healthwatch

What did people tell us about cancer services during the pandemic?

April 2021 – March 2022

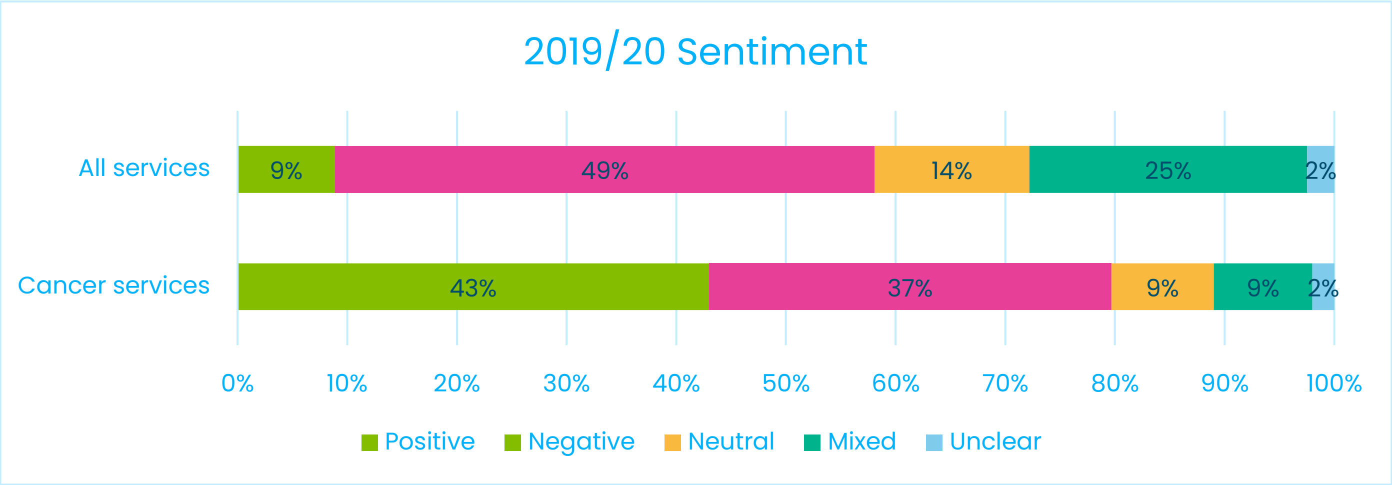
Introduction

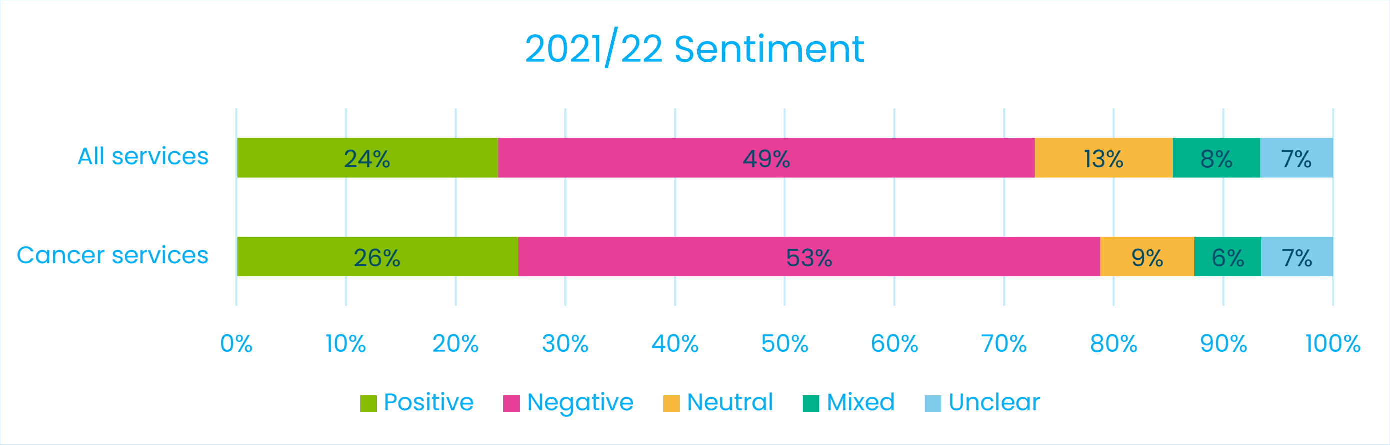
In 2019, Healthwatch engaged over 40,000 people across England to find out what people wanted from the next ten years of the NHS. We heard from over 5000 people with cancer, who shared largely positive experiences of care.

61% of people with cancer who shared their experiences with us in 2019 described their experience of support positively. Reasons for this include timeliness of diagnosis and treatment, access to rehabilitation and support courses, complementary therapies that support general wellbeing, rehab nurses, annual check-ups, good information and good communication from professionals. However, people shared experiences of long waits for referrals and appointments to specialist services.

Before the pandemic, the majority of feedback we heard about cancer services was positive. However, in 2021 and 2022, feedback was largely negative. Between April 2021 and March 2022, Healthwatch England heard directly from 684 people about their experiences of cancer services. Just over half (53%) of these experiences were broadly negative, 26% were broadly positive, and 6% were mixed. We heard about delayed and cancelled screening and treatment, experiences of misdiagnosis, limited information and support during and after treatment, and limited support during end of life. We also heard about health inequalities for people accessing cancer screening and treatment, including people with language barriers and people with learning disabilities.

In 2019, feedback on cancer services was largely positive and feedback on other services was largely negative; 43% of feedback on cancer in April 2019 – March 2020 was positive, compared to 9% of the feedback across all services. However, in the same period in 2021/22, positive sentiment around cancer services had fallen by nearly 50%. Only one in four people told us they had a positive experience of cancer services in 2021/22.





Key findings from this research:

- Long waiting times to speak with GPs during the pandemic meant longer waits for referrals to cancer diagnostic and treatment services.
- A concerning number of the people who contacted us shared that their cancer had been initially misdiagnosed by their GP because their GP didn't take their concerns seriously.
- Routine screening and tests were cancelled during the pandemic, and there were long waiting times to hear the results.
- People experienced long waits for treatment for their cancer.
- Once discharged, people aren't offered adequate information or follow-up support.
- We heard from people with language barriers, people with learning disabilities and women about specific issues these groups have when accessing cancer services.

Methodology

Where is our data from?

Macmillan estimate that, in England, around 320,000 people are diagnosed with cancer every year[1]. Our sample reflects the experiences of over a thousand people from across England, who shared experiences of every stage of the pathway through cancer services.

- **Local Healthwatch feedback and signposting data** – between April 2021 and March 2022, we heard from nearly 50,000 people via our CRM. These data come from local Healthwatch hearing individual stories and signposting people to services. This briefing's sample of 648 people's experiences of cancer services is drawn from this larger dataset. It covers 286 people's experiences of specific cancer services including screening, and 362 people's experiences of using other services while they had cancer.

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[1] Macmillan Cancer Support – Statistics fact sheet: https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf

- **Local Healthwatch reports** – local Healthwatch conduct individual research projects throughout the year, engaging with specific groups about their experiences of services. Thirteen local Healthwatch completed work looking at over 500 people's experiences of cancer services between April 2021 and March 2022 and this briefing includes their specific findings as well as drawing on larger themes.

How did we reach our conclusions?

We conducted a thematic analysis on our feedback and signposting data, reading through each individual story and categorising it based on overall sentiment, services involved, and overarching themes. We were able to calculate how much of the feedback was negative, positive, or neutral, and indicate common issues people experienced, based on this coding. We also included supporting figures from local Healthwatch research. Quotes are anonymised and used to illustrate wider themes.

We compared our findings to those from work completed in 2019 by Healthwatch England to inform the development of the Long Term Plan, as well as to the 2019 Cancer Patient Experience Survey (CPES). We also used wider work by Healthwatch England to support our conclusions.

This briefing is informed by:

The experiences of **648 people**, shared with 58 local Healthwatch across England, between April 2021 and March 2022.

Research completed by **13 local Healthwatch**, including the experiences of over 500 people, a review of 105 pieces of literature, and mystery shopping exercises.

1,048

Common issues across our feedback

GPs and referrals

Throughout the pandemic, increased demand for GP services as well as additional responsibilities for GP staff has meant that GP surgeries are struggling to provide care for all patients. Consequently, we've heard from people who aren't getting the support they need from their GP; each month, over 60% of the feedback we hear about getting care from a GP are negative experiences. Many of the issues that we heard about – long waiting times for appointments, difficulty speaking with a GP face to face, and issues with referrals for specialised care – affected people who suspected they had cancer.

In CPES 2019, 84% of respondents stated that they felt they were seen by their GP as soon as they thought was necessary[2], after they first thought they might have cancer. But in 2021 and 2022, we heard from many people with cancer or symptoms of cancer who found it difficult to speak with their GP, or who had to wait weeks or months to be seen. Some people told us they found it so difficult to speak with their GP that they stopped attempting it altogether.

> In November 2020 I discovered a breast lump. After several attempts to contact my GP online and via telephone I eventually spoke with a GP who agreed to refer me directly to the breast unit. 2 weeks later I was diagnosed with cancer. … contacting the GP has proved so difficult I no longer even try and seek help …. – Healthwatch Bury

Waiting times for GP appointments has had a knock-on effect on the waiting times for secondary services. We heard about patients with a history of cancer being unable to speak to their GP to discuss the recurrence of cancer symptoms. We also heard about people who waited over a month to be triaged at their GP, during which time their cancer worsened.

> I didn't get called for my mammogram in my 50th year, and when I found a lump in my left boob in June 2020 it took me 2 months to be able to get through to the doctor. Then I waited another month to get seen by which time the lump had doubled in size. I was referred to the breast care unit, had a biopsy and told I had cancer. A lumpectomy revealed grade 3 cancer, but not clear margins so I had a mastectomy and lymph node clearance where 4 more tumours were found. 5 months of chemotherapy followed, and when I went to my radiotherapy set up, more cancer was found. 3 weeks of radiotherapy ensued, and a [long] wait of 4 months before I could have another scan, which revealed even more cancer, which is now classed as incurable. I'm Stage 4. I'm 52 years old. Had I had that mammogram when I should have done, would I now be looking a death sentence? How would you feel if I was your mother, daughter, sister, aunt, friend? I'm sure you'd feel pretty let down due to one simple screening that wasn't done, and then the delays in seeing a doctor because they basically shut their doors during the [coronavirus] pandemic. I'm pretty bloody angry about the whole thing – Healthwatch Milton Keynes

NHS targets aim for 93% of people to be seen by cancer outpatient services within two weeks of a hospital receiving their referral[3]. But we heard stories of people's treatment being impacted due to administration issues. This included people's referrals being lost, appointment letters

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[2] CPES 2019: https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf

[3] National Cancer Waiting Times Monitoring Dataset Guidance: https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2020/09/national-cancer-waiting-times-monitoring-dataset-guidance-v11-sep2020.pdf

arriving after the date of the appointment, patient notes not being sent to consultants, being given the wrong booking information, and being unable to book appointments.

Administration issues have a knock-on effect on patients' ability to access treatment by delaying access to appointments at cancer services. But because many of these issues occur before a hospital receives a referral, these delays are not counted when monitoring waiting times. Similarly, people's GPs are often their first port of call when they suspect that they have cancer. Long waiting times for appointments at GPs, especially face to face appointments, delay people's referral to outpatient services. But this is not considered in NHS waiting times targets because these start from hospitals receiving the initial referral, not the referral being sent, or the patient raising the concern themselves.

A large number of those who contacted us also shared that their cancer had been initially misdiagnosed by their GP. Often, this was due to practitioners not listening to them, or not taking their symptoms seriously. Sometimes, peoples' GPs refused to offer alternative tests, or offered inappropriate treatment. Healthwatch Doncaster interviewed fourteen people about their experiences of cancer care. They reported that patients felt as if they had to advocate for their own health and push against doctors in order to receive a diagnosis.

Sometimes, people felt they were misdiagnosed because of their appointment being virtual or over the phone. People told us that they felt virtual appointments were inappropriate, especially for diagnosing visible symptoms such as moles, discoloured nails, and white throat patches. Healthwatch Norfolk and Healthwatch Suffolk spoke to healthcare professionals who also expressed concerns about virtual appointments, stating that they felt impersonal and could increase feelings of anxiety in patients.

> After having a sore throat for 3 weeks, they called the surgery and spoke to one of the doctors who asked if they had a temperature which the client did not, which the client stated ruled out tonsillitis. The client explained to the doctor that they had white patches on the back of their throat, and the doctor then prescribed medication to be taken for a two-week period for thrush. After two weeks the client called the surgery again and spoke to the doctor, explaining that it was now five weeks that they had had the continuous sore throat and the medicine prescribed had not helped them. The client stated that the doctor then asked them to send a photo of the back of their throat, which the client did. The following day the client states that they received a text message from the doctor that said they were reassured that they were "unable to see any ongoing patches of concern". … The client consequently decided to pay privately to see an ear, nose and throat consultant as they felt that there had to be something more serious … The consultant found a suspicious lump on the back of their throat that turned out to be cancerous. … The client felt that it should have been evident that there was an "obvious major problem with [their] throat". The client then needed to have six weeks of intense radiotherapy and two sessions of chemotherapy

and was awaiting the final results of their treatment. – Healthwatch Hertfordshire

However, many local Healthwatch who conducted research into people's experiences of cancer services reported that people had positive experiences with their GPs. Generally, care was prompt and sensitive.

"I managed to get an appointment on that Monday. My GP was fantastic and really put me at ease. She examined me and booked me straight into the breast clinic … on the next available date" – Healthwatch Derbyshire

Screening, tests, and diagnosis

Routine screening and testing were also delayed or cancelled during the pandemic. We heard about blood tests, cervical cancer screening, bowel cancer screening, and mammograms being delayed and cancelled throughout the pandemic. We also heard that people were waiting months to hear results of their tests, which had a significant impact on their mental health. Healthwatch Oldham heard from 31 people about their experiences of cancer care during the Covid-19 pandemic. Over half of these people had their treatment delayed or cancelled, and 3 were not told why.

Throughout the pandemic, restrictions on visitors for people in hospitals meant many people felt anxious and isolated during treatment. We heard from people with cancer or suspected cancer that had to attend diagnostic appointments and treatment alone. People shared that they wanted loved ones to accompany them and found attending appointments alone difficult. This was especially hard when receiving a diagnosis of cancer. People found it incredibly difficult to be told life-changing, upsetting news without a loved one there, and often found it hard to take the news in or remember advice and information.

"The wait was the worst thing. Every day I was panicking. All that was on my mind was how was I going to get through being on my own at the appointment" – Healthwatch Derbyshire

Once diagnosed with cancer, people were often not given adequate information and advice, so did not know what help was available or how to access it. This was a common theme in research by local Healthwatch; many people shared that they were given too much information at diagnosis and could not remember it because they were in shock. People told us that clinicians did not tell them what support was available or offer advice on side-effects following treatment.

"I was given oceans of information at diagnosis but was overwhelmed with the news". – Healthwatch Derbyshire

Treatment, and support during treatment

People also experienced long waits for treatment, including ongoing treatment for chronic cancer. One person told us that they had multiple appointments for treatment for chronic lymphocytic leukaemia cancelled, with no alternatives put in place. We heard from one person diagnosed with prostate cancer in July 2021, and still waiting for treatment in November, and another who has been waiting for a prothesis for 11 months. Many told us that their appointments were cancelled or delayed, with very little notice, or without scheduling alternative appointments. They also shared that they were not offered any information on support available while waiting for care.

While waiting for care, people told us they felt incredibly stressed and anxious, and were offered very little support. This is supported by wider work on waiting times for care we completed in 2021. Healthwatch England surveyed 1,075 people in September 2021[4] about their experience of waiting for elective care in the past 18 months. Four in five people felt they weren't given enough information about their wait, and the same number were not given support while waiting for treatment. From the qualitative data on cancer it would appear the same issues are prevalent in cancer care.

People also told us they resorted to using private healthcare to access cancer treatment, even when they couldn't afford it. Again, in our research in 2021, people told us they were considering paying for private treatment, but 65% of respondents said they could not afford to do so.

Long waiting times for treatment has a financial impact on patients, as well as increasing anxiety and potentially worsening symptoms. Ultimately, delays to treatment and diagnosis led some people's cancer to worsen. In some cases, we heard from people who felt that their loved ones had passed away because of delays to treatment, which impacted on their trust in the NHS to provide care.

We also heard that, when people had quick access to care, often the support offered was exemplary and people told us they were happy with the care the NHS offered them. People felt supported by staff, reporting that staff were helpful and kind, and that questions were answered. People felt they had a high standard of care from secondary services.

> After a mammogram just before Christmas when a lump in her breast turned out to be cancer. The treatment my wife has received from the cancer unit in the QE has been impeccable. The nurses have explained all the procedures and provided I had a negative LF test I was allowed to accompany her. She is now recovering from a mastectomy operation, but a scan showed that it hasn't spread. Love the NHS – Healthwatch Birmingham

Discharge and aftercare

We heard from several people who were discharged from cancer services once their treatment had ended but not offered adequate information or follow-up support. Many people were sent home with no support in place, such as care plans, hospital beds or other equipment. Following treatment, some people were not offered adequate pain relief once discharged. Condition

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[4] What are people telling us about delays to hospital care and treatment?: https://www.healthwatch.co.uk/reports-library/what-are-people-telling-us-about-delays-hospital-care-and-treatment

This suggests that services are not always implementing mandatory national guidance on hospital discharge which should ensure that people are discharged with a designated single point of contact, appropriate medication, and receive a follow-up assessment in their home for ongoing care needs if necessary. People are apparently continuing to experience many of the same issues with hospital discharge which our research highlighted in October 2020.

Healthwatch Dorset surveyed 142 people, and many of these people said they needed emotional support following treatment, as well as support for aftercare following treatment.

> "I needed more aftercare – especially when in remission. It seems that once treatment has finished you are just left." – Healthwatch Dorset

End of life care

We also heard from people whose loved ones were not offered appropriate end of life care. Many families told us that they were not given enough time to prepare for their loved one to return home, not given information about how to care for them at the end of their life, and not offered social care support such as care plans. Many felt that the lack of adequate palliative care made an already distressing time more difficult.

> Family feels that the doctors were not always honest about the prognosis for the patient. Discharge from the hospital when it was discovered that the condition was terminal was not comprehensive. A hospital bed was ordered but nothing else and no communication between support services. Main carer was given one-hour training on how to support their relative we feeding but not medication administration. Communication about the condition was insensitive and not appropriate. – Healthwatch Cambridge & Peterborough

Health inequalities

People with language barriers struggle to communicate with their doctor

We heard from several people who spoke limited English about their experiences accessing care when they had cancer. Women told us that they were called for smear tests, but, because of their language barriers, did not always understand the importance of cervical screening. We also heard of staff asking inappropriate and insensitive questions, making people feel uncomfortable and upset during an already uncomfortable situation.

When having a cervical screening appointment, the women were asked in a very directly way whether they had been experienced FGM. Many of the women experienced FGM trauma mentioned how uncomfortable they felt about being questioned in this way and almost enhanced the fear of cancer screening – Healthwatch Tower Hamlets

We also heard from people who were not offered interpreters and had to rely on friends and family to translate. This made people feel their privacy was not protected, and was also upsetting for their loved ones, who may have to translate a cancer diagnosis.

My granddaughter had to interpret the consultation where the doctor was giving me the diagnosis of prostate cancer. She cried for so long and was so distressed from the news.

Often, when I receive a letter from the hospital and when my family is not around, (because I don't live with them) I go to my neighbours to ask them to translate the letter for me. I don't always feel comfortable doing it but considering mine and my wife's poor health I am worried that the letter may say something needing immediate action. I wish I was able to receive letters in my own language so I don't need to rely on anyone to read them for me. – Healthwatch Birmingham

Healthwatch Dorset, Hampshire, Isle of Wight, Portsmouth, and Southampton reviewed literature about people's experiences of attending breast cancer screening. They state that British-Pakistani women found NHS materials difficult to understand. Often, this was due to the difficulty of translating terms such as "screening" and "mammogram" into languages such as Urdu, in which no direct translation exists. They recommend that information be provided in a variety of languages, and that community links are used to ensure translations are able to be understood by all.

People with learning disabilities experiences of screening

Healthwatch Brent interviewed 28 people with learning disabilities about their experiences of cancer screening. They found that people with learning disabilities are not offered information in Easy Read formats, and this contributed to a lack of understanding around the importance of self-checks and how to conduct these. Respondents also reported that health professionals did not adapt their communication for people with learning disabilities, often talking to fast or using jargon, and that reasonable adjustments were not made in appointments.

'They sometimes just put it in any other pictures in easy read, they need to make sense' – Healthwatch Brent

'I get letters from your GP saying you need to go for breast screening, I've been a lot, but not for down below [cervical screening]. I can't relax, there's all these noises, I was very nervous.

> The next time I had it, I was put to sleep to have it done’. – Healthwatch Brent

Women feel their symptoms are dismissed

In our data, Healthwatch England often hear from women struggling to access services. Many tell us that they find it difficult to receive a diagnosis for their symptoms and therefore access further support. Our recent data on cancer services reflects this trend; more women than men reported feeling that their symptoms or concerns were dismissed because of their gender. We heard from women who had repeatedly raised concerns with their GP or other practitioners, only to be told it was just a “women’s issue” or a mental health problem.

> A doctor delayed the process for my mother to be diagnosed with bowel cancer, Saying it was lady’s issues and Inserting an apparently none surgical plastic strengthening ring to her that caused other symptoms, roll on to 2019 when operation had to be done bowel resection to remove cancer tumour that breached bowel wall, lymph nodes indicated spread, months of chemo finished pre Covid lockdown 1 Now in 2021 scan advised cancer and its aggressive but small secondary’s, lungs and another organ – Healthwatch Shropshire

Black men’s experiences of cancer services

In 2021, eight local Healthwatch conducted research focusing on specific groups’ experiences of health and social care services in order to understand how NHS England could improve the integration of care systems. One of the groups focused on was Black men with a number of health needs, including a recent experience of cancer. Healthwatch West Sussex and Healthwatch Manchester completed in-depth work with ten Black men to understand their experiences of health and social care, including cancer services.

Largely, the experiences that Healthwatch West Sussex and Healthwatch Manchester discussed align broadly with the same issues we found in our overall analysis. Black men spoke about delays to appointments, mixed experiences of speaking to their GP, but positive overall experiences of care.

Healthwatch Manchester found that many of the men they spoke to highlighted the importance of having a good relationship with their GP, and the importance of having a GP from their community. Those who had Black GPs felt that this was a key reason why their GP listened to their symptoms.

> “I wasn’t happy with where I was, I did not even know I had a serious problem with my kidney until I moved practices, I am so glad I have a Black GP now because he took me seriously when I had problems and needed an examination for prostate cancer” – Healthwatch Manchester

Some of the people that Healthwatch Manchester spoke to reported feeling that some of the services they used as part of their cancer treatment were not culturally appropriate. For instance, one man spoke about being referred to a support group but feeling out of place; he then moved to a group specifically for Black men and had a better experience.

What do our findings say about the LTP's vision for cancer?

In 2019, the Long Term Plan outlined a number of milestones in order to improve cancer survival by 2028. It highlighted the need for early diagnosis and accelerated access to diagnosis and treatment, as well as the importance that every person diagnosed with cancer would have access to personalised care. Finally, it was proposed that follow-up care would be tailored to people's individual needs.

The goals of the Long Term Plan largely match what people have told us needs improving about their experiences. Long waiting times for GP appointments and referrals has a knock-on effect on every part of the cancer treatment pathway, resulting in people waiting longer for assessment and diagnosis. We've also heard that screening appointments and cancer treatments have been postponed or cancelled, in many cases resulting in worse patient outcomes. The Long Term Plan's goal to improve access to diagnosis and lower the threshold for referral by GPs matches the needs people shared with us. The plan also acknowledges the importance of personalised aftercare and treatment, which many people told us was currently lacking from their experiences of cancer services.

However, there are still gaps in the Long Term Plan's vision of cancer services. The impact of misdiagnosis was a key theme in our feedback, as was the importance of compassionate care and comprehensive, accessible information. People emphasised the importance that information and advice were accessible to everyone, including people with learning disabilities and those with language barriers.

Overall, it seems that many of the goals of the 2019 long term plan do align with people's needs but have so far not been met. With overall sentiment become more negative, especially in comparison to other services, it seems that more work is needed to implement the plan and ensure that people with cancer receive timely, high-quality cancer care.

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