

Healthwatch Birmingham's response to NHS England and NHS Improvements consultation on clinical review of standards for cancer

Over the years, Healthwatch Birmingham has received a considerable amount of feedback concerning access to cancer services. This feedback shows that patient's experiences are varied when it comes to waiting times to see a cancer specialist and for diagnosis, waiting times for treatment and quality of care including post-surgery and post discharge care. Other concerns people have told us about are poor communication with patients about outcomes following tests or scans, lack of regular checks for people especially those that are 70+ and missed diagnoses. In addition, GP access problems have meant that people have failed to meet their Drs which has resulted in missed opportunities to identify cancer symptoms and make appropriate referrals.

Healthwatch Birmingham therefore welcomes the opportunity to respond to NHS England and NHS Improvement's consultation on *clinical review of standards for cancer*. Our key role is to make sure that patients, the public, service users, and carers (PPSUC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- Patient and Public Involvement.
- Whether the proposals are responsive to the needs of the people of Birmingham

We are pleased to see that there is a review of the NHS access standards for cancer, that the standards will be informed by what matters most to patients and the public to enhance clinical outcomes. Overall, most people in Birmingham have clear information and guidance about the current timescales and easy signposting about where to go if they need further support. As a local Healthwatch, we are often contacted by members of the public about long waiting times for treatment including the 2-week cancer waiting time. We are therefore confident that the majority of the public in Birmingham are aware about cancer waiting times.

Healthwatch Birmingham response to the questions asked in the questionnaire is 'neither agree nor disagree'. Based on the experiences people share with us, certain things need to be in place or need to take place for these new proposed waiting times to work well for everyone, have the desired impact and not lead to health inequalities. For instance, we believe that there needs to be a strong communications campaign about these new standards, and this must be accessible to different groups or communities. It needs to be made clear how these standards are better than the previous ones despite being longer including an illustration of how they will work in practice. Otherwise, we fear that failure to engage and inform people about these new standards could potentially lead to misinformation and reduced trust. As this piece of feedback, we received in December 2020 illustrates:

The caller's mother died of cancer. The caller believes her mother's treatment was 'deliberately delayed' as she was Muslim, and the surgeon was Indian. Originally, the caller's mother had been displaying symptoms which the caller picked up on as she used to be a nurse. Up until this point she had only been prescribed Gaviscon. However, she believes a doctor at the GP surgery ignored



her concerns when she suggested her mother be tested for leukemia. She did have a cancer diagnosis following this. The oncologist at the hospital states 'they were lucky to have found out about the cancer in the early stages'. Daughter says they were not lucky at all, and this should have been diagnosed much earlier' Daughter says they felt the doctor did not like her mother. Says other Muslims feel the same and said that the doctor was "murdering people" because they were Muslims.

In our [report](#) into health inequalities amongst Somali people in Birmingham, we found that there was not enough information for the community concerning Covid-19. Where information existed, it was not accessible to the community and as a result there was a lot of misinformation circulating.

In addition, people have varying levels of health literacy, thus poor knowledge, and information about how the system works and people's rights within the system. Healthwatch Birmingham therefore believes that clear accessible communication and engagement on the proposed standards will ensure that everyone is able to access cancer services, not only those with knowledge of the system and understanding of the issues. Consequently, reduce the likelihood of the standards increasing inequality or inconsistencies across the UK.

Whilst we agree that the 2WW standard might serve as a barrier in some cases and does not consider how long patients wait for a diagnosis, we neither agree nor disagree with the proposals in this consultation. The experiences that Healthwatch Birmingham hears from patients shows that there is considerable anxiety about waiting for a diagnosis. The experiences below demonstrate the anxiety that people face when waiting for a diagnosis but also the fear of their condition worsening whilst they wait.

Caller has contacted us on behalf of his wife who attended a clinic for a scan on her underarm following a cancer scare. The clinic in question has not sent the results of the scan to callers GP, saying that they had sent them by fax, when the GP does not have a fax machine. Caller has been waiting nearly 2 months for the results, which has resulted in a great deal of stress for him and his wife. He has tried to complain to the clinic, but with little response from them.

Caller is a Nurse at Care Retirement Village. She has a patient who 2 weeks ago was diagnosed with a mass in his bowel and severe pain and losing blood. His GP sent referral to hospital and marked as urgent as he required a diagnostic test and they have come back to say it will be 4-6 weeks before they can test him because of the backlog due to Covid-19. The doctor has advised that he is 99.9% certain that he has got cancer and urgently needs a biopsy. The patient is generally a very fit man, and she is worried that this could spread and can't believe that they won't see him sooner. The doctor has chased, and they are still saying at least four weeks.

In 2019, the caller had bowel problems. His GP booked him in for a colonoscopy. He didn't hear anything from the hospital, when he called, they said they couldn't give him a date - they said he could attend A&E if necessary. He was told they would phone but he didn't get booked in. He decided to pay privately to book for a colonoscopy. A week after, he had a call from another hospital offering to book him for a colonoscopy. Following this, 3-4 weeks later, he received a call from the original hospital offering to book him in. He explained he had already had it.



His GP was surprised to learn this info, as he thought he could have the onset of cancer and should have been booked within 6 weeks of the initial appointment.

Although having a definitive diagnosis or ruling out of cancer period (e.g., 28 days) might address some of these issues, are there steps within these 28 days that need to be made clear. For instance, how long does one wait to be contacted for tests/scans after a referral or will it be an issue of someone being called within 7 days, another within 10 days or 15 days for tests? This lack of clarity of what happens within the 28 days might lead to confusion, distrust and potentially different outcomes for people. People have told us how crucial it was to have a prompt response from referral to treatment for their recovery.

My elderly mother developed a lesion next to her eye. GP action got her referred to dermatologist at local hospital within 2 weeks. Over the next few weeks, she had a biopsy, a CT scan, cancer diagnosis, mask fitted and radiotherapy. Total time from speaking to GP to end of treatment was 8 weeks. Four weeks on she has made a remarkable recovery. Follow up appointment with Oncologist was via phone which I was concerned about but went well with option for face to face if necessary. Very pleased with GP and hospital services. She was offered district nurse to do dressings but with pressure on NHS I have been doing them with GP/Consultant approval.

I seen Dr about bowel problems, within 2 weeks he had arranged for me to have several tests that resulted in cancer surgery. He then looked after me during the recovery period. Due to his quick response, I am now cured of bowel cancer.

There are various other issues that people in Birmingham have told us about that need to be addressed to ensure the effective implementation of these standards:

Dismissive attitudes of professionals

Some people who have told us about feeling dismissed by healthcare professionals and that their symptoms were not taken seriously.

Caller has contacted us after several visits to his GP in which he has complained about feeling pain. Caller reports that GP has told him that the concerns relate to his diabetes, although caller is convinced that this is not correct and believes he may have cancer. Caller has recently collapsed and has asked his GP for a cancer assessment, which he says his GP is denying him. Caller has arranged an appointment with a private doctor to get a second opinion but would like to raise concerns about the GP practice.

My sister had visited a GP here to discuss a lump on her hand that continually bled. She had a complex medical history and had already beaten cancer as a teenager. The GP dismissed her for months on end even suggesting she only wanted something done to the lump due to vanity. Needless to say, she went private and within a week we found out it was cancer. Within a month it had spread to her lymph nodes and burst resulting in the cancer spreading to her rib cage and surround areas. She had her arm and scapula removed in Newcastle by an amazing surgeon but unfortunately they couldn't get it all. Due to the location the cancer it was too risky to take more. She did everything she could to keep herself alive, to live this life. All this because a GP didn't refer her in time, didn't



take her concerns seriously, didn't consider her medical history. He saw a 20 something wanting to shake hands with people.

The caller was diagnosed with cancer in 2020. He had raised concerns multiple times about his health but said he was never taken seriously. He went again and was seen by a student doctor who said she was unhappy with the way he had been treated and ordered further tests. He was then diagnosed with cancer.

I have health's problems that haven't been addressed and have been offered no help even though cancer runs in my family

Communication

People have told us about long waits for outcomes of their tests/scans which then delays treatment. For others it is poor communication between hospitals and GPs about the patient's treatment.

Caller has been diagnosed with cancer and has received very poor treatment and been the victim of a chronic lack of communication. Callers' cancer diagnosis started last year, and resulted in her losing the sight in one of her eyes. She was not informed of her diagnosis by the hospital she attended, but by her GP, despite attending several consultations at the hospital. Her operation to remove the cancer took 5 months to arrange, by which time she was told that she would need a further diagnosis to assess the damage caused, delaying the operation time further. After losing her eye, she has now been told that the cancer still remains, and that it may be in a different place. During her time in hospital receiving chemotherapy and radiotherapy she was not cleaned and was not kept informed of her status, being told on one occasion that she was not expected in the hospital, despite having been referred there from a specialist. Caller is very distraught at her treatment and is keen that others do not receive the same level of care that she does.

Caller is concerned about the communication between her Hospital and her GP over his cancer treatment. Callers husband has been undergoing cancer treatment through the hospital and has been released from care with the instruction that he will receive a regular injection of hormones from his GP. However, his GP has said that in order to proceed with the injections he will need a letter confirming transfer of care from the Hospital, which the hospital have not provided. Caller has contacted the hospital to be told that the situation is 'not their problem' leaving the caller concerned that her husbands care will be left in limbo. She wants the situation resolved but does not wish to make a complaint due to her husbands

Delays in cancer diagnosis/ Missed symptoms

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I was regularly going to Hospital for the last three years and they were unable to detect my cancer. It was only detected eight months ago and I got part of gum removed.

The issues raised above are of key concern in Birmingham as it has a diverse population with varying needs. There are over a hundred different languages spoken in Birmingham. Some areas of the city are mainly (at least 80%) populated by residents from Black, Asian and Minority Ethnic groups. More than half of Birmingham's population is under the age of thirty. Forty-six percent of Birmingham's population live in the 10% of most deprived areas in England, which accounts for some very poor health outcomes. There is a prosperity gap of 10 years between the most affluent and least affluent people living in Birmingham. As a result, experiences of access to healthcare are quite varied.

Information and guidance needs to be easily accessible to all those with language support needs. Information will also need to be culturally sensitive and appropriate. There needs to be an understanding of the barriers and challenges different groups face and consideration of whether these standards will help address these barriers and improve outcomes for people. Healthwatch Birmingham has found that referral rates to specialist services is lower amongst minority ethnic groups and for those in less affluent areas. Indeed, an NHS report¹ observed that patients in the most deprived areas are less likely to be diagnosed through cancer screening. In addition, Black patients are considerably less likely to be diagnosed through screening.

We look forward to reading about how the findings/responses to this consultation have helped shape the standards being proposed.

Yours Sincerely,



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¹ [09-pb-29-03-2018-scene-setter-on-current-trends-health-inequalities.pdf \(england.nhs.uk\)](http://09-pb-29-03-2018-scene-setter-on-current-trends-health-inequalities.pdf (england.nhs.uk))



