

How do people in
Doncaster experience
Cancer services?



“Local Voices”

Healthwatch Doncaster

Engage, inform, influence

July – September 2018

1 Introduction

In the summer of 2020, Healthwatch Doncaster completed an engagement project, which involved gathering the views of local people in relation to their cancer journeys.

Early discussion with local commissioners and providers identified that this survey would provide opportunities to gather qualitative data as opposed to quantitative data and facilitate options for local people to convey their real lived experiences of cancer services.

The purpose of this project was to find out what people's experiences of cancer services are like from their own perspective.

Healthwatch Doncaster commenced this engagement in May 2020 with an end date of October 2020 among other things, Healthwatch were keen to gather extensive narrative to understand:

1. How patients' journeys were affected by the Covid-19 pandemic
2. Patients' experience with receiving consultations digitally or via phone
3. What went well in patients' opinions?
4. What did not go well in patients' opinions?

Patients were recruited with the support of specialist nurse practitioners and local group members. Previous engagement projects entailed face to face interviews with participants, due to the current Covid-19 pandemic and the barriers created by national restrictions this approach was not possible and alternative options had to be considered.

As patients were asked to volunteer for this programme, Healthwatch Doncaster had no control in relation to the type of cancer that the patient had and the stage of their journey. Fourteen patients in total told stories and

Fourteen respondents contributed to the project, stories were led by the respondents themselves with no focus on specific subjects or topics, Healthwatch wanted them to tell their story in their own way and not shape the story telling or create any distress by being prescriptive in their approach.

There was concern that this cohort may predominantly contain females as evidence shows that females participate more willingly when asked to share their views and opinions and men are often underrepresented. The final cohort of 14 included the stories of eight women and six men and one story was told by the wife of a man who had passed away.

Participants of this project received services locally that involved Inpatient and Day care services at Doncaster Royal Infirmary, Bassetlaw Hospital and Mexborough Montague hospital (all three part of Doncaster and Bassetlaw Teaching Hospital NHS Foundation Trust) The Royal Hallamshire Hospital Sheffield and Weston Park Hospital Sheffield.

Patients received variable treatment options, including surgery, chemotherapy and radiotherapy and some had multiple treatments.

All findings were analysed by the two facilitators of the project and the themes were identified, whilst a number of themes were identified, it was the case that the information was very diverse and some isolated issues arose from the findings and all the issues raised have been included in the report. Quotes used throughout the finding in this document will be formatted in a way that will not reveal the identity of any individuals, although many are used as they were conveyed to ensure they illustrated the powerful messages shared.

The National Cancer Patient Experience Survey has been completed yearly since 2010 and monitors national progress on cancer care to inform providers and commissioners and influence local services. These questionnaires facilitate feedback however; they do not facilitate opportunities for recipients to share qualitative information and are sent out by post for recipients to complete. One cancer patient involved with this project stated that these surveys ask too many questions and do not allow patients to truly reflect their real lived experiences and for that, reason was particularly enthusiastic about this project.

The stories were captured by either recording the interviews (after seeking explicit consent from the participant) and transcribing them or taking notes during the interview session and collating them into a story. After interviews were transcribed, thematic analysis was performed and the report consists of five sections, each of them split into themes.

The common themes were:

- The start of the journey
- Treatment and on-going care
- Impact on emotional well-being
- Impact of the COVID-19 pandemic
- Timing
- Miscellaneous

1. The start of the journey

1.1 Recognition of symptoms

- I had water work problems and was referred to Urology at DRI; a PSA test completed was within a normal range however, a subsequent MRI Scan identified cancer on the wall of the prostate. My care was excellent from the beginning as the urology consultant at DRI went the extra mile to do additional tests and not rely on the PSA. I am thankful that I received the MRI in addition to the blood tests as this identified the problem. I feel my journey was influenced by a previous cancer journey which helped me to understand the situation I was in.
- I found a lump in my breast and went to see my GP who made a two week referral to see a consultant at the hospital. I was very pleased with the speed at which I received the appointment at the hospital
- I was very pleased with the speed at which I received my appointment at the hospital and I have been pleased with the care and treatment I have received and consider myself very lucky.
- I was very well in July 2020, fit, active, healthy, walking with my dog for miles and enjoying lockdown. I started with some symptoms but felt they were related to being dehydrated and took measures to correct this however the following day I realised it had taken me 6 hours to walk 2 miles and the next day I could not walk 500 yards without feeling very sick. I contacted my doctor and had a telephone consultation and blood tests were ordered, I would have preferred a face to face appointment as that would have helped him understand how ill I was.
- I attended my GP with unspecified symptoms (pre Covid) and tests were completed, I was treated with antibiotics but had to return due to continued symptoms. My GP was very good and listened to me, I was sent for investigations and received a diagnosis of cancer and have had surgery and chemotherapy during the pandemic.
- I had visited my GP previously however I returned with continued symptoms and investigations which revealed an advanced cancer and I have a terminal diagnosis. I feel that bowel screening for a younger cohort may have detected my cancer earlier.
- My husband attended Accident Emergency (A and E) and did not find the experience positive mainly due to the people within the department. He was treated for an infection but the symptoms continued however he remained reluctant to attend A and E even when advised to do so after ringing 111. Following a continued delay he attended the GP at my insistence and was sent the same day for investigations, the GP was amazing and on the ball.
- I feel that I experienced a delay in receiving my diagnosis as there was a complete failure in reporting results of my scan. Prior to Covid I attended Accident and Emergency with an unrelated problem and had a scan, which showed abnormalities, however I was not informed until a number of weeks later. I was sent an appointment to attend the Jasmine Suite at Doncaster Royal Infirmary, however cancelled it as I did not know why I had received it. Weeks later, I received another appointment and was reluctant to attend but telephoned the department and was advised to do so. Delays in investigations and procedures resulted and I feel that these have contributed to development of a secondary cancer.

- I was visited by the GP at home (pre Covid) and sent to A and E, investigations were completed however these results were not conveyed to me or my GP. My GP assisted me to obtain results and instigated further investigations that prompted a fast track referral. I feel that these events created a delay in my diagnosis and has resulted in having an impact on my ongoing treatment and prognosis.
- During Covid, I attended Accident and Emergency with symptoms, immediate surgery was required, and following this I received a cancer diagnosis. The cancer was removed however it has since recurred and although a delay of chemotherapy occurred due to the pandemic this has recommenced.
- At a routine appointment with my GP, I showed the doctor a lump on my neck that I thought was a bite mark and nothing to worry about. My doctor immediately did an examination and sent me for a blood test on the same day, I worried by this but I tried to be positive.
- My cancer was identified at an unrelated appointment, at an annual review with the nurse, she noticed my voice was not right and made me an appointment to see the GP the following day when a prompt referral was made to ENT at Doncaster Royal Infirmary.
- I attended my GP for an unrelated problem and enquired about routine testing for a prostate test, although I had no symptoms. An examination was completed at the same appointment and resulted in a prompt referral and a subsequent cancer diagnosis. I feel incredibly lucky that my cancer was detected as after googling the symptoms, I had none.

1.2 Receiving the diagnosis

- I was in such a dark place when I was diagnosed and I never thought I would be able to get out of it. I had a lot of support but this didn't matter at the time, I feel by reading and hearing all the information I had I could get better and that I wasn't just going to die. Finding out you have cancer makes you feel down and depressed and you always feel on edge as you don't know what is happening. You feel like constantly crying and cannot imagine not feeling any other way, it's so terrifying I felt my life had ended when I was diagnosed.
- I received my diagnosis in hospital during the pandemic, things were explained to me well, and I was devastated but I was helped to feel optimistic. I was fortunate to be supported by a family member (who worked on the adjacent ward) whilst being told my diagnosis as family members were allowed to visit me. Subsequently I was told my prognosis was very poor and they had months to live, as well as having to process the information alone, it was very distressing having to tell my family over the telephone.
- It was big shock to be told I had cancer; I had convinced myself that it was benign, the consultant was sensitive and the mood was sombre. I was given lots of time to ask questions and I was given details and the options in relation to my care pathway. The consultant was very good and explained everything. I was given a quiet room and access to the cancer nurse to ask questions, she was lovely. It was very emotional and difficult, I was frightened to death, no one made it difficult for me; it was the situation I was in.
- On receiving my diagnosis I had all the information I needed the registrar explained everything, I could not have explained it any better, and he was up front and told me it was 50:50. Once I knew what needed to be done I told them to get on with it.

- I was pleased with the speed at which the appointment came through and receiving my diagnosis and treatment.
- My husband and I waited 4 hours in the department for his results and it was horrific, we were both afforded privacy and the opportunity to ask questions at the consultation. We left the department with relevant contact details for services and professionals. I did not feel I had enough information and went home and googled, which was neither useful nor helpful.
- I was told I had advanced cancer and it did not look good, the Consultant was brilliant and calming just like my GP. Subsequently I was told that I had a terminal diagnosis, the consultant was very good when he told me. I was very pleased with all stages of my diagnosis and treatment, I was diagnosed and treated quickly.

1.3 GP Help and Support

- I was very happy with my GP, he referred me immediately to Doncaster Royal Infirmary following identification of a lump in my breast.
- I attended the GP with symptoms for the second time having been treated for an infection previously, my GP acted promptly in sending me for investigations which resulted in my diagnosis
- The GP was amazing and on the ball, he arranged tests for the same day, all the practice have been very supportive in particular the reception staff who continue to be supportive after my husband's passing.
- I attended my GP for another reason and they acted upon my concern immediately which resulted in a timely diagnosis of my cancer.
- I had weeks in hospital and received a devastating prognosis and returned home without a discharge plan in place, which created a number of problems and I felt abandoned. My GP, was not aware of my medication regime when I asked for a repeat prescription and this caused unnecessary upset. On another occasion I rang my GP as I was ill and I was advised to attend Accident and Emergency, the paramedics contacted my GP to arrange a direct admission as they thought I was too ill to go to Accident and Emergency.
- I was waiting for a date for a scan and found out the request had been lost, my GP Practice would not complete a repeat referral for the scan and I was really wanting to get this scan done. I spent time addressing this issue which made me mad as hell, the request was completed again and I was advised to complain but didn't as I was going through a difficult time.
- During the pandemic I was ill and received a phone consultation, I would have preferred a face-to-face appointment and it would have helped my GP understand how ill I was. On the telephone call I was asked if I was jaundiced and I had no idea.

2. Treatment and ongoing Care

This section includes a number of themes, which were particularly important to many of the participants and include the following:

- Accessing information and services
- Fighting your own corner
- Effective communication and relationship building
- Fear of the unknown.
- Inpatient services
- Day patient services and other services of support services
- Community and Home care

2.1 Accessing information and services

- I was in hospital for weeks and I thought support was being organised for my discharge. When I was discharged from hospital I had no services, no contact details and no plan, I felt abandoned and did not know where to turn. A family member contacted the GP and they were given the contact details of the District Nurse and the Palliative care team and advised to contact them. The District Nursing team and the Palliative care team came out to visit me and they have been extremely helpful and it is a relief to have them. I felt weak and had pain and I managed to borrow a wheelchair and then the district nurse made a referral to wheelchair services.
- I received useful information about cancer and felt better about having this, I feel by reading and hearing all the information I have it helped me realise I was not going to die.
- Googling to get more information was not useful or helpful but I needed to know more.
- I researched widely so I knew more about my cancer and was able to ask the right questions in order to receive the right care.
- Nothing was mentioned to me about local support for my financial or emotional needs.
- I had heard about “Buddha sessions” and the pampering that Aurora provide and was looking forward to these but received no communication in relation to any of these services.
- I found it disappointing that another patient told me about a form for benefits, I had not been told this information by any clinician.
- At times communication could have been better, I could have received the right information and been made more aware of services.
- It was only when I got home and felt stronger that I researched what might be available and felt that I could be proactive in seeking the right treatment and able to ask the right questions which I could not do when I was ill in hospital.

2.2 “Fighting your own corner”

- At my review, concerns were discussed in relation to a recurrence of my cancer, I asked for a scan for peace of mind and the doctor dismissed the request based on my normal PSA value. This made me uncomfortable as my cancer was not found through the PSA test and this was not going to give me any reassurance. I had to fight my corner and I am grateful to my GP who supported me to get a MRI Scan, I needed to know what was going on and my PSA had always been normal so I wanted a scan for peace of mind, doctors need to understand that patients need to know what is happening with their cancer. I have had a previous cancer journey and this gave me the confidence to challenge the doctor, other people might be overlooked because they are intimidated and don't have the insight. I was able to do what I did due to previous experience of cancer.
- Following attendance at Accident and Emergency I had to return to the ward for investigations, the doctor in A and E told me to “stand my ground” explaining how ill I was and that I should not allow anyone to send me home again. I was concerned that I might be sent home as it seemed there was a reluctance to admit people due to the risks posed by Covid-19.
- I had difficult conversations about my treatment options at the early stages of my treatment, however I built a trusting relationship with my oncologist and on one occasion in a clinic setting with my family, the consultant and the Nurse specialist we had a frank discussion about the cost of treatment.
- I was discharged from hospital having had tests and investigations however I did not get any results following discharge and I feel that this along with other issues contributed to delays in my diagnosis and impacted the prognosis. Throughout the whole experience I have not been communicated to properly and had to chase all results myself, with the help of my GP.
- I had to get involved in finding my husband's records, they had been lost and this resulted in the cancellation of his biopsy and I wasn't going to let it happen a second time. I was ringing the secretary to locate the records and actually did so
- I have had to fight to have my voice heard in relation to being part of my cancer journey, I want to hear my results, see my scans, have them explained to me, contribute to my care plan and treatment and feel I am not involved. I think people should be respected and not made to feel that they have been excluded as they don't understand, patients should be given options to be part of any discussions. I am now transferring care to my preferred place but I have had to fight to get this and believe the pandemic has delayed this option.

2.3 Effective communication and relationship building

- The consultant was sensitive in his approach when he delivered my diagnosis, it was a big shock however I was given lots of time to ask questions and was given details and the options in relation to my care pathway.
- The registrar explained everything, he could not have explained it any better.
- I was given all the information and options required to make choices about my treatment.
- I was pleased to receive a copy of the communication to my GP as it provided reassurance that I was doing well.
- I spoke to my oncologist prior to my first consultation and I found it very reassuring when I was told I will be given all the information I need and that I will have a plan and any trials will be discussed at my consultation. I feel optimistic about my pending appointment, I have researched what might be available and after speaking to my Oncologist I feel I can be proactive in seeking the right treatment and having open discussion at my appointment.
- I have read widely about my cancer and am aware of clinical trials and innovative treatments however when I have asked about these I have been told these are not for me without any discussion or explanation. I feel that many of the questions I have asked have been unanswered or had inappropriate answers.
- Following referral to Weston Park Hospital I have had preliminary conversations with the consultant to discuss my options. I shared that I have fears that I will have to go alone and it has already been agreed that my partner will join the consultation on speakerphone. I am pleased that I have been assured I will receive all the information I need and that I will have a plan.
- I do not feel I had much opportunity to speak to my previous consultant, I now have a new oncologist and we got on well together at my last meeting, I have a short term plan regarding my treatment and feel I am able and have more opportunity to talk to my consultant.
- Overall, the attitude of staff was positive but on a couple of occasions some staff were a little dismissive, I asked for more information from a nurse and emotional support for my husband but was told they could not talk to me in relation to this request.
- I felt uncomfortable questioning the doctors and nurses when they said there was nothing to worry about and found the medical staff at Doncaster very rude. I felt like I was left alone to wait for a long time and asked random questions by medical staff approaching me that I had never seen before, without even introducing themselves.

- I think that some of the text, messages related to the cancellation of chemotherapy during Covid -19 were too complex and would confuse and frighten some patients.
- I have had conflicting information about my care, told I do not require chemotherapy at one stage and then I do and I feel I am not part or any decisions about my treatment and not spoken to about it.
- I received a letter post treatment saying I needed to go to the DRI urology suite because a digital consultation was not appropriate, I went to the appointment and it was a total disaster. I was told I was in the wrong place and redirected only to be told I was not on the list for a face to face appointment, but rather a digital consultation. I persuaded the receptionist to ask if I could be seen and this was agreed however whilst I was waiting another doctor phoned me to complete a digital consultation. I felt hopeless and like I had just lived a nightmare.
- Doctors are amazing, but sometimes they lack people skills and don't really understand what it's like to be a patient and be on the receiving end. Some staff explained everything fully and they gave me contact details to call should I have any questions.
- I attended for a scan and went to the wrong place as the letter was not clear, it was a lengthy walk to the right department and a very kind porter got me a wheelchair, took me there and then returned to take me back to my car. I was upset at going to the wrong place but so happy that someone was willing to help me.
- Communication had not always been satisfactory or there has not been enough communicated to me.
- I was told things in drips, it felt like they determined what they thought I could be told. Terms like "sinister" were being used and then I was asked if I knew what that meant, I would have preferred that the word cancer be used. I had to ask, "Have I got cancer?"
- The District Nurses who visited me had very little knowledge of the specific and complex care I required, it was a "drama" and one I could do without.
- When my chemotherapy went on hold, I was left not knowing when I would receive it, I feel that improved communication should have been sent out to keep people updated as to when treatment would resume.

2.4 Fear of the unknown

- After my treatment I needed more reassurances that the treatment had been a success, professionals class you as if your cancer has gone because your treatment has finished. I felt abandoned after my treatment, I still needed answers and tests that could tell me of the success of the treatment. I requested a MRI Scan, not routinely done at this stage and my fears remained whilst waiting for the tests. I needed to know what was going on.

- I was frightened about the anaesthetic when I went in for planned surgery however the anaesthetist took time to come and talk to me to and gave me reassurance.
- I had to stay in hospital during Covid waiting for a procedure and was worried about going home as I was told that I might not get readmitted, I got to the point of leaving but didn't
- I was worried about having a tracheostomy but I got good lessons in how to care for it on the ward.
- When I was diagnosed with throat cancer 3 years ago it was so terrifying I felt my life had ended when I found out, I cannot fault the staff at Doncaster or Sheffield hospitals as they have stayed by my side during treatment and have been reassuring when I have been in such a bad place, I have had 33 sessions of radiotherapy and staff were so helpful and supportive.
- Finding out you have cancer makes you feel down and depressed and you always feel on edge as you don't know what is happening, you feel like constantly crying. I was in such a dark place when I was diagnosed and I never thought I would be able to get out of it. I have attended the Cancer support group Western Park – counselling, calming therapy which I never knew existed, this has helped me so much.
- It was scary when I attended for radiotherapy and saw the machinery on the first treatment session, this and the thought of the side effects made me frightened and intimidated.
- I was helped by a member of staff who walked me through how the machines worked and what was going to happen during their session on my induction visit to the treatment centre. I felt more relaxed when I knew what it was about.
- I was worried that the Jasmine Centre was not open on a weekend so I visited on a Friday, this helped me to get through the weekend although I did have some problems which meant I had to go to the ward at the weekend which was not ideal.
- I check myself however a check from a doctor gives me more confidence, I would have taken a video call but this is not like a face to face appointment and would not be helpful.
- We were waiting for results suspecting that my husband may have cancer and it was purgatory, the nurses were caring and sympathetic, offering to make us tea and sandwiches whilst we were waiting to hear results, this made us worry more and think it was not good news
- I did not know what was happening to my husband, he had been admitted to Accident and Emergency (during Covid)and I could not be with him and did not know what was happening and could not get through on the phone, I tried over 30 times to get through.

- After my diagnosis I stared at the wall for about a month and did not know what was happening and was waiting for someone to contact me.
- I have too many unanswered questions and gaps in knowledge about my cancer and this worries me.

2.5 Inpatient Services

- I had a planned mastectomy in January 2020 staff were excellent, I cannot find any fault with the staff, particularly the consultant and the anaesthetist, I was very nervous and the anaesthetist took time to visit me prior to surgery. There was a slight delay due to an emergency and this was explained to me. The approach from the consultant enabled me to be calm and I was happy with the environment in the hospital. A diary made by my family members during my stay states the junior doctor who was caring for me was kind and jolly and looked after me well.
- I had a delay in my planned surgery but I was not concerned as everyone had convinced me that it was not cancer and the consultant told me it was unlikely, When I was told it was cancer I feel that my surgery should have been earlier. Going in for my surgery was the worst part, it was not a very good experience, it was like being on a conveyor belt. I was not given a bed space until after surgery which was not helpful, I was sat in a hot waiting room with others for hours waiting to go for surgery, I felt like a farm animal and was very frightened and scared stiff, it was very busy. I got changed into my theatre gown in an office and walked to theatre, communication was poor and I did not know where I was going back to following surgery. I was in hospital for 2 days following surgery and I was looked after well
- My experience was appalling, I spent 5 weeks on the ward during Covid- 19 with minimal opportunity for visitors, and not having visitors was distressing. I received my diagnosis with the support of a family member who was working on another ward, and I then had to tell the rest of my family over the phone. I had a delay in a procedure which kept me in hospital, the nurses were very nice however they were stretched as it was a very busy ward with very demanding patients.
- The service, care and treatment I received at Doncaster Royal Infirmary was good, the staff were very friendly

2.6 Day patient services and other services of support

Jasmine Suite, Doncaster Royal Infirmary

- I cannot speak highly enough of the staff, they are stupendous and I have no complaints about the care I received however I had to access the ward a few times at the weekend and would welcome a service at the Jasmine Centre over the weekend. Sometimes I would go the Jasmine Centre on a Friday to be checked before the weekend and that at times would be panicking over the weekend and knowing no one was there would wait until Monday and then get straight on the phone to them. When I have contacted them

they have arranged an appointment either immediately or later in the day, I have received brilliant treatment.

Weston Park Hospital

- I received radiotherapy at Weston Park up to March 2020, the service was excellent.
- I have attended the Cancer support group Western Park – counselling, calming therapy which I never knew existed. This has helped me so much, it gave me something to look forward to.
- I am on review but I had radiotherapy at Weston Park Hospital Sheffield 5 days a week for 4 weeks; and they were brilliant and marvelous.
- I was very excited to ring the bell at the end of my treatment because everyone started clapping; I feel it's such a shame that they have taken that down
- I have had 33 sessions of radiotherapy at Sheffield they were so helpful and supportive
- I have transferred my care to Weston Park Hospital. My new oncologist is superb, he agrees I should be involved in any Multidisciplinary meeting about myself.
- The Weston Park Nurses specialist nursing team have been very helpful and provided advice when I needed it with my other medication needs.
- I had to attend alone for radiotherapy during June and July 2020 during the Covid-19 pandemic and I cannot complain about the services, systems were in place and appropriate precautions were followed, I felt safe.

Royal Hallamshire Hospital Sheffield

- At The Royal Hallamshire they could not do enough for me, I received good lessons in how to care for myself and my prosthesis. Travelling was difficult for my family so it was good when I was moved to Doncaster Royal Infirmary. I was well looked after and I had a good relationship with staff but I was lonely on the ward, it was good to have a TV but it is expensive.
- I received a call from the surgeon to tell me how my husband's surgery had gone and this made me feel good. (pre Covid)

Chatsfield Suite

- From May until October 2020 I had to attend the Chatsfield Suite for my chemotherapy alone and wear Personal Protective Equipment, the experience was very good, the staff were welcoming and lovely, the environment was happy and I was absolutely happy with the whole experience.
- The girls in the Chatsfield Suite were fantastic, very attentive, they all came to assess me when I was ill whilst receiving treatment. I felt reassured that there was a team

consensus on the situation and was attended to by a doctor and the issue was discussed by the whole team.

- I went to the Chatsfield Suite for 2 years for treatment (not during 2020) the staff are really good and the care I received was second to none. On one occasion I was receiving treatment and became unwell and the staff were quick to recognise this, very attentive and took appropriate action.
- I attended with my husband for the second visit and was surprised by the friendliness of a member of staff who greeted us as we walked in, this helped us both as it made us feel welcome and that someone cared. Receiving care from the same nurse each week was a really valuable part of the experience. On a visit after my husband's passing I was shown empathy by the staff at the Chatsfield Suite, they said how they wanted to embrace me but could not due to Covid-19. I also received a letter from the Chatsfield Suite, the fact that it was hand written and made reference to my husband really made me feel happy. The staff were lovely, kind and helpful, I cannot praise them enough, there was nothing bad about this experience, the staff were amazing.
- I have no issues with the care they provided, the girls are good and lovely. I felt safe in the Suite, my privacy and dignity was respected but I do not think that Track and Trace was used.
- After my first treatment, I received a card from the department congratulating me on completing the first session and apologising that friends and family could not accompany me, this was a nice touch.

McMillan services

- I initially resisted input from this service but saw the benefits when I had it in 2019, my counsellor was a great help and I have recently started again after I referred myself.
- I was not made aware or encouraged to take up McMillan services.
- Nothing was discussed with me about the McMillan services
- I was very upset and felt dismissed by the McMillan service and therefore reluctant to be involved with them at all.
- The McMillan service helped us with financial advice, they were a great service with great people.

Accident and Emergency

- My husband had a bad experience in Accident and Emergency, he thought the department was full of people who did not need to be there and couldn't stand it being there. This prevented him from returning when he rang 111 and was advised to go back. He was admitted from the Chatsfield Suite as he was very ill during his treatment and there was no doctor available in the Suite. I was not allowed in the hospital due to Covid and I had no idea what was happening or where he was. I was sat outside in my car, he was not answering his phone and I tried many many times to get through on the phone

to find out what was happening. I did not see him again until hours later on the ward where he passed away.

2.7 Community and Home Care

- I was visited at home by the district nursing service and unfortunately, they had very little knowledge of the drainage system I had in place and the whole episode was a debacle, appalling and a bad service and meant I had to attend the ward. My second visit, from the District Nursing Team had a more positive outcome as they knew more about my drainage system.
- Following surgery I was discharged without any plan or support in place, I felt abandoned. My family members contacted the GP and was given contact details of the District Nurse and the Palliative care team and advised to contact them. Both teams are supporting me now and visiting me weekly and it is a relief to have them. The District Nurses and the Palliative care Nurses have been helpful, they have answered questions and addressed some practical issues, they have sorted a wheelchair for me as I had to borrow one and I now have appropriate pain relief should I need it.

3. Impact on Emotional Wellbeing

3.1 Impact on the patient

- I had many problems following my diagnosis, I became depressed and was unable to work and my emotional state impacted on my relationship with my family. I stared at the wall for a month as I did not know what was happening and did not recognise how unwell I was. I did not know counselling was available and what it entailed. I may have been offered counselling and may have rejected it, I did not know what it meant and thought I was ok. I did end up accessing counselling through McMillan support and they were a great help.
- I had experienced a previous family diagnosis and I was frightened to death when I found myself in the same position and it did not get any easier.
- I was in such a dark place when I was diagnosed, and I never thought I would be able to get out of it. Finding out you have cancer makes you feel down and depressed and you always feel on edge as you don't know what is happening. You feel like constantly crying and cannot imagine not feeling any other way. I attended calming therapy which gave me something to look forward to.
- My husband buried his head in the sand and found it hard to admit the impact of his diagnosis. I approached staff to request help but did not get a positive response to my suggestions. I feel that little consideration was attributed to my husband's emotional status.
- I think I should have been given emotional support, my family needed it too as they were struggling.

3.2 Impact on Family and Friends

- I had to communicate my diagnosis to my husband over the phone, I arranged for friends to be available to support him as I knew how distressing this would be for him.
- I was supported by family members, friends and staff on the wards, I was in a very dark place emotionally.
- I could not attend chemotherapy sessions with my husband due to the pandemic restrictions, I sat and waited outside for a long time and was not being kept informed . I felt hopeless as I did not know what was happening and was very distressed. I made over 30 phone calls to the ward; clinic and A&E whilst sat outside the department, I saw him being transported through the door but did not know where he was going.
- Following the passing of a my husband I received communication from the Oncologist who apologised that I had not been supported appropriately due to the impact of Covid-19. It was incredible that a man who is so busy made the effort to call me and this made a massive difference, when people acknowledge that things may not have been quite right it makes all the difference
- My daughter has supported me but I know she has found it very difficult, neither of us have had any support and I do not know what is available. My emotional health has not been considered seriously enough let alone that of my daughter.

3.3 Psychological Safety

- I had previously been to Weston Park as a Firefly driver but following my cancer diagnosis I found it scary and daunting to return to the hospital as a patient as I had never been inside. I did not know what to expect and I felt embarrassed because of staff looking at my body during treatment. I was worried by the machinery and being alone in the room but it soon got easier.
- I felt upset and distressed at times but the closeness and good relationships with the staff helped me feel safe.
- The staff are amazing and we couldn't do without them, but they need to understand that a patient needs to know what is happening with their cancer. The doctors lack people skills and do not really understand what it is like to be a patient and be on the receiving end. It was all down to my feelings and he [the doctor] wasn't grasping that.
- Following a delay in treatment, I was told another few weeks won't make much difference. This was very distressing I thought that staff did not care about me and their feelings.
- The friendliness of staff and their greetings as we walked into the clinic made me feel cared for and safe

- I had a feeding PEG installed which was very traumatic, I could not manage the feeding system and my partner unfortunately could not get support from work to leave every 4 hours to help with my feeding and he had to give up work.

4. Impact of the COVID-19 pandemic

4.1 Attending hospital

- My treatment for radiotherapy went on despite restrictions, I felt relieved that I was allowed to remove my facemask during the session, as I felt very claustrophobic. Staff put me at ease, they were kind and thoughtful despite the difficult times and I really appreciated the staff's effort to make me feel relaxed during treatment by playing music and distracting me.
- The number of patients allowed into the hospital was carefully restricted, I felt that staff were protecting me appropriately and I never felt frightened about what I might be exposed to by being in the hospital. I felt safe at Weston Park and needed to attend for my much needed treatment.
- All treatments were off and I was devastated, the Oncologist explained the risks of receiving chemotherapy during Covid and advised against it as government advice was being sought in relation to cancer treatment during the pandemic. I did receive chemotherapy between May and October 2020 and faced the usual restrictions and the experience was very good, the staff were welcoming and lovely. The environment was happy and I was absolutely happy with the experience.
- My husband may not have died prematurely if he had continued to receive chemotherapy (this was discontinued in March 2020 due to associated risks). He had a terminal diagnosis and the previous treatment had been successful, Covid-19 did reduce the time we had together. From March, the Covid-19 Pandemic affected his appointments and they were virtual rather than face to face, my husband received calls from a different oncologist to his usual one, he was well informed of his case and we were happy with his input. My husband attended for blood tests during the lockdown, he was in and out with no waiting, no one was around and he felt safe. My husband recommenced chemotherapy in the pandemic, in addition he had to go into the Chatsfield Suite for a blood transfusion, I was not allowed in and sat in the car park for the duration of the session. He deteriorated rapidly and was sent to Accident and Emergency, I could not get through to him or the hospital to find out what was happening, it was dreadful. I sat outside, no idea what was happening and completing over 30 telephone calls, first to A and E and then the ward to try and establish the situation.

I realised he was very ill and insisted that the nurses put an alert on the notes, I wanted to be informed if there was any change as I was determined he would not die on his own. I heard nothing from the ward and thought no news is good news, then I got a call at 01.00hrs and dashed to the hospital, everyone was doing their best, however I was told he was going to die. All the staff wore PPE and they were kind and lovely, apologising that they could not be tactile with me and providing care in the best way that they could.

It was evident that the staff were rushed off their feet which impacted in their ability to communicate with outsiders and keep me updated.

I feel strongly that Covid -19 was responsible not the clinicians or the NHS, I cannot blame the NHS they tried really hard

- Covid has created additional worries for me; I do not feel that there is sufficient protection in the Chatsfield unit in relation to Track and Trace. There was no evidence of Track and Trace in the waiting room at the Chatsfield Suite or at Parkhill Hospital and it felt wrong to me. I would have opted for treatment elsewhere but was persuaded to stay locally due to the risks associated with Covid. I have transferred my care now, I feel more reassured that prior to my treatment at Weston Park I will have a Covid test as I have not really felt safe at Doncaster when I have attended for treatment as I did not have a Covid test, I was asked how I was and they would check my temperature.
- My chemotherapy was put on hold during the pandemic and it was not communicated clearly, when this would restart. By September 2020 all my treatment and appointments were back to normal. Attending alone does not cause me any distress, there are no waiting times and the staff are friendly and reassuring.
- I would have preferred a face to face contact, although I fully understand the need for phone consultations given the world we are living in.
- In the peak of the lockdown I may have worried about the risks associated with attending an appointment at the hospital and would have been worried about going but would have been happy to go in June if I had felt the need. I feel I was given a choice as I was offered the opportunity to go to the hospital but decided to have a telephone call as I had no concerns. I have always been happy with my care and was happy with the call from my Oncologist who checked how I was feeling and whether I had any symptoms.
- I have not seen anyone at the hospital face to face but I have had 3-4 telephone calls from the ENT team who suggested that I contact them should I have any concerns. I was expecting a review by the Lymphedema Service since the start of the year but I have just had a telephone call recently and been provided with some advice and support and I now have an appointment.
- I have had telephone consultation, I was not offered the opportunity to attend the hospital and was encouraged not to go due to the risks of Covid as I am immunosuppressed. I have seen my consultant once during the pandemic but I know I can ask for an appointment if need one and as I am now experiencing increased symptoms I have organised a face to face appointment, I have no concerns about attending the hospital site now.

4.2 Impact of the restrictions on the support network

- It was a nice touch when I received a card from the hospital department after my first treatment session, apologising that my friends and family could not accompany me.
- I have had to attend appointments on my own; I have connected by telephone during the appointment with my daughter so that she has been able to hear the conversation.
- I received my cancer diagnosis alone due to the pandemic and found the lack of family and friends support was very unsettling and upsetting. My husband was allowed to visit once a day, but my children were not and this was very distressing.
- I feel it will be difficult for me to attend appointments alone and retain all information so it has been suggested that my husband will join on the telephone.
- I felt panic about having to attend treatment alone as I had always previously done so with my partner. At one appointment I had to fill in a form and this worried me as he always helped me fill out forms
- I felt depressed during Covid-19, I had noticed friends keeping away even before shielding was in place because I had cancer. I think this is because people don't know a lot about cancer and think it is catching. More education is needed so people know more about cancer.
- The last thing I wanted was for my husband to die on his own and I requested staff to phone me when the situation changed. Communication was complicated by the pandemic and the ability to contact the ward by telephone to get any updates. In the end, I was able to be with him in his last moments, the staff did their best.

4.3 Digital care versus Face-to-face care

- I was offered a face to face appointment but decided to take a telephone consultation instead while waiting for restrictions to ease. A telephone call has limitations in relation to a thorough medical examination, I would have loved to have had a video consultations which I was offered but I felt I was unable to because of my lack of technology skills.
- I feel I would have been diagnosed faster if the clinician had seen me in person., I received a telephone consultation which did not demonstrate my jaundice which I was not aware of.
- It's hard to know what a person is feeling over the telephone; sometimes you need that embrace of a doctor to make you feel safe.

5. Timing

- I was pleased with the speed at which my appointment came through; I was diagnosed and treated very quickly

- I was happy with the timing of my referral and intervention after seeing my GP with continued symptoms.
- I was given the results of the scan by my GP, I was happy with the timing and the approach of my GP.
- After the nurse found my problem I was seen by my GP and was promptly referred to ENT at Doncaster Royal Infirmary
- Events at the time of my diagnosis were timely and I cannot complain about my treatment
- My husband had delayed accessing health advice, he visited the GP and the GP was amazing, on the ball with very timely actions
- I had a slight delay with surgery on the ward due to an emergency, this was communicated timely and effectively and the reasons were fully explained.
- I was pleased with the speed at which my appointment came through; I was diagnosed and treated very quickly.
- I was given a 6 month follow up after my treatment finished and told to call them if I was worried, this felt like a very long time. It's hard when you're older to recognise what symptoms are related to the cancer and it's hard to know what a person is feeling over the telephone; sometimes they can pick up what can't be seen over the phone
- I was given a prognosis of months to live then I sat in hospital for five weeks with nothing happening waiting for a procedure during the lockdown
- My urgent referral for an MRI Scan was lost; this was very distressing and caused a delay in my investigation. I was panicking about not hearing from the department, I wanted to have the test and get on with things.
- I did not have a long wait to see the Oncologist but Covid -19 had an impact on my treatment and I was told that all treatments were off and this was devastating.
- Waiting for results and knowing that cancer is being considered was the worst part. We had to wait for four hours in a department for a doctor to give us results and stated it was horrific.
- The timing of my counselling was not ideal, I would have benefitted from counselling earlier and may have been offered it earlier not knowing how it might help and refused it. Once I got to the point of accepting counselling I had to wait too long, when you get to the point that you want it, you don't want to wait.

- I feel that I could have received my diagnosis earlier as I had seen my GP previously with similar symptoms.
- My diagnosis was delayed because I did not receive tests results timely following a hospital admission and my GP had to chase results and arrange further tests
- My diagnosis was delayed, when results were available but not passed on to me or my doctor. This resulted in a delay in my surgery and treatment options and I feel this has contributed to progression of my cancer and development of secondaries.
- The wait we experienced to see the Oncologist for an initial appointment was distressful for both of us, my husband felt he was being left to die. We were horrified when told we might have to wait a month and when the McMillan Nurse told them it won't make much difference we felt like screaming. The wait for chemotherapy was also too long as was the wait for a biopsy, the biopsy was further delayed as my husband's notes went missing. All these events were distressing and we were very angry and we didn't think that people cared. The surgeon was the only one who apologised.
- I think that if documentation had been completed earlier I would have received much needed benefits at an earlier stage. I knew my condition was terminal but the documentation was not completed and the benefits not received. Once completed I received a "blue badge" disability pass within a week, PIP Benefit was processed, and I no longer had to pay prescription fees.

6. Miscellaneous

The common areas are listed below:

- Firefly
- The Ambulance service
- Discharge planning
- Respect form and DNAR
- Hair loss and wig provision
- Use of the word Palliative
- Screening programmes

Firefly

- Firefly were extremely accommodating, they were always willing to go the extra mile to make sure you arrived at your session on time and got back home safely. The drivers are very knowledgeable about different types of cancer and what they entail, as many of them have gone through cancer themselves. It was also easy to contact them.
- I was so impressed by the service, they were brilliant, I made a donation at the end of my treatment to match the costs of my journeys,

Ambulance service

- After my discharge, I felt unwell and called an ambulance, the paramedics were helpful and they were looking at what actions would be best for me they took time to talk to me about the services and the Respect Form. The paramedics helped me and prevented an admission, I believe I was having an anxiety episode associated with my situation.
- I had difficulties breathing and reached out to my GP through the district nurses who had suggested I might need an inhaler .My GP advised me to attend A&E and an ambulance was called. The paramedics were supportive and recognised I was too ill to sit in A&E and contacted the GP to arrange a direct admission to the ward.

Discharge planning

- I came home following my surgery with no services, no contact details and no plan. This made me feel abandoned and I did not know where to turn. I now have support from the District Nurse and the Palliative Care team and both have been a great support and it's a relief to have them.

Respect Form and DNR

- I found out staff had put a Do-not-resuscitate on my forms, I was not consulted or informed, I felt disrespected and made a formal complaint. Throughout my journey I felt a sense of sadness and anger, I did not feel that people were respectful and I was not involved in decision-making around my health.
- I felt let down in relation to information about "End of Life" the Respect form may have been mentioned previously by the District Nurses and /or the Palliative care team but the paramedics suggested I get one. My family have collected the form from the GP but I have not completed it yet.

Hair Loss and wig provision

- I am a Chemotherapy patient: and have been told I will lose my hair, last week I received a package with information telling me my wig prescription would have to be redeemed through one agent. I feel a patient should have their own choice in this matter. I have spoken to Cancer Patient and Patients with Alopecia who say that they have been stopped from making their own choices in respect their own appearance.

I would like to have the opportunity to personally view and feel the wigs, be able to upgrade them

I think that patients feel their rights are being taken away from them, which is particularly devastating when they are at their most vulnerable. Patients do not have the energy or strength to fight for their choice and options at this time and should not have their choice stripped away. I have lots of views in relation to this and I have sent these to the relevant stakeholders.

I particularly needed emotional support at the time that I was losing my hair, my hair is important to me and losing it was devastating. It has been bad and no one has helped me through this. Patients do not want to be singled out at this vulnerable time in public, which often happens with hair loss and ill-fitting wigs, a patients' dignity is paramount at this time.

Use of the word “Palliative”

- The use of the term palliative has caused me great upset, it was like a death sentence, no real explanation was offered as to what this might mean and this left me to my own perceptions which was that my life would be cut short considerably. I feel that whilst professionals understand the meaning of this word, it is used when people do not fully understand the meaning and creates distress as it has done for me. I was trying to come to terms with my prognosis and this word created more angst, I have now had discussion with other clinicians and read about my prognosis and now have a better understanding of the term.

Screening programmes

- I felt that my breast cancer would have been detected if I had still been part of the breast screening programme however, I am too old to be included in the programme.
- I was too young for the bowel screening programme but think there would have been an increased chance of my bowel cancer being detected earlier if I had been included, I think the age should be reduced.

Conclusion and Recommendations

This project was developed to gather the views of local people with a cancer diagnosis to establish their real life experiences and find out what went well, what did not go so well and what needs to change.

Local commissioner and providers have been keen to hear the views of this group and it is encouraging that so many people were willing to participate. Engaging with local people over the last year has been particularly difficult due to the pandemic however; creative approaches helped this project to be a success. Participants engaged readily and demonstrated a willingness to share their lived experiences.

The findings confirm the important of clear communication and information in order to avoid patients unnecessary stress and worry, and how a small gesture or spending some time explaining relevant procedures can have a huge positive impact on someone's journey through the healthcare pathways.

Healthwatch acknowledge the participants of this project who trusted in us and shared their very personal experiences with us in order to help shape future services and improve outcomes for themselves and others who find themselves in similar circumstances.

The themes in this report have facilitated a number of recommendations which are contained in the main report.