Cancer Services in Derbyshire

Experiences of using cancer services in Derbyshire, as told by patients, friends, family and carers.

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1.0 Acknowledgement

Healthwatch Derbyshire would like to thank the many services who offered their support to this piece of work by making our staff feel welcome whilst interviewing participants. We would also like to thank the many participants who gave up their time to talk to us about their experiences.

2.0 Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, friends, family and carers who have experience of cancer services, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that patients, friends, family and carers have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3.0 Background

3.1 Healthwatch Derbyshire

Healthwatch Derbyshire is the local consumer champion for health and social care. The Healthwatch network is made of up of local Healthwatch organisations across 148 local authority areas and Healthwatch England, the national body.

Healthwatch has a common purpose – to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; Healthwatch Derbyshire is the eyes and ears on the ground finding out what matters to our local community.

4.0 Rationale for the Report

Healthwatch Derbyshire wanted to understand more about experiences of using a wide range of services in Derbyshire in connection with a cancer diagnosis. This led Healthwatch Derbyshire to choose cancer services as a work priority from January – March 2015. The aim was to explore these experiences in more detail, to find out what was working well, and what could be improved.

This report is intended to provide service providers and commissioners with some useful insight into experiences of cancer services in Derbyshire, and will support service development plans and provide suggestions for improvement.

5.0 Methodology

From January - March 2015, our four Engagement Officers spent their time out and about in the community, at groups, in clinics and at hospices, listening to what people had to say about cancer services.

During this period, 102 interviews were conducted. A number of participants became tired and did not complete the interview - the responses given by these participants are still included in this report.

Our Engagement Officers developed a series of discussion prompts to use when talking to patients, friends, family and carers about their experiences of cancer services. These prompts were very broad and covered the whole journey, starting with referral and diagnosis.

These prompts were used informally to help steer the conversation when necessary but staff used a flexible approach with this as a prompt sheet rather than a formal interview style. This is because although questionnaires or structured interviews would have given more measurable data, this could have been a barrier to engagement.

The amount of feedback collected over the course of 102 interviews was enormous. This report has been complied by reviewing all of the feedback, which was then themed to reflect the main topics that arose. The feedback which was neither positive nor negative was then excluded. This report contains comments given when there was an experience that was particularly positive or negative. As a result, this report has two functions, firstly to highlight the topics most relevant to cancer patients, and secondly to give a real flavour of positive and negative experiences surrounding each topic. The intention is not to give a numerical indication of how many times a particular experience was positive, negative or indifferent.

6.0 Information and Signposting

In addition to ensuring that the voices of service users, patients and the public are heard by decision makers within health and social care, we also provide an Information and Signposting service to the public about accessing health and social care services. During this piece of work, Engagement Officers signposted participants and their friends, family and carers to a range of appropriate groups and services.

7.0 Summary of Findings

Referrals and Diagnosis

- Several participants spoke about their experience of diagnosis being triggered by routine screening, and gave other examples of prompt and speedy diagnosis.
- Other participants spoke about apparent delays with referral and treatment.
- Some experiences describe difficulties and delays within primary care created by symptoms being attributed to the wrong condition.

Choices

- Many participants told us that they felt their choices, post diagnoses, were explained well, and they had choice when there was a choice to be made.
- There were some specific negative issues relating to choice for cancer in pregnancy, and prostate cancer treatment.

Dignity and Respect

- There were very few accounts given from participants about events that had compromised their dignity and respect.

Communication

- Some participants felt that in hospital their cancer diagnosis had not been delivered sensitively.
- Other participants felt that the number of staff involved in their care resulted in communication problems between professionals which gave an inconsistent message to the patient.
- Many participants spoke of good communication between primary care and hospital, and good communication between a hospice and primary care.

Quality of Care

- There were very few accounts given from participants about events that they felt represented poor quality of care. Out of the accounts given, one related to prostate cancer and one to laryngectomy patients.

Family Involvement

- There were very few accounts from participants about events that they felt had not involved their family, although one participant spoke of their son being given the news of the cancer diagnosis before the patient.

Equipment and specific needs

- Some participants told us of issues and challenges to do with the order and supply of equipment.
- Laryngectomy patients also described some other issues with understanding their specific needs.

Nursing support

- Mainly, participants had a clinical nurse specialist and spoke favourably about the care and support they offered, and the care offered by Macmillan.
- Many participants had seen a clinical nurse specialist and had telephone contact details for when required, and felt that they got back promptly to patients when messages were left.

Information

- Some participants felt that they had received plenty of information and had been signposted to support groups. Others had the opposite view.
- Several suggestions from participants emerge from this section, which will be highlighted in the report recommendations.

Transport

- Transport, parking and accessing appointments using public transport was highlighted as a real issue, especially so for particular hospitals.

Hospice Care

- Some participants felt that the word 'hospice' was associated with a place you went to die, which did not represent the range of work done by hospices in the experience of those participants. Suggestions were made about rebranding. Unanimously positive feedback was given regarding the hospices used by participants.

8.0 Findings

8.1 Referrals and Diagnosis

It is apparent that there are polarised experiences regarding referral and diagnosis. The comments that follow come from the participants that recounted a particularly positive or negative experience.

Routine Screening leading to Diagnosis

- I had routine bowel screening done – it came out positive ...
- I had breast screening in October 2014 on 'the truck' (mobile screening unit) in Ashbourne, this initiated the process ...

Prompt Diagnosis

- Due to a cough, patient visited GP and sent immediately for scan at Chesterfield Royal Hospital, result same day – lung cancer.
- Colonoscopy preceded diagnosis of bowel cancer and patient told there and then.
- A quick diagnosis of prostate cancer in November 2014 resulted in all treatment starting at Stepping Hill Hospital before Christmas.
- I went to see my GP with a cough and he referred me straight away for a CT scan.

Delay in Referral/Diagnosis

- Patient was waiting about 6 or 7 months before diagnosis … Originally thought to be piles, turned out to be cancer.
- Initial problem with diagnosis – thought to be adhesions due to hysterectomy but actually bowel cancer.
- Originally diagnosed with Fat Necrosis and told 'not to worry' before eventually discovered patient had breast cancer.

- Patient had been suffering pain at the bottom of her back and eventually paid to see a consultant at Stepping Hill Hospital. GP had stated, 'don't waste your money.' It was discovered that patient had myeloma tumour on spine and fractured back.
- One patient saw four GPs at their practice before being diagnosed.
- I had blood in my stools … at first appointment the GP first thought it was piles. At the second appointment the GP referred to hospital for further tests. Diagnosed in September 2014, operation in December 2014.
- I went to see my GP numerous times raising concerns that I was bleeding, almost like I was on my period which was worrying because I am 70 years old. He did send me for tests but it took a year. I was diagnosed with cancer on my womb and I had to have an emergency hysterectomy.
- My late wife's cancer wasn't picked up very well, she went to see her GP after developing pains and spasms down her left side. Her GP put it down to arthritis, she had pains developing in her arm after three weeks and her GP just said that her arthritis was getting worse. Doctor didn't refer her anywhere or offer her any treatment. She later was diagnosed with cancer after an emergency admission to hospital.
- Saw three different GPs before being referred but then referral was quick, 7-10 days, then cancer detected.
- The consultant at the hospital was really empathetic, he said that he couldn't do anything to help my wife; he did say that if my GP identified it earlier they could have offered treatment.
- GP was treating for a bad chest initially... time was the biggest factor as cancer developed whilst waiting to start the treatment.

8.2 Choices

- Many participants told us that they felt their choices, post diagnoses, were explained well, and they had choice when there was a choice to be made.
- Many participants felt that consequences and side effects were explained well.
- Some participants had been given information about likely hair loss, and reported that this factor influenced their treatment choice.
- Many participants did not have a choice, as treatment could not be offered but most felt that this was explained and communicated well.
- One participant expressed worry and concern that financial pressure on the NHS would limit treatment options and expensive drugs for future cancer patients.
- One participant spoke of receiving conflicting information about which treatment would be most effective, and two participants felt that they did not understand the side effects.
- Other participants highlighted variation in the way that prostate cancer treatment is offered.
- Other participants reported an issue with choices for those who have cancer during pregnancy:

  <u>Cancer in Pregnancy</u>

- There are real problems with treatment for molar pregnancy, which is cancer during pregnancy. Treatment for such can only take place at Weston Park, Sheffield or Charing Cross, London, whether you live relatively close by or not. Both are Centres of Excellence. The cost to get to the centres in some cases is phenomenal [transport and overnight stays].
- Choices are taken away from those who have cancer during pregnancy. For example, not being given option to defer treatment, not being able to have home birth, not being able to have water birth, donor breast milk options [not offered at all hospitals] therefore breast milk option taken away from them.
- Some participants commented on an apparent general lack of understanding and nervousness from GPs and some Oncologists about when diagnosing cancer during pregnancy and options to choose, such as not giving chemo during pregnancy [which can be given as long as after first trimester]. Participants added that this has sometimes resulted in advice being given 'to terminate the pregnancy' when the treatment could actually be deferred, and they felt that each case needs individual consideration.

Prostate Cancer

- Some participants reported that men with prostate cancer are being treated by hormone injections to the stomach, some are told to get it from the chemist and a district nurse will visit, whilst others have a choice to visit the practice nurse to get the injection.

8.3 Dignity and Respect

When participants were asked if they had been treated with dignity and respect most felt that they had. By exception, the comments referring to a negative experience are as follows:

- One or two staff could have had respect for my age at the hospitals.
- Loosing hair affects a person's dignity, lost my eye brows and lashes.
- For a scan, six members of staff had to slide patient from bed onto the scanner bed, but then there was no provision made to transfer from scanner bed back to the bed. Patient had to wait ¾ hour for the porter which was not dignified.
- The hoist had no battery in it; this didn't help maintain my dignity.

8.4 Communication

Many participants spoke of good communication between primary care and hospital, and good communication between a hospice and primary care. Exceptions to this as reported for different parts of the system are as follows:

Primary Care

- No communication from GP after diagnosis.
- Patient seen by GP, and then GP waited until he had returned home before phoning patient and telling him that it was 'terminal'.

Hospitals

- Lack of consistency with staff results in mixed messages and conflicting information which is unnerving for cancer patients because of reliance on staff to get things right.
- Consultant was 'very blasé.' The first thing the consultant asked was, 'Do you have life insurance, mortgage and pension benefits?' Patient said that this does not inspire a patient with confidence. Felt that people skills left lots to be desired.
- There was some jargon used which she did not understand.
- Training is required in breaking bad news to patients. Not told in a private space. Was in A&E.
- When the patient goes for a scan, the results can take 2-3 weeks to be given to the patient. There is no appreciation given to the patient and relationships due to the waiting. Get snappy and worried.
- When you have been slapped in the face with a diagnosis of cancer, you don't really digest it all. It would be nice to have a follow up appointment to understand everything; this could be with a Macmillan support officer.
- Communication issues between GPs and between different consultants. Example given by patient was that at one point she had 3 consultants, all knowing a bit about her, but not the whole picture. She felt as though she was the 'co-ordinator.'
- One participant commented that the Oncologist doesn't understand British humour or culture and things often get lost in translation. For example, when the patient said, 'How bad is it?' She replied, 'Good to get your affairs in order.' An impression given it was very serious. This put the patient and spouse 'through hell.' Made decision to go on clinical trial after that. When patient went back, told it was good news and not bad news.

8.5 Quality of Care

Mainly, participants spoke of very positive, high quality care – using words and phrases like 'second to none', 'marvellous' and 'cannot fault it' for hospital services and hospices. Any exceptions to this are as follows:

<u>Negative</u>

- Father is being treated for cancer but he has never been given a diagnosis.
- When I was on the ward I noticed nurses just leaving meals on trays and they did not provide any assistance to help people to eat.
- The Oncologist doesn't have a great bedside manner - he said there is no point having radiotherapy, it won't make you live any longer, he was very harsh.
- I went to A&E because I lost my valve, I needed an X-ray because they said that something could have gone in my lung, I had to wait until the next day with it being a bank holiday. I went the next day but their computer systems had broken down.
- Some members of a Prostate Cancer Support Group would like more Prostate Specific Antigen (commonly known as PSA tests) to be done at GP Surgeries, some only get one test a year which has to be requested. Members suggested that men

have four a year without having to request them. One member had to fight for a PSA test when he saw his GP, he felt that the GP was 'fobbing him off.' The group felt that there was a general reluctance to diagnose prostate cancer and that it was vital that men are screened with a PSA test to get caught early.

- Radiotherapy appointments don't run on time because the machines keep breaking down. This has a tremendous knock-on effect on patient and family life. The patient works, so if he has an appointment for 9am he would be back at work for 11am but he often gets in at 1pm. Sometimes there is no explanation given of what has caused the delay.
- Patient has to have a regular review after radiotherapy which is always the same set of questions/discussion. Often having to wait 1 hour after a 10 minute radiotherapy slot to go through this process.

8.6 Family Involvement

Most participants felt that their family had been kept well informed, and that professionals asked and considered how families were coping. One participant mentioned that her daughter was allowed to see her having chemotherapy to alleviate daughter's fears of how/where it was conducted. The exceptions to this are as follows:

- Father's consultant was changed from one to another, daughter was not told.
- Family made to feel like a nuisance. Would take 20 minutes for someone to answer the phone on the ward. Nursing staff were often overheard talking about their social lives. Would have to chase staff to get answers – information was never forthcoming.
- Son of patient was told she had cancer before hospital told the patient.

8.7 Equipment and Specific Needs

Some participants told us of issues and challenges to do with the order and supply of equipment. Laryngectomy patients also described some other issues with understanding their specific needs:

- There are inconsistencies with supplies for laryngectomy patients; some individuals contact the supplier directly to get a quicker service rather than going through the GP.
- I need three specific brushes for my prosthesis, they are very important to me to keep my prosthesis clean. I tried to order some recently and I waited 3 months.
- It is a waste of time ordering supplies from the GP, you have to wait for them to order items but we end up chasing the order up ourselves after a couple of weeks. Problems with stomas; obtaining suitable stoma, to be allowed to keep one 'spare' [some reluctance by medical staff to allow this] caring for stoma, soreness around stoma. One patient had adapted stoma fitment to suit, as ones that are more suitable cost £75 as they are not on prescription.
- Laryngectomy patients are encouraged to self-manage but then there appears to be a reluctance to let patients have spare valves.
- My pick line has to be kept clean so a district nurse comes to clear and sterilise it. She won't use the dressings given from Royal Derby as she says that it is protocol that she uses her own, so the supply of dressings has accumulated at the patient's house.

- Laryngectomy patients reported a lack of understanding by some GPs in terms of when they are ill with conditions such as a chest infection. They are often questioned if they can breathe through their nose when quite clearly they breathe through their neck. This does not instil confidence in GPs.
- One participant felt that too many hospitals have no policy of dealing with laryngectomy patients. One patient had a very dangerous experience at A&E when a nurse administered a tube down nose – patient passed out [breathes through throat].

8.8 Nursing Support

Mainly, participants had a clinical nurse specialist and spoke favourably about the care and support they offered, and the care offered by Macmillan. Many participants had seen a clinical nurse specialist and had telephone contact details for when required, and felt that they got back promptly to patients when messages were left. Any exceptions to this were as follows:

- Saw a Macmillan Nurse once whilst at Ilkeston Hospital but had gone off sick. Another came in her place, saw her once then she went on holiday. She sorted out Attendance Allowance for patient. Patient said not sure what else they can help with or what help they offer.
- This person felt not enough emotional support offered as she had no family and few friends.
- A few participants did not have an allocated nurse, or were not sure if they did or not.

8.9 Information

Participants spoke about the range of information they had received and how this felt as an experience. This was a very mixed picture, with some participants feeling that they had all the information and support they required, yet others feeling quite the opposite.

Some patients felt that they would like all the information regarding support groups etc. at the time of diagnosis while others thought it should be given from your own GP or some dedicated cancer person/care co-ordinator at your own GP surgery.

A further suggestion was that there should be some kind of educating facilitators to talk to GPs and other health professionals about palliative care. Another suggestion was to have Macmillan nurses affiliated to GP practices.

<u>Positive</u>

- We found out about Blythe House by word of mouth, it is a really great service and we really enjoy talking to people who are in similar situations.
- Macmillan produce a lot of information about support.
- We get support from Macmillan which is great but we find great value in the peer support from the Head and Neck Cancer Support Group.
- Good information particularly at Chesterfield Royal and Ashgate Hospice regarding management of pain for example.
- One patient had Macmillan support and mentioned they gave her £250 for new clothes as she had lost so much weight and nothing fitted.
- Patient was signposted to Macmillan Support. Also made aware of support for partner too.

Negative

- There is inconsistency with services signposting individuals with prostate cancer to support. There are numerous support services but not a lot of people know about them. Some people are signposted for Macmillan support.
- I was not signposted for any support.
- We weren't signposted anywhere, my husband found it really difficult to deal with my diagnosis. We would have really liked some support.
- There are still a lot of things that I don't know about; I am still employed so there are a lot of benefits that I can't apply for. I haven't been given any welfare rights information.
- Nothing has been mentioned to me about carer support for my husband, he has taken it worse than me.
- My wife was treated in hospital; she didn't receive any counselling she was just given books to read.
- It was stated that there is, 'Little information about cancer during pregnancy, only snippets of information on Macmillan site. There are no NICE guidelines for cancer during pregnancy.'
- Information given to patient in a folder, but no details regarding Macmillan nurse.
- It was stated that, 'Insufficient information given regarding services, need someone specific within GP surgeries to have responsibility for contacting cancer patients.'
- Patient has never been given any information of support groups or outside help/support.
- Only noticed that the Macmillan Information Centre was open for the first time today as we normally visit in the morning ... maybe they could have more flexible opening hours.
- 'I wish there were more support groups available ... if there are any, the hospital and oncology staff should tell people about them, especially those that do not have a large family for support and where children may need some support.'

8.10 Transport

Transport seemed to be a problem for patients, with many participants reporting that the whole process of finding a parking space, attending an appointment, and then waiting for medication makes hospital trips protracted and expensive. Specific feedback was given regarding particular hospitals:

Weston Park

People having to go to Weston Park, Sheffield struggle to get there if they have to use public bus services. It takes 3 buses there, 3 buses back. There is a bus service run by Nenna Kind Cancer Support to Weston Park and this needs to be more publicised. The people we talked to used it 5 days per week [Monday to Friday]. Charge is £5 return.

- Travel in and out to Weston Park, Sheffield a problem.
- The Head and Neck Cancer Support Group said that transport to Weston Park was awful, it would take 3-4 bus journeys to get there which is not great with the anxiety you have when you are having radiotherapy.

- Nenna Kind's transport service to Weston Park is absolutely brilliant, the drivers are great. One lady felt really unwell following her radiotherapy treatment and the drivers wrapped her up got her on the bus and took her back into Nenna Kind where they waited until a family member picked her up.
- Transport an issue – neighbours helped out when needed to go to Weston Park.

Tameside Hospital

- Transport a real problem for someone living in Glossop to get to appointments at Tameside Hospital.

Northern General/Hallamshire

- Car parking is awful at the Northern General Hospital and the Sheffield Hallamshire Hospital, the car parks are massive and you have to allow yourself plenty of time to get to your appointment. You have to ask a lot of people for directions and some aren't able to help. This can cause increased anxiety for individuals going to see consultants.

8.11 Hospice Care

Some participants felt that there was an issue with the word 'hospice' - many people see this as 'end of life' and 'you go there to die.' Hospices offer much more, and therefore a suggestion was regarding re-branding to something like ''Living Well' even if as a charity, the word 'hospice' has to be retained somewhere in the name or description of the organisation.

All patients interviewed by one staff member at a particular hospice had self-referred. Their own GPs had not suggested they go there and all of them could not speak highly enough of the services offered.

Unanimously positive comments were recorded about Ashgate Hospice

'First class.'
'Food is fine.' 'Food is great.'
'Staff absolutely excellent.'
'Wonderful staff.'
'Marvellous, like being at the Ritz.' 'Wonderfully kind.' [When asked about any difference between day/night staff] 'No difference.'
'Total continuity at Ashgate, absolutely wonderful.'
'I came in at death's door, now much better. They work miracles. Fantastic team. All done a damn good job.'
'Nice to come here.'
'100% nice.'
'Very good, very good food.'

Unanimously positive comments were recorded about Blythe House Hospice

'No hesitation in coming to Blythe House.'
'It's like my top up for the week.'
'One of the most important things is learning to accept.' [This is something which appears to be taught at Blythe House].
'Unbelievable.'
'Every month a prostate group is run at Blythe which is really useful.'

'Positive, living well philosophy – get something out of every day by coming to Blythe House.'
'Blythe House make the time to talk and offer peer support.'
'You are made to feel safe and secure at Blythe, you can be yourself.'

9.0 Recommendations

Based on the information provided, Healthwatch Derbyshire would recommend that the providers and commissioners of relevant services in Derbyshire consider the following:

1. That newly diagnosed cancer patients receive the right information at the right place, delivered by the right person and at the right time for them after their diagnosis.
2. That special consideration is given to the specific and detailed information required by women experiencing cancer in pregnancy.
3. That special consideration is given to the specific and detailed information required for specific cancer types, such as prostate cancer.
4. The specific needs of laryngectomy patients are recognised (where necessary in policy and procedure) and are delivered through training and awareness raising.
5. That all staff involved in communicating sensitive information and informing patients and their family of a cancer diagnosis do this in a consistently sensitive and appropriate way.
6. Steps are taken to ensure that every patient visit is as straightforward and streamlined as possible in terms of travel, parking and time in clinic plus wait for any medication.
7. That hospices consider their branding, and how to raise referral rates from Healthcare professionals and to develop a wider awareness of the portfolio of services offered.
8. That specific steps are taken to ensure that information and signposting is thorough and routine.

10. Responses

Response to Healthwatch by Erewash CCG

We would like to thank Healthwatch for looking at patients, friend's family and carers' experiences of using cancer services in Derbyshire, and also the service users and their carers who have shared their stories.

As is evident from this report it is essential that we ensure that services are effective, easily accessible, provide high quality care, and that clear service information is provided so that everyone understands the differing services available, and what they do/provide. A local hospice has added 'Caring' to the name of their service in a bid to challenge misconceptions of this is where people go to die, as they offer a variety of services.

Despite there being very few accounts about events that participants felt represented poor quality care, we would always aim to reduce these accounts. Therefore this report is very timely for Erewash CCG as we are about to embark on a project of reviewing and

scoping the End of Life and cancer services within the area to ensure that patients are receiving the right services, at the right time, and in the right place. We welcome this report from Healthwatch as we can use this information and the recommendations as part of this project.

Response to Healthwatch by Chesterfield Royal Hospital NHS Foundation Trust

The Trust welcomes this Healthwatch report which, alongside existing assurance processes, allows us to reflect on the quality of services delivered to our patients.

Over the next year the Trust will be working with MacMillan to build a new cancer centre that will mean that people with cancer in North and North East Derbyshire will be able to receive vital treatment, care and support in one purpose-built centre providing joined up services closer to home.

The new centre has been designed to provide vital support for local people affected by cancer. Currently cancer care and treatment is provided in different locations across the hospital site and the chemotherapy unit is too small for the number of patients it sees. The new centre will enable the specialist teams to provide all out-patient chemotherapy and clinical haematology in one place. It will provide vital support for local people, including:

- treatment and care in one location
- specialist information and advice
- counselling
- complementary therapies, welfare benefits advice, practical support and dietary advice
- access to self help and support groups
- signposting to the voluntary and community sector for support

The following details the Trust's response to the key recommendations in the report.

1. That newly diagnosed cancer patients receive the right information at the right place, delivered by the right person and at the right time for them after their diagnosis.

The Trust understands the importance of ensuring that all patients with a cancer diagnosis receive appropriate information, in an appropriate manner. To support this the Trust aims to ensure that all clinical nurse specialists and lead clinicians have attended advanced communication skills training. Changes in the network arrangements have led to difficulties in accessing this training. A provider and funding has now been identified and the Trust is currently scoping the number of staff who require training.

In addition to verbal information, a wide range of written information, including condition specific information is given to patients, at the time of diagnosis and at relevant points throughout their treatment. Additional information is available from the Cancer Information Centre, which is located in Suite 1; this service is staffed 8-4 Monday – Thursday and is able to provide additional literature and signpost patients and carers to other agencies.

The plans for our new cancer centre include an extended cancer information centre.

The national cancer survey includes a number of questions relating to communication, including:

Q12 – patient felt that they were told sensitively that they had cancer – the Trust scored in the top 20% of Trusts.

Q67 - Given the right amount of information about condition and treatment – the Trust scored in the mid 60% of Trusts.

2. That special consideration is given to the specific and detailed information required by women experiencing cancer in pregnancy.

Cancer occurring for the first time in pregnancy is rare and it is a challenge to provide the safest care for both the mother and baby. A shared care approach with all agencies involved is taken to ensure that the most appropriate care is given.

A new diagnosis of cancer in pregnancy is unlikely to lead to a straightforward pregnancy and therefore extra monitoring of the baby in labour, medication and the provision of blood products may be necessary depending on the type of cancer. Water births and home births are only safe options when the pregnancy is straightforward. Sometimes one has to compromise the other for example; an early birth to allow for chemotherapy.

Molar cancer during pregnancy is very rare, approximately 1:2000 so it is vital that this is treated in Centres of Excellence.

We are fortunate to have strong links with the Oncologists at Weston Park Hospital. Our Oncology team are well aware of the specific challenges facing patients with cancer in pregnancy. We are able to make recommendations based on the individual needs of the patient, taking into account the stage of their disease and how far into the pregnancy they have progressed. We do our utmost to ensure that patients are informed of the choices available to them, as well as the risks and benefits of cancer related treatments such as chemotherapy, during or after pregnancy. For example, it is now understood that surgical intervention for breast cancer can go ahead at any stage during pregnancy and allowing the pregnancy to continue to term is preferable. However, we do our best to avoid treatments and investigations which are known to be harmful to the foetus, such as those involving radiation exposures.

In response to this report our lead cancer nurse has highlighted this issue to all of our nurse specialists and circulated details of support groups and information sources for women facing cancer in pregnancy.

3. That special consideration is given to the specific and detailed information required for specific cancer types, such as prostate cancer.

As per 1, each cancer site has its own tailored information packs and staff give additional verbal and written information dependent upon the precise nature of the patient's condition and treatment.

Each site undertakes a local survey each year which includes an assessment of the type and quality of information provided and action is taken to address gaps identified.

4. The specific needs of laryngectomy patients are recognised (where necessary in policy and procedure) and are delivered through training and awareness raising.

The Trust has a protocol which sets out the procedure for the care of patients undergoing laryngectomy following a diagnosis of cancer of the larynx.

A multi-professional approach to education has been adopted with support from Medical staff, Speech and Language Therapy, Nurse Practitioners and the Divisional Clinical Educator.

All equipment is initially supplied by the Trust but is then accessed through countrywide supplies rather than the GP. It is acknowledged that there have been some difficulties with this company due to change of ownership, which has led to delays in accessing appropriate supplies.

Contact cards, giving the details of the Nurse Practitioner for Head and Neck, are given to all patients who are encouraged to call or visit them for support if difficulties are encountered.

5. That all staff involved in communicating sensitive information and informing patients and their family of a cancer diagnosis do this in a consistently sensitive and appropriate way.

See response to recommendation 1.

6. Steps are taken to ensure that every patient visit is as straightforward and streamlined as possible in terms of travel, parking and time in clinic plus wait for any medication.

The repatriation of services to Chesterfield over the last 10 years, with Oncologists from Sheffield undertaking outreach services aims to reduce the need for patients to travel and wherever possible services are set up as one-stop clinics to reduce the number of visits.

In addition, the Trust has worked with Nenna Kind to advertise the bus service for those patients who do need to travel to Sheffield and dedicated parking has been factored in for the new Cancer Centre.

7. That hospices consider their branding, and how to raise referral rates from Healthcare professionals and to develop a wider awareness of the portfolio of services offered.

Not applicable.

8. That specific steps are taken to ensure that information and signposting is thorough and routine.

See response to recommendation 1.

Response to Healthwatch from Jessop Medical Practice

Since reading this report, we will '… aim to do cancer care reviews in a timely manner and consider appropriate signposting to relevant services at that review.'

Response to Healthwatch from Dr Louise Merriman, GP Cancer Lead for NDCCG and Y&H SCN

1. Good cancer care requires collaborative working across primary and secondary care and all too often I hear people report statements from a secondary care colleague to the effect of, "If only your GP had diagnosed it earlier." This is very unprofessional at best and at worst not true. Yes, GPs will sometimes get it wrong but they are trying to spot sinister diagnoses in amongst a myriad of non-sinister pathology whilst pressured by ten minute consultations. Our secondary care colleagues sit higher in the pyramid at a point that many patients have already been excluded - this is a thoughtless and fruitless comment to make about their primary care colleagues which only serves to potentially destroy the relationship between the newly diagnosed cancer patient and their GP at a time that this relationship is very important having just received such a devastating diagnosis.

2. Cancer in pregnancy is extremely rare and as such should only be treated by those who have sufficient experience to do so, i.e. tertiary centres!

3. PSA is not a screening tool for prostate cancer in the UK! However, PSAs should be done in men when appropriate after sufficient counselling and information has been given to the individual about the test. GPs generally should ensure they are up to date with the PSA advice and have leaflets available for patients.

4. Macmillan nurses are affiliated to GP practices in Derbyshire. It should be appreciated that Macmillan nurses are a "specialist" resource as there are very few for the size of the population and generally they help to support district nurses and community matrons and GPs deliver good palliative care.

5. Under recommendations, I whole-heartedly agree that newly diagnosed cancer patients should receive the right info at the right time etc. The new build at Chesterfield Royal is prioritising its information centre and the Cancer Steering group at Chesterfield Royal is addressing the number of specialised nurses available in outpatient clinics to ensure the patient is aware of their CNS/keyworker. In GP practices in North Derbyshire, care co-ordinators have been recognised as a way of ensuring the practice team remains in contact with patients requiring support.

6. Communication training for doctors is expensive and in short supply but certainly at Chesterfield Royal they have a rolling programme of doctors being sent on this training. In North Derbyshire there is a very good system for palliative care training for GPs and nurses.

7. The voluntary part of North Derbyshire's Single Point of Access is a good source of information for many patients including cancer patients about support groups etc. Perhaps we need to ensure that GP practices increase their usage of this valuable source of information.

Trust Response - Derby Teaching Hospital

We have taken on board the feedback and recommendations and thank Healthwatch and the people of Derbyshire for providing such valuable feedback. Improving the experience of patients living with cancer is of vital importance to the Trust, and providing information for patients/carers, as well as the freedom to communicate with health professionals, is essential. This will enable patients to be involved in decision making, if they wish, and allow them to fully understand their ongoing treatment. We recognise some patients will need additional support to understand and act upon the information they are given and this will require staff training in good communication skills and regularly updated patient information in plain language, in a variety of formats.

The cancer environment continues to change rapidly as knowledge of how to prevent, diagnose and treat cancer continues to expand. The number of new cases of cancer is set to rise and more people will be living with and beyond cancer or also live for long periods on active treatment. Delivering a world class cancer service will require effective planning. As an organisation we embrace this report and are taking a number of actions from the report forward

Actions from the Trust

- The Trust is pleased that the majority of patients received a positive experience whilst undergoing treatment for cancer and that they were involved in the treatment plan and decision making.

- The Trust is undergoing 2014/15 National Cancer Patient Experience Survey and, in conjunction with the Healthwatch report, an action plan and work programme will be devised to improve the experience for all our patients.

- It is very difficult to achieve the right balance when giving out information at the right time and, as a Trust, we need to revisit the information provided; this will be part of the work programme going forward.

- The Trust, in partnership with the Commissioners, is implementing a Cancer Treatment Care Plan which all newly diagnosed patients will receive a copy outlining the treatment they will be receiving. In addition the patient's GP will also receive a copy.

- Pathway work is ongoing this year within Cancer Services and we have started our focus on Urology which will be covering Prostate Cancer.

- The Macmillan Cancer Lead Nurse is working closely with a Macmillan GP to improve communication and ensure a seamless service for all cancer patients.

- Staff do currently have discretion to offer car parking voucher to a patient if they have been kept waiting beyond 2 hours for an appointment. This is one little thing we can do that would ease anxiety for that patient. We need to make sure staff are fully aware that they can do this.

- The Macmillan Cancer Lead Nurse, in conjunction with the Clinicians, Matron, Senior Sister and Clinical Nurse Specialist will, aim to ensure we can support the patient

and carer through the emotional journey of cancer, or ensure that we can point them in the right direction for them to receive the support required on individual basis.

- Work is ongoing with the Trust and Macmillan to acquire additional sessions around benefits; this is also a national problem for cancer patients.

- The Trust advocates that End of Life is everybody business and the Trust is working closely with commissioners to develop an EOL strategy. It is the Trust's belief that each individual, regardless of diagnosis, race, gender, sexual orientation will receive and have fair access to EOL care.

Denise Crouch
Macmillan Cancer Lead Nurse
November 2015

Ashgate Hospicecare's response to Healthwatch report on Cancer services in Derbyshire

We very much welcome this report and the opportunity to be able to respond to the findings. We aim to seek the views of the public and our patients and their carers in a number of different ways and this valuable information will enable us to continue to develop a responsive service.

We are of course delighted to see the unanimously positive comments recorded about Ashgate Hospice but are working hard to ensure that the people of North Derbyshire realise that we are much more than just the services we provide within the hospice building.

Our Clinical Nurse Specialists (previously known as Macmillan Nurses) therapy teams, hospice at home service and medical team, also provide care to people with specialist palliative care needs with cancer as well as other non-cancer related conditions in their own homes in order to manage their symptoms and at the end of their lives if that is their choice, across the whole of North Derbyshire, as well as having a small team of specialist nurses within Chesterfield Royal Hospital.

We work closely with our colleagues within General Practice and other community services to ensure that people are referred into our care as soon as it is needed. Many people are admitted to our inpatient unit just to have their symptoms controlled, if they cannot be managed at home, and 50% of those admitted go home again or come for a weekly visit to our day hospice to continue treatment. We do acknowledge however, that there is still work to do in continuing to inform other clinicians about our service and we are currently looking at different ways of doing that.

Your Feedback – Cancer Services

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

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3) Since reading this report:

a) We have already made the following changes: ……

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b) We will be making the following changes: ……

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Your name: ……

Organisation: ……

Email: ……

Tel No: ……

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire, DE56 0RN