



Cancer Insight

Experiences of diagnosis and/or treatment during the
COVID-19 pandemic

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1. Executive Summary

The purpose of this project was to hear from patients and their friends, family members and/or carers who have been through a cancer diagnosis and/or treatment during the COVID-19 pandemic.

Experiences were gathered through the style of a detailed patient story, which were shared with the relevant Hospital Trust, University Hospitals of Derby and Burton NHS Foundation Trust (UHDB) and Chesterfield Royal Hospital NHS Foundation Trust (CRH) for a personalised response. The insight gathered will be used to help inform future cancer commissioning decisions in Derbyshire.

This report provides an overview of all the experiences captured.

Key findings:

- **People need clear information on how to prepare for, and what to expect from their first appointment:** It was felt that this could include latest COVID-19 restrictions, whether or not a friend/family member could attend for support and how a serious mental illness (SMI) is noted.
- **Importance of recognising the level of support an individual may need as early as possible to ensure they feel supported throughout their journey:** Some people felt they had limited professional and/or family support at their diagnosis and throughout their treatment, whereas others were thankful to have a family member/close friend accompany them for support.
- **Information and advice throughout a cancer journey should be delivered in a tailored way to the individual:** Some people were provided with a lot of information, others were provided with booklets and one person was left with a number of unanswered questions.
- **People should be informed on the most up to date COVID-19 safety measures:** A number of people felt it was important to know what to expect when attending the hospital for treatment, including temperature checks on arrival, pre-op COVID-19 tests and restrictions on visiting.
- **People spoke very positively of staff involved within their care and treatment:** Continuity was seen as vital with professionals to enable people to build up trust and get to know them.
- **Most people found virtual appointments work well:** However, it is important where possible for people to have choice regarding their type of appointment, i.e. phone, video or face-to-face.
- **More available support from clinical nurse specialists (CNS):** A number of comments were made regarding a lack of CNS support through various stages of their cancer journey and particularly for secondary cancer patients.
- **Ongoing support should be discussed with patients to ensure a personalised approach:** The level and type of support will vary depending on the individual and it is important for people to have a named contact to discuss any questions or concerns.
- **Support for carers:** Cancer affects the whole family, so it is important to ensure that family/carers feel supported.

Healthwatch Derbyshire (HWD) will continue to liaise with both UHDB and CRH around any learning taken to improve patient experience with regards to cancer services.

This summary alongside the full patient stories and the individual responses provided by both Trusts will be shared with the Head of Cancer Commissioning and Derbyshire Sustainable Transformation Partnerships (STP) Cancer Programme Lead and used to help inform future commissioning decisions.

2. What people told us

Referral:

➤ Initial concerns:

Once signs were noticed, most people contacted their GP to raise their concerns.

Some explained how they were able to get an appointment very quickly and the process ran smoothly, whereas others experienced difficulties getting through to their GP.

Following the initial referral, a suggestion for improvement made by one person was for patients to receive advice on how to prepare for their first appointment, including what to expect and information regarding the support available (including restrictions and precautions in place due to COVID-19).

Sample of comments:

- “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 at [named hospital] on the next available date”
- “I was told to go to the walk-in centre ... for someone to examine me ... I felt this was inappropriate and so called the consultant’s secretary again as I was very upset, distressed and in tears and did not know where to go for help. They agreed to see me the following [week]”
- “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 ... What could have helped me was some advice about how to prepare for this appointment, whether someone could come with me, how I could let them know about my anxiety, could I record my appointment or have someone on FaceTime whilst I was there?”

Diagnosis:

➤ Recognising the level of support needed:

In the process of an individual being diagnosed with cancer, it is important to consider the level of support they may need.

Professionals should also consider an individual’s mental health needs to understand whether additional support may be required.

During unprecedented times, many people receiving a cancer diagnosis and/or treatment may not have their ‘usual’ family/friend support networks in place.

Sample of comments:

- “We are fragile and may need additional support to get to and get through our essential medical appointments”
- “I was worried and anxious that night, all I wanted to do was visit my mum, but I couldn’t because of COVID-19 restrictions”.

➤ **Support when receiving the diagnosis:**

Tailored support when receiving a cancer diagnosis is vital as this may vary for each individual.

Some people felt they had limited professional and/or family support at their diagnosis stage, whereas others were thankful to have a family member/close friend attend their appointment for support.

Another person explained how they felt there was an “inequality” in professional support from primary to secondary cancer.

Sample of comments:

- “No support when I needed it the most. I was in utter shock and had to work out how to tell the news to my children”
- “Being on my own was terrifying. To have had an auxiliary nurse in the reception area to support anyone who was particularly anxious between the procedures would have made all the difference”
- “I was told I had stage 4 cancer and limited life expectancy. My clinical nurse specialist (CNS) from [named hospital] was not with me, I had no support”
- “The words of the doctor were devastating”
- “I was so glad to have had my mum with me at the appointment for my biopsy results as it was confirmed I did have cancer”
- “My diagnosis was a bolt from the blue and I was seen at [named hospital] by a consultant oncologist. Without any kind of preamble, he simply stated that I probably had around 18 months to 2 years”
- “I was taken into a room with my husband and we were not expecting to be told anything serious but we were told that the pathologist had found a cancer”
- “There is definitely inequality in support from primary to secondary cancer ... yet when you most need support after receiving a terminal diagnosis there is only one part-time CNS”.

➤ **Information received at diagnosis:**

It was felt that information and advice following a diagnosis should be delivered in a tailored way to the individual. One person explained, “I was given oceans of information at diagnosis but was overwhelmed with the news”.

One person suggested, “The process of diagnosis should be better considered with the opportunity to talk to someone. I understand you cannot have a long time with the consultant. Give out information or a phone line, or a linked nurse to call with any concerns. It would be especially useful to be put in touch with someone on a similar pathway, to get some idea of what was ahead”.

Sample of comments:

- “I saw the doctor again at the end of the procedures who told me he was 90% sure I had cancer. My anxiety escalated. He didn’t know I was fragile. I told him about my anxiety disorder and the nurse gave me a card with details about the Macmillan clinical nurse specialist who I could ring. How could he have been so sure? Did he need to tell me when I was on my own?”
- “I would like to see improved communication with patients. There needs to be discussions with patients at the start of the cancer pathway to find out how people want information, in what format and to what level of technical detail”
- “I have also found the folder of information about breast cancer that I was given at my appointment with [named professional] really useful. A section in this refers to it being a good idea to use a diary/log of who you have seen and what was said. I’ve kept a diary myself which has enabled me to feel in control and understand what is happening as you see so many people”
- “When staff are given a cancer diagnosis we don’t always know everything so don’t assume we do”
- “The Macmillian Information and Support Centre at [named hospital] provides limited information beyond Macmillan’s own services”
- “I was told that my new CNS would contact me the next day, but that did not happen. I was physically sick that night with worry as I had so many questions and no one to go to”.

Treatment:

➤ **Attending the hospital during a pandemic:**

Experiences and feelings of attending the hospital for appointments and treatment during the COVID-19 pandemic were mixed.

One person felt ‘safe’, whereas two people commented upon the ‘daunting’ feeling of attending a hospital for treatment due to the ‘fear’ of catching COVID-19.

Many people had to attend the hospital on their own for treatment, due to national restrictions in place.

Sample of comments:

- “The hospital was quiet, I felt 100% safe; it was well signposted with lots of information. The care continues to be brilliant”
- “On the day of lockdown ... my chemotherapy started. This was the most daunting thing coming into a hospital because of COVID-19 being there”
- “My husband was not allowed to come in with me for treatment because of COVID-19. He had to leave me at the main entrance. It was a very emotional time, I was scared, and I felt alone ...”
- “It was so hard when my husband had to drop me outside as he could not come in and I had to walk down the corridor alone, feeling ill and very fatigued”
- “... all the treatment was received alone. I have attended all subsequent appointments on my own and you don’t always remember what’s been said”
- “The hardest thing was going in for the treatment on your own. It felt like such a long hard walk when you are alone. This is a big thing which I would have liked to have been different for me and other people”
- “I now have to go on my own for treatment which is very stressful and lonely”

- “I found the treatment hard and the chemotherapy made me very sick. It was hard when you were being sick in the treatment room and no one was with you to pull the curtains round to give you privacy”
- “I remember being taken for an x-ray in another part of the hospital; it was really scary due to the fear of catching COVID-19”.

➤ **COVID-19 Safety Measures:**

One person explained the importance for patients to be fully informed of COVID-19 safety measures put in place to keep people safe prior to their appointment so they know what to expect, for example, temperature checks on arrival.

It was also explained how patients have to have a ‘pre-op COVID-19 test’ but will only get the results of the test if positive, which can cause people to feel ‘anxious’ and felt it would be better and a ‘relief’ for patients to be notified of their results regardless.

In terms of restrictions on visiting, another person explained how they were an inpatient during COVID-19 and felt improvements such as access to free Wi-Fi, technology and support to set up calls to maintain links with family and friends would have been hugely beneficial.

Sample of comments:

- “What I didn’t realise is that the first thing they would do [when attending for treatment] was test my temperature ...”
- “Due to COVID-19 and being at higher risk, I had to isolate through this time [of treatment around 6.5 months]. Sometimes this was good, as I did not always want to be with people ... My children could not come and see me and I could not go out for a walk to get fresh air ... I found this distressing as I could not go out and be with people who I love”
- “There was no visiting allowed for anyone. I did understand the reason for this but this did not make it any easier for me and my family. It was emotionally hard for both me and my family ... It was possible to zoom and skype but only if you paid for the Wi-Fi yourself as there was no phone signal”
- “It would be good if the hospital could create a better system so that someone on the ward proactively contacts the relatives to give an accurate update on the patient. This could be done once a day or if there was any change. If people at home knew they were going to get this update, then they would not ring the hospital”.

➤ **Communication around treatment:**

One person explained their treatment and side-effects were discussed, which allowed any queries or concerns to be raised. However, another participant had to be proactive and read through a booklet.

One person felt professionals should have a conversation with patients, so that information can be delivered in a personalised way and to get a sense of how much information and detail patients want to receive.

Another person found the Macmillan Information and Support Centre app (HealthZone UK) very informative and felt the information on the app would help people going through a cancer diagnosis and/or treatment during COVID-19 restrictions.

Sample of comments:

- “[named professional] explained the course of treatment and possible side-effects that may be experienced”
- “I feel I am in good hands. I have regular contact and feel informed”
- “... the next stage was to begin hormone therapy medication ... When I returned home I read the medication booklet which identified some medications you shouldn’t take with [named medication] ... A call to the CNS the following day confirmed that I should seek advice from my psychiatrist to change my medication for my SMI ... Had I not read the booklet, the medication would have not been as effective”
- “Before the first session [of chemotherapy] I met an oncologist who gave me an idea of what was ahead ... I asked where the cancer was in my body. I felt it was quite patronising as the staff member used words that I felt gave no recognition to my level of knowledge of anatomy, using words to describe the thorax area of my spine as ‘tummy’ and my cervical area as ‘neck’
- The information (through the Macmillan app) is incredible ... The most useful thing I have found was the video section ... I managed to find a video showing the whole process of what happens at [named hospital] when you arrive from your radiotherapy planning appointment to your treatment ... Watching this video has made me feel so much better about my appointment. Seeing what the place is like, what measures they have put in place to be COVID-19 safe, has helped me to prepare. There is so much information on the app, I think it is absolutely fantastic. It will make such a difference to people who are going through a cancer diagnosis and treatment during COVID-19 restrictions”.

➤ **Positive experiences of staff:**

People spoke very positively of staff involved with their care and treatment.

Sample of comments:

- “Wonderful ... phenomenally good care and treatment with empathy, care and kindness”
- “My operation was just before Christmas ... The staff immediately put me at ease. They were amazing, very kind, friendly and explained things to me. There was a lovely atmosphere on the ward. One of the nurses asked the patients if we wouldn’t mind if they put the radio on; the Christmas songs were the first time I had properly thought about Christmas. It was really nice and gave me a little bit of hope, something to look forward to”
- “The surgeon and anaesthetist both explained the procedure well and were lovely, even the porter that transported me around was friendly”
- “As I left the ward early evening a nurse carried my bag for me and advised me to ask my mum to pick me up directly outside. It was so nice to know that they wanted to make sure I was ok right to the point I was picked up”
- “My consultant is great. Over the three years I have built a good relationship with her of mutual respect”.

➤ **Continuity with staff:**

Two people commented upon the importance of continuity with staff members.

Sample of comments:

- “It’s one thing going in to be treated, it’s another knowing the person treating you. You get to know them and that’s something I value enormously”
- “They (CNSs) were kind and supportive during my appointments. I built up trust and a good rapport with them. But as soon as I was referred to an oncologist from [named hospital] I never saw or heard from them again. I felt I was dropped like a stone”
- “I have had five different oncologists throughout the last number of years, the constant changes being stressful in itself”
- “We are real people, who will not grow old. We need the support now; continuity of care is vital for effective support”.

➤ **Virtual appointments:**

Due to COVID-19 restrictions, all experienced some form of virtual appointment.

Two people explained how phone/video appointments had worked well for them, particularly around convenience and time, i.e. not having to travel.

It was felt that, wherever possible, people should be able to choose their ‘type’ of appointments, for example, phone, video or face-to-face.

Sample of comments:

- “I quite like it; it saves the driving”
- “I have 3-monthly consultant appointments. Since COVID-19 they have taken place on the telephone. This has worked well for me as it means I do not have to travel”
- “I would find it even more beneficial if they [phone consultations] were to be via video call and these were offered to all. There is a great opportunity for the benefit of the patients and the NHS for greater use of digital and virtual appointments, ensuring that patients are asked which they prefer and which is best for them to meet their need”
- “Appointments ... have mostly been by telephone. This makes it difficult to build relationships up with any new team members as you cannot see their faces or expressions which is extremely important. Surely video consultations could be offered? After all, they literally do have your life in their hands”
- “I was relieved that I was booked in so quickly and was offered the choice of a phone call the following week for the results of this biopsy which meant I didn’t need to come to the hospital again”
- “Improved communication so that appropriate appointments are made to meet the need of the patient. With developments in digital appointments, patients and doctors together should agree the best appointment method and for the IT system to be able to record and update this as necessary. This will save time for staff and patients and will make the service more effective and efficient”.

After care:

➤ **Ongoing Support:**

Experiences of ongoing professional support were mixed. It was felt there should be different types of support available and these should be discussed with patients to ensure a personalised approach.

One person explained they have continued contact with the Macmillan Information Centre and which they found was very beneficial as it provided them with the opportunity to talk to someone when things got 'tough'.

Another person expressed the need for more CNS time to support secondary cancer patients.

Sample of comments:

- "When things have got tough for me, I can get emotional at times. [Named professional] provides me with an opportunity to offload in a very friendly and informal manner"
- "Please invest in additional CNS time to support secondary cancer 'outreach' patients at [named hospital] so that we receive as much support as primary cancer patients and, vitally, continuity of that support"
- "I think there should be different types of support for patients and it should be more personalised. Time should be spent with patients asking what help, support and possible activities they may wish"
- "I cannot remember when I last saw them [CNS]; it'll be well over a year. I can ring and leave a message on the CNS team's answerphone, but I can be waiting for a week for their reply so I tend to look elsewhere first for answers to my questions".

➤ **Psychological Support:**

One person explained there should be timely support for people to access psychological support when it is needed.

Sample of comments:

- "From an emotional perspective I was not in a very good place. I did not want cancer, I did not want to 'ring the bell' and I did not want it under the circumstances that I got it. I was angry with the world and to some extent I still am ... Psychological support was mentioned but not pursued as there was a long wait to get help with these issues ..."
- **Support groups and peer support:**

Two people commented upon the benefits of support groups for both information and the peer support element.

Support groups were described as 'a great way to share new treatments, hear feedback from clinicians and for the peer support element ...'

Sample of comments:

- "I found my main source of information and support by accident when joining a group set up by people with secondary breast cancer; it has been my lifeline. I've had to become an expert about my cancer, the side-effects of treatment and how to look after myself"
- "The prostate cancer support group has not met for over a year. They are not yet running virtually. I think this is something that should be considered and would be a great benefit for many patients ... I have certainly missed the meeting and comradery and the opportunity to share views, thoughts and experiences. The support group does have a Facebook page which has been updated but this is not

sufficient in my opinion ... This would be especially important for people who have been diagnosed in the last year or so as they have not had the opportunity to attend the support group. This will address the gap in peer support ...”

➤ **Support for carers:**

Some people highlighted the importance of ensuring family and carers feel supported during their loved one’s cancer journey.

Sample of comments:

- “Carers need help and support too”
- “There needs to be more proactive support for carers at the hospital as cancer affects the whole family and they are the ones who can be forgotten”.

3. Follow up

UNMET NEED	FOLLOW UP:
1. Lack of clinical nurse specialist (CNS) support and advice following diagnosis, continuity of CNS support into secondary cancer and access to CNS support at NGS Macmillan Unit as an outreach patient	1. Continuity of CNS support available to secondary breast cancer patients 2. How is CNS support promoted within the Breast clinic and how can people contact the CNS? 3. Has additional advice/information relevant to secondary breast cancer patients been included on the NGS Macmillan Unit section on the website? HWD has established a link with the Breast Cancer CNS at CRH and will continue discussions in relation to CNS support at CRH for secondary breast cancer patients
2. Access to video consultations	1. Has uptake of video consultations increased? 2. How are patients made aware they can request a video consultation? 3. Are patients given the choice regarding the type of virtual appointment, i.e. phone, video, etc.?
3. The process of diagnosis should be better considered with the opportunity to talk to someone	1. Has the nurse support in clinics increased to ensure support during and after consultations? 2. Are people provided with a named contact, i.e. key worker who they can discuss any concerns or queries with?
4. The IT and medical results systems should be able to talk to one another and there should be interconnectivity	1. How is work progressing with regard to issues around digital systems and sharing of information?
5. Patients need to be informed about attending alone for their appointments and any exceptions to this	1. Has this information now been included on the website?

6. People need to be informed about ‘what to expect’ during their pre-op assessment	1. In addition to being provided with information during the appointment, is this information now available on the website?
7. Access to psychological support	1. Has the waiting time for accessing psychological support improved and/or been addressed?
8. Support for carers	<ol style="list-style-type: none"> 1. Has the Trust provided more support to carers where possible? 2. Has there been an increase in attendance to the ‘bespoke carer support groups’ piloted by the Macmillan Information and Support Centre?
9. COVID-19 Safety Measure	1. Are posters now displayed at each entrance to ask visitors to replace face masks with a surgical one on arrival at the hospital?

4. Methodology

The project was conducted following a number of conversations with the Head of Cancer Commissioning and Derbyshire STP Cancer Programme Lead at the CCG and the insight gathered will help to inform future commissioning decisions in Derbyshire.

HWD worked in partnership with University Hospitals of Derby and Burton NHS Foundation Trust (UHDB), Chesterfield Royal Hospital NHS Foundation Trust (CRH) and Derby County Community Trust (DCCT).

HWD began promoting this project in November 2020 with a digital flyer and it was agreed that participants would be recruited by UHDB, CRH and DCCT, through their clinical nurse specialists (CNS), Macmillan centres and social media channels.

The active engagement phase was between 1st January 2021 and 31st March 2021. HWD gathered a total of five patient stories to understand the experiences in detail, of people who have received a cancer diagnosis and/or treatment during the COVID-19 pandemic.

In order to collect consistent information across the county, HWD developed a series of prompts to provide a framework for discussions. The headings included (appendix 1):

- Referral
- Diagnosis
- Treatment
- After care

Once the patient story was complete, these were shared in full with the relevant Trust which highlighted areas of good practice and areas of improvement. This provided both Trusts with the opportunity to provide a personalised response to each participant.

5. Thank you

HWD would like to thank all participants who gave their time to talk to us about their experiences of cancer services during the COVID-19 pandemic. We also extend our thanks to the many groups and services who supported and cooperated with this engagement activity.

6. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, family, friends and carers who have experienced cancer services within Derbyshire but nevertheless offer useful insight.

It is important to note that the engagement was carried out within a specific time frame and therefore only provides a snapshot of patient experience collected. They are the genuine thoughts, feelings and issues participants, carers and healthcare professionals have conveyed to HWD. The data should be used in conjunction with, and to complement, other sources of data that are available.

7. About us

HWD is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

HWD was set up in April 2013 as a result of the Health and Social Care Act 2012 and is part of a network of local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who builds a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.