

CANCER LISTENING PROJECT

February - May 2015

Introduction

Following a larger than expected number of stories coming into Healthwatch West Sussex (in part triggered by the CAB Macmillan information service contributions) from July 2013 to December 2014, the engagement team targeted cancer groups to further investigate themes and trends. Our listening project ran from February to May 2015.

Healthwatch contacted over 25 organisations and met with 21 groups across the county and we spoke to over 200 people. Our work included speaking to individual group members; group leaders; and service providers. We would like to formally thank the individuals and groups who have supported our work.



The majority of people we spoke to welcomed the listening project and offered to signpost people to Healthwatch with their stories. One organisation has added Healthwatch to their new member checklist, to remind interviewers to refer patients to Healthwatch if they think we should hear the member's story. However, we struggled to arrange some targeted listening events and we felt this was attributed to the fact most groups are associated directly with clinicians, who have many demands on their time. In a few cases, we encountered gatekeepers to the groups who were not receptive to Healthwatch attending a group's meeting. Continued efforts are being made to connect with cancer patients even after our targeted engagement is completed, as we feel there are a number of stories still to be heard.



The project was successful in building closer links with some, but not all, voluntary sector colleagues, and a greater understanding of local provision was obtained. With the lead cancer centres for West Sussex residents being in Brighton and Portsmouth, we recognise the need to work more closely with other Healthwatch in these areas to access these groups.

Coming out of the listening activities we undertook, we heard the following information relating to local service provision:

- Radiotherapy unit is due to be built at St Richards Hospital by December 2017 and there will not be radiotherapy at the Worthing Hospital site.
- There are concerns a Chemotherapy unit at St Richards Hospital is not being used to its full potential with one voluntary group leader feeling it has *“been mothballed, despite continued fundraising efforts”*.
- There are no plans to make either St Richards or Worthing Hospital a full cancer centre. These are in Brighton, Guildford and Portsmouth, with cancer units at East Surrey, Chichester and Worthing and some cancer services provided at Queen Victoria Hospital (East Grinstead). There are also tertiary (hospitals that provides specialist services) pathways to London Hospitals and to Southampton. However, people we have spoken to feel they are often left with little choice and long journeys.
- Recruitment is progressing for the Worthing Hospital support unit for nurses but there is no space to recruit at St Richards Hospital even though there is funding. The support staff are being funded by Macmillan and will free-up some of the clinical nurse specialists’ time.
- Clinical Nurse Specialists (CNS) cover nine tumour groups at Western Sussex Hospital NHS Foundation Trust (WSHFT) and anecdotally we have heard there is less than one nurse for each tumour area covered by Trust. It is felt the nurse is currently overstretched and there is no holiday cover.
- The cancer patient’s forum (now known as Cancer Patient Voice) at St Richards Hospital has been dormant for some time but there are plans to rejuvenate it (see page 10 for an update).

We have been told that both NHS England and the Clinical Commissioning Groups (CCGs) commission cancer services in accordance with national Improving Outcomes Guidance (IOG) requirements. Such guidance stipulates requirements for patients to be treated by specialist clinicians for their cancer and this can mean that patients are required to travel to specific ‘centres’ for this care. Coastal CCG has told us *“we await with interest the National Cancer Strategy due to be published shortly by the National Cancer Taskforce. This will provide a key focus for future service development. It will be very important that we involve patients and public at the outset to inform our development plans. We will share how we plan to do this as soon as possible, and it would be helpful to have Healthwatch input into this.”*



About the stories

Whilst the stories contained both positive and negative experiences, no particular trend could be identified through the pre-project information we had received. The stories ranged from:

'Steyping community nurses very caring'

'I was diagnosed with prostate cancer and I felt tests and treatments at St Richards Hospital were very professional. Very well done.'

to

'My cancer was misdiagnosed and missed, which led to incorrect treatment at several different hospitals.'

'I suffered severe pain which affected my ability to walk. I was diagnosed as having endometriosis by my GP, who refused to send me for tests. It took five months for a tumour to be diagnosed'.

Healthwatch has summarised what we have heard as follows:

PATIENT PATHWAY

Co-ordination of services and records management

1. Patients told us going to Royal Sussex County Hospital (Brighton) cause problems including: the sharing of notes and MRIs, often there were gaps in communication. Things have improved because the outreach facilities run by Surrey and Sussex Hospital Trust (SASH) at Crawley Hospital, means patients are not having to go outside their more local area for radiotherapy. Though communication between out of area hospitals remains patchy.
2. Following a patient's MRI scan there can sometimes be a period of time where communication with the patient goes quiet. This may be because the scan is done on a Friday and the multi-disciplinary team (MDT) does not meet until the following Friday. This period of quiet can be very distressing for a patient who is awaiting a diagnosis. Communicating to the patient what is happening and when they can expect to hear from the MDT, could help some patients feel less anxious. MRI results can also take a surprising length of time to be delivered.
3. Some patients opt to have private treatment. These patients then become unclear about who to contact within the NHS. There is a lack of information for these patients and Clinical Nurse Specialists (CNSs) are no longer pro-active in offering support and advice to these patients.

Waiting times

A patient who lived abroad was told by their doctor there to return to England and to go to A&E with a wisdom tooth problem. When the patient presented to A&E in Worthing, advanced cancer of the Jaw was diagnosed. The patient had to then wait over 6 weeks to get a jaw cancer operation from Royal Sussex County Hospital and felt it worsen during this time.

Coastal Clinical Commissioning Group stated *"Whilst this is regrettable, and indicates a need for patients to be appropriately advised as to the maximum length of time they should expect to wait to receive definitive treatment, this is actually well within the national 62 day target and in keeping with national guidance, and therefore constitutes good care"*.



Access to information

1. Patients are often unclear on who their CNS is.
2. Patients often do not know a CNS is assigned to them even after treatment.
3. Worthing Colonaid Support Group observed their leaflets were not being distributed to patients who had experienced a colorectal procedure. Members of the Support Group have to find out about the group through other means. The Support Group however is named as a strength in a Brighton and Sussex University Hospital Trust (BSUH) peer review.

Referrals

1. There is a difficulty getting referred by Worthing based GPs for a colonoscopy, as symptoms can be attributed to irritable bowel.

PATIENT CHOICE

Choice of service provider and personalisation

1. A patient with a cancer diagnosis went to their GP and asked to be referred to a hospital outside of area (the normal referral route). The GP refused to refer them. The patient went to a local support service to check whether they were within their rights to ask to be referred to a hospital outside of area (which they are). Fortunately the patient had the confidence to return to the GP to pursue where they want to be treated, rather than where their GP determined this should take place.
2. Cancer treatment can often leave a patient feeling very out of control of what is happening to them. Things happen very quickly and patients feel things are done to them without them having say over it. Patient choice and involvement are often overlooked, for example alternative methods of treatment.
3. A patient from Littlehampton was referred to Queen Alexandra Hospital and felt they were given no choice in where they were referred. The patient had to make decisions really quickly and felt they were not given any time by their GP to consider all their options.

STAFF

Staff levels

1. When a patient first meets their assigned Breast Care Nurse (north of the county), the impression can be that they are extremely busy and do not have time for you. This means patients can be reluctant to contact the nurse for advice and support, especially with what can be interpreted by someone other than the patient as a minor concern but for the patient does not feel minor.
2. For breast care, Crawley Hospital fails on telephone response. When a patient wants to call their nurse, they phone the Crawley Hospital switchboard who then redirects their call to an extension line number. Often calls are not answered and voicemail messages which are left are not responded too. Patients would prefer a direct-line telephone number, though recognised staff would still need to either answer the call or respond to messages left by patients.



3. A patient felt that both Royal Sussex County Hospital and Queen Alexandra Hospital were too busy, with over 30 people waiting at anyone time to be seen in the Breast Clinic.
4. When recovering from a bowel operation, a patient was unable to eat solid food, but did not get to see a nutritionist in hospital for advice on what they could/should eat.

Staff attitudes

1. A patient with two different types of cancer, over a couple of years was treated successfully at Princess Royal Hospital. They were full of praise for all the staff and the service they received, and crediting them with '*saving my life*'.
2. A consultant at Worthing Hospital refused to give a patient all the information on their diagnosis, which meant the patient felt unable to make a decision. The patient requested a second opinion, which they found to be a better experience.

QUALITY

Dignity and respect

1. Badly photocopied information leaflets being given to cancer patients with their appointment letters, has given some patients the impression they are worthless, which they felt was a very negative message to receive prior to any treatment. Printed or well photocopied leaflets would make such a difference.
2. A patient was discharged from Worthing Hospital without knowing how to change their Stoma. The patient had been shown in hospital by a student nurse, who said it was the first time they had done it. The patient was left feeling embarrassed and anxious about the situation and approached a local support group for advice.
3. A patient felt belittled by a consultant at Royal Sussex County Hospital when asking questions over bras and breast plastic surgery following a mastectomy.
4. A skin cancer patient went to have skin cancer grafts at Lewes Hospital. They were told to arrive first thing in the morning. Which they did. They waited all morning and at 2pm were told to '*go out for a bit*'. They finally saw someone at 4pm.

Food and Hydration

1. When recovering from a bowel operation some patients are under the impression they can only eat ice-cream. Whilst ice-cream is on the menu at Worthing Hospital, there is not necessarily enough for everyone in the hospital to have it. Therefore it runs out and not everyone receives it. As the patients recovering from bowel operations cannot eat from the standard menu, it would appear to make sense for them to be prioritised to receive the ice-cream or appropriate menu options are discussed and made available.
2. Patients feel communication between nurses and catering staff at Worthing Hospital is lacking. Every day the catering staff would ask patients recovering from bowel operations to select what they wanted from the menu, even though they are not allowed to eat. The patients and their family members felt very frustrated by this.



3. Fortisip nutritional drinks can be in short supply in Worthing Hospital, therefore patients do not always receive them, even when they are unable to eat solid food. The drinks are on prescription and a number of individuals reported having to 'fight' to get them. One patient reported their experience had been that the MacMillan nurse had the drinks in the ward kitchen.

It was observed the drinks are often given to the patient warm, when they taste nicer if cold.

Upon being discharged, one patient had to buy their own drinks privately (for a few weeks) until they were able to get a prescription through their GP.

Medication management

1. One patient reported their consultant had not been fully open about the side effects of a drug they was taking. The patient had read it caused diabetes but their consultant at BSUH had not fully agreed with this. However when raising the issue with another consultant, this consultant agreed with what the patient had read. The patient made the request to the second consultant that consultants become more knowledgeable, open and honest about how drugs can affect a patient.

Quality of treatment

1. A patient went to Worthing Hospital A&E by ambulance suffering effects of radiotherapy treatment, which they had undergone earlier that day at Royal Sussex County Hospital (RSCH). The patient had a severely swollen tongue (their cancer was in their jaw). They waited four hours to see an A&E doctor. When they assessed the patient, the A&E staff did not know what to do about the patient's symptoms. It was the patient who flagged it was probably caused by the radiotherapy. The A&E doctor tried to track down the doctor from RSCH but it was out-of-hours. Eventually the patient was admitted to hospital overnight and had to wait until the Macmillan staff came on shift in the morning before anything could be done. The patient felt doctors in A&E should have been able to spot the symptoms and know how to treat someone suffering from radiotherapy side-effects.

PATIENT AND PUBLIC INVOLVEMENT

Engagement

1. Crawley CCG had a listening event for breast cancer groups in September 2014. A support group member, who we spoke to, attended the event and at the end of the event the CCG said they would feed back to all who were present. To date nothing has been heard (February 2015) and the group member said they would not attend any future engagement events due to the lack of communication and understands that others who attended the event feel the same. Healthwatch feels this is an important message for all local CCGs to take away.

The Northern CCG have responded to this feedback and told us "we were concerned to read [above]. Until recently, the [Northern] CCGs' Cancer Frameworks have been going through our internal process, including both CCGs' Executive Groups and to the Governing Bodies (June 2015), as well as being widely distributed across South East Coast to other commissioners and trusts. We have had some press coverage in the Horsham and Mid Sussex area as a result of the attendance at the public meetings.



More details here <http://www.horshamandmidsussexccg.nhs.uk/news/new-ccg-approach-to-cancer-commissioning/#.VZKeiRtViko> (and duplicated for Crawley CCG website too). All documents have been shared on the public websites, including feedback reports of the events. Now this is done, we are in a position to contact the patients who helped us to start this process to thank them for their involvement and provide an overview of how their input will shape our forward direction. Therefore, we will shortly be writing to them to summarise the huge amount of work that has been going on to pull together these substantial documents. In addition, as we are expecting a new national Cancer Strategy imminently, we believe the framework puts us in a strong position to put together plans that reflect the new national strategic direction for cancer.”

Change of service

1. Charters Equipment have provided colostomy supplies for a number of years and until recently, the company held a patient’s prescription. This enabled the patient to call them direct to request more supplies and within two days the supplies would be delivered to the patient. Now, however, the patient’s GP holds the prescription and this has meant the patient has to telephone the company direct, and Charter Supplies then has to contact the GP for release of the prescription. This has led to supplies now taking two weeks to reach a patient.

This increase in delivery time means a patient is now having to look ahead to try and guess when they are close to running out of supplies. The patient’s condition can be unpredictable, there can be good and bad days, so foreseeing when to order supplies is very difficult. The patient is understandably concerned about running out of supplies, which would be impossible for them to manage. The knock effect could mean patients stock-piling at the cost of the NHS.

GETTING THE MOST FROM THIS VALUABLE INFORMATION

Healthwatch still has a number of liaison/listening events to attend and stories will continue to come in and be monitored. Healthwatch is looking for organisational leaders to use this information to implement change and has shared this report with providers and commissioners, before publication.

Healthwatch has received positive feedback from Clinical Commissioning Group and WSHFT and these has been included after the recommendations.

We will be seeking to have discussions with providers and commissioners to put forward the following recommendations and seek assurance these will be given careful consideration and where appropriate implemented without delay.



RECOMMENDATIONS

1. WSHFT to be asked to participate in a local listening event, facilitated by Healthwatch, to provide local support members the opportunity to talk about their experiences and to hear what the Trust is planning to doing to improve services. This will include evidence from this report.
2. WSHFT to include details of the Colonaid Support Group in their patient information packs/leaflets and on their website.
3. All Trusts to review their leaflets and literature to ensure these are well produced and if any need to be redesigned, to seek input from patients and support group members early on in the design process.
4. All CCG communication and engagement teams to review their engagement practices to ensure contributors to engagement events and consultation understand how and when they can get feedback.
5. The report to go to the next Food and Nutrition Strategic Group meeting for Worthing Hospital to look at how patient experience can be improved, using the learning from this report.
6. WSHFT to look at how patients are shown how to use Stoma bags and how nursing teams can support them to feel confident in fitting these when at home.
7. Healthwatch to support information gathering by the Cancer Patients Forum and Macmillan at St Richards to find out more about patients views of services and communications.
8. GPs to make sure patients, who asks for a private referral for cancer treatment, are aware that the follow-up support provided by Cancer Nurse Specialists (e.g. the services linked to NHS hospitals) may not be provided. This information is important to ensure the patient and their carers/family are fully informed when making a treatment decision.
9. GPS to make sure patients are aware of the national guidance for how long a patient should expect to wait for treatment and advise them accordingly.

PLANNED FOLLOW-UP WORK

Our engagement team are sharing this report with the groups who supported us to hear their members' voices, and we hope in turn, these groups will share the report with individuals. We will welcome any comments people and/or groups have on this work and will use this for future learning.

We are keen to go back to groups to see if their newer members can offer more positive accounts in the areas detailed in the report, and aim to revisit this project in November 2015. The subsequent findings, and an update to this work, will be published in early 2016.

Healthwatch will continue to have a dialogue with providers and commissioners to use the information in this report to influence change and challenge gaps and areas where there maybe potential for poor patient experience.



Response from Amanda Parker, WSHFT Director of Nursing

The Cancer Listening Project Draft Report was reviewed by the Lead Cancer Nurse at WSHFT and the Food and Nutrition Strategy Group. Below summarises the comments back from those groups on areas relevant to their expertise.

Food and Nutrition Strategy Group Comments:

1. **When recovering from a bowel operation some patients are under the impression they can only eat ice-cream. Whilst ice-cream is on the menu at Worthing Hospital, there is not necessarily enough for everyone in the hospital to have it. Therefore it runs out and not everyone receives it. As the patients recovering from bowel operations cannot eat from the standard menu, it would appear to make sense for them to be prioritised to receive the ice-cream or appropriate menu options are discussed and made available.**

Catering manager confirmed that Ice-Cream is available at all and any time in the Trust.

Actions:

- Matrons to be reminded at the next Heads of Nursing (HONs) that it can be requested at any time
 - Review information given to patients about what can be eaten post op.
 - Patient can request to see a Dietitian at any time regarding their diet.
2. **Patients feel communication between nurses and catering staff at Worthing Hospital is lacking. Every day the catering staff would ask patients recovering from bowel operations to select what they wanted from the menu, even though they are not allowed to eat. The patients and their family members felt very frustrated by this.**

Catering staff do not have direct access to patients, could this be Healthcare Assistants (HCA's)? The group considered it disappointing if staff asking Nil-by-Mouth patients what they want to eat.

Actions:

- Matrons to be reminded at the next HONS of the sensitivity of patients who are unable to eat for whatever reason and how distressing/frustrating this is for their patient.
 - Ensure that those patients have 1) a note on their bed-boards 2) are mentioned at handovers 3) Ensure all teams are aware.
 - Ward accreditation Matron will also follow this up as a part of ward assessment.
3. **Fortisip nutritional drinks can be in short supply in Worthing Hospital, therefore patients do not always receive them, even when they are unable to eat solid food. The drinks are on prescription and a number of individuals reported having to 'fight' to get them. One patient reported their experience had been that the MacMillan nurse had the drinks in the ward kitchen.**

All wards hold stock of Fortisip and other nutritional supplements.

Nursing staff/teams have request forms available to top up their ward supplies. Wards responsibility, normally up to 20 cartons can be bulk ordered. Stocks can also be collected directly from the kitchens (on both sites) if emergency or borrowed from other wards. Fridges should hold a minimum stock on all wards.

Actions:

- Remind Matrons next HONS
- Dietician will also remind Band 7's and Acute leads.
- Nomination of a ward staff member to ensure ward supplies kept topped up.



4. It was observed the drinks are often given to the patient warm, when they taste nicer if cold.

Patients should be offered the supplements cold but given the option to have them non-chilled as well.

Action:

- Remind Matrons at next HONS to ensure their teams are all cited on this option and confirm storage arrangements.

5. Upon being discharged, one patient had to buy their own drinks privately (for a few weeks) until they were able to get a prescription through their GP

Patients are discharged with a 7 day supply following which their GP is required to take over the responsibility of continued prescribing for this supplement.

Lead Cancer Nurse Comments:

Healthwatch were invited and attended WSHFT patient forum at St Richards Hospital (SRH) earlier this year.

6. It is correct that there is a plan is to build radiotherapy at SRH and not Worthing.
7. The chemotherapy unit at SRH is not being used to its fullest potential. WSHFT have been working with Portsmouth Hospital Trust (PHT) on this and have increased activity from half a day per week to two days over the last 2-3 year.

Action

- Further dates have been identified to meet with them to further move this forward though much relies on additional medical support that PHT needs to provide to their patients.

8. WSHFT is very unlikely to become a cancer centre in the short/medium term as this would require a lot more in the way of specialist staff and the current model of care for cancer centres and cancer units works well on the whole.
9. Space is a massive challenge and we have not currently advertised the band 4 posts at SRH due to lack of office space.

Action

- The lead cancer nurse is working with the CNSs on a solution but it is currently challenging. This action is also being addressed by the lead for facilities and estates as creating space for new staff is a broader trust issue.

10. It is not accurate to state that we have less than one nurse per tumour site, there are 9 tumour site and also cross cutting specialities such as palliative care and acute oncology. Nationally the CNS census has indicated we are a low provider of CNSs and it is true a significant proportion are single handed and therefore there is no service when they are away.

Action

- WSHFT are addressing this through a roaming CNS posts and Macmillan are keen to support 2 posts cross site.
- We are currently undertaking a review of all our CNS posts and their activity, the aim to ensure they are available for patient activity / support.
- The cancer patient forum at SRH is now called Cancer Patient Voice and we have held a recruitment drive during June to attract new staff.



Further comments relate to specific page references:

Patients are normally told about their investigations and when they may hear results. If patients opt for private treatment our CNSs do sometimes contact them but the information is obviously not held within our own records so this can be a challenge. WSHFT felt unable to comment about the waiting times for head and neck but usually we operate within national guidance and therefore 31 and 62 day targets. All CNSs at Worthing and St Richards Hospital have cards and these are usually given out.

Colonaide was initially supported and set up with our CNS at Worthing Hospital and the lead cancer nurse has fed back to the teams about patients not hearing about support groups - they usually do refer patients in.

Page 4: The Lead cancer nurse stated *'We have a dietician dedicated to cancer on both sites but they only look after certain tumour groups at the moment due to capacity. They tend to see our Upper GI and lung patients who have significant issues with weight loss.'*

Page 6: WSHFT has an acute oncology team to manage emergency admissions now during the day Monday to Friday. Our statistics indicate that radiotherapy toxicities are very rare, though there is always an on call oncologist within the cancer centres that we get advice from.

Additional Query raised:

A further query was raised regarding the access to regarding information sharing and access to blood results - trusts can arrange to see x-rays across organisations via PACS but this is currently not possible with blood results. Further information has been requested but currently this is not available due to the variety of IT systems.

Response from Clinical Commissioning Group

Coastal CCG have told us that they *"value the insight provided by the 'listening exercise" and that the report "raises a number of concerns relating to local service provision and we particularly recognise that there are recruitment issues for clinical nurse specialists (CNS) for cancer across Sussex, and this is an area that I will ensure is highlighted for discussion with my senior executives colleagues both within Sussex CCGs and provider organisations, both NHS and those in the independent sector"*.