also an opportunity for us to draw together two recent bits of work by the General Medical Council and the CQC that could help promote the value of GPs gathering feedback from their patients. As part of their review of revalidation the GMC stressed the importance of GPs using feedback to support professional development and CQC in their review of Primary Care found that the practices that prioritised patient feedback were more likely to found 'outstanding'. We could look to push this general message through partnership with the Royal College of GPs and encourage GPs to work with local Healthwatch to find ways of making the most out of patient feedback.

Due to the volume of feedback we receive on this area, we will be using the large volume of feedback we receive to identify regional variation in people's experiences of GP services comparing against our previous findings on Primary Care. We will also be looking at what works highlighting initiatives that have generated positive experiences for patients.

We will also be reviewing feedback on NHS111 to identify any geographical variation and correlation between providers of the NHS111 service.

What are people telling us about Secondary Care?[3]

A&E and Urgent Care

Local Healthwatch have produced 8 reports about A&E departments during the last quarter involving the views of 1191 people. We also received 134 pieces of individual feedback from members of the public relating to A&E departments. This represents 3.7% of all individual feedback received. We identified the following themes from this feedback.

The following ongoing themes have been identified across this feedback:

- **Organisation and staffing is hit or miss**
  Feedback about staff remains one of the key themes of this information. In general, people recognise the pressures of hospitals in A&E and urgent care however people felt that staff didn't work well together and did not necessarily show enough empathy towards the patient.
- **Still waiting to be seen in A&E**
  In this quarter, we continued to hear about people waiting between 5 to 12 hours in A&E (~32%) before receiving treatment. We also heard a few cases of people waiting for hours for an ambulance.

"My wife had breathing difficulties at night which had gotten worse so we too her to the A&E department at Pontefract. What can I say other than they were fantastic. They saw to her almost immediately without delay and had her triaged and with a doctor in no time. That doctor was superb, checked her thoroughly and spent time assessing and treating her. Everyone made her feel better and calmer thus helping her breathing. The care and attention she received by the staff was great. Brilliant example of an excellent NHS."

Healthwatch Wakefield

What are we doing?

We recommend that we develop our evidence into something more formal specifically looking at urgent care and people's experiences alongside the four hour A&E target. This would help to paint a more accurate picture for the system on what the real impact of winter pressures is on people using services.

Hospitals

In Q1, we received 20 reports from the local Healthwatch network about hospitals involving the views of 2,714 persons. In addition, we received 998 individual pieces of feedback covering 50 hospital services which made up just under a quarter (27.3%) of the total feedback.

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

This quarter we've heard less about delays in discharge, though we continue to receive a lot of feedback about quality of care, appointments, and access to services. Generally feedback about hospitals is mixed with 39% negative feedback, 31% positive and the rest being mixed.

The following emerging theme has been identified across this feedback:

Emerging theme – Lack of BSL interpreters and blue badge parking

In this quarter we heard of problems with blue badge parking which delayed patients' attendance at their appointment. We also heard about problems with accessing British Sign Language (Interpreters) during appointments making it impossible for some deaf people to communicate effectively. On some occasions we heard that patients were to organise their own BSL interpreter.

The following ongoing themes have been identified across this feedback:

- **Patients have concerns about follow up care.**
  Whilst we heard positive experience about care in hospital people had more trouble receiving follow up care from GPs due to long waits and a perceived lack of empathy. We heard specifically about the level of care given to elderly parents and felt they weren't always as informed as they should have been.
- **Appointments running to time**
  We heard more positive comments about hospital appointments in this quarter than we have heard previously, with fewer people having to wait on arrival. Most people felt pleased with the level of care provided during appointments.
- **Long waiting times for consultant appointments**
  Waiting times to see consultants or have operations continue to be a negative barrier to services; we've heard people waiting up to 11 months for 'urgent' appointments and left without information on what to do in the waiting period.

"After my operation I was never seen by surgeon. I saw a registrar post-op for a couple of weeks before being signed off. I was expecting a few weeks of recovery or pain but it went into months. I am still experiencing increasing pain. I went to the GP, who managed to get one further appointment at the hospital. No follow up appointments offered. I then had a recent test for cancer, unfortunately positive. I saw a consultant whose attitude was difficult, lacking in people skills. I'm a carer, so I need to plan ahead. The consultant again had an abrupt and tactless manner, lack of empathy, as if I am expected to know what to do."

Healthwatch Cornwall

What are we doing?

On long waiting times it may be worth us considering gathering our evidence in the same way as proposed for urgent care. We could assess people's experiences alongside the 18 week referral to treatment target and use patient insight to explore the impact of system pressures on people.

On missed appointments we have shared our insight with the Chief Nursing Officer and an offer extended to help NHSE use our evidence over time to understand why people are missing appointments. We await a response.

We will be looking at how the feedback about empathy towards patients in hospitals has changed over time.

What are people telling us about Social Care?[4]

During the last quarter, 55 local Healthwatch reports were published on services relating to social care capturing the views of 1,350 people. This included 48 Enter and View reports on Care Homes, which have been mostly positive.

We also received 388 pieces of individual feedback from members of the public through the Healthwatch network, representing 11% of our total individual feedback during this same period. The majority of our feedback involves people talking to us about domiciliary care, followed by care homes and equipment services.

We identified the following emerging theme from our feedback:

Emerging theme: increase in requests for information about equipment services

In this quarter, we had more request for information about equipment and related services including incontinence pads, wheelchairs and home adjustments being the main types of equipment needed. We also continue to receive questions about social care assessments and people wanting to set up carers to help with elderly family.

We identified the following ongoing themes from our feedback:

- **Lack of consistent and accessible information about care at home services**
  Continuing from the report we published on domiciliary care last year, we have had high levels of feedback about care at home. People still tell us they have trouble accessing the most appropriate home care services, with some people needing help to set this up for themselves or a family member.
- **Unreliable staff and care at home appointments rushed due to demand**
  Most people receiving care at home want to build relationships with their carers but due to care staff having many patients appointments are often rushed or carers do not turn up. This also impacts on those who have time sensitive needs such as medication.

"The individual attends a support group every eight weeks and normally a carer attends with him. However, today they told me last minute that my carer is not able to come with me as she is attending training. They only told me this about an hour before I had to travel and this made me feel very anxious, upset and stressed. I was devastated. I would have liked to know in advance so I could have prepared myself better to travel on my own. I don't want this to happen ever again. I am serious about this as it made me feel very stressed. I want you to tell them because if I do, they might not respect me. I am very happy living at this care home as I have been living here for many years. I definitely do not want to move as I want to stay local. I just want them to know how this incident affected me."
Healthwatch Birmingham

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

- **Poor staffing limiting the quality of care provided for resident**
  We have received more positive feedback about care homes in this quarter. However, we have also heard of people not receiving adequate care in care home – for example one elderly woman with dementia was severely dehydrated and went to hospital as a result. Another person said that their sister who has learning disabilities was not taken for her appointments and finds the staff to be rude.

What are we doing?

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

As part of this work we had a positive meeting with the Minister of State for Care, Caroline Dinenage MP, in February picking up on the poor level of information available to help people judge the quality of care and find services that are right for them.

Following this session we commissioned further research to help inform the development of the Green Paper.

We conducted two deliberative focus groups sessions and some national polling activity to explore people's needs/wants around social care. We have shared our insights from these events and from public polling we conducted with the Department of Health and Social Care, as well as a range of other stakeholders from across the sector.

The key finding from this work was that there is a lack of a trusted independent information and advice to support people to plan for their social care. We highlighted the fact that this lack of trusted information was often a barrier to effective planning, and we suggested that a consistent, independent and trustworthy information and advice service was developed to support people to understand and make the right decisions about their social care.

The green paper was initially due for publication in the summer; however the Department for Health and Social Care has since announced that publication will be delayed to align with the NHS long-term plan – likely to be November.

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

Last year the Competition and Market's Authority's report on care homes picked up on the concerns we submitted around the lack of complaints advocacy in social care. The Government's response to the CMA has agreed to take forward a review of this to put complaints in social care on an equal footing with the NHS.

The CMA have since developed draft guidance for care homes to comply with consumer law, we submitted a response to the consultation that was broadly positive, though made a range of suggestions about the guidance could be implemented and communicated more effectively.

On 11 April we met with the DHSC takes the review of this issue forward as part of their broader health and social care feedback strategy which is being developed. We will continue to make our long-standing point that there should be the same offer of advocacy support to help raise complaints regardless of the health or social care service used.

In the June the DHSC published the Carer's Action Plan, which sets out a series of practical policy initiatives to improve the lives of carers. We have conducted research into issues faced by carers, looking at feedback local Healthwatch have received from carers, we also gathered information

from councils about waiting times for carer's assessments and analysed secondary data. We will be publishing these findings later this year.

We are also on schedule to publish our work with the LGO on a 'single complaints statement' as part of the Quality Matters initiative which aims to help provide some consistency in complaints handling in social care.

What are people telling us about Mental Health?

We received 13 reports involving the views of 1008 people on mental health services, on topics ranging from acupuncture efficacy to crisis services. In addition, we have received 166 pieces of feedback about mental health. We identified the following themes from this feedback:

From the feedback we have identified the following emerging theme.

Emerging theme: variations in waiting times and number of sessions

In this quarter, we've heard more about IAPT Services than previously with 35 people talking about these services. We hear about variation between services available. For example, we heard one person was promptly given six months of one-to-one support which they found really helpful and another person was told to wait three months for four counselling sessions. It is unclear as to why these variations occur. A number of people wanted to get more than their allotted sessions and had to wait three months after their sessions to self-refer again.

"Another Carer was referred to Think Action (IAPT) by Carers' Support. She really benefited from the service, but was told that they could only offer 8 sessions at a time and so she waited the 3 months and then re-referred herself each time. She had not long been receiving support when she took an overdose with the intention of ending her life, but she did not take enough. She spoke about this to her Counsellor, but she was still told that they can only offer 8 sessions at a time. During one of the 3 month gaps she experienced extreme suicidal thoughts again and came to Carers Support and told staff that she wanted to jump in front of a train. We referred her to Single Point of Access who assessed her and she is now under the care of Coleman House. She has a history of self-harm and extreme anxiety with regular panic attacks. She also has a long term physical health condition."
Healthwatch Kent

- **Still no straightforward pathway for young people**
  We continue to hear about problems with diagnosis and subsequent support from CAMHS. Young people and their parents/carers often tell us they have struggled to access services due to waiting times for diagnosis and unclear care pathways for young people.
- **Adults waiting for support**
  We have heard that because of the long waiting times for appointments with mental health services, adults are seeking alternative routes of help and support mechanisms for their mental health between appointments.

What are we doing?

Recent stakeholder meetings in support of the development of the Mental Health Programme suggest there is appetite for us to use the insight we gather to help identify the gaps which the

current MH Forward View is not addressing. In particular they would like to know more about the experiences of the groups with more severe mental health conditions as there is perhaps less policy focus on support for these groups at the moment.

Stakeholders engaged so far have also suggested that using our insight to test the effectiveness of the early interventions prioritised by the MH Forward View would be useful.

We have conducted a scoping of the patient experience we have received which has identified a number of areas of focus. We are using criteria developed with the Healthwatch England Committee to prioritise these areas and provide the onward direction of the Mental Health work programme. Further areas of focus may be identified throughout the work programme.

A literature review and focus groups have been undertaken, the findings from which will be overlaid on the patient experience outlined above to identify any potential opportunities for additional research work. We plan to publish content on this initial phase of work in the forthcoming months.

We have started working on two specific areas of mental health support, maternal mental health and transitioning from childhood to adulthood.

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

This feedback from stakeholders should be used to help us prioritise the individual issues we explore further over the course of the programme.

What are people telling us about protected characteristics and seldom heard groups?

Protected characteristics

In the quarter we have received 29 local Healthwatch reports involving the views of 8840 persons that specifically look at health and social care issues of specific protected characteristics. In addition, we received 303 pieces of individual feedback where protected characteristics were specified in full. This means that no protected characteristic detail was recorded for 1973 pieces of feedback.

Older persons – Dementia

We continue to hear significant levels of feedback about dementia. In the last two years we have heard from 2582 people who live with dementia or carers; feedback about dementia support accounted 4% of our data last year. The key themes across this feedback are as follows:

Information provision remains a key concern for many people, especially carers. People have told us there is not enough information that can be easily accessed, especially after they have been diagnosed.

Consistently available support remains a key theme especially with services in the community. We've heard that care pathways can feel unrealistic and unsupportive, with professionals not always communicating in a clear way. Services don't work together as well as they could.

Greater awareness of dementia is needed and on how to keep people with the condition active in the community for as long as possible.

Family Carers are increasingly asking for support. Up to 76% of our unsolicited feedback on dementia comes from carers, which indicates that carers continue to struggle to get the information they need to care effectively. A full briefing can be found here.

What are we doing?

We will be reviewing the feedback we have received to update on the state of dementia care and awareness following on from the Healthwatch England report published in Jan 2017. This will include what has changed and what still needs to be done.

Under-represented groups

In the last quarter we have received seven local Healthwatch reports involving the views of 526 persons from the homeless community. We have been able to identify 17 individual pieces of feedback that concern members of under-represented groups. This feedback highlighted two key areas of interest that have been

Under-represented groups - Homelessness

One area we have started to hear more about is health and social care needs of homeless community. In the last two years we have heard from 886 people shared their views on health and social care for this community. The key themes across this feedback are as follows:

Access to health services is impeded by factors around homelessness such as lack of address, lack of identification, lack of phone credit, and chaotic lifestyle which can make it hard to attend appointments or follow health advice.

Registration with GP services in particular has been a challenge with at least 5 local Healthwatch reporting on this; there appears to be variation in whether someone can register without a fixed address.

Services didn't truly understand challenges of being homeless and were unable to give holistic support. People need to feel understood by professionals and be able to get help with housing, their health, and work all together in one place.

What are we doing?

We will be undertaking development work to understand experiences of vulnerably-housed and homeless people using health and care services. This development work will focus initially on primary care subsequently extending to other service areas in line with stakeholder focus.

There is opportunity to build the local Healthwatch network into this development to help identify regional variation in services and potential solutions that could be applied on a wider national basis. Part of this work may involve identifying where Healthwatch could signpost and raise awareness of services that can help the homeless population.