

**Patient Experience  
Review of Cancer  
Services in  
Cumbria**

March 2015

your  
**voice**  
**counts**



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*The Furness General Oncology Department cannot be praised highly enough. The staff cannot do enough for you. Having chemotherapy there is not an unpleasant experience. Your every need is met. The staff are calm, caring and extremely professional. Any concerns are listened to and sorted out. My consultant is very thorough with explanations and gives me plenty of time to ask questions and discuss concerns and worries. I feel he does the very best he can for me within the constraints of my age and funding. I feel very 'looked after' and safe even though my prognosis is not great.*

## Executive Summary

This report provides a summary of the research findings and analysis undertaken by Healthwatch Cumbria (HWC) in relation to the delivery of cancer services in the county.

HWC has become increasingly aware of the number of public concerns regarding cancer services in Cumbria. These concerns were raised by patients and families through a variety of different means including direct contact, email and via the Independent Advocacy Service for NHS Complaints.

Healthwatch embarked on a programme of engagement and research to gain an understanding of the key concerns raised by patients and to compare performance against national targets, where available.

Whilst in most cases service provided by acute trusts is felt to be good there are certain aspects of care which are a concern, these include:

- The number of times a patient visits their GP before being referred and the time it takes for patients to receive test results. In some cases patients visited their GP 5 times before being referred to a specialist
- NICE timeframes are not being consistently met.
- Communication between acute trusts and primary care can be poor, which is sometimes exacerbated by delays in transferring medical records between services and/or sites.
- Information for patients can be inconsistent and is not always accessible to all patients.
- Ineffective communication between specialists/consultants and patients.

From patient feedback gathered it was evident that nursing staff are providing good care across main service providers/trusts. On the whole, staff show empathy and care for patients and their families.

In response to the concerns raised Healthwatch Cumbria makes the following recommendations:

1. We recommend that NHS England carry out a review of GP assessment and referral practice in line with NICE guidelines, which currently state that referrals for suspected cancer are carried out within 14 days;
2. We recommend that service providers review procedures and make necessary improvements to ensure that diagnosis is confirmed, in writing within 14 days.
3. All service providers must ensure that clinicians are encouraging health care staff to communicate the long term effects of treatment and consider the patients view on treatment options;
4. We recommend that the provision of information on complaints procedures and financial assistance is available, alongside other relevant information, and is accessible to all patients.
5. We recommend that providers of patient transport review eligibility criteria for cancer patients and ensure that the criteria applied is fair and equitable across Cumbria;
6. Clinicians should receive training and guidance to improve emotional support for patients undergoing treatment;
7. Service providers must ensure that medical records are available for all treatments appointments and consultations;
8. Service providers and commissioners should review communications between GP's and treatment clinicians to ensure that all parties involved in care pathways are updated on progress and prognosis.

HWC will be sending this report to service providers, regulators, commissioners and Healthwatch England and expect a response to the issues and recommendations raised within the statutory 20 day framework as set out in the Health and Social Care Act 2012.

## Introduction

Over the last 12 months Healthwatch Cumbria (HWC) has received intelligence from the public relating to cancer services in Cumbria. In many cases the intelligence received was positive but in some cases concerns were raised. HWC was also aware of complaints being brought against cancer service providers through the Independent Advocacy Service for NHS Complaints and through complaints received directly from the Department of Health via Healthwatch England.

The nature of complaints and concerns is varied and includes:

- Failure to diagnose;
- Late diagnosis;
- Chemotherapy being unavailable;
- Radiotherapy being unavailable locally;
- Patient records being mislaid causing delays in treatment;
- Poor coordination of services between Trusts and community services.

Whilst HWC had already received a number of patient experiences it was felt that in order to strengthen the evidence base and better understand the service area a survey would be created to capture the experiences and views of current and past patients and their families across the county and across all providers of cancer treatment and services.

As an independent statutory organisation Healthwatch Cumbria is required to present reports to service providers, regulators and commissioners, and to request a response to any recommendations within a statutory timeframe of 20 days.

HWC will make this report public and will forward to Healthwatch England, the Care Quality Committee and appropriate Council committees.

## Methodology

A survey was designed in line with the National Cancer Survey and with support from members of the Cancer Advisory Panel. The survey was available online and through hard copies which were circulated through existing HWC contacts, cancer support groups and networks throughout the County. Support was received from numerous Third sector support agencies with the preparation, and circulation, of the survey.

Visits to clinics at the Cumberland Infirmary Carlisle, West Cumberland Hospital, Furness General Hospital and Westmorland General Hospital took place over a two week period, giving patients who are currently receiving treatment an opportunity to complete the survey and share their experiences. Talking with patient's added value to the survey by providing real-time experiences and views on service provision and standards of care.

*Oncologist at the Cumberland Infirmary had no bed side manner, no compassion, was very matter of fact. However, the breast care nurse was wonderful, and available by phone if I had questions later.*

## Demographics

A total of 228 responses to the survey were received prior to the Healthwatch survey deadline of 27th October 2014. The survey responses were in addition to evidence/intelligence already presented to HWC.

The demographics show that of the respondents 63.5% were the patient and 36.5% were family members, carers or friends.

64.3% of respondents were female and 35.7% were males.

The age range of respondents was as follows:

- 2.7% were aged 18-30;
- 1.8% were aged 31-40;
- 13.1% were aged 41-50;
- 18.0% were aged 51-60;
- 30.6% were aged 61-70;
- 33.8% were aged 70+

Of those respondents 26.1% lived in Allerdale, 13.1% lived in Copeland, 25.7% lived in Carlisle, 12.2% lived in Furness, 7.7% lived in Eden, 14.4% lived in South Lakeland and 0.9% lived out of county.

Of those who responded, 54.6% of patients were currently receiving treatment, 31.7% had completed treatment but continued to be monitored and 13.8% of patients had been discharged from treatment.

*The breast care nurse at the Cumberland Infirmary was wonderful, and available by phone if I had questions later, which of course I did, once the news had sunk in.*





## Part One

### 1.1 The Referral System

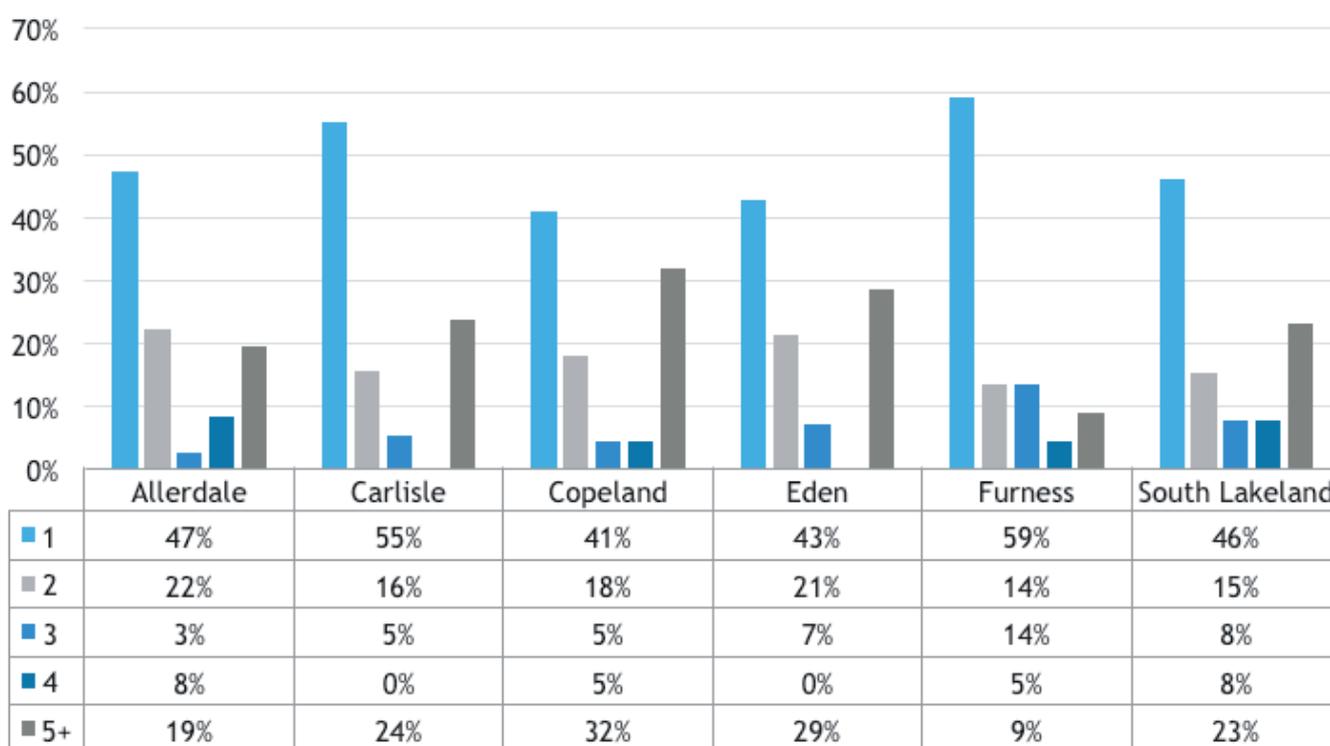
This section looks into the process and time taken from GP appointment through to referral to a cancer specialist and treatment thereafter. There are national guidelines relating to timescales from GP appointment for suspected cancer to appointment with specialist/consultants and treatment thereafter.

The national guidelines can be viewed on the NICE website and the NHS England website:

<https://www.nice.org.uk/guidance/cg27>,

<http://www.nhs.uk/conditions/cancer/Pages/Introduction.aspx>

#### 1.1 'How many times did you see your GP about your health concern, which was later diagnosed as cancer?'



For reference the NICE Referral timelines state:

#### Immediate:

an acute admission or referral occurring within a few hours, or event more quickly if necessary.

#### Urgent:

the patient is seen within the national target for urgent referrals (currently 2 weeks - 14 days)

**Non-urgent:** all other referrals

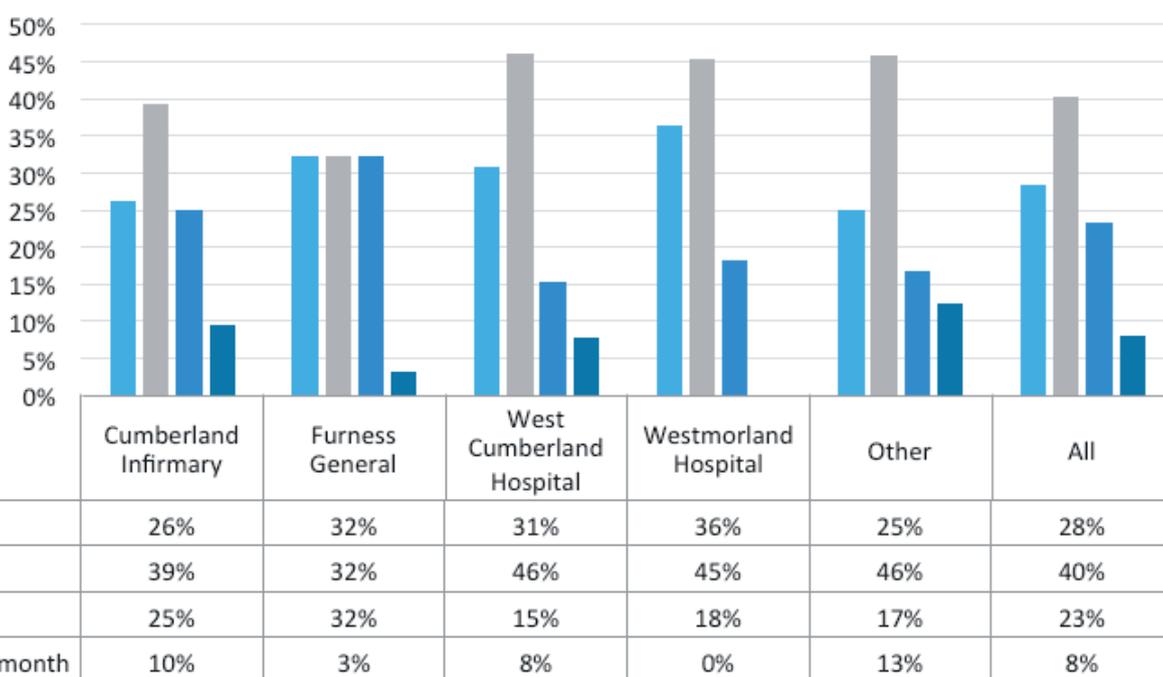
Making the decision to refer for specialist diagnosis may take some time and will depend on the symptoms presented. However, NICE guideline 1.2.14 states *'In patients with features typical of cancer, investigations in primary care should not be allowed to delay referral. In patients with less typical symptoms and signs that might, nevertheless, be due to cancer, investigations may be necessary, but should be undertaken urgently to avoid delay. If specific investigations are not readily available locally, an urgent specialist referral should be made.'*

The results demonstrate that although the majority of patients saw their GP once or twice before being referred for investigation and subsequent diagnosis, there was a significant number of patients who visited their GP up to 5 times before being referred to specialists and who were later diagnosed with cancer.

In Copeland, Eden and Carlisle the percentages of patients visiting their GP on 5 or more occasions was higher than the rest of the County and further investigation may be required to fully understand why this is the case. Patient symptoms may not have been consistent with cancer symptoms for example and time may have been allowed for symptom recovery.

That said, the evidence suggests that there could have been missed opportunities for early diagnosis, which could have had an adverse effect on the individual's recovery.

### 1.2 How long did you wait to see a specialist at the hospital?



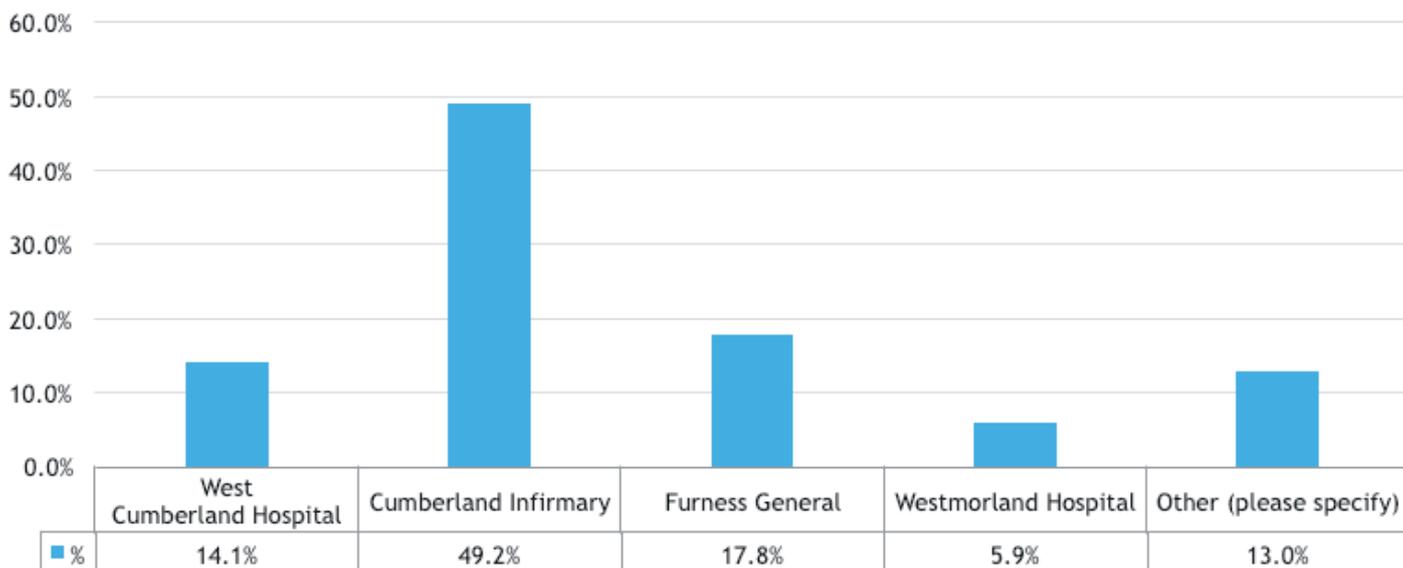
The results of this question suggests that overall 68% of respondents were seen within the 14-day target period, and 31% waited over 14 days with some patients waiting more than a month before seeing a specialist.

Of those that responded Westmorland General Hospital and West Cumberland Hospital had the highest percentages (81% & 77% respectively) of respondents seen within the 14-day target time with Furness General Hospital and Cumberland Infirmary Carlisle showing the lowest with rates of 64% & 65% respectively. It is worth noting that the NHS operational Standard for patients who are seen by a specialist within 14 days of being urgently referred for suspected cancer by their GP is 93% (2013/14 -NHS England Waiting Times for Suspected Cancer and Diagnosed Cancer Patients).

The conclusion reached in relation to the survey respondents suggests that in most cases patients were not seen by a specialist within 2 weeks/14 days. Whilst there is an appreciation that not all standards will be met for a number of reasons including the patient delays (delaying their treatment for various reasons) it is well documented that shorter waiting times can lead to earlier diagnosis, quicker treatment and improved outcomes.



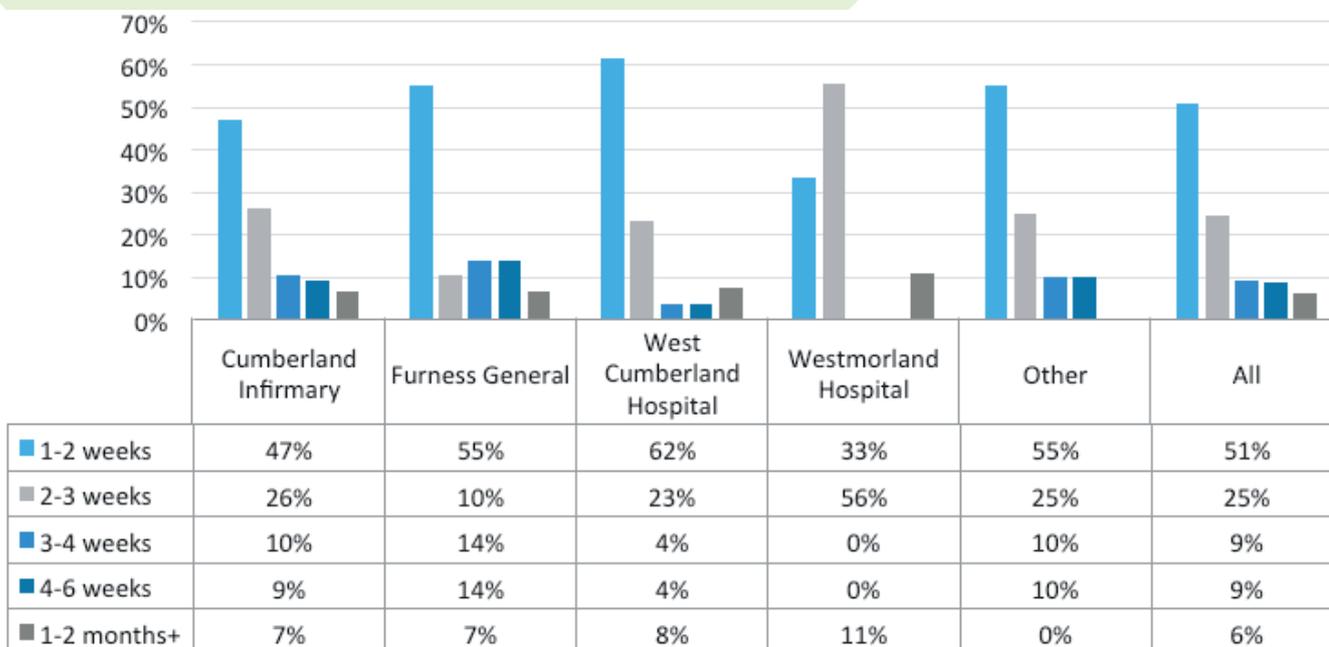
### 1.3 Which hospital were you referred to?



This graph shows that almost half of all respondents (49%) were referred to Cumberland Infirmary Carlisle and 13% were referred to “other” settings.

A significant proportion of patients are seen out of the area and this may be due to the type of cancer and where specialist treatment is unavailable within Cumbria. It is worth noting that patient who live on the border areas such as Cumbria/Lancashire may choose to receive treatment in Lancashire for example. It is also worth noting that University Hospitals Morecambe Bay Foundation Trust provide acute services in both Cumbria and Lancaster.

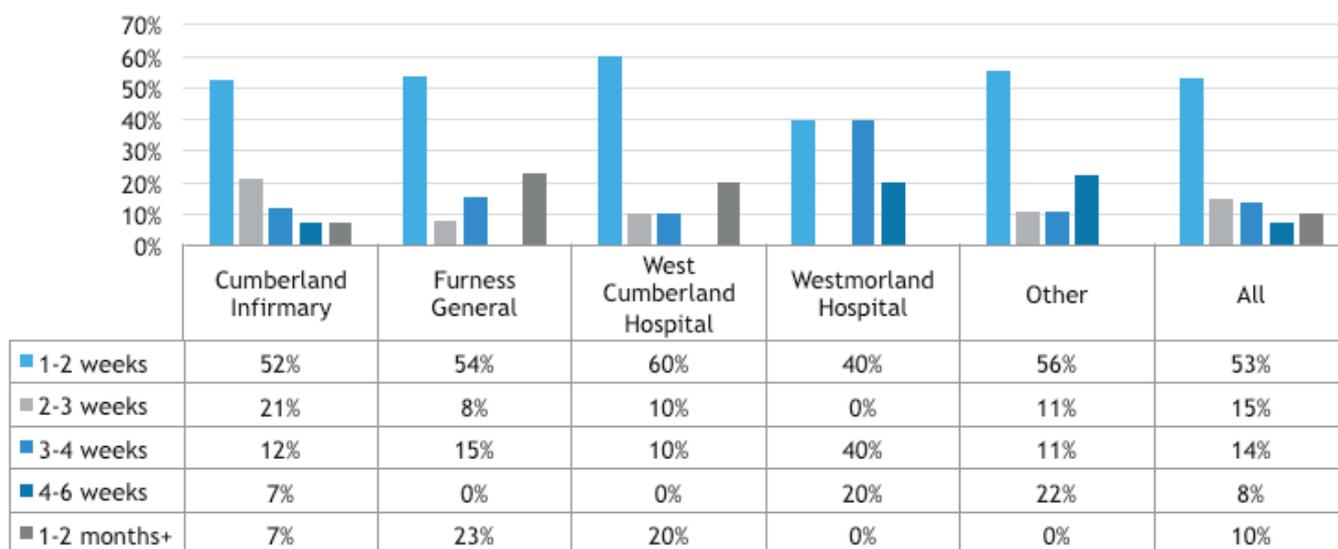
### 1.4 How long did you wait to have your diagnosis confirmed by the hospital?



Just over half of all respondents, 51%, had their diagnosis confirmed within two weeks of their first visit to the specialist.

From the respondents West Cumberland Hospital achieved the highest number of diagnosis confirmations within two weeks - 62%, Westmorland General Hospital was the lowest with 33% of respondents waiting for their diagnosis between 1-2 weeks and 56% receiving diagnosis between 2-3 weeks. Westmorland General Hospital had the highest number of respondents (11%) waiting for over a month for a diagnosis confirmation.

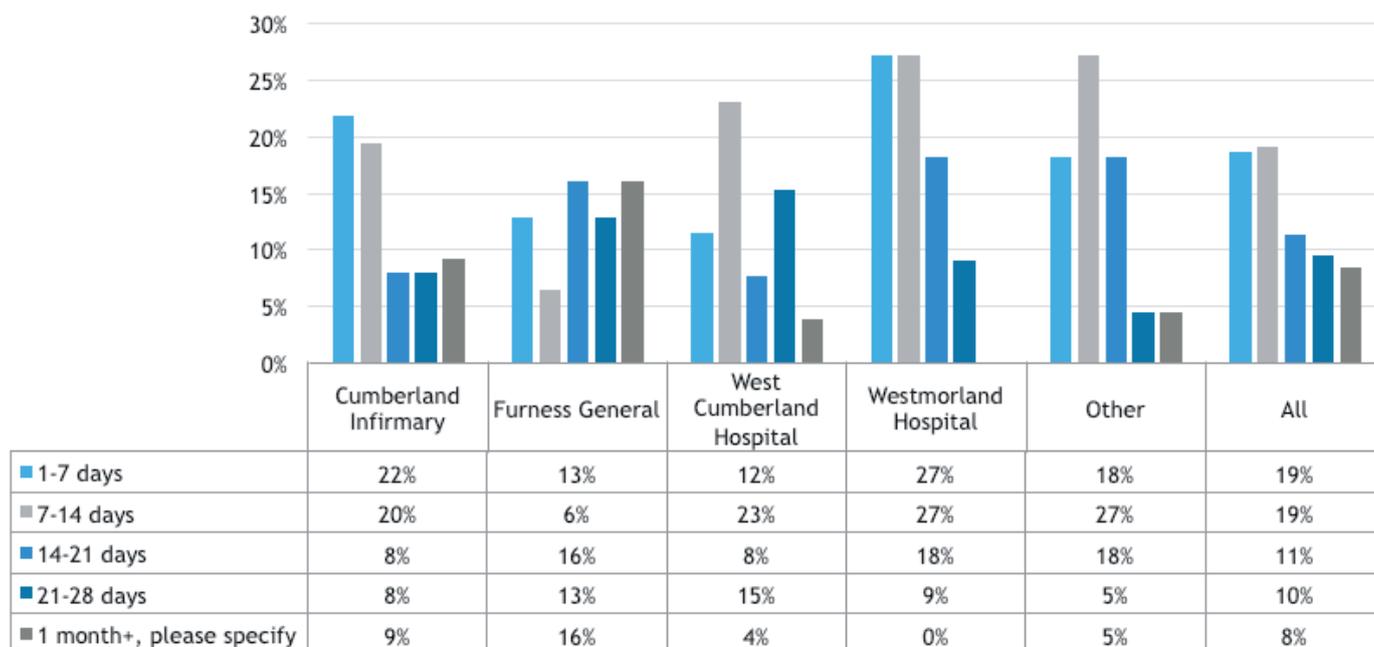
### 1.5 How long did you wait to have your diagnosis confirmed by the hospital (if you were referred to a second department)?



Of those respondents who were referred to a second specialist department, 53% received confirmation of their diagnosis within two weeks. West Cumberland Hospital confirmed diagnosis within two weeks for 60% of the respondents, whilst Westmorland did so for 40% of the respondents.

10% of all respondents had to wait over a month of confirmation, with Furness General Hospital (23%) and West Cumberland Hospital (20%) having the highest percentages. None of the respondents from Westmorland General Hospital had to wait for more than a month for diagnosis confirmation.

### 1.6 How long did you wait from the diagnosis to the decision to treat?



Overall the majority of respondents waited no longer than 28 days for the decision to treat following diagnosis, however 8% waited over 1 month for the decision to be made.

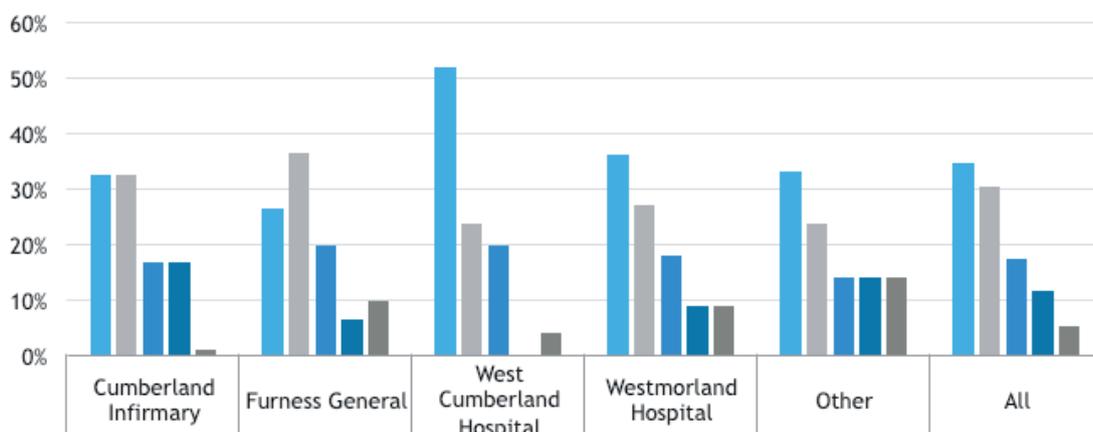


In relating to individual hospitals:

- At Cumberland Infirmary Carlisle 58% of respondents received a decision within 28 days
- At Furness General Hospital 48% of respondents received a decision within 28 days
- At West Cumberland Hospital 58% of respondents received a decision within 28 days
- At Westmorland General Hospital 81% of respondents received a decision within 28 days
- And 68% of respondents using ‘other hospitals’ received their decision within 28 days.

There is a clear disparity between patients from Westmorland General Hospital and Furness General Hospital, both operated by University Hospitals Morecambe Bay. The decision making process involves both the patient and their families and the specialist/consultant. In some cases a period of time may be required for patients to come to terms with a diagnosis, research the options and make a decision with the support of healthcare professionals.

1.7 How long did you wait from the decision to treat until treatment began?



|                            | Cumberland Infirmary | Furness General | West Cumberland Hospital | Westmorland Hospital | Other | All |
|----------------------------|----------------------|-----------------|--------------------------|----------------------|-------|-----|
| 1-2 weeks                  | 33%                  | 27%             | 52%                      | 36%                  | 33%   | 35% |
| 2-3 weeks                  | 33%                  | 37%             | 24%                      | 27%                  | 24%   | 31% |
| 3-4 weeks                  | 17%                  | 20%             | 20%                      | 18%                  | 14%   | 18% |
| 4-6 weeks                  | 17%                  | 7%              | 0%                       | 9%                   | 14%   | 12% |
| 1-2 months+, please state: | 1%                   | 10%             | 4%                       | 9%                   | 14%   | 5%  |

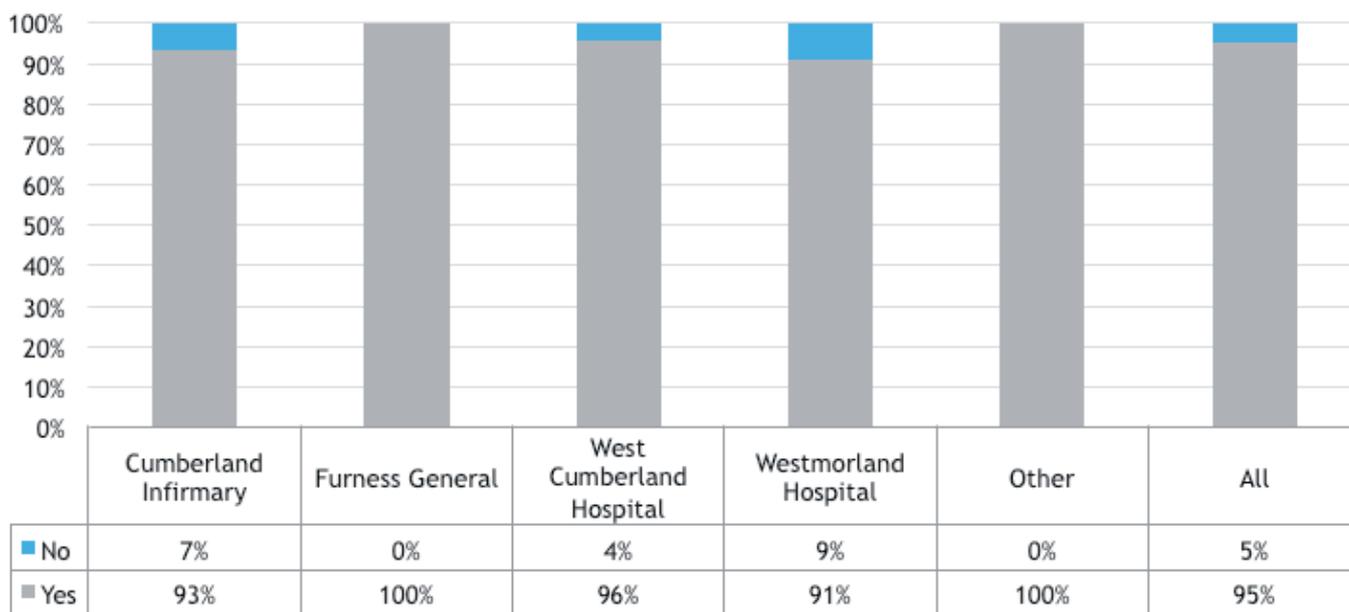
NICE guidelines and the NHS Waiting Times for Suspected and Diagnosed Cancers Patients state that there should be a maximum of 31 days between first diagnoses to the first definitive treatment to commence.

In total, 84% of respondents’ treatment commenced within four weeks of a decision being made, with 17% waiting more than 4 weeks.

- 83% of respondent at CIC started treatment within 4 weeks
- 84% of respondents at FGH started treatment within 4 weeks
- 96% of respondents at WCH started treatment within 4 weeks
- 81% of respondents at WGH started treatment within 4 weeks

The NHS Operational Standard is set at 96% of patients should commence treatment within 31 days of diagnosis. Other than for respondents at West Cumberland Hospital (96%), the remainder of respondents did not receive treatment within 31 days.

1.8 Were you told the results of the tests in a way you could understand?



The National Cancer Patient Experience Survey 2012/13 (Question 9) shows that the national average for patients who felt they were informed in a way that they could understand is 78%.

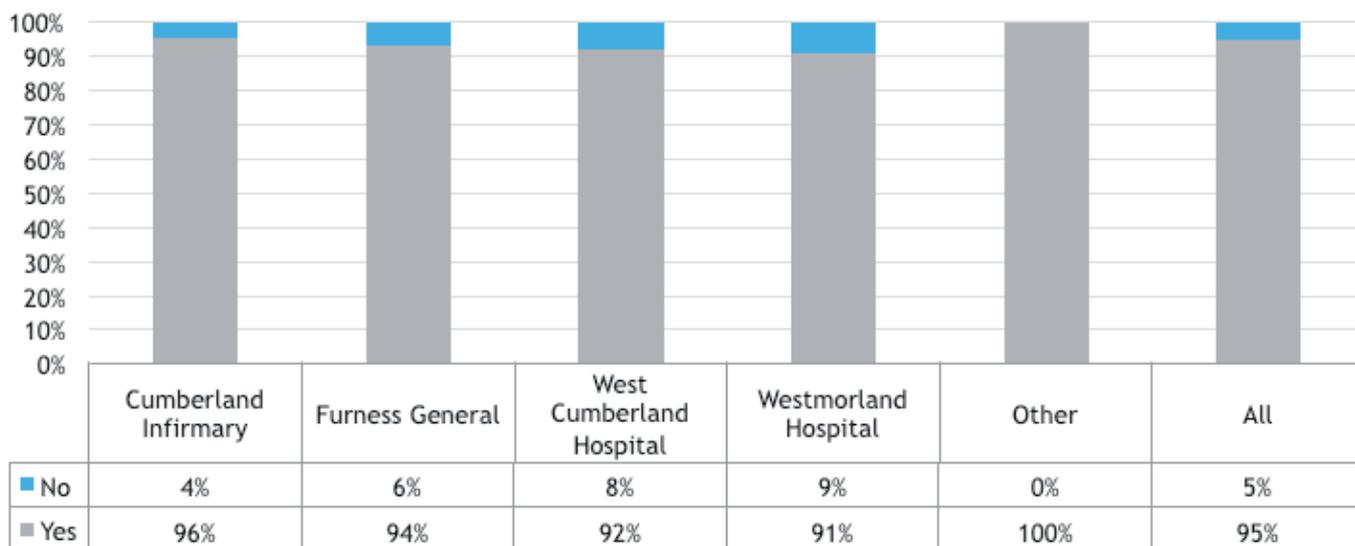
Of the respondents who took part in this survey 95% were informed of test results in a way that they could understand, with 100% of respondents treated at Furness General Hospital and Other settings (out of County hospitals) understanding the way test results were explained. This demonstrates that patient communication needs are considered and staff show respect, dignity and compassion when communicating with patients

*My surgery was carried out promptly and efficiently. The Oncology Department at Furness General have always been polite, helpful and highly professional.*





### 1.9 Were you given the opportunity to be accompanied when you were informed of the results/prognosis?

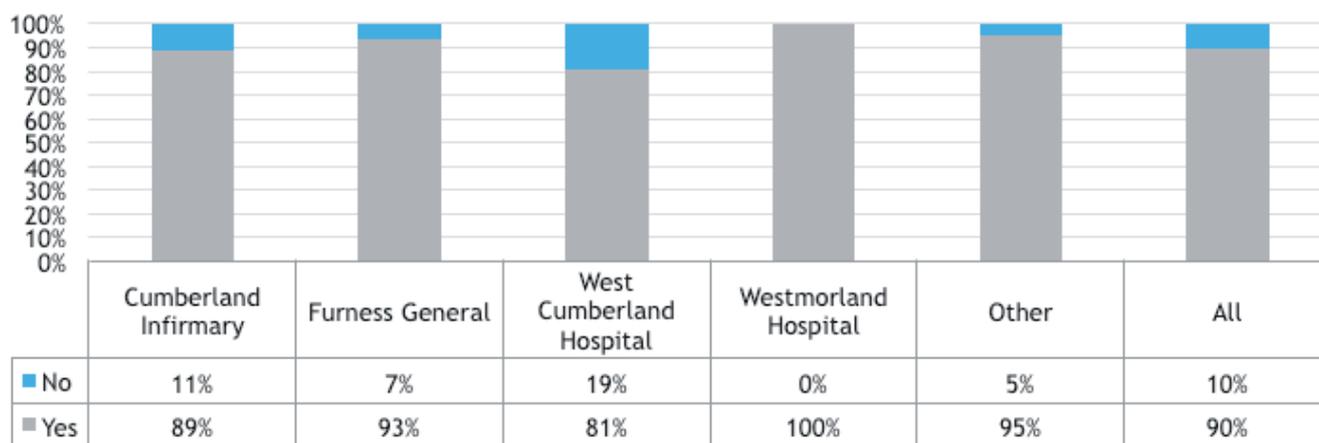


The National Cancer Patient Experience Survey 2012/13 (Question 11) shows that the national average for this question was 74%

95% of respondents from Cumbrian Hospitals were given the opportunity to be accompanied when they were informed of the results/prognosis.

Whilst the majority of patients were given the opportunity to be accompanied when they were informed of diagnosis/prognosis there remains a small percentage across all hospitals that were not given this opportunity. There may be a need to review policies at each Trust to ensure that ALL patients receive the same opportunities.

### 1.10 Do you feel you were told in a sensitive manner?



The National Cancer Patient Experience Survey 2012/13 (Question 12) shows that the national average for this question was 84%

90% of respondents from Cumbrian Hospitals felt they were informed of the results in a sensitive manner. In most cases hospitals perform well against this standard however West Cumberland Hospital had 19% of respondents who felt their results had not been told in a sensitive manner. Staff should be aware of the importance of communicating appropriately and taking into consideration the needs of all patients.

## 1.2 The Referral System - Key Issues

- There is a clear disparity between the number of times a respondent visited their GP prior to being diagnosed;
- Only 68% of respondents were seen by a specialist within the NICE Guidelines of 14 days;
- Half of all respondents had to wait more than two weeks for a diagnosis confirmation, after visiting a specialist;
- In relation to the people who took part in this survey most were not treated within the national 31-day timescale;
- The provision of information and communication throughout the referral system appeared to be appreciated by the respondents.

*I have had excellent treatment from all departments at the Cumberland Infirmary and I can't praise the staff enough.*

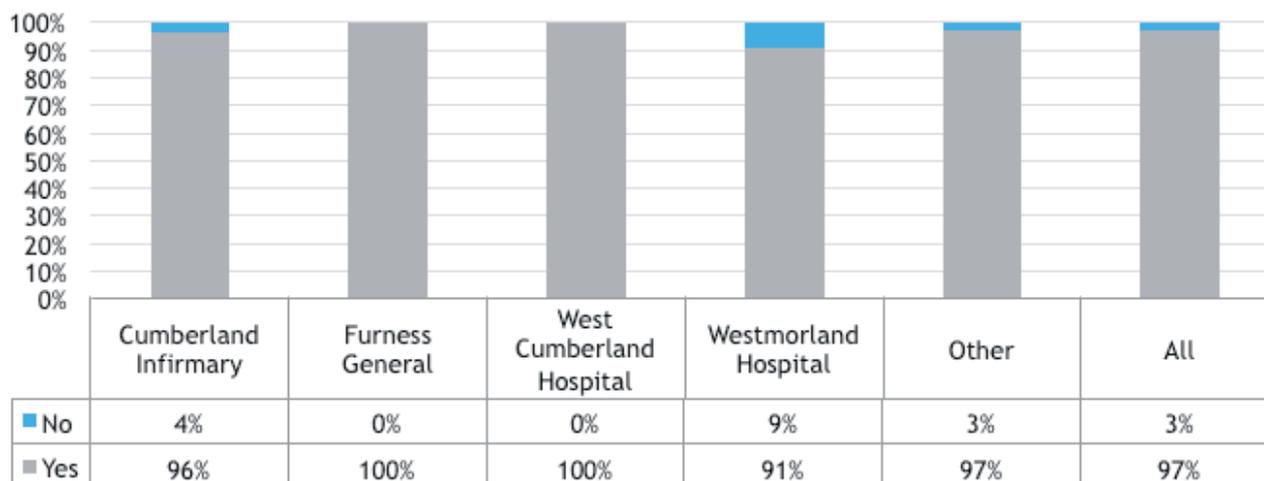


## Part Two

### Treatment

This section focuses on treatment provided by 4 acute hospitals in Cumbria, the results also include 'other' out of county service which are unnamed.

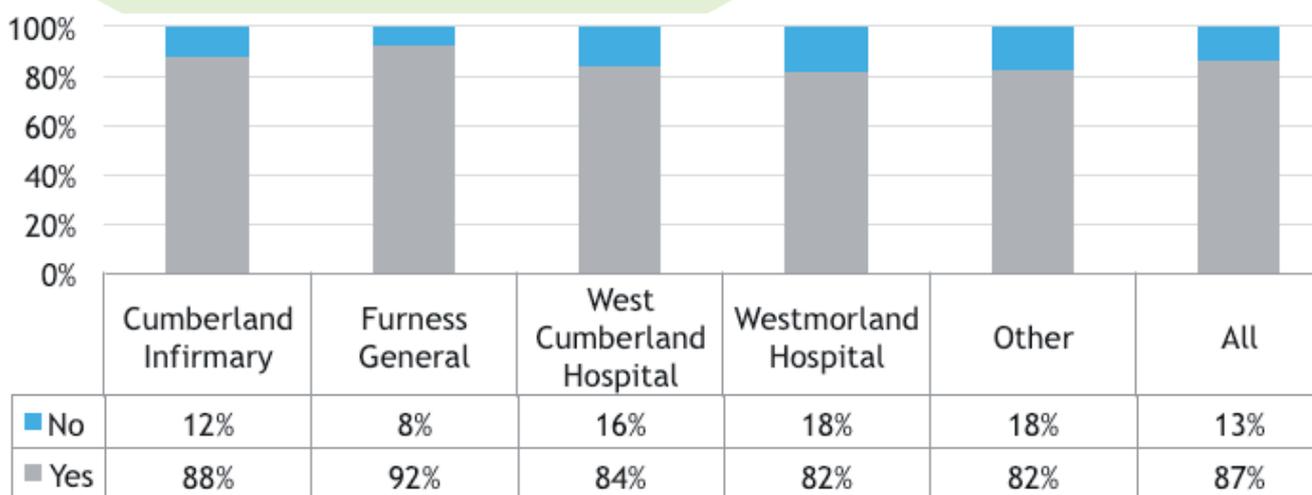
#### 2.1 Were you given information about your illness/treatment?



Question 14 of The National Cancer Patient Experience Survey 2012/13 asks “Patient given written information about the cancer they had”, and shows that the national average for this question was 71%

Overall 97% of all respondents were given information about their illness/treatment, this figure is 26% above the national average.

#### 2.2 Were you informed about the different types of treatment?

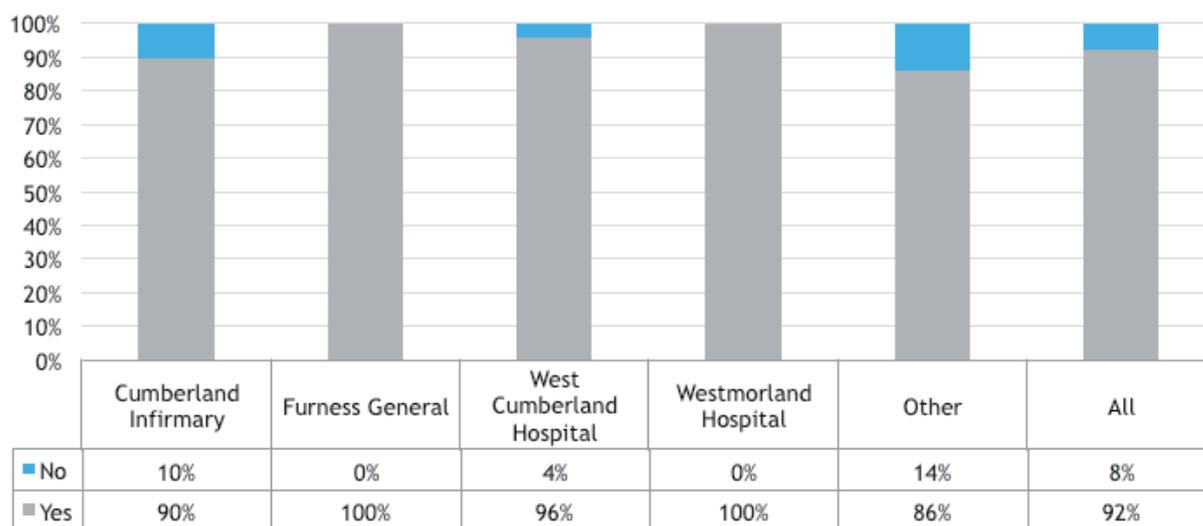


The National Cancer Patient Experience Survey 2012/13 (Question 15) shows that the national average for this question was 85%.

87% of all respondents to this survey were informed about the different types of treatment available, this is 2% above the national average.

The spread across all hospitals was similar. This may be due to the nature and severity of some conditions being treatable by one type of treatment only, meaning effectively no choice was available for the patient.

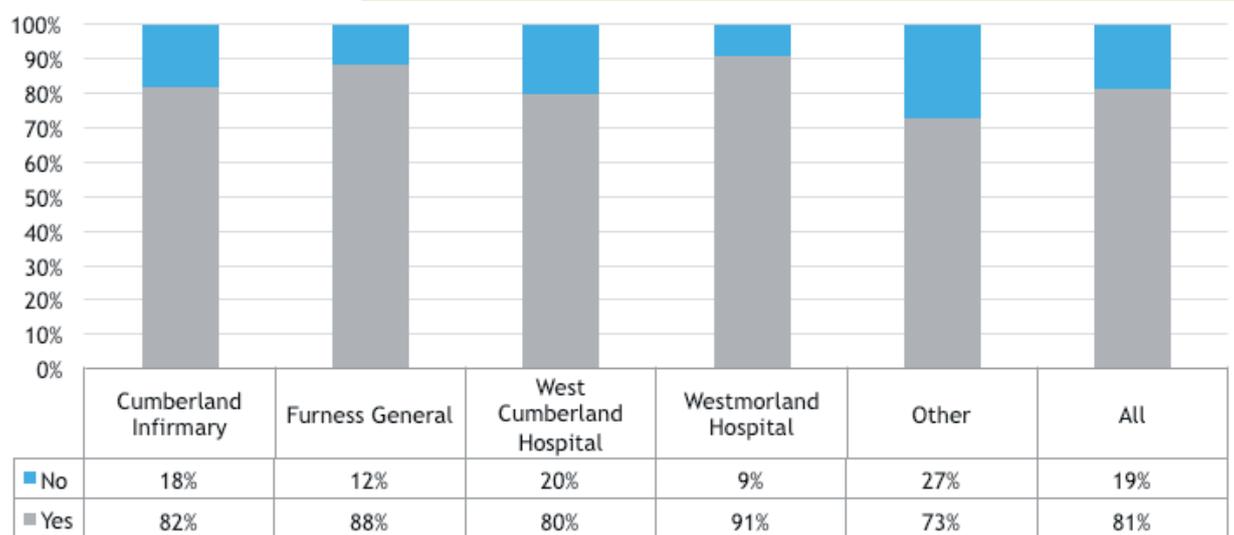
### 2.3 Do you feel your views were taken into account when discussing treatment?



Overall 92% of respondents felt their views were taken into account when discussing treatment, which exceeds national standards.

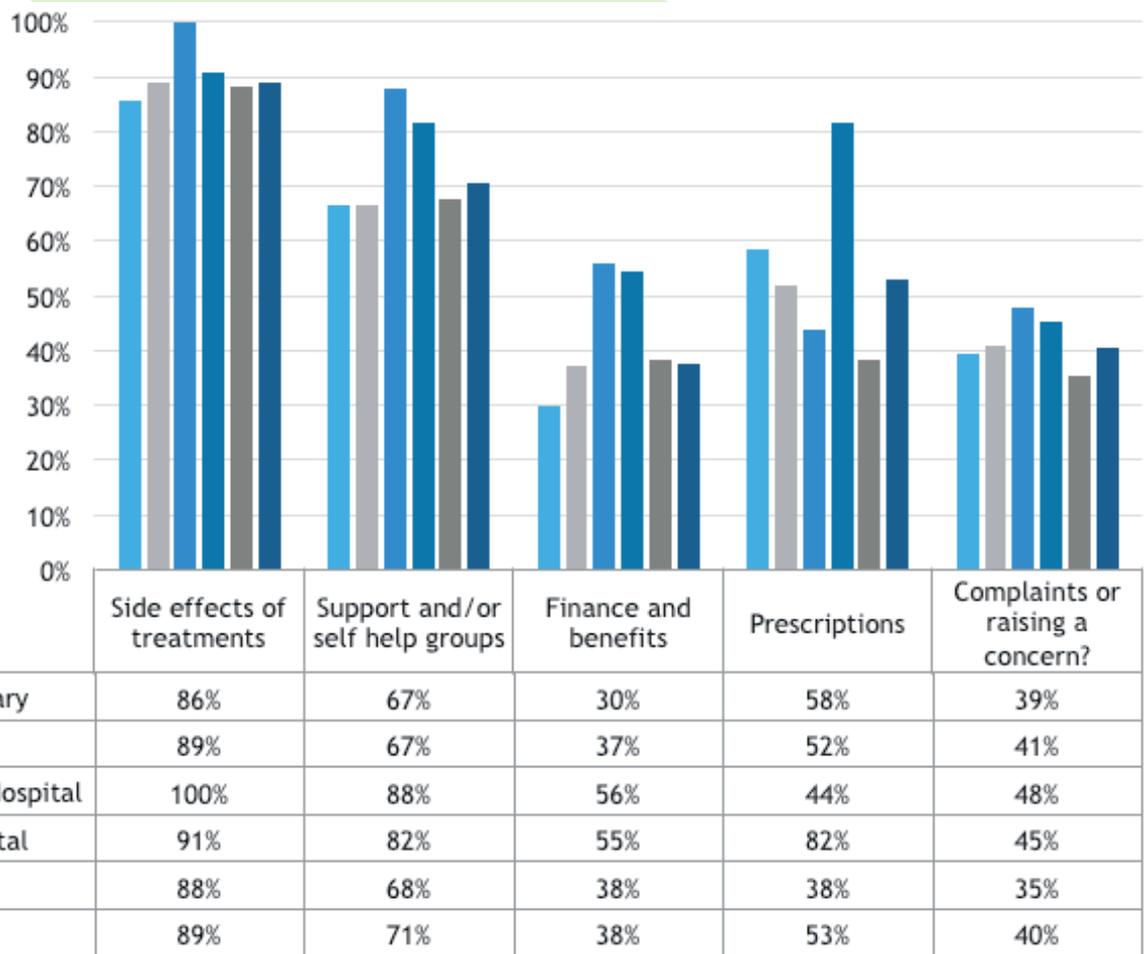
The highest number of respondents that did not feel this was the case were those treated at other settings (out of County hospitals), followed by Cumberland Infirmary Carlisle with 10%. These two figures are significant when considering the need for patient (or carer) inclusion in treatment planning.

### 2.4 Were you made aware of the long term effects of the treatment?



In the main respondents felt that the long term effects of treatment were explained to them. Whilst the majority of patients responded positively it is clear that there are still a number of patients who may not be receiving information in a way that is appropriate to their needs.

2.5 Were you given written information or was information available about the following 5 areas?



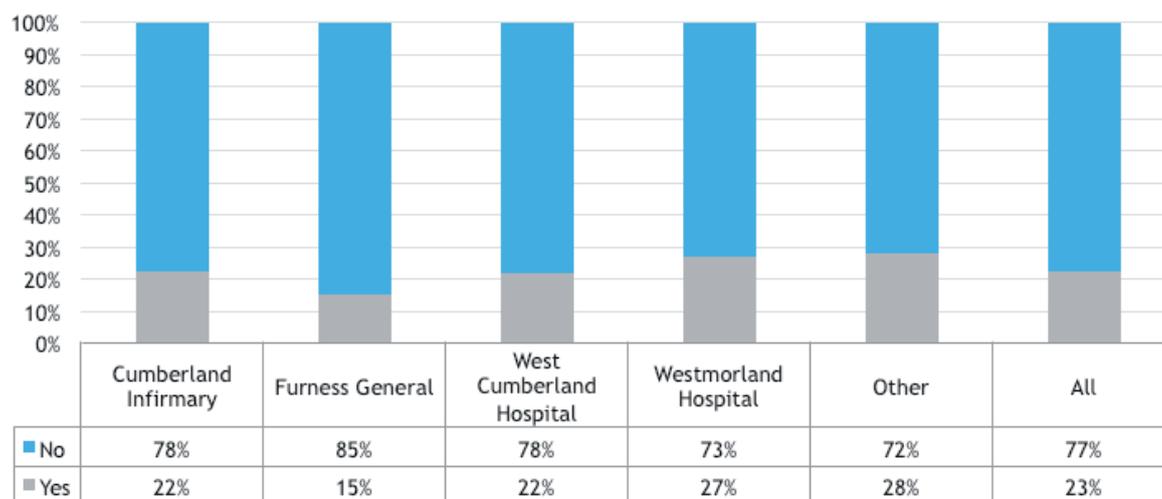
The results to this question suggest that respondents taking part felt that they had received information on side effects of their treatment, however the results vary in relation to other information provided.

According to the survey results little information is provided on finance and benefits and on how to make a complaint or raise concerns. Information on prescriptions appears to be provided but is not consistent across all hospitals. Some hospitals are clearly more proactive at providing certain types of information than others.

Steps should be taken to ensure that ALL patients are provided with the same level of information in an accessible way, which meets patient needs.

*Experience at the Cumberland Infirmary X Ray Dept/radiotherapy was poor. No explanation and no letters were sent for some of the three monthly check ups or annual mammogram. Had to ring on own initiative. Follow up correspondence not sent.*

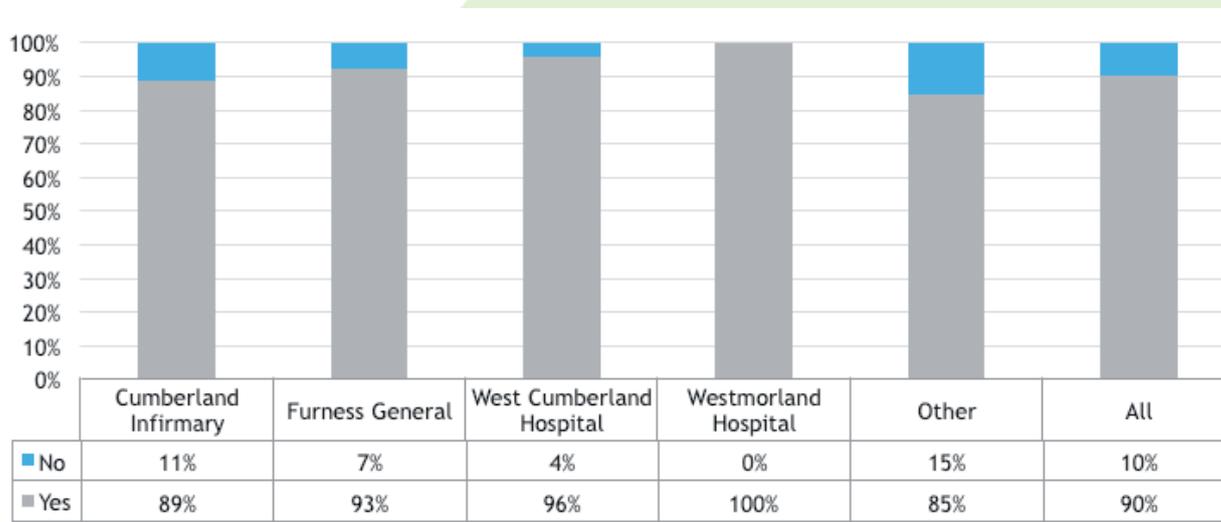
## 2.6 Have you ever been given conflicting information?



23% of respondents felt that they were given conflicting information at some point during treatment, this figure is more than double that of the national average (11%).

Patients treated out of county received the highest level of conflicting information at 28%

## 2.7 Do you feel you have been treated with respect and dignity?



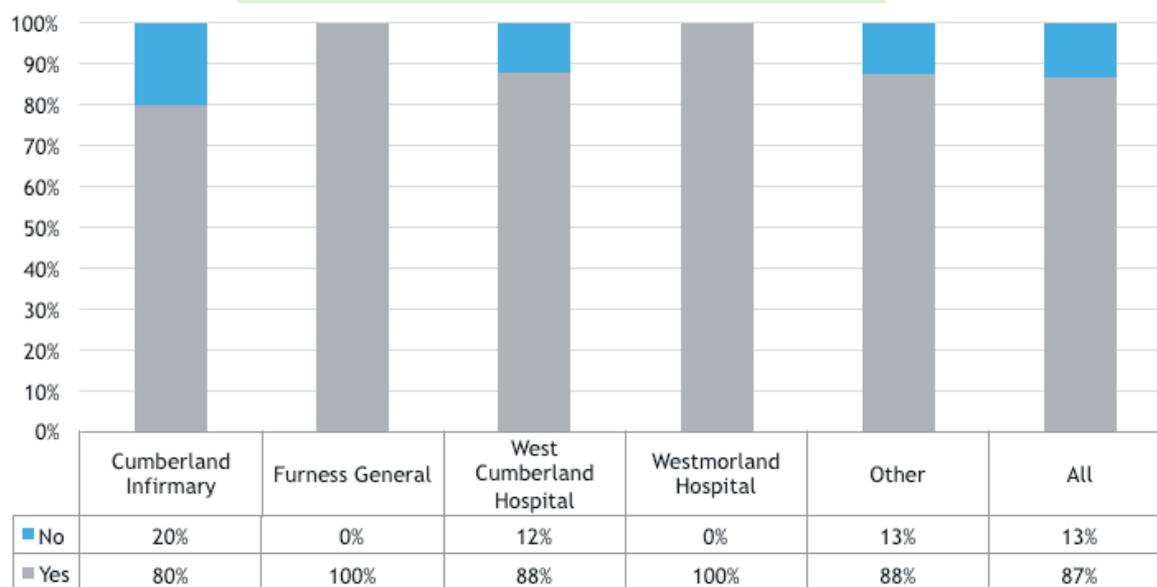
The National Cancer Patient Experience Survey 2012/13 (Question 52) shows that the national average for this question was 83%.

90% of all Cumbrian respondents felt that they had been treated with dignity and respect during their treatment exceeding the national average by 7%.

*We were told the diagnosis at Furness General in a cold empty examination action room where we had waited for nearly an hour.*



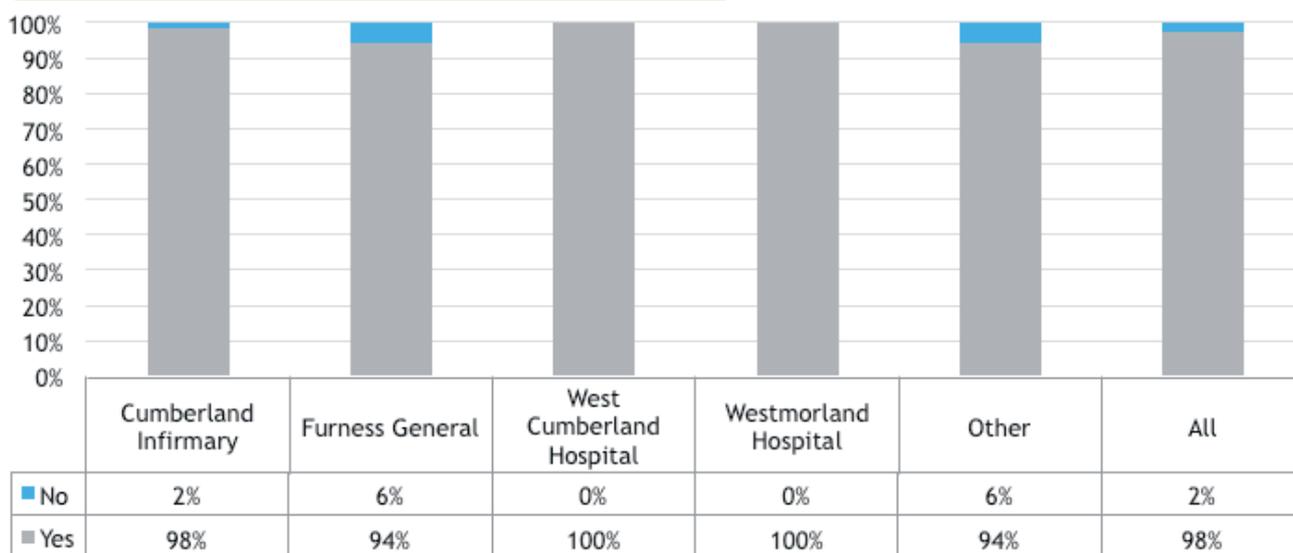
### 2.8 Do you feel you have been supported with pain relief and self-management of your illness, if required?



The National Cancer Patient Experience Survey 2012/13 (Question 51) shows that the national average for this question was 85%.

Overall 87% respondents felt they had been supported with pain relief and self-management of their illness, which is slightly above the national average. One in five respondents treated at Cumberland Infirmary felt that they were not supported, whilst 100% of respondents treated at Furness General and Westmoreland General Hospitals felt adequately supported.

### 2.9 Do you feel that staff do everything they can to control the side effects of chemotherapy/radiotherapy?

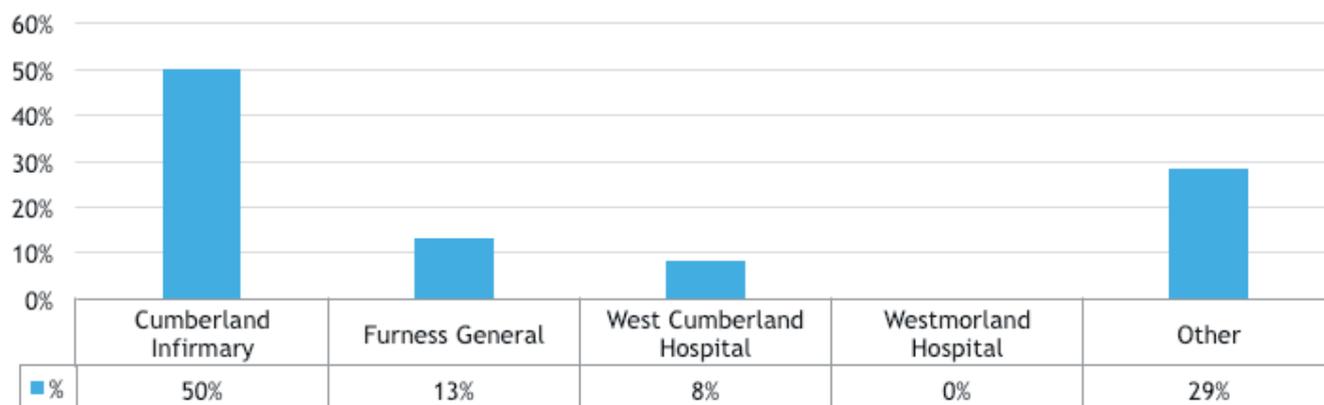


The National Cancer Patient Experience Survey 2012/13 (Question 57) shows that the national average for this question regarding radiotherapy was 79%.

The National Cancer Patient Experience Survey 2012/13 (Question 58) shows that the national average for this question with regard to chemotherapy was 81%

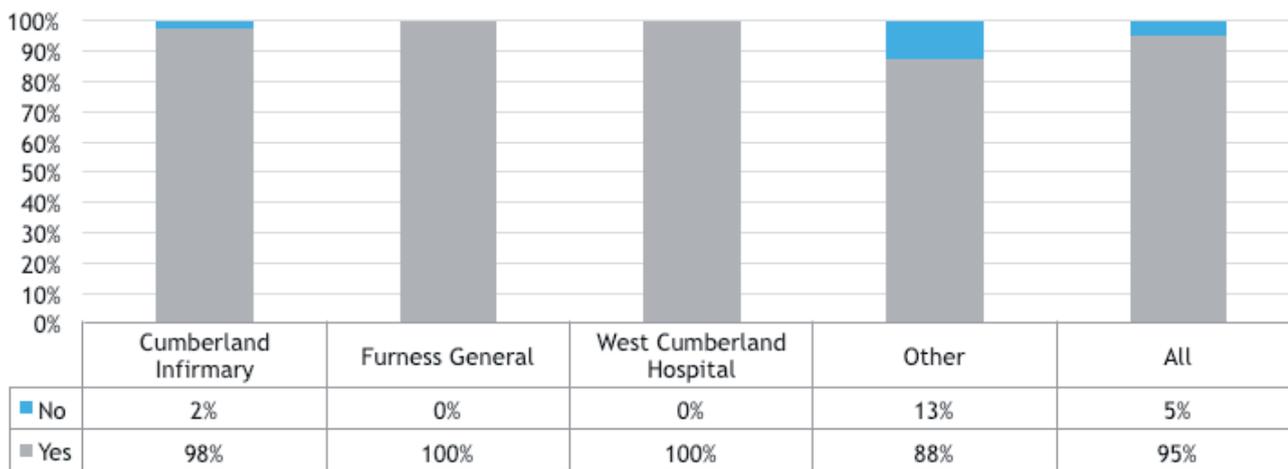
Although we cannot make a direct comparison as the two treatments were combined in our survey question, 98% of all respondents felt that staff did everything they could to control the side effects of the treatment, a figure much higher than the national averages.

### 2.10 At which hospital did you receive surgery?



Of those respondents who received surgery, half were operated on at Cumberland Infirmary, Carlisle, whilst 29% of surgeries were performed at other settings (out of County hospitals).

### 2.11 Were you given information about the surgery beforehand?



The National Cancer Patient Experience Survey 2012/13 (Question 33) shows that the national average for this question was 87%.

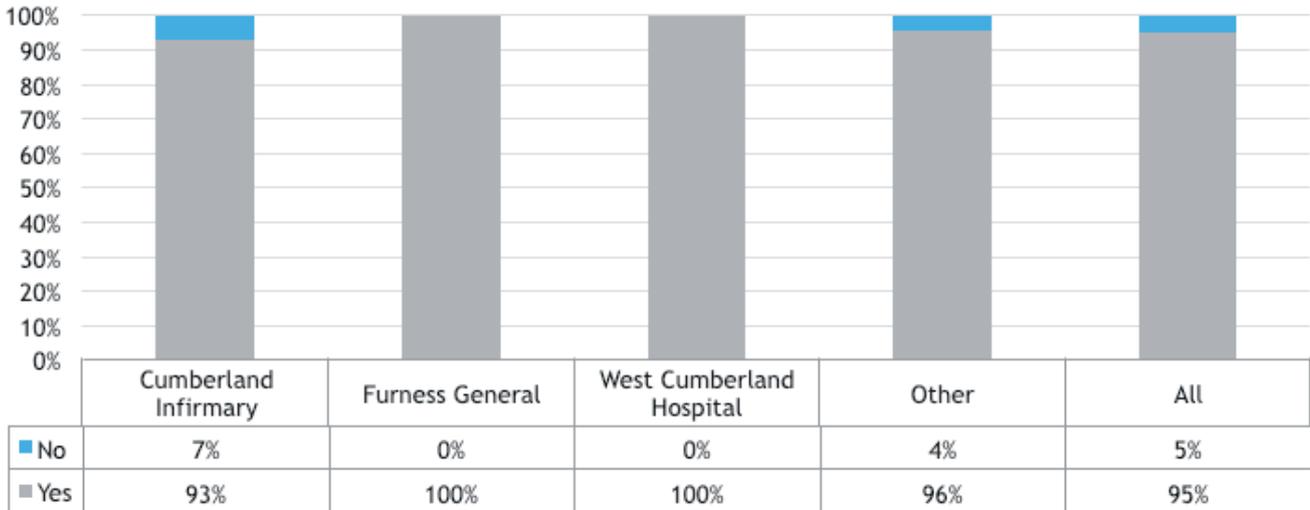
This question was in relation to those patients who had required surgery during the course of their treatment and therefore could have received surgery for a variety of reasons in relation to their cancer.

95% of those respondents who had surgery were given information prior to their operation, however 13% at 'other settings' (out of County hospitals) were not. Again the Cumbrian hospitals score highly with regard to the communication of information to the patient.

*Our biggest issue the Cumberland Infirmary is the waiting time after a scan for results whilst treatment is ongoing. Although we already know what the illness is having to wait to find out if treatment is working or helping just isn't acceptable.*



### 2.12 Were the results of the surgery discussed with you?



The National Cancer Patient Experience Survey 2012/13 (Question 35) shows that the national average for this question was 77%.

Overall post-surgery results were discussed with 95% of respondents, which is 18% above the national average.

Although this question was specific to the Healthwatch Cancer Survey, the National Cancer Patient Experience Survey 2012/13 (Question 20) shows that NCUHT scores 3% lower than the national average and UHMB scores 3% higher.

## 2.2 Treatment - Key Issues

The results from the treatment section of the survey suggest:

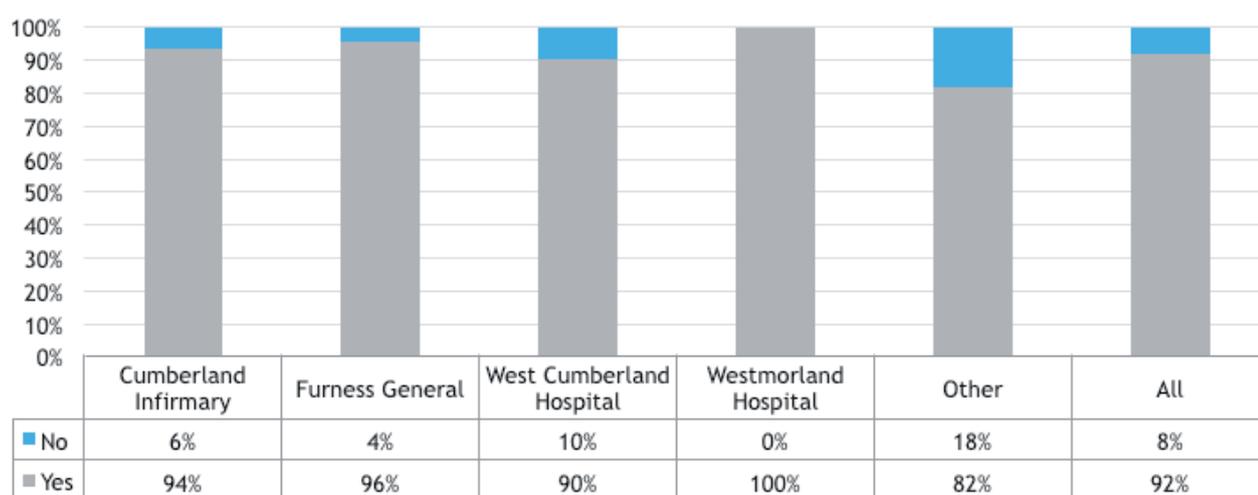
- The respondents who lived in South Lakeland did the most travelling to Other settings (out of County hospitals);
- Those respondents from Carlisle, Eden and Furness Districts were mostly treated at their nearest Acute Hospitals;
- The use of NHS sponsored transport differed significantly depending upon which setting the respondent was being treated at;
- Nearly one in ten respondents felt their views were not taken into account when discussing treatment;
- Nearly one in five respondents were not made aware of the long term effects of their treatment;
- Fewer than half of respondents received written information on the Service Provider’s complaints procedures and financial support available;
- Just under one in five of all respondents felt there were insufficient staff available to care for them whilst undergoing treatment;
- The responses on pain relief and self-management vary significantly from setting to setting;
- Nearly all respondents felt that staff did everything they could to control the side effects of the treatment.

## Part Three

### Outpatient Appointments

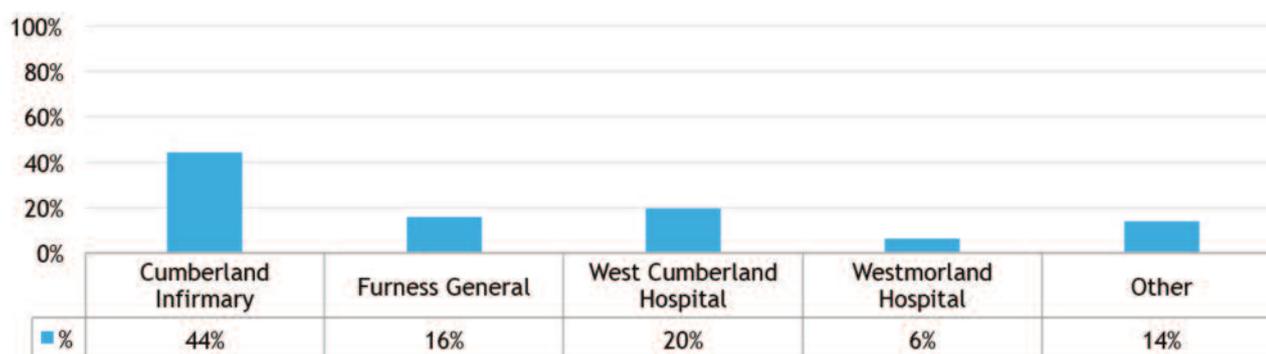
This section looks at outpatient appointments and services provided at each hospital. Outpatient appointments may be necessary for therapy and/or specialist appointments where a stay in hospital is not required.

#### 3.0 Did the healthcare staff check that you fully understood any instructions regarding follow up care/medication?



92% of the respondents said that healthcare staff checked that the patient fully understood medication and follow up care instructions. However, one in ten respondents treated at West Cumberland Hospital felt that staff had not checked their understanding of instructions or follow-up care.

#### 3.1 Where was the outpatient clinic?

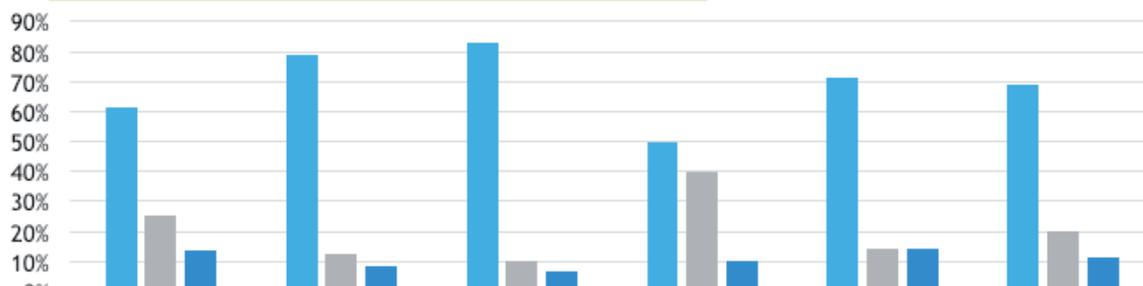


44% of all respondents attended outpatient clinics at Cumberland Infirmary, Carlisle. Whilst 14% attended clinics in other settings (out of County hospitals).

Possible explanations for the higher number of respondents attending outpatient clinics at the Cumberland Infirmary could be because more operations are carried out at there (50% as shown in graph 3.0). Furthermore NCUHT consultants may only offer clinics at Cumberland Infirmary Carlisle and not at West Cumberland Hospital.



### 3.2 Do you feel your emotional needs have been met by the clinical staff?

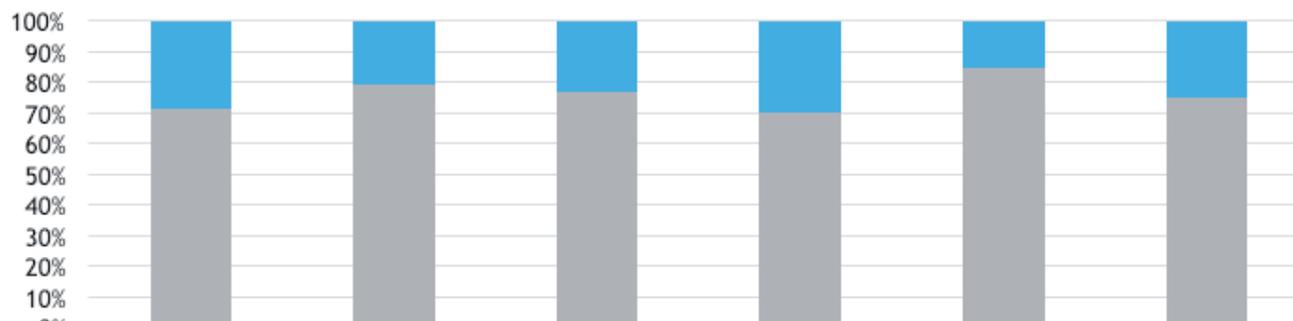


|                     | Cumberland Infirmary | Furness General | West Cumberland Hospital | Westmorland Hospital | Other | All |
|---------------------|----------------------|-----------------|--------------------------|----------------------|-------|-----|
| Extremely well/well | 61%                  | 79%             | 83%                      | 50%                  | 71%   | 69% |
| Adequately          | 25%                  | 13%             | 10%                      | 40%                  | 14%   | 20% |
| Not at all          | 13%                  | 8%              | 7%                       | 10%                  | 14%   | 11% |

The National Cancer Patient Experience Survey 2012/13 (Question 60) shows that the national average for this question was 70%.

69% of all respondents felt their emotional needs were met by the clinical staff who treated them. However, one in ten felt that their emotional needs were not at all met by the clinical staff. This could be because the Healthwatch survey provided a third response option of “adequate” which the National Patient Cancer Experience Survey did not. This would provide another option for those respondents who felt they were not in a position to give a definite yes/no response. However, overall there is a significant number of patients whose emotional needs are not being fully met.

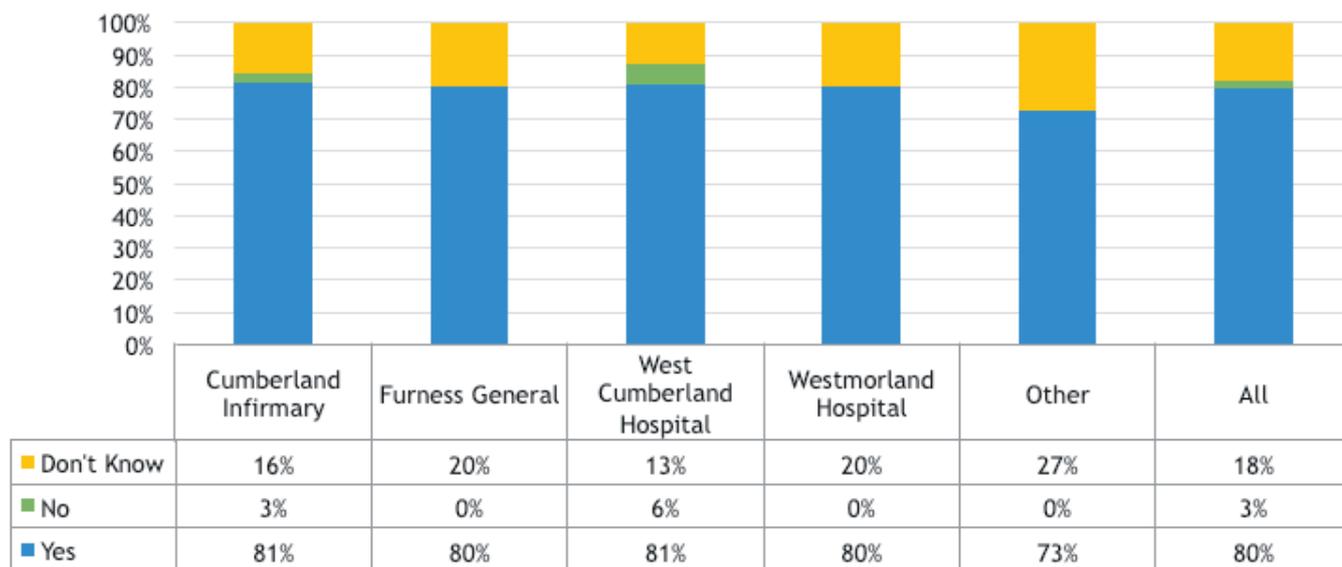
### 3.3 Have the clinical staff always had the necessary medical details available to them for your appointment?



|     | Cumberland Infirmary | Furness General | West Cumberland Hospital | Westmorland Hospital | Other | All |
|-----|----------------------|-----------------|--------------------------|----------------------|-------|-----|
| No  | 29%                  | 21%             | 23%                      | 30%                  | 15%   | 25% |
| Yes | 71%                  | 79%             | 77%                      | 70%                  | 85%   | 75% |

The National Cancer Patient Experience Survey 2012/13 (Question 62) shows that the national average for this question was 96%. Hospitals in Cumbria scored an overall figure of 75% and failed to reach 80% across all Trusts. We are aware that some Trusts are centralising records and some are using more IT systems for patient records. It is hoped that with the introduction of more robust administrative systems will reduce delays and eliminate ‘lost / missing notes’.

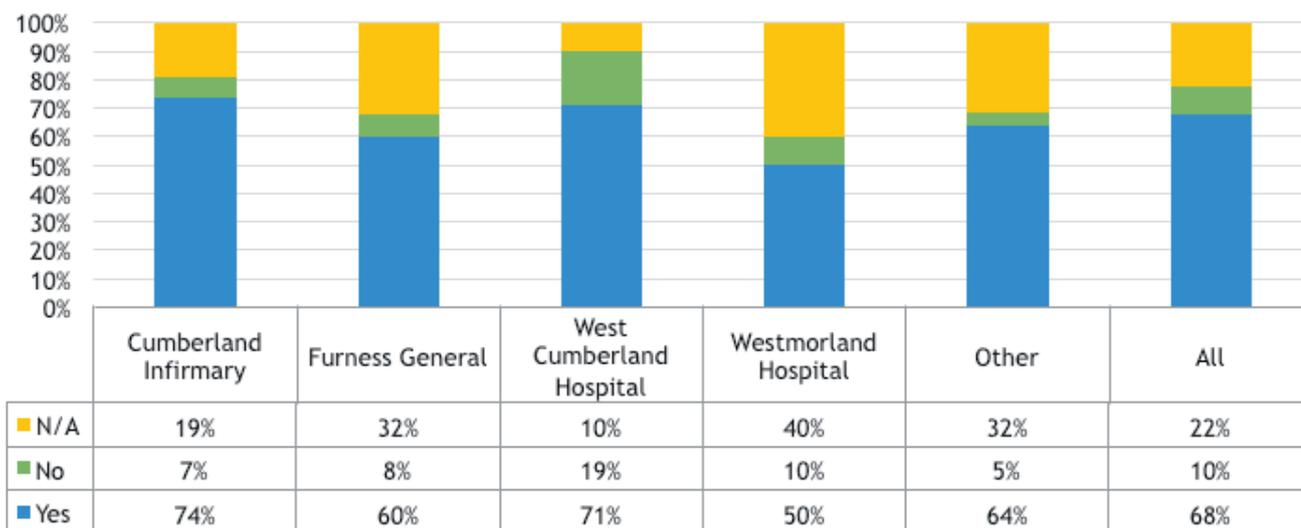
### 3.4 Do you know if your GP has been given information about your condition from the hospital?



The National Cancer Patient Experience Survey 2012/13 (Question 63) shows that the national average for this question was 95%.

80% of all respondents knew that their GP had been given information of their condition, however 3% said the GP had not and 18% did not know. These figures were reflected across the settings. This raises a question about GP follow-up appointments and whether appointments are being provided for patients. For respondents answering 'don't know or no' it would suggest that they have not seen their GP following cancer related treatment.

### 3.5 Has your GP been helpful/supportive to you during your treatment

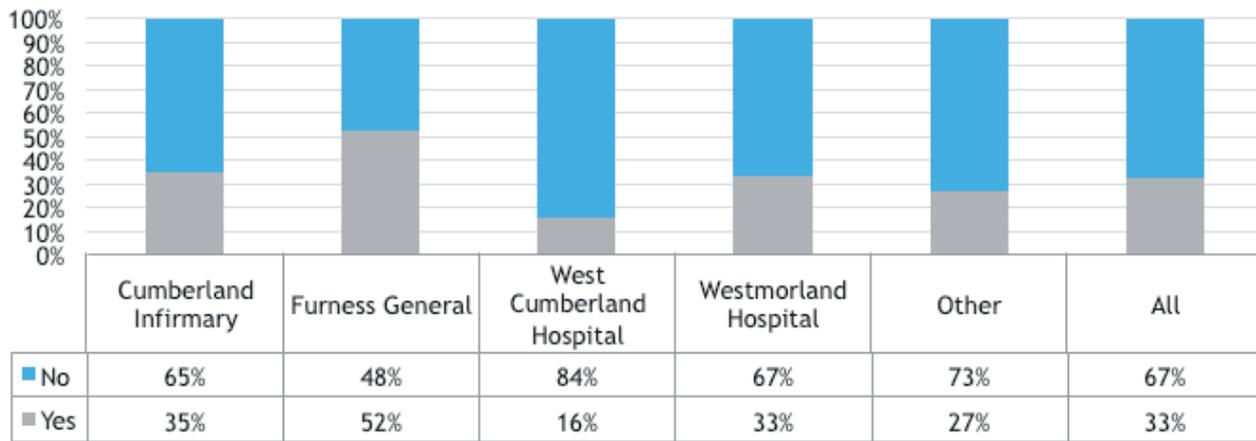


The National Cancer Patient Experience Survey 2012/13 (Question 64 - is phrased "practice staff" not just the GP) shows that the national average for this question was 68%

10% of all respondents felt that their GP had not been helpful or supportive during their treatment, with only 50% of those treated at Westmorland General Hospital feeling that the GP had been helpful or supportive.

Due to the nature of some cancers some patients may not have required follow up treatment/support from their GP which may account for the 22% of respondents who answered N/A. Although the overall figure is the same as the national average the disparity between the Cumbrian hospitals is vast 24% between Westmorland and Cumberland Infirmary.

### 3.6 Have you been provided with a written care plan?



The National Cancer Patient Experience Survey 2012/13 (Question 68) shows that the national average for this question was 22%.

Overall 33% of respondents in Cumbria were provided with a written care plan which is, although low, still higher than the national average. Considering each hospital individually the results are quite poor with West Cumberland Hospital provided the fewest care plans - 84% of respondents.

HWC is aware from discussions with patients that terminology may occasionally cause confusion, some patients said they have been given treatment plans and some referred to care plans but overall there was little recognition of what a care plan is and why it may be provided for patients.

### 3.2 Outpatient Appointments - Key Issues

The results from the treatment section of the survey suggest:

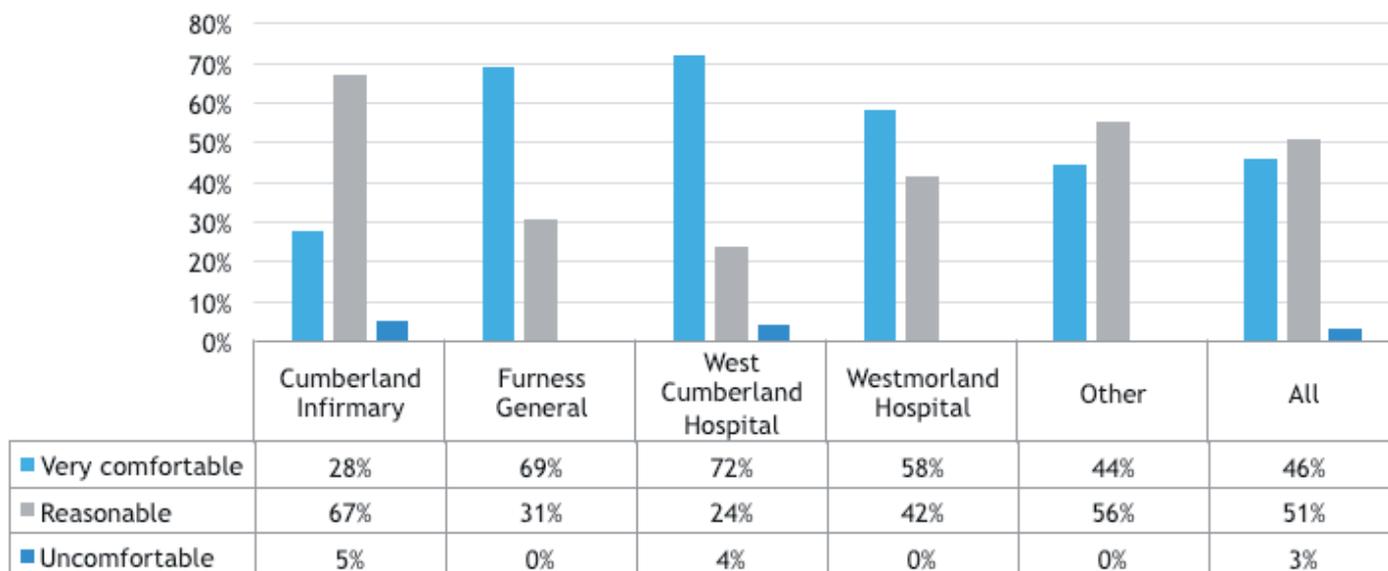
- One in ten respondents felt that their emotional needs were not at all met by the clinical staff;
- Patients rely upon their own family and friends for emotional support, Nearly three quarters of
- The availability of medical records at appointments appears to be an issue, as a quarter of all respondents reported that clinicians did not always have the necessary medical details available to them for the patient’s appointment ;
- Communication between the Trusts and the respondent’s GP during treatment was also an issue, with only eight out of ten respondents aware that their GP had been given information of their condition, however 3% said the GP had not and 18% did not know;
- Support from the respondents GP during treatment was not forthcoming either, with one in ten respondents feeling that their GP had not been helpful or supportive during their treatment;
- Care plans are not being provided to patients going through Cancer treatment, as a matter of course, with only a third of respondents receiving one.

## Part Four

### Environment and Facilities

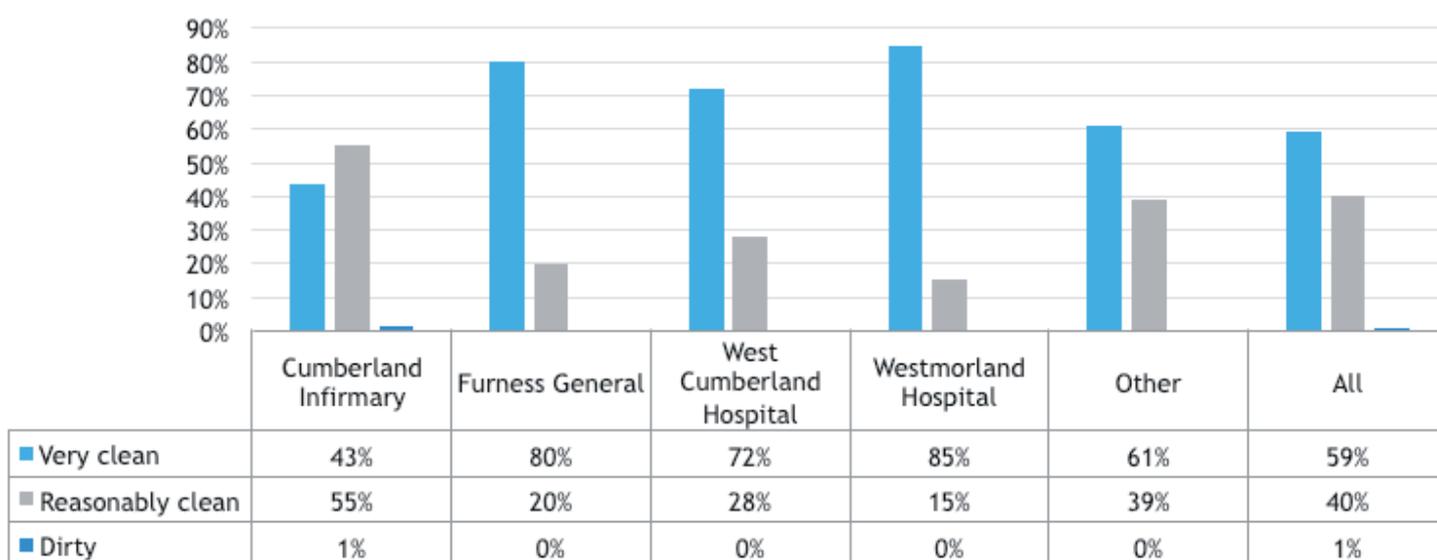
This section looks at the surroundings and facilities provided for patients at each hospital.

#### 4.0 How comfortable do you find the unit?



97% of all respondents found the unit they received treatment in either very comfortable or reasonable.

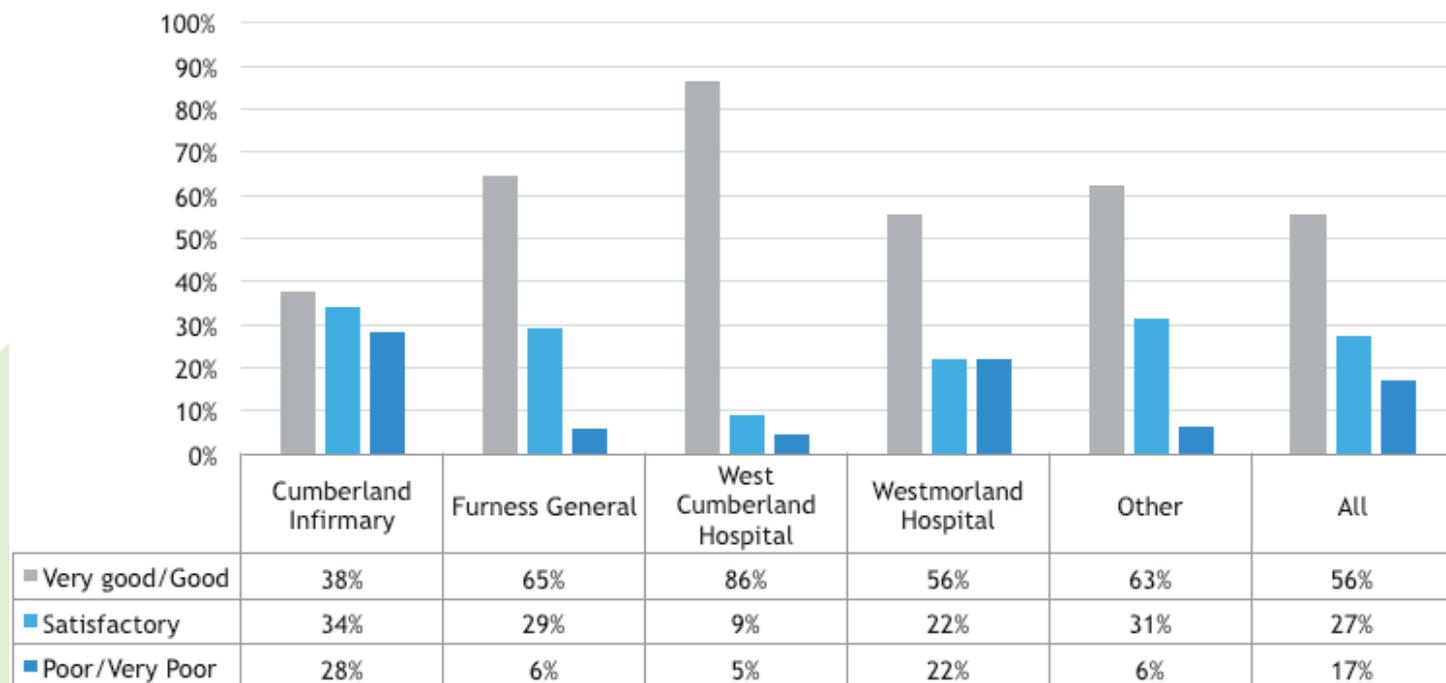
#### 4.1 How would you rate the cleanliness of the unit?



59% of respondents found their treatment unit to be very clean, and 40% to be reasonably clean.

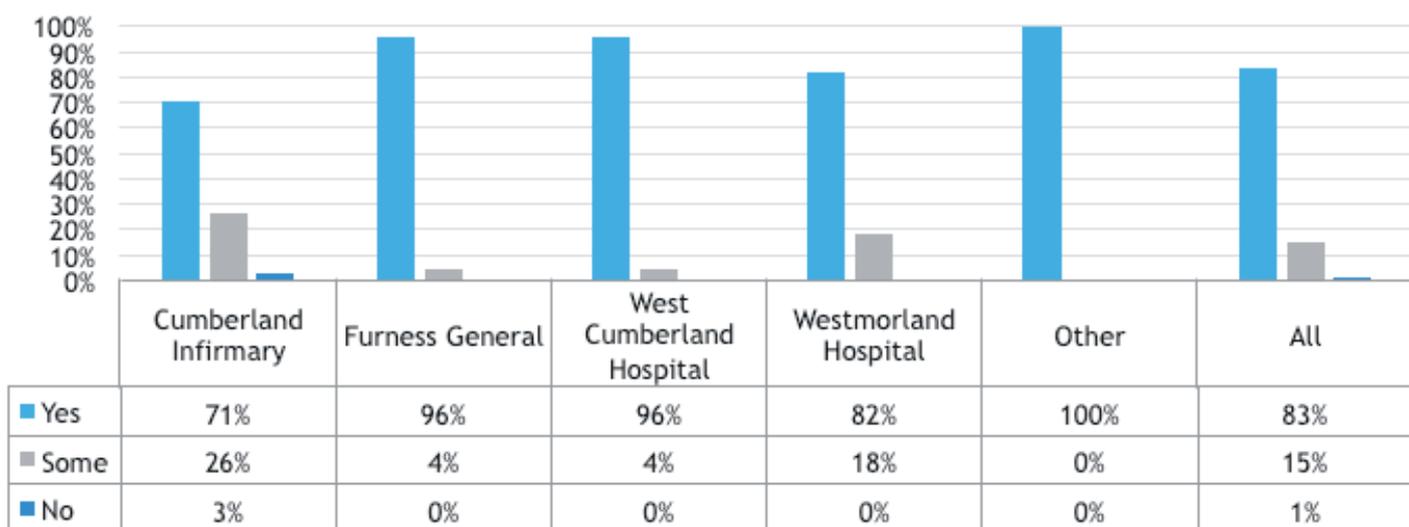


### 4.2 If you have used the catering service whilst on the unit, how did you find the food?



56% of respondents found the food from the catering services to be either very good or good. 17% found the food to be either poor or very poor. The setting with the highest percentage of respondents rating the food as either very good or good was West Cumberland Hospital with 86%. Cumberland Infirmary Carlisle had the worst rated food with 28% of respondents rating it poor or very poor, followed by Westmorland general Hospital with 22%. Although NCUHT manage both West Cumberland Hospital and Cumberland Infirmary Carlisle the catering providers were different at the time of this survey.

### 4.3 Was the general equipment in good working order? I.e. bed, TV, bed table, chair



83% of respondents found that the general equipment across all settings was in good working order. The equipment at other settings (out of County hospitals) appears to be in better working order than those in county, with 100% saying that the general equipment was in good working order.

## 4.2 Environment and Facilities - Key Issues

The results from the Environment and Facilities section of the survey suggest:

- The units that the treatment is provided within were comfortable, with 97% of all respondents finding the unit they received treatment in either very comfortable or reasonable;
- The units that the treatment is provided in were clean, with 99 % of respondents stating they were either very or reasonably clean;
- The general equipment within the settings was in good working order.

### Key Issues Summary:

The survey suggests that:

#### Part 1 - The Referral System

1. There is a disparity between the districts on the number of times a respondent visited their GP prior to being diagnosed.
2. Only 68% of respondents were seen by a specialist within the NICE Guidelines of 14 days;
3. Half of all respondents had to wait more than two weeks for a diagnosis confirmation, after visiting a specialist;
4. There is a large disparity between the times that respondents had to wait for treatment to commence, once a decision to treat had been reached, depending upon which setting they were treated at;
5. The provision of information and communication throughout the referral system appeared to be appreciated by the respondents;
6. The respondents who lived in South Lakeland did the most travelling to Other settings (out of County hospitals);
7. Those respondents from Carlisle, Eden and Furness Districts were mostly treated at their nearest Acute Hospitals;
8. Those respondents from Allerdale and Copeland were sent to all Cumbrian Acute hospitals (bar Westmorland General Hospital) for treatment;
9. The use of NHS sponsored transport differed significantly depending upon which setting the respondent was being treated at;

#### Part 2 - Treatment

1. Nearly one in ten respondents felt their views were not taken into account when discussing treatment;
2. Nearly one in five respondents were not made aware of the long term effects of their treatment;
3. Fewer than half of respondents received written information on the Service Provider's complaints procedures and financial support available;
4. Just under one in five of all respondents felt there were insufficient staff available to care for them whilst undergoing treatment;
5. The responses on pain relief and self-management vary significantly from setting to setting;
6. Nearly all respondents felt that staff did everything they could to control the side effects of the treatment.



### Part 3 - Outpatient Clinics

1. One in ten respondents felt that their emotional needs were not at all met by the clinical staff;
2. Patients rely upon their own family and friends for emotional support, Nearly three quarters of respondents relied upon family and friends for help with their emotional needs;
3. The availability of medical records at appointments appears to be an issue, as a quarter of all respondents reported that clinicians did not always have the necessary medical details available to them for the patient's appointment;
4. Communication between the Trusts and the respondent's GP during treatment was also an issue, with only eight out of ten respondents aware that their GP had been given information of their condition, however 3% said the GP had not and 18% did not know;
5. Support from the respondents GP during treatment was not forthcoming either, with one in ten respondents feeling that their GP had not been helpful or supportive during their treatment;
6. Care plans are not being provided to patients going through Cancer treatment, as a matter of course, with only a third of respondents receiving one;

### Part 4 - Environment and Facilities

1. The units that the treatment is provided within were comfortable, with 97% of all respondents finding the unit they received treatment in either very comfortable or reasonable;
2. The units that the treatment is provided in were clean, with 99 % of respondents stating they were either very or reasonably clean;
3. The general equipment within the settings was in good working order.

*A two year delay in GP referral has apparently lessened my chances of long term survival. I feel strongly that GP's need to understand symptoms better in order to refer people faster, i.e.; when someone keeps presenting with 3 or more symptoms there should be some process to look back through notes and act. The Cumberland Infirmary was in contrast, superb.*

## Part Five

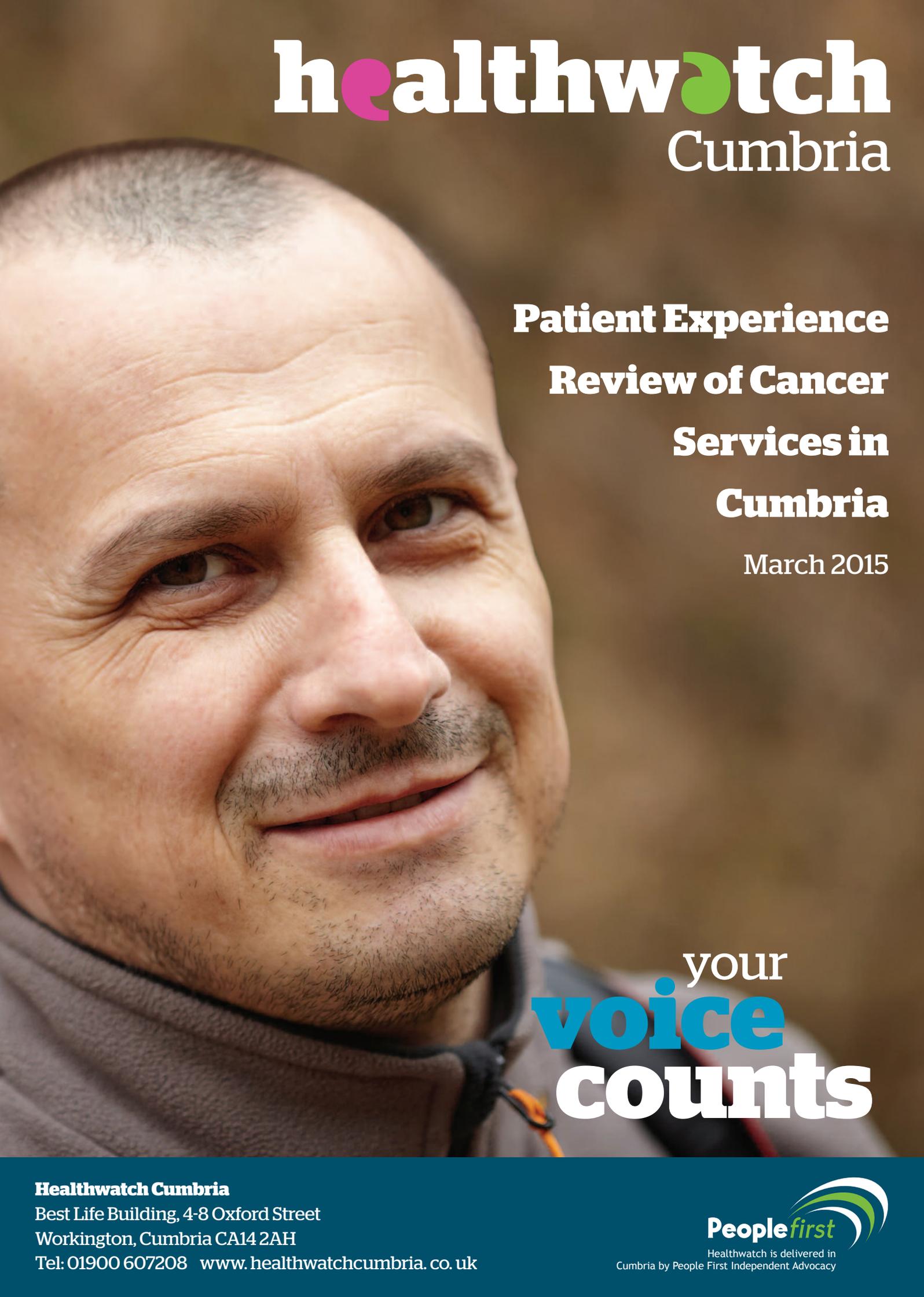
### Recommendations

Healthwatch Cumbria make the following recommendations to the commissioners and providers of cancer services in Cumbria:

1. We recommend that NHS England carry out a review of GP assessment and referral practice in line with NICE guidelines, which currently state that referrals for suspected cancer are carried out within 14 days;
2. We recommend that service providers review procedures and make necessary improvements to ensure that diagnosis is confirmed, in writing within 14 days.
3. All service providers must ensure that clinicians are encouraging health care staff to communicate the long term effects of treatment and consider the patients view on treatment options;
4. We recommend that the provision of information on complaints procedures and financial assistance is available, alongside other relevant information, and is accessible to all patients.
5. We recommend that providers of patient transport review eligibility criteria for cancer patients and ensure that the criteria applied is fair and equitable across Cumbria;
6. Clinicians should receive training and guidance to improve emotional support for patients undergoing treatment;
7. Service providers must ensure that medical records are available for all treatments appointments and consultations;
8. Service providers and commissioners should review communications between GP's and treatment clinicians to ensure that all parties involved in care pathways are updated on progress and prognosis.

*The nurses at the Cumberland Infirmary were first class.*





# healthwatch

Cumbria

## Patient Experience Review of Cancer Services in Cumbria

March 2015

your  
**voice**  
**counts**

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