08/04/2022

Healthwatch Birmingham’s response to 10-year Cancer Plan: Call for Evidence

Healthwatch Birmingham welcomes the opportunity to respond to Department of Health and Social Care’s call for evidence for the 10-year cancer plan. Over the years, Healthwatch Birmingham has received a considerable amount of feedback concerning access to cancer services.

People have shared varied experiences when it comes to access to information, as well as cancer treatment at all stages. This includes lack of accessible information, waiting times, quality of care post treatment. Often poor communication is highlighted to us, with patients waiting to hear results and outcomes longer than they would like or feeling like they don’t have enough information about their own condition. We have also heard concerns about misdiagnoses.

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.

Access to information

Healthwatch Birmingham has found that people have varying levels of health literacy within the city. This affects how easily they can access information about sign and symptoms of cancer before diagnosis, but also any information and instructions they need after being diagnosed. 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 how to address these barriers and improve outcomes for people. Information and guidance needs to be easily accessible to all those with language support needs.

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

> *There needs to be some information that someone goes home with and translation. Even those of us who speak English struggle when the doctor rushes through things and uses terms that are difficult - they use medical terms that if they are not explained to you then you won’t understand what’s going on. I have sat with a doctor and he is using 10 different medical terms and I don’t understand what is happening. I have to keep asking ‘what this means and what does that mean?’ Imagine for the person for whom English is not their first language, they are not going to understand. I think for things like that people need information packs or links to information so that they can go off and read by themselves or get someone else to support them*

We have also heard from people with sensory disabilities who have struggled to get clear information allowing them to look after their own health. This is also the case at medical appointments due to limited time with an interpreter or the wearing of face masks.

Where people are aware of the signs and symptoms of cancer, we have heard there is often 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 complaint 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.*

Cancer Treatment

People have told us about good experiences they have had when services have worked quickly to diagnose and treat them, and there has been good communication between primary and secondary (or tertiary) services.

> *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.*
>
> *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.*

> *Having recently being diagnosed with cancer I have found it extremely difficult to get my pain managed via the consultant. My Dr has been nothing short of brilliant both in terms both his prescribing and his communication with me and my family. He has gone way beyond my expectations of a GP and has had to recently contact my consultant to ensure my hospital stay was more comfortable. During this difficult time for me and my family my Dr has allowed us to focus on the important things ensuring all things medical are not a source of further stress.*

There are however various other issues that people in Birmingham have told us about that need to be addressed:

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

08/04/2022

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 being 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 health*
>
> *The caller received contradictory information from the hospital regarding her cancer treatment. Her oncologist explained she would need chemotherapy. However, when she later saw a different oncologist, they said that they wouldn't be going ahead with the chemotherapy. She is confused and has been waiting for a follow-up for two weeks.*

Delays in cancer diagnosis/ Missed symptoms

> *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 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 caller is upset because she has been diagnosed with breast cancer despite raising concerns with her doctor multiple times. They did tests and found no evidence. However, they never called her to tell her this. They said she should*

> *have phoned to follow this up. Later on, she had an appointment at hospital where it was diagnosed.*

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.

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 report 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 see work towards the 10-year cancer plan progress.

Yours Sincerely,

Kalebe

Sarah Walmsley

Data & Insight Officer

Chipiliro Kalebe-Nyamongo

Research and Policy Manager