

**People's experience of
cancer services and
pathways in Doncaster**

Healthwatch Doncaster

Engage, inform, influence

July – October 2020

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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. Extensive discussion had taken place in the early part of 2020 with relevant stakeholders and both providers and commissioners were receptive and willing to support the project.

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 opportunities for local people to convey their real lived experiences of cancer services.

In light of local concerns about cancer targets, Commissioners were keen for Healthwatch Doncaster to engage with local people and gather qualitative feedback regarding cancer services.

Unfortunately the project was put on hold for a number of months due to the Covid-19 pandemic, however this engagement was to become more of a priority when the impact on cancer services from the pandemic were highlighted in local and national media.

The purpose of this project was to find out, from their own perspective, what people's experiences of cancer services are. Healthwatch Doncaster had an original target of 10 participants – cancer is not a subject that people find easy to discuss and therefore this would be a realistic target and would provide good qualitative information.

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

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

Previous engagement projects involved face to face interviews with participants but due to the Covid-19 pandemic and the barriers created by national restrictions, this approach was not possible and alternative options were considered.

Patients were recruited with the support of specialist nurse practitioners and local group. People were given the choice to select either phone or the digital platform Zoom to complete the interview. For any patients who demonstrated discomfort with both, they were given the choice to submit their experience as a written story.

Fourteen respondents contributed to the project. Stories were led by the respondents themselves with no focus on specific subjects or topics. Healthwatch Doncaster

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.

All findings were analysed by the two facilitators of the project and from the analysis common 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. All the issues raised have been included in the report.

The report consists of five sections with each of them split into themes.

1. The start of the journey

Three themes came from the feedback around this part of the journey:

- Recognition of symptoms and instigating advice
- Receiving the diagnosis and treatment
- GP Help and support

Many of the participants spoke of the recognition of their symptoms, their reaction to this and their subsequent actions in seeking medical advice. Some referred to the fact that the speed of appointments and their diagnosis was prompt. One patient felt let down at this stage by the restrictions of Covid-19 in accessing a face to face appointment to discuss their health concerns with their GP.

Most people describe the point at which they were diagnosed with positivity and commented that clinicians were calm and supportive in their approach, which helped them feel optimistic. A number of patients talked of how they were given opportunities to ask questions and that everything was explained to them. People shared the positivity of their first consultation stating they were pleased with how their diagnosis was conveyed to them. The pandemic was particularly distressing for one patient who had to receive their diagnosis alone due to constraints on hospital visiting.

The support and competence demonstrated by GPs was highlighted by the majority of patients interviewed at the start of their journey. The respondents appreciated the prompt responses of GPs in relation to referrals or booking the appropriate tests/investigations to check for the presence of cancer. There were two occasions where experiences related to GP services could have been more positive, again, constraints in relation to the pandemic prevented a patient from attending their GP appointment face to face and they felt it negatively influenced their journey. Another patient did not feel supported by their GP to access a scan when a request was lost.

2. Treatment and ongoing care

This section includes the following common themes:

- Accessing information and services
- Fighting your own corner
- Effective communication and relationship building
- Fear of the unknown
- In Patient services
- Day patient services and other services of support

- Community and Home care services

People spoke of receiving information about their cancer. However, accessing the relevant information and having tests and results explained in a simple comprehensible way was a struggle for a number of the respondents.

Technical language used by staff or rushed explanations left patients with a sense of confusion. Not only did some patients have to source information about their cancer, they also had to source information about services available to them and organise some services for themselves.

“Fighting your own corner” became a theme as a number of participants appeared to have to do this and one actually used this term to describe their plight in achieving what they wanted. A few patients reported feeling as if they had to advocate for their own health and push against doctors’ initial indications to receive a diagnosis or treatment.

It is without doubt that the importance of effective communication runs throughout this report and that where ineffective communication is present this had a profound impact on patients. Those who had a generally positive experience with the cancer pathways in Doncaster, reported staff communicating with them in a clear way, whilst being respectful and allowing patients the dignity of which they are worthy.

However, when communication fails uncertainty and stress take over. This was the case for some and resulted in negative feelings and additional trauma for patients. A small number of patients unfortunately did not feel that they were communicated with appropriately and shared their feelings about this.

Fear of the unknown was a common theme related to various stages of the participant’s journey. From the feedback received, it is evident that there is a lot of uncertainty and unclear information and expectations around what each individual cancer journey might look like for patients. This uncertainty resulted in a sense of fear of the unknown for most of the patients interviewed.

Three of the participants experienced inpatient services as either an unplanned or planned admissions. A number of positive comments were received about care and treatment but two participants described poor experiences. One in patient stay was referred to as “appalling” because they felt abandoned on the ward, having to spend weeks during the pandemic waiting for treatment. The other stated they felt like “they were on a conveyor belt” when they attended for surgery due to the lack of appropriate facilities and lack of attention.

Feedback was received about experiences at the Jasmine Centre, the Chatsfield Suite at Doncaster Royal Infirmary, Weston Park Hospital and the Royal Hallamshire at Sheffield. All received very positive feedback in relation to care and treatment. Staff were praised significantly in all four venues. One comment was that services from the Jasmine Suite would be much appreciated at the weekend and it was suggested that this would have more positive outcomes for patients.

The McMillan service received some praise, however it was also highlighted that for a few patients they had no knowledge of the service, let alone how it would assist them.

A participant who was unwilling to accept the offer of counselling did not feel that this was actively encouraged throughout their journey and had to seek it out when their emotional wellbeing was of concern. Another participant spoke of a direct request for support being dismissed.

Feedback on community and home care described a number of experiences where needs were not met appropriately due to a lack of effective communication and discharge planning.

3. Impact on emotional wellbeing

The following themes were identified:

- Impact on the patient
- Impact on family and friends
- Psychological safety

A cancer diagnosis has a profound impact on patients and their family and friends. Much of the feedback received demonstrated that under normal circumstances family and friends play a huge part in supporting cancer patients.

Discussions evidenced that Covid-19 and the associated constraints had a negative impact on the support networks for people diagnosed with cancer. Whilst some efforts were made to alleviate the gaps – allowing families to listen to consultations via a telephone link when patients had to attend appointments alone – the emotional impact of Covid-19 on patients and their families and friends was huge and had very negative outcomes for many.

Psychological safety was an issue for some who suggested that attitudes, friendliness and really feeling that someone cared, helped people to feel safe. Additionally psychological safety is influenced by being in unfamiliar surroundings and new experiences. Some participants spoke of why being informed positively about their cancer diagnosis influenced psychological safety. One patient spoke of the fear of going somewhere new and being fearful of the equipment. However, once they were shown the equipment and given an explanation of how it worked then this alleviated their fears.

4. Impact of Covid-19

The common themes identified from people's experiences included:

- Attending hospital
- Impact on restriction of the support networks
- Digital care versus face to face care

For cancer patients specifically, the invitation to shield and the restrictions put in place in hospitals and treatment centres caused concern and consternation. Many patients saw their treatments discontinued or postponed, as well as their surgeries and other hospital activities related to their cancers cancelled. Patients completed treatments or attended hospital without their loved ones by their side, creating additional fears and anxieties. Whilst it was upsetting having to access the session alone and deal with the

associated restrictions, many reported positive experiences and feeling safe and protected.

The patients interviewed expressed views on impact of the pandemic on their inpatient stays, treatments, follow-ups and isolations caused by the inability to have loved ones around.

Digital care was substituted for face-to-face care in many cases. Patients recognised the need for this change and appreciated the staff's efforts to protect them. Opinions about digital consultations were varied.

Participants told how they were accepting of the situation and happy to take telephone calls as they were well. However the situation would be different if they felt the need for a clinical examination and the reassurances of a clinician. Some shared the fact that they had been reassured that they were to ring at any time should they be worried and felt happy that this option was available to them and that they would be seen if they had any major concerns.

A number of people that Healthwatch Doncaster interview have had digital appointments and were looking forward to a face to face appointment in the autumn of 2020 as a result of restrictions easing slightly.

5. Timing

In sharing their stories, the participants of this project regularly made reference to timing. Spontaneous accounts of their journeys included specific points where they felt timing was significant and had either a positive or negative impact on their experience.

Many were happy with the timeliness of referrals to services particularly by their GP. Some talked of the negative impact that a delay in receiving a diagnosis caused and the undesirable outcomes as the result of their delay.

Feedback included examples such as accessing appointments, speed of referrals, receiving test results, receiving a diagnosis, waiting to see specialists, waiting for treatment and delays in implementation of documentation to facilitate services and/or benefits.

6. Miscellaneous

There were a number of varied themes that came out of the conversations with people:

- Firefly
- Yorkshire Ambulance Service
- Discharge planning
- Respect forms and DNACPRs
- Hair loss and wig provision
- Use of the word palliative
- Screening programmes

Firefly and the Yorkshire Ambulance Service both received very positive feedback and clear gratitude for the positive impact that they provided for patients.

The need for effective discharge planning was evident in two stories particularly. The participants described the gap in appropriate services and support as the result of poor or no planning and their journeys were significantly affected. This caused upset and trauma for the patients and their families.

A decision regarding Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) was reported to be used on one occasion without a patient's knowledge. This caused them undue distress. The lack of use of a Respect Form resulted in a profound impact on another patient causing a delay in their care.

Wig provision was identified as being a prescriptive process where the patient had little choice and input. Again the same patient talked about the negativity created by the use of the word "palliative".

The parameters around screening programmes were discussed by two patients who feel that being excluded from screening programmes due to their age was detrimental, because screening may have detected their cancer earlier.

Conclusion

The findings and recommendations within the report will be shared with providers and commissioners of local services so that they are aware of the perceptions of local people about their lived experiences of cancer pathways and services. There is an opportunity for both provider and commissioners to reflect and learn from these stories.

The main issues raised by this report appear to identify that patients need to be more involved in their journey and that if this was the case a number of the issues of concern raised would be avoided.

It was an overriding suggestion from most participants that at some point in their journey they did not feel that they had a voice and were not able to contribute to some decisions about their own health.

Healthwatch Doncaster has listened to the experiences shared and is making a number of recommendations for service improvement. The recommendations include a common thread that person-centred care and person-centred care planning is of increased focus in all local Cancer pathways.

Recommendations

NHS England state:

"Evidence tells us that supporting patients to be actively involved in their own care, treatment and support can improve outcomes and experience for patients, and potentially yield efficiency savings for the system through more personalised commissioning and supporting people to stay well and manage their own conditions better. NHS England has made a commitment to become much better at involving patients (and their carers) by giving them the power to manage their own health and make informed decisions about their care and treatment"

Many of the themes identified in this report provide feedback that evidences gaps in the provision of Person Centred Care.

Healthwatch Doncaster have made a number of recommendations that focus on person centred care and person centred planning. The evidence indicates that the journey and experience of people diagnosed with and receiving treatment for cancer would be enhanced if person centred care and care planning was improved.

Recommendation 1: Enhancing communication, involving patients and use of Care Plans

Throughout the report lived experiences related to communication were shared and discussed. Many patients described how clinicians communicated positively with them and provided information they needed and involved them in the conversation. There are examples, however, that communication, at times, was ineffective and attitudes and approaches were not satisfactory to the needs of patients.

It is widely evidenced that the lack of information, use of jargon and unfamiliar terms can cause confusion and distress. Additionally there were gaps identified in relation to what and how information was communicated to patients throughout their journey.

People wanted to have more knowledge about their cancer. This was a common theme throughout the report. Some people did not feel involved in decisions about their treatment or care pathway and this created undue distress and fear. It may be that locally many patients are offered this option however the lived experience of this cohort was that they had little involvement in much of their journey.

People need to have clearly written care plans documenting their cancer treatment pathway with a patient held record. People should be involved in and be part of their own care and treatment plans. Staff should consider what and how they communicate with patients so that they can facilitate discussions which allow patients to participate and be involved in their plan.

Recommendation 2 – Continued offer of digital consultations

All the patients under review were offered digital consultations and were happy with them. They were received more positively because many people believed this was a short to medium term arrangement and face to face appointments would be available to them in the near future.

Patients with cancer often have to attend a plethora of appointments throughout their journey and offering digital appointments to patients should be an option.

Digital appointments should be offered alongside opportunities to access a face-to-face appointment should it be necessary.

Recommendation 3 – More effective planning for End of Life Care and robust discharge plans and use of Respect forms

It was evidence that one person was let down considerably by not having a discharge plan, this led to increased trauma and distress for the patient and their family and could have been avoided if a robust discharge plan had been in place. Similarly, one patient

heard of the Respect form from the Ambulance service during an acute episode of illness. This patient did not have one in place and as an inpatient had been told that they were 'end of life'.

Healthwatch Doncaster recommends is that patients all who have a terminal diagnosis have a discharge plan and timely completion of a Respect Form. Training and support about how to involve people, families and carers in the completion of Respect forms should be in place for all staff.

Recommendation 4 – Offer of emotional and financial support throughout the patient's journey at pivotal points evidenced within the Care Plan

Considerable feedback was heard in relation to the emotional needs of patients and their families. Some patients accessed such support with very positive outcomes, however, it was evident that many did not access this service at the right time or at all due to lack of knowledge about the service.

It is also evident that some of the participants accepted that at some stage they were offered such service but did not understand what the benefits might be so refused it.

It is recommended that such services are offered initially with a dedicated appointment then routinely throughout the patient's journey but specifically when there are significant changes to a patient's physical needs. One patient spoke specifically about embarking on treatment knowing they would lose their hair and that support at this point would have been appreciated.

People were not informed of services to provide financial support and other benefits such as the Blue Badge and knowing that they did not have to pay for prescriptions when they had been given a terminal diagnosis. People felt that they were compromised as result. Healthwatch Doncaster recommends that the provision of these support services to patients be embedded in care plans.

Recommendation 5 – Person centred approach to wig provision

Participant's struggled, as many people do, with their hair loss and subsequently the provision of a wig. Their perception was that they had little consultation in relation to this provision and that the process is very prescriptive and restrictive. This participant would have liked more say and control in relation to wig provision and reported that they had taken it upon themselves to seek a change in this service to positively influence the journey for others.

Healthwatch would recommend that, as with a number of the other recommendations patients are more involved with a person centred approach to wig provision.

Recommendation 6 – Weekend provision at the Jasmine Suite

Patients mentioned the positive feelings associated with consistency and familiarity and how this creates a sense of belonging and wellbeing. They told Healthwatch Doncaster that this has a positive impact on their emotional wellbeing. One such statement was that it was so good to have the same nurse administer my chemotherapy each week.

Another patient describes the care that received at the Jasmine Centre where they received tests and examinations. There was nothing but praise for the staff and the care they received. There was a feeling, however, that they would have felt more supported by the service being available to them at weekends.

This patient described going to the Jasmine Suite on a Friday just for reassurance before the weekend and that at times they would be panicking over the weekend knowing that no one was there. At one point, this patient had to go to the ward twice over one weekend. This was not this patient's preferred option and they feel that it would be beneficial to so many patients if it opened for a few hours at the weekend.

Healthwatch Doncaster recommends a review into the practicalities of providing access to the Jasmine Centre over the weekends.

Acknowledgements

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Healthwatch Doncaster 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.

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