

Exploration and analysis of free-text comments from the 2013 Wales Cancer Patient Experience Survey (WCPES).

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Dr. Mike Bracher

Dr. Richard Wagland

Professor Dame Jessica Corner

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Executive Summary

ES1 - Introduction and objectives

- The Cancer Delivery Plan (2012) outlined the Welsh Government's commitment that the NHS in Wales would improve patient experience and health outcomes, and set out the means by which these would be achieved and measured.
- The first Wales Cancer Patient Experience Survey (CPES) was conducted in 2013 through a partnership between the Welsh Government, Macmillan Cancer Support and Quality Health. The survey was distributed to patients (n=10,945) who were undergoing treatment between July 2012 to March 2013 in NHS Wales.
- The results of the 2013 Wales CPES were published in January 2014 (Quality Health, 2014), and reported a response rate of 69% (n=7352 patients). Overall the survey results demonstrate a positive experience of cancer care in Wales, with 89% of patients rating their care as excellent (58%) or very good (31%). However, there are a number of areas in the survey where wide variation exists in patient experience, and there are also groups of patients who report less positive experience.
- At the end of the WCPES questionnaire, following the closed tick-box questions, a separate free-text box invited patients to provide comments to three separate questions:
 - Was there anything particularly good about your NHS care?
 - Was there anything that could be improved?
 - Any other comments?
- In total 4672 patients provided comments in the survey, representing 64% of those who returned questionnaires. This study was commissioned by Macmillan Cancer Support to analyse the content of the free-text responses. The aim was to determine the themes that emerged from patients' comments and the insights they provide regarding their experiences of cancer care in Wales.

ES2 - Method

- Free-text comments were extracted from the WCPES data set as individual text files and loaded into the NVivo qualitative data analysis software package. Comments were cleaned by one researcher (Dr. Bracher), who read each of the free text comments and sorted (coded) them into categories (nodes) according to whether the comments were positive, negative or contained material that was unclassifiable or otherwise unusable (e.g. miscellaneous details).
- Data were then subjected to a four-stage process of coding and analysis.

- **Stage one: semantic-level coding for areas of cancer patient experience** – this involved analysis of the semantic content of free-text responses (i.e. whether they contained references to nursing care, surgery, chemotherapy etc. and whether comments in relation to these areas were of a positive or negative nature). Through this process, a coding framework was produced for sorting qualitative data on patient experiences of cancer care.
- **Stage two: semantic-level coding for specific categories within different areas of cancer patient experience** - At stage two, comments within the stage one categories were sorted further according to sub-categories (i.e. what specifically was ‘positive’ or ‘negative’ about the area of care or treatment, for example, patient perceptions of information provided by nurses or the manner in which they were dealt with by staff). Categories derived from stages one and two of coding provide the basis for themes discussed in the main findings section (five) of this report.
- **Stage three: identification of latent themes** - In addition to themes derived from the semantic content of free-text responses, several overarching themes emerged from analysis of similarities between the different areas identified in the data. These emergent themes refer to aspects of cancer patient experience within the data that cut across different phases of the cancer journey (e.g. managing uncertainty).
- **Stage 4: comparisons between closed questions and free-text responses** - The coding framework for free-text data was developed deductively from the semantic content of the comments received. In the final stage of analysis, one researcher (Dr. Mike Bracher) identified semantic-level themes in the free-text data that mapped to specific closed questions in the WCPES data.

ES3 - Findings

- 4672 participants provided free-text responses. Of these, 2313 respondents provided negative comments on aspects of their care and treatment, while 3818 provided positive comments (a ratio of 0.60 : 1). Of these, 237 negative and 1727 positive comments were general (e.g. ‘my care was excellent’ or ‘poor care generally’) or miscellaneous, and these are identified as NOS (not otherwise specified). By comparison, in the closed questions section of the WCPES survey, 58% (n = 4093) of respondents rated their cancer care as ‘excellent’, 31% (n = 2187) as ‘very good’, 8% (n = 595) as ‘good’, and 2% (n = 166) as ‘fair’, and 1% (n = 51) as ‘poor’ (QualityHealth, 2014)¹.
- The findings of this report present a range of experiences from 4,672 cancer patients in Wales which provide many examples of positive care but also areas of concern. These comments were distributed across three main stages of the cancer journey:

¹ Data were missing for 260 participants.

ES3.1 - Diagnostic phase

- **GP** - Concerns were raised by a number of participants in relation to GP care in the pre/diagnostic phase of the cancer journey, particularly around **speed of GP reaction to presenting symptoms**. In contrast, positive comments in relation to GP care tended to be of a more general nature, but crucially almost all commented on the **speed with which their presenting symptoms had been investigated**, including referral for further investigations. These responses were often allied with more general comments expressing feelings of satisfaction and reassurance in terms of the overall care and treatment received during the cancer journey, suggesting that the GP represents an important starting point for building confidence.
- ***Investigations and diagnostic procedures*** - The majority of comments relating to investigations and diagnostic procedures at this stage were negative, and reflected general concerns around waiting for investigative procedures. A smaller sub-set of respondents providing negative comments expressed **concern over the conduct of investigations** (i.e. that their cancer had been missed in earlier investigations). In terms of positive comments, these related almost entirely to the **speed and accuracy of diagnostic procedures**, and, once again, often appeared within the context of general comments regarding treatment across the cancer journey. These comments suggest that waiting times for investigations may be one area for further exploration with regard to improving care at this stage of the cancer journey.
- ***Initial disclosure of the cancer diagnosis*** - Some patients described the way that the **news of cancer was delivered by staff as insensitive or dismissive**, with little time allocated to discuss patient needs or help manage their reactions. Comments indicated that patients who were given their news alone expressed a desire that they should have been advised to bring someone with them for support. One other area of significance was **inadvertent disclosure of a cancer diagnosis** of which the patient had been unaware hitherto. Patients reporting such experiences tended to associate these events with poor communication between staff. While it is difficult to find in the data direct parallels regarding delivery of the diagnosis in the positive comments due to their comparative generality, a greater number of participants praised the **sensitivity, attentiveness and emotional support** given by staff throughout their cancer journeys, which would appear to incorporate initial disclosure of their diagnosis.

ES3.2 - Treatment phase

- ***Speed of treatment and management of delays*** - Participant comments indicate **perceptions of financial constraints on health services, poor inter/intra-agency communication and shortages of available beds** as factors that have delayed their care. One area of particular concern involved **patients who appear to have been sent home on the appointed**

day of their surgical procedure due to a lack of available beds (in some cases, on multiple occasions). Participants have also reported **difficulties in contacting specialist staff, failure of staff to honour promises to return phone calls, and lack of clear timescales for completion of their treatment**. Conversely, in the positive comments, **clear and accurate communication** often went hand-in-hand with **speed of diagnosis and treatment**, with attendant expressions of confidence in the treatment and care given.

- **Information and support during treatment** - The opportunity to **discuss and be informed about the impact of cancer and treatment**, including likely side effects and the support that is available to mediate them, was the subject of many patient comments. **Limited opportunities for contact with specialist nursing staff** were a significant source of negative comments in this data set. Such comments often linked to **inadequate staffing levels** and **perceptions of staff in this area being overburdened**, and thus not able to respond in a timely manner. There were comparatively far fewer attributions of such negative experiences to shortcomings in staff per se, and when specialist staff were available **the value of having a central point of contact for meeting needs during treatment** (commonly through a Key Worker or specialist nurse) was emphasised heavily in the positive comments. A number of participants identified information and support for accessing benefits and services as an area of improvement during the treatment phase. For those living alone in particular, the social and financial burdens of cancer can be additional stressors that exacerbate the already considerable challenges of living with and beyond cancer.

- **Nursing care**
 - **Specialist nursing** - Findings relating to specialist nursing care reflect **high levels of satisfaction with all nursing specialities**, praising the **dedication and skill of specialist nursing staff** and their responses to patients' needs during treatment. Where **negative comments** did arise in relation to specialist nursing, these were **almost entirely with regard to the availability and/or ability to contact specialist nursing staff** during the treatment phase of the cancer journey. Once again, **both negative and positive comments** were attended by observations of **inadequate staffing levels and/or staff** commonly under pressure due to resource constraints. These findings suggest that while **care provided by specialist nursing staff perceived to be of a high standard generally, staffing and resource levels constitute one area for further investigation with regard to service improvement**.

 - **General nursing care (not otherwise specified)** - the overall weight of comments relating to this area of nursing were **positive** and reflected what were often **high levels of satisfaction with both the**

practical aspects of care, and the manner in which this was provided. However, general nursing did attract both a **greater number and proportion of negative comments** relative to positive responses when compared with specialist nursing. The majority of these negative responses appear to relate to instances of **poor care within hospital in-patient wards**, particularly those identified as non-specialist. General nursing was also the area within which concerns about **staffing levels** were present most strongly, and were also associated with **extended waiting for pain relief in hospital**.

- **Specific treatments –**

- **Surgery** - Comments relating to surgery were to a large degree positive, with participants **praising the speed of surgical treatment** received, and the conduct of procedures (although there were some negative comments in each of these areas). The majority of **negative comments** centred upon **information provision relating to surgery** and **access to surgical staff for information and support**. In terms of negative comments, of particular concern were a significant number of responses detailing **experiences of poor care during post-operative recovery**. Within this group, a number of participants **contrasted perceptions of good nursing care on specialist wards**, where staff were familiar with their condition, **with non-specialist wards where problems were encountered**.
- **Chemotherapy** - Participant **experiences of chemotherapy were in the main positive**, and the content of comments (especially those relating to specialist chemotherapy nursing) reflect experiences of **efficient, committed staff who very often went to great lengths to ensure patient wellbeing during treatment**. Respondents praised both the **professionalism and efficiency** of their treatment, and the **sensitive and caring** manner in which they had been dealt with by staff, linking this to **reductions in stress** associated with chemotherapy. The few **negative comments** that were provided tended to focus on **lack of opportunity to discuss side effects** with staff during the initial stages of treatment, rather than the care provided per se.
- **Radiotherapy** - The majority of respondents who commented on the care and treatment provided during radiotherapy, **praised both the conduct and the manner in which staff had treated and cared for them**. Where **negative comments** were received, these **related almost entirely to information about and opportunities to discuss side effects of radiotherapy**.

ES3.3 - Aftercare phase

- ***Continuity of care and support following treatment*** - Following the completion of treatment, whether chemotherapy, radiotherapy, surgery or other treatment programmes, **participants identified a lack of general aftercare provision (this was true for participants giving otherwise positive responses)**. The generality of negative comments here appears indicative of a **profound gap in services after treatment has finished**. **Support from specialist medical and nursing staff**, as well as **emotional, social and psychological support** while recovering from cancer treatment, were unmet needs reported by many participants in this data set. **Fear of recurrence** linked to a **lack of clear plans** as to how the **success of treatment** would be confirmed, and if found to be successful **how their condition would be monitored over the longer term**, were also significant concerns. Several participants described **actual recurrence** of cancer, and reported its discovery was delayed due to failure to conduct what they considered to be appropriate follow up investigations. Conversely, for the smaller group of respondents who provided **positive responses** relating to aftercare, the majority of positive comments reflected the security provided by a **clear programme of regular check-ups following completion of treatment**. Aftercare was one of the few areas of treatment where negative responses greatly outnumbered positive ones, and it is notable that these in some cases accompanied otherwise positive comments praising many or all other aspects of their cancer journey.
- ***Emotional, social, psychological and financial support after treatment*** - For some of those moving out of the treatment phase, the **sudden disappearance of sources of support can come as a shock**, bringing **emotional problems** linked to **uncertainty about the future** and **loneliness** (particularly for those living alone) as patients look to move on with their lives. Beyond overcoming fear of recurrence, challenges can include **rebuilding social aspects of life**, coming to terms with **stressors and emotional or mental health issues** that may have arisen during treatment, and addressing financial problems incurred during treatment. This is an area in which a **broad range of support services may be necessary**, and for which **provision at present appears lacking for many participants**. Just as at the start of treatment it may be necessary to **explore what needs individual patients may face**, and what services may be available to meet them, so too might this be an **appropriate step following the end of treatment**.

ES4 - Key messages

- **Staff should communicate with patients with compassion, courtesy and respect** - Previous research has indicated the importance of the quality of interactions between health professionals and patients for much of the success of healthcare provision (Drew et al 2001), and being treated with courtesy and respect is one of the most important predictors for cancer patients' perception of quality care (Sandoval et al 2005). Patients responding to this survey attest to these findings by choosing to describe the impact, both positive and negative, that interactions with staff members have had upon them. These interactions occur across the treatment pathway, beginning in the GP surgery where patients' concerns should be treated seriously, to being given a diagnosis in a sensitive manner with due concern for privacy and emotional support, and being treated with compassion and respect by medical, nursing and allied staff during treatment and post-treatment. Treating patients respectfully extends to keeping them informed when there are delays waiting for appointments, administrative staff returning phone calls when promised, and nurses ensuring as little noise at night as possible.
- **Delays to diagnosis, investigations and treatment should be minimal** - Any delay to diagnosis and treatment of cancer has the potential to impact negatively on patient outcomes (O'Rourke et al 2000). For patients who suspect they might have cancer and are conscious of the risk of progression of the disease, delay also causes psychological distress, which has been shown to correlate positively with the length of that delay (Risberg et al 1996). Nevertheless, despite the NICE guidelines on patients suspected of cancer (NICE 2005), delays in referrals, investigations and diagnosis continue to occur. Previous research has found that patients are often not satisfied with the time it took for the GP to identify their problem and for a diagnosis to be reached (Davidson et al 2005). Delays for investigations and referral are often caused through 'misdiagnosis' with GPs either treating patients symptomatically or relating symptoms to a health problem other than cancer, while for some cancers this could also be linked to inadequate patient examination, use of inappropriate tests or failing to follow-up negative or inconclusive test results (Macleod et al 2009). Previous studies have also found large variations in GP referral rates of patients with suspected cancer to specialist care (O'Donnell 2000), with two-thirds of this variation remaining unexplained (O'Sullivan 2005). Our findings from patient comments would indicate, therefore, that some of this delay may partly be addressed by GPs more often taking patients' concerns seriously and acting on them swiftly.
- **Patients should be prepared for what they face** - The need for patients to be prepared for the potential impact of their diagnosis and treatment thus pervades the patient journey, and includes: available treatment options and the relative advantages and disadvantages for the individual; information concerning possible physical problems, how to manage them, when they might resolve, what to do if they don't; emotional and psychological issues, such as fear of recurrence and other anxieties and how to find support should this be needed; managing financial and other practical problems, such as returning to work and benefit applications. Such support and guidance have previously been found to be important factors in patients' satisfaction with their quality of care (Davidson et al 2005), it also but requires sufficient and accessible specialist staff for its provision. Nevertheless, while there is a clear and consistent

finding that information directly from health professionals, during the consultation is the preferred source of information for patients, there is also evidence of a recognition of the workload of health professionals, the needs of other patients who are waiting and these factors influence whether further information is sought or requested (Bungay & Capello, 2009; Leydon, et al., 2000; Manning & Dickens, 2007). This finding is important when considering the utility of information provision interventions based in alternative approaches using video, print material or interactive electronic sources. The potential role of clinical staff in advocating for alternative sources of information, e.g. recommended websites or referrals to information centres, may help bridge this issue. Finally, as patients do not always want information at the same time or at the same level (Leydon et al 2000), patient preparation should be tailored for individuals and it therefore incorporates personalised care.

- ***Patients should experience good continuity of care*** - Continuity of care has been defined as one patient experiencing care over time as coherent and linked (Reid et al 2002), and has become one of the key policy themes in cancer care (WG 2012; DH 2008; Freeman & Hughes 2010). Continuity of care incorporates three components: informational, management and relational (Haggerty *et al.* 2003). Informational continuity links one service to another and one healthcare event to another so that aspects of a patient's medical condition, preferences for treatments and the context of their illness are accounted for; management continuity is the delivery of health care by several services in a complementary and timely manner through shared management plans that are consistent and flexible; relational continuity bridges past and current care while providing a link to future care, achieved through a core of consistent staff working together with the patients on their treatment plans (Nazarath et al 2008). Evidence indicates that greater continuity of care experienced by patients and their families is associated with lower future needs for supportive care and better psychological outcomes (King et al 2008; NCCDSO 2007). Thus, if patients receive adequate preparation for what to expect with regards treatment side effects and self-management strategies, and then experience good continuity of care, their post-treatment needs may also be reduced. In the free-text comments, this was supported by frequent references to both positive and negative experiences of care continuity across all stages of the cancer journey. In particular, concerns exist over transitions from primary to secondary care at the diagnostic stage, and then from secondary to primary care in the post-treatment phase.
- ***Key workers should facilitate holistic care planning*** – Factors fundamental to continuity of care are holistic assessment and care planning and the development of a key worker role to facilitate these processes (DH 2008; NHS Wales, 2010). Key workers, usually a clinical nurse specialist, should be responsible for coordinating treatment and care during active treatment to ensure good communications between the healthcare team and the patient and their families and to act as their point of contact. Post-treatment this role should be transferred to GPs or their practice nurses. A full holistic assessment should be undertaken and a written plan of care developed a copy of which should be offered to the patient. However, it appears that this is not occurring in many instances and very few patients' comments referred to care plans or used the phrase 'key worker', possibly indicating these are not terms with which they are familiar.

Many patients did refer to their clinical nurse specialist (CNS), and almost always described them as ensuring a more positive experience of care: the main criticisms being difficulties with accessing or contacting them. Specialist nurses play a key role in the coordination of care and provision of emotional support, information and supportive interventions and are central to improving the quality of nursing care (NICE 2009; Lancet 2011). However, many patients did describe uncoordinated and interrupted care, especially during the transition between secondary and primary care at the end of treatment. This finding indicates that there is still work to be done to implement and ensure consistency of care planning and continuity of care.

- ***Staffing levels should be adequate*** - There has been much recent discussion regarding safe staffing levels in hospitals, particularly of nursing staff (RCN 2012). Growing international evidence indicates that lower ratios of nurses to patients are associated with both poorer outcomes for patients and greater job dissatisfaction for nursing staff (Needleman 2002; Aiken 2002a; 2002b; Rafferty et al 2007). It is probable that inadequate levels of staffing will also contribute to other problems experienced by patients, such as instances of uncoordinated care, lack of individualised care and waiting for treatment and pain control (both significant sources of concern for patients in this study). In particular, inadequate staffing levels were perceived as a problem at night by respondents providing free-text comments. Accessibility of specialist nurses was also an issue.. Recent evidence shows that care coordination and emotional support and support for the control of side-effects are better in Trusts / Hospitals with more specialist nurses (Griffiths et al 2013). Nevertheless, significant variations across Trusts / Hospitals remain in patient access to specialist nurses (Trevatt & Leary 2010).
- ***Patients should have access to adequate post treatment services*** - Patients often feel 'cut adrift' by the health system after the period of hospital treatment and are left feeling vulnerable and isolated (Armes et al 2009; Penny et al 2000). The transition from secondary to primary care can also mean patients need to adapt to the changed care setting, where they obtain prescriptions from different prescribers and sometimes find it difficult contacting appropriate health professionals for guidance (Coleman & Berenson 2004). Evidence indicates that approximately 30% to 50% of cancer survivors have unmet needs, mainly for psychological support and coping with fear of recurrence (McIlmurray et al 2001; Boberg 2003; Hodgkinson et al 2003). While unmet needs reduce for some patients in the months following treatment, one study found that for 60% of these patients the situation did not improve over a six month period (Armes et al 2009). Patients' comments within the WCPES often did not describe specific issues related to aftercare, other than to describe its lack, which reinforces findings from previous studies.

1 – Background and Aims.

The Cancer Delivery Plan (2012) outlined the Welsh Government’s commitment that the NHS in Wales would improve patient experience and health outcomes, and set out the means by which these would be achieved and measured. The first Wales Cancer Patient Experience Survey (WCPES) was conducted in 2013 through a partnership between the Welsh Government, Macmillan Cancer Support and Quality Health. The survey was distributed to patients (n=10,945) who were undergoing treatment between July 2012 to March 2013 in NHS Wales. The results of the 2013 Wales CPES were published in January 2014 (Quality Health, 2014), and reported a response rate of 69% (n=7352 patients). Overall the survey results demonstrate a positive experience of cancer care in Wales, with 89% of patients rating their care as excellent (58%) or very good (31%). However, there are a number of areas in the survey where wide variation exists in patient experience, and there are also groups of patients who report less positive experience.

At the end of the WCPES questionnaire, following the closed tick-box questions, a separate free-text box invited patients to provide comments to three separate questions:

- Was there anything particularly good about your NHS care?
- Was there anything that could be improved?
- Any other comments?

In total 4672 patients provided comments in the survey, representing 64% of those who returned questionnaires. This study was commissioned by Macmillan Cancer Support to analyse the content of the free-text responses. The aim was to examine themes that emerged from patients’ comments and thereby obtain insights into their experiences of cancer care in Wales.

2 – Methodology

2.1 - Data extraction and cleaning

Free-text data were received from Macmillan Cancer Support in the form of a spreadsheet, together with full data from the Welsh Cancer Patient Experience Survey (WCPES). Free-text responses were provided for each case (respondent) in separate columns, according to whether the comment had been entered under response headings for ‘good’ experiences of care, areas to be ‘improved’ and any ‘other’ comments. Responses had been anonymised by Quality Health (the company that conducted the WCPES survey) prior to receipt of data² (i.e. by removing names of people, specific places and other details that could be used to identify respondents). Free-text comments were extracted from the WCPES data set as individual text files and loaded into the NVivo qualitative data analysis software package. Comments were cleaned and subjected to stage one coding (see below) in batches of 200 comments selected by random sampling.

Data were then cleaned by one researcher, who read each of the free text comments and sorted (coded) them into categories (nodes) according to whether the comments were positive, negative or

² There were a number of occasions when details remained in the data, and these have been removed from the quotes used in this report.

contained material that was unclassifiable or otherwise unusable (e.g. miscellaneous details). Responses were coded in their entirety to each of these nodes depending on their content – i.e. if a comment contained both positive and negative material it would be coded at both nodes. This was necessary in order to ensure that positive and negative comments had been identified correctly, as many respondents included both positive and negative material in the responses.

2.2 - Data analysis

Stage one – semantic-level coding for areas of cancer patient experience.

Data were subjected to a thematic content analysis, informed by a multi-stage coding of the free text data (Mason, 2002). Stage one involved analysis of the semantic content of free-text responses (i.e. whether they contained references to nursing care, surgery, chemotherapy etc. and whether comments in relation to these areas were of a positive or negative nature). Through this process, a coding framework was produced for sorting qualitative data on patient experiences of cancer care, developed by one researcher (MB³) and discussed with two further researchers (RW⁴ and JC⁵). Once the main coding framework had been established (i.e. the framework was able to accommodate the majority of comments without the need for additional categories), a sample of 200 randomly selected comments was double-coded by two researchers. Coding agreement between the two researchers was 80% (calculated using Cohen's Kappa), and conflicts were resolved through discussion between coders.

Stage two – semantic-level coding for specific categories within different areas of cancer patient experience.

Once all comments had been cleaned and coded to stage one level, individual categories (codes) were subjected to a second stage of more detailed sorting, in order to explore specific content within different areas of cancer care. For example, at stage one comments relating to nursing care were coded to the categories 'Nursing' and then 'NursingPositive' or 'NursingNegative' depending on their character. At stage two, comments within these categories were sorted further according to sub-categories within nursing care (i.e. what specifically was 'positive' or 'negative' about the care, for example, patient perceptions of information provided by nurses or the manner in which they were dealt with by staff). Categories derived from stages one and two of coding provide the basis for themes discussed in the main findings section (five) of this report.

Stage three – identification of latent themes.

In addition to themes derived from the semantic content of free-text responses, several overarching themes emerged from analysis of similarities between the different areas identified in the data. These emergent themes refer to aspects of cancer patient experience within the data that cut across different phases of the cancer journey (e.g. managing uncertainty), and are explored in the discussion section (six) of this report.

Stage 4 – comparisons between closed questions and free-text responses

³ Mike Bracher

⁴ Richard Wagland

⁵ Jessica Corner

The coding framework for free-text data was developed deductively from the semantic content of the comments received. In the final stage of analysis, one researcher (MB) identified semantic-level themes in the free-text data that mapped to specific closed questions in the WCPES data. Comparison between results of closed question and free-text responses were conducted, and the results appear under the relevant theme headings in the findings section (4) of this document.

3 – Free-text respondent demographics.

Demographic data for free-text respondents (n = 4672) indicate that this sub-group are representative of the total survey respondent group for the WCPES survey (n = 7352). Specific demographic breakdowns are given below.

3.1 – Age groups

The most populous age group of free-text respondents was the 65-74 (years) category (n = 1509, 32%). Over half of respondents were aged 65 and over, with 58% (n = 2728) of respondents falling within this category. The percentage of free-text respondents in each category mirrors closely that observed in the total survey respondent group (see Figure 1 and Table 1).

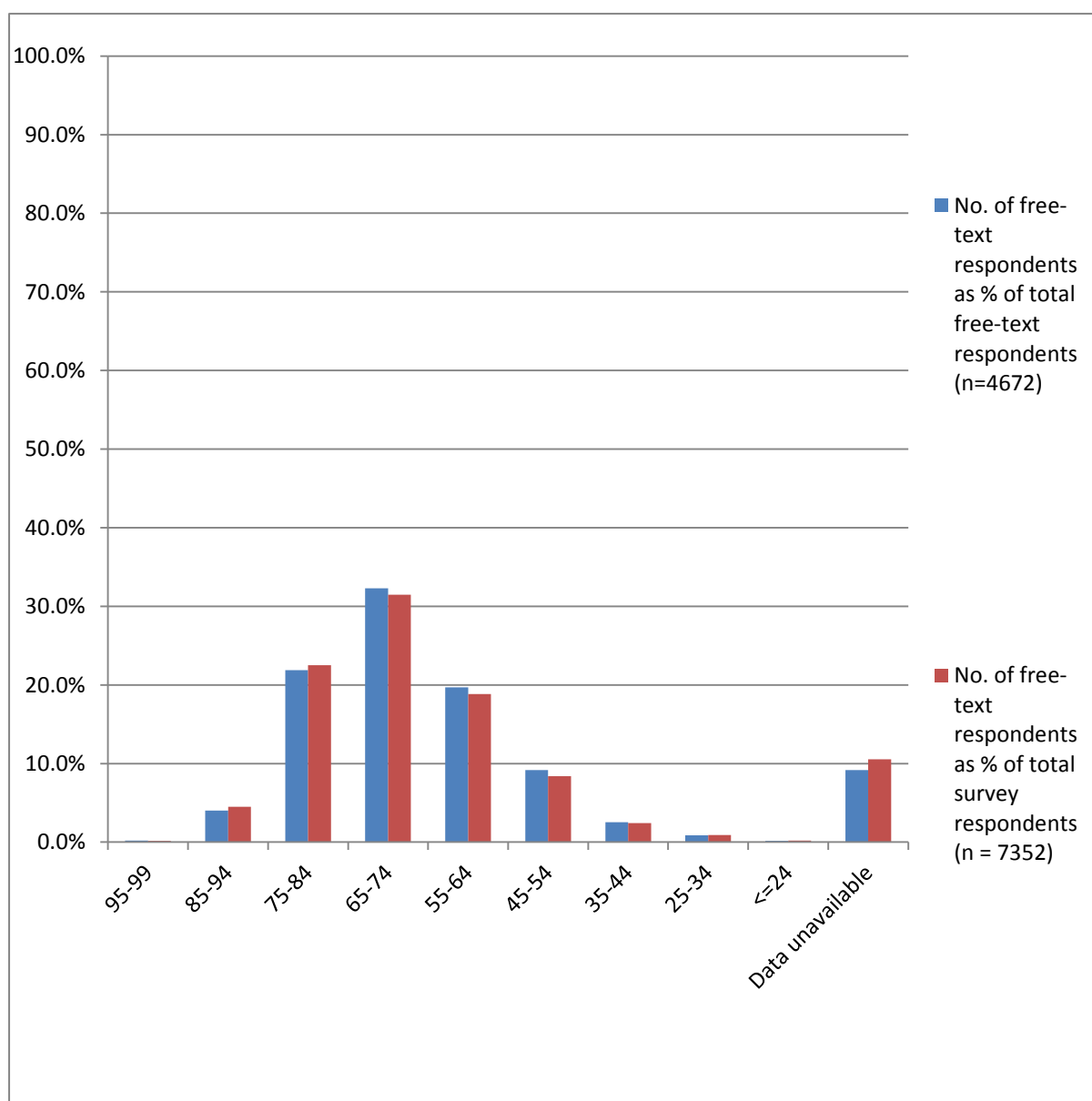


Figure 1 – Age group of free-text and total survey respondents (as %).

Approximate age range (years)⁶	Number of free-text respondents / No. of survey respondents as % of total free-text respondents (n=4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
95-99	9 / 0.2%	12 / 0.2%
85-94	188 / 4%	332 / 5%
75-84	1022 / 22%	1656 / 23%
65-74	1509 / 32%	2315 / 31%
55-64	920 / 13%	1386 / 19%
45-54	428 / 11%	616 / 8%
35-44	119 / 8%	178 / 2%
25-34	41 / 6%	66 / 1%
<=24	7 / 2%	15 / 0.2%
Data unavailable	429 / 9%	776 / 11%

Table 1 - Approximate age of free-text and WCPES survey respondents.

⁶ Participants were asked to give their year of birth. Approximate age was calculated by subtracting the year given from 2014.

3.2 – Sex

Male respondents made up 43% and female respondents 46% of free-text respondents, compared with 46% (n = 3397) and 51% (n = 3785) of total survey respondents for males and females respectively (see Figure 2 and Table 2).

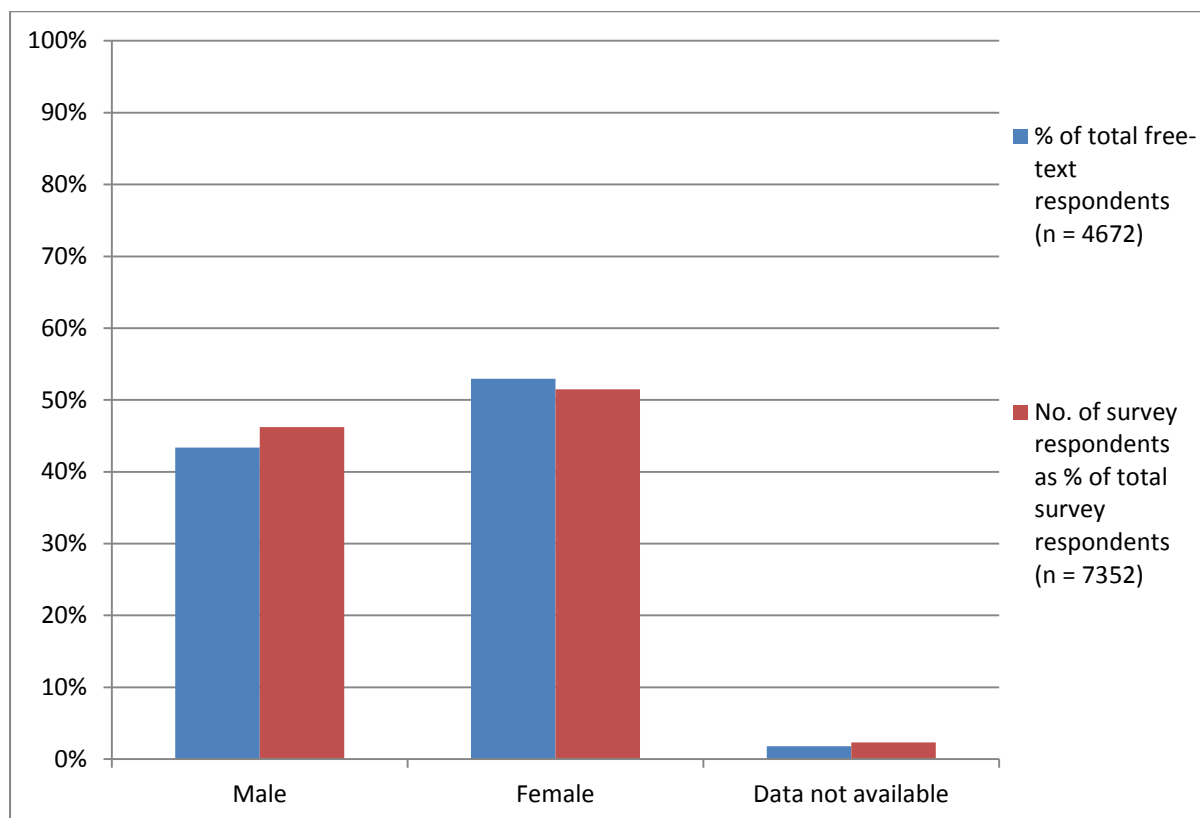


Figure 2 - Sex of free-text and total survey respondents (as %).

Sex	Number of free-text respondents / No. of free-text respondents as % of total free-text respondents (n = 4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Male	2065 / 43%	3397 / 46%
Female	2522 / 53%	3785 / 51%
Data not available	85 / 2%	170 / 2%

Table 2 – Sex of free-text and total survey respondents.

3.3 – Tumour type

Breast (n = 1168, 25%), colorectal (n = 722, 15%) and prostate (n = 587, 13%) were the most common tumour groups among free-text respondents. Number and proportions for all tumour groups among free-text respondents reflected broadly those observed among total survey respondents (see Figure 3 and Table 3).

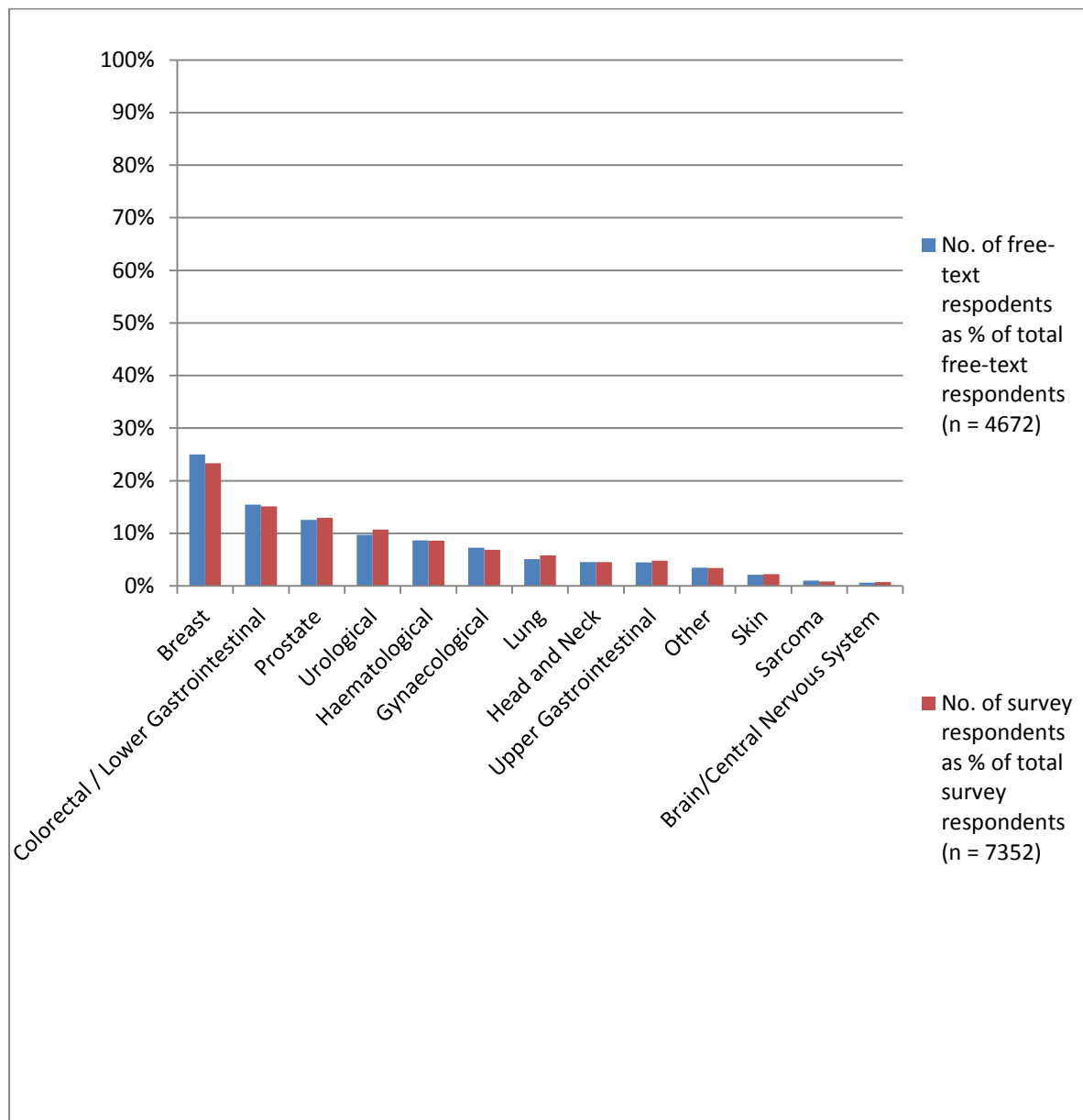


Figure 3 – Tumour type of free-text and total survey respondents (as %).

Tumour Group	Number of free-text respondents / No. of free-text respondents as % of total free-text respondents (n = 4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Breast	1168 / 25%	1717 / 23%
Colorectal / Lower Gastrointestinal	722 / 15%	1112 / 15%
Prostate	587 / 13%	954 / 13%
Urological	455 / 10%	787 / 11%
Haematological	405 / 9%	633 / 9%
Gynaecological	340 / 7%	504 / 7%
Lung	238 / 5%	427 / 6%
Head and Neck	212 / 5%	332 / 5%
Upper Gastrointestinal	210 / 4%	354 / 5%
Other	161 / 3%	252 / 3%
Skin	99 / 2%	163 / 2%
Sarcoma	46 / 1%	64 / 1%
Brain/Central Nervous System	29 / 1%	53 / 1%

Table 3 - Tumour group breakdowns for free-text and total survey respondents.

3.4 – Longstanding conditions

The majority of respondents in both the free-text (n = 2361, 56%) and total survey groups (n = 4082, 56%) did not declare a longstanding condition. For free-text respondents who did declare a longstanding condition, longstanding physical conditions (n = 865, 19%), longstanding illnesses (n = 660, 14%) and deafness or hearing impairment (n = 504, 11%) were the most populous categories. The proportion of respondents for each longstanding condition category was very close to that for the total survey respondent group (see Figure 4 and Table 4).

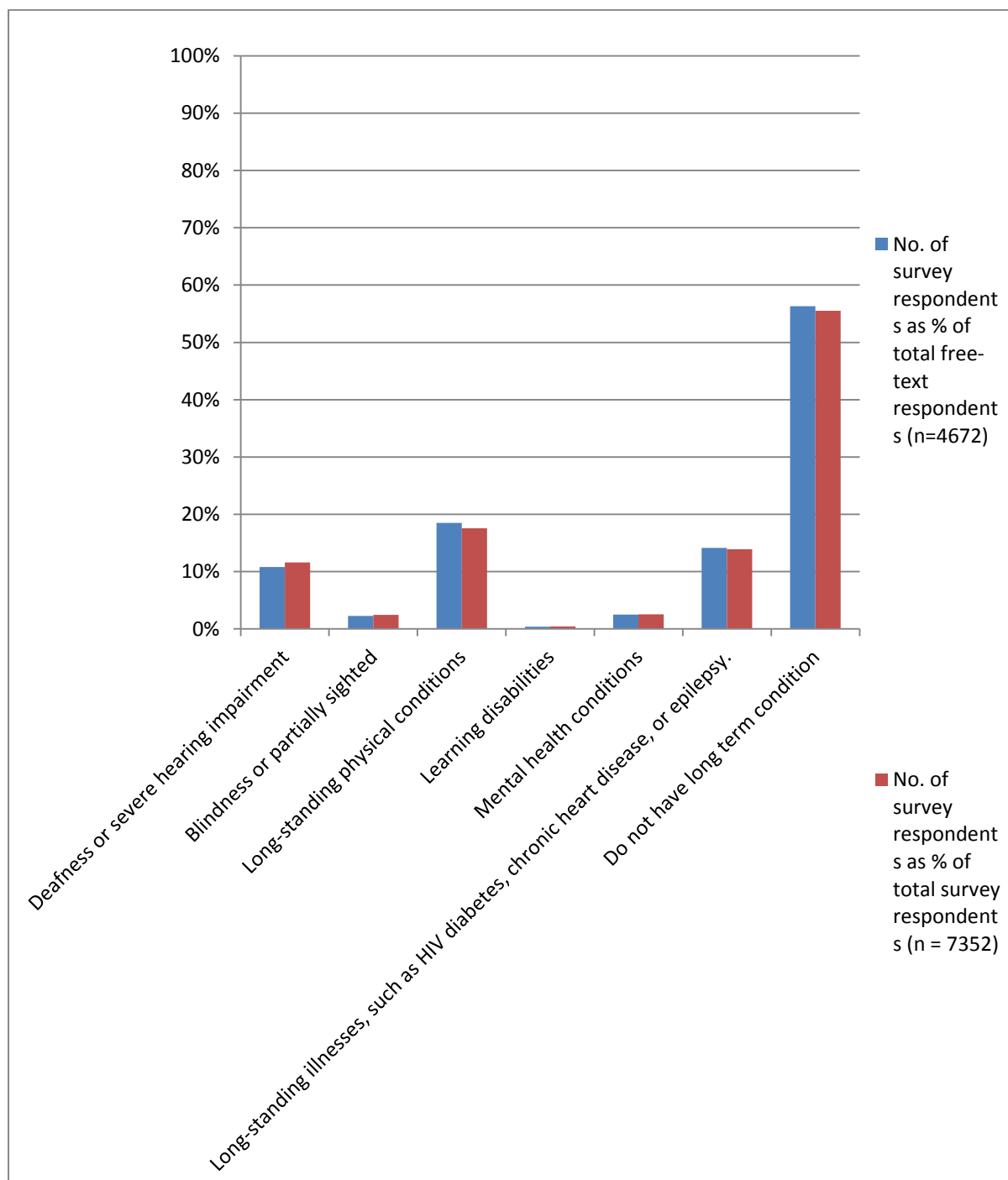


Figure 4 – Breakdown of free-text and total survey respondents with longstanding conditions (as %).

Longstanding conditions	Number of free-text respondents / No. of survey respondents as % of total free-text respondents (n=4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Do not have long term condition	2631 / 56%	4082 / 56%
Long-standing physical conditions	865 / 19%	1291 / 18%
Long-standing illnesses, such as HIV diabetes, chronic heart disease, or epilepsy.	660 / 14%	1023 / 14%
Deafness or severe hearing impairment	504 / 11%	852 / 12%
Mental health conditions	117 / 3%	187 / 3%
Blindness or partially sighted	106 / 2%	179 / 2%
Learning disabilities	17 / 0.4%	31 / 0.4%

Table 4 – Breakdown of longstanding conditions among free-text and total survey respondents.

3.5 – Employment status.

The majority of respondents in both free-text (n = 2892, 68%) and total survey (n = 4608, 63%) groups identified themselves as retired. Proportions of respondents in the remaining categories were similar for both free-text and total survey respondents (see Figure 5 and Table 5).

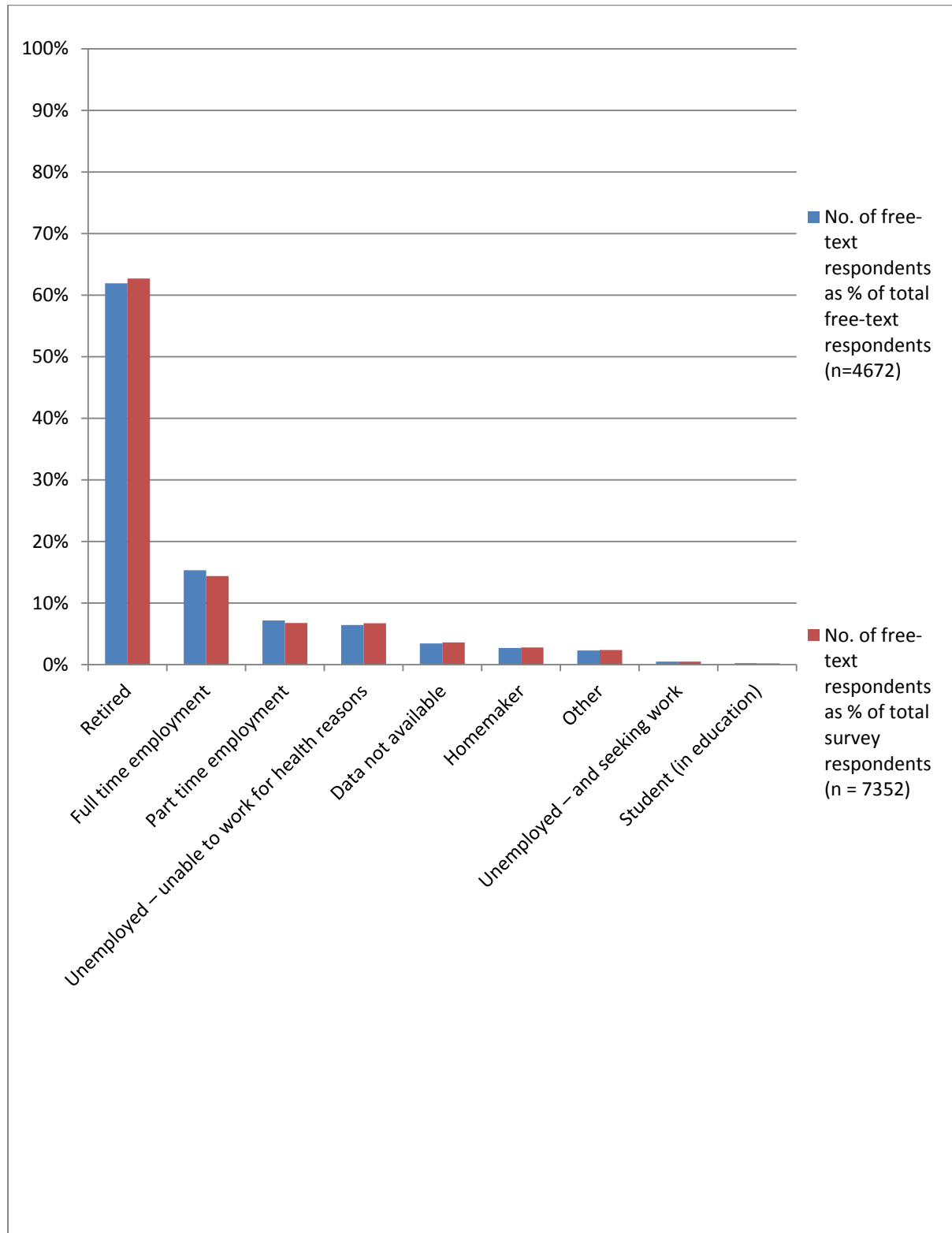


Figure 5 – Employment status of free-text and total survey respondents (as %)

Main employment status	Number of free-text respondents / No. of survey respondents as % of total free-text respondents (n=4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Retired	2892 / 62%	4608 / 63%
Full time employment	715 / 15%	1056 / 14%
Part time employment	334 / 7%	497 / 7%
Unemployed – unable to work for health reasons	300 / 6%	494 / 7%
Data not available	161 / 3%	266 / 4%
Homemaker	127 / 3%	206 / 3%
Other	108 / 2%	174 / 2%
Unemployed – and seeking work	23 / 0.5%	36 / 0.5%
Student (in education)	12 / 0.3%	15 / 0.2%

Table 5 – Employment status of free-text and total survey participants.

3.6 – Ethnicity

The vast majority of participants in both free-text (n = 4467, 96%) and total survey (n = 6991, 96%) responses identified as White British ethnicity. Proportions of respondents in the remaining categories were comparable for both free-text and total survey respondents (see Figure 6 and Table 6).

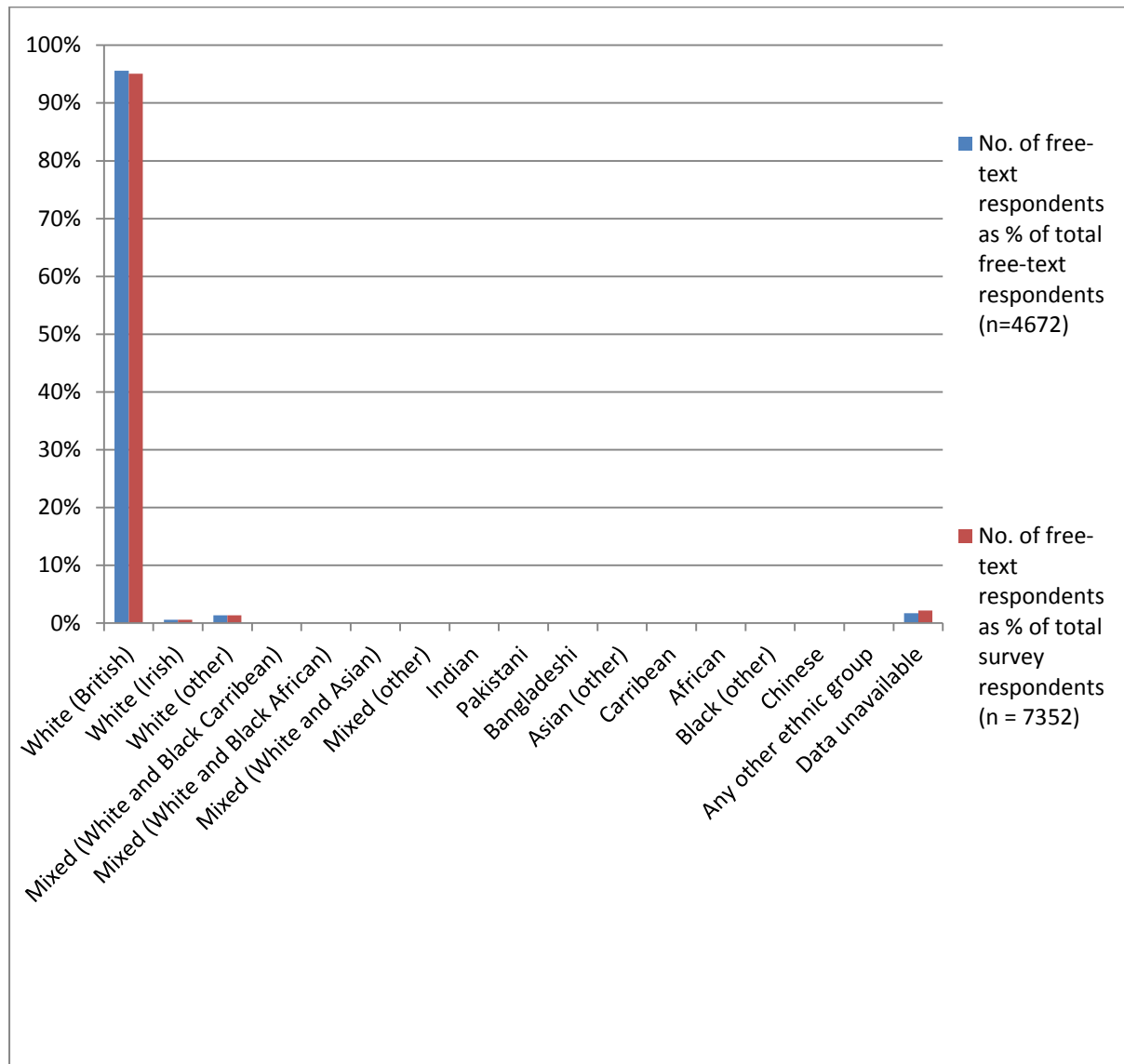


Figure 6 – Ethnicity of free-text and total survey respondents (as %).

Ethnicity	Number of free-text respondents / No. of survey respondents as % of total free-text respondents (n=4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
White (British)	4467 / 96%	6991 / 95%
White (Irish)	27 / 0.58%	44 / 1%
White (other)	64 / 1%	102 / 1%
Mixed (White and Black Caribbean)	5 / 0.11%	7 / 0.1%
Mixed (White and Black African)	1 / 0.02%	4 / 0.1%
Mixed (White and Asian)	3 / 0.06%	4 / 0.1%
Mixed (other)	2 / 0.04%	2 / 0.03%
Indian	6 / 0.13%	7 / 0.1%
Pakistani	3 / 0.06%	5 / 0.1%
Bangladeshi	0 / 0.00%	1 / 0.01%
Asian (other)	4 / 0.09%	6 / 0.1%
Caribbean	2 / 0.04%	3 / 0.04%
African	4 / 0.09%	5 / 0.1%
Black (other)	0 / 0.00%	0 / 0.00%
Chinese	1 / 0.02%	5 / 0.1%
Any other ethnic group	3 / 0.06%	4 / 0.1%
Data unavailable	80 / 2%	162 / 2%

Table 6 – Ethnicity of free-text and total survey respondents.

3.7 – Sexual orientation

The majority of respondents in both free-text (n = 4275, 92%) and total survey (n = 6595, 90%) groups identified as heterosexual. Proportions of respondents for the remaining categories were comparable between both free-text and total survey respondents (see Figure 7 and Table 7).

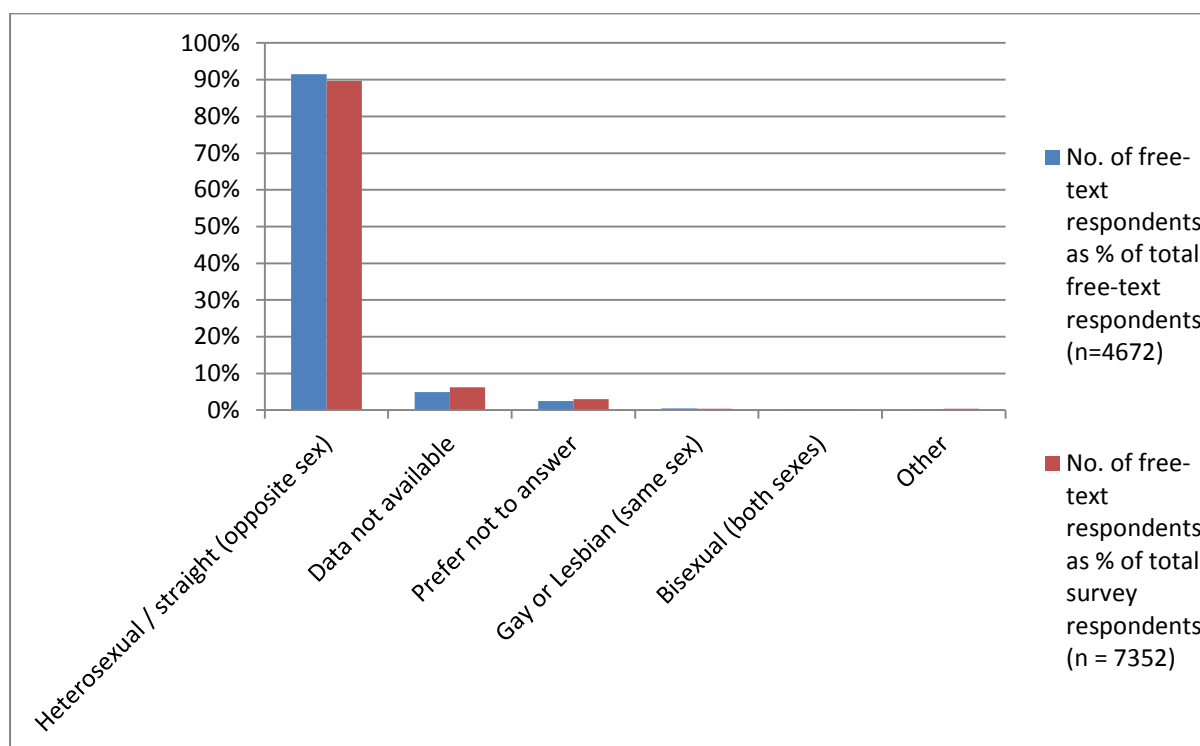


Figure 7 – Sexual orientation of free-text and total survey respondents (as %).

Sexual Orientation	Number of free-text respondents / No. of survey respondents as % of total free-text respondents (n=4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Heterosexual / straight (opposite sex)	4275 / 92%	6595 / 90%
Data not available	231 / 5%	459 / 6%
Prefer not to answer	117 / 3%	222 / 3%
Gay or Lesbian (same sex)	21 / 0.4%	27 / 0.4%
Bisexual (both sexes)	14 / 0.3%	19 / 0.3%
Other	14 / 0.3%	30 / 0.4%

Table 7 – Sexual orientation of free-text and total survey respondents (as %).

3.8 – Health board

The majority of free-text respondents were identified as belonging to either Velindre NHS Trust (n = 1283, 27%), Betsi Cadwaladr University Health Board (n = 1097, 23%), or Abertawe Bro Morgannwg University Health Board (n = 962, 21%). Proportions of respondents for all health boards for both free-text and total survey respondent groups were comparable.

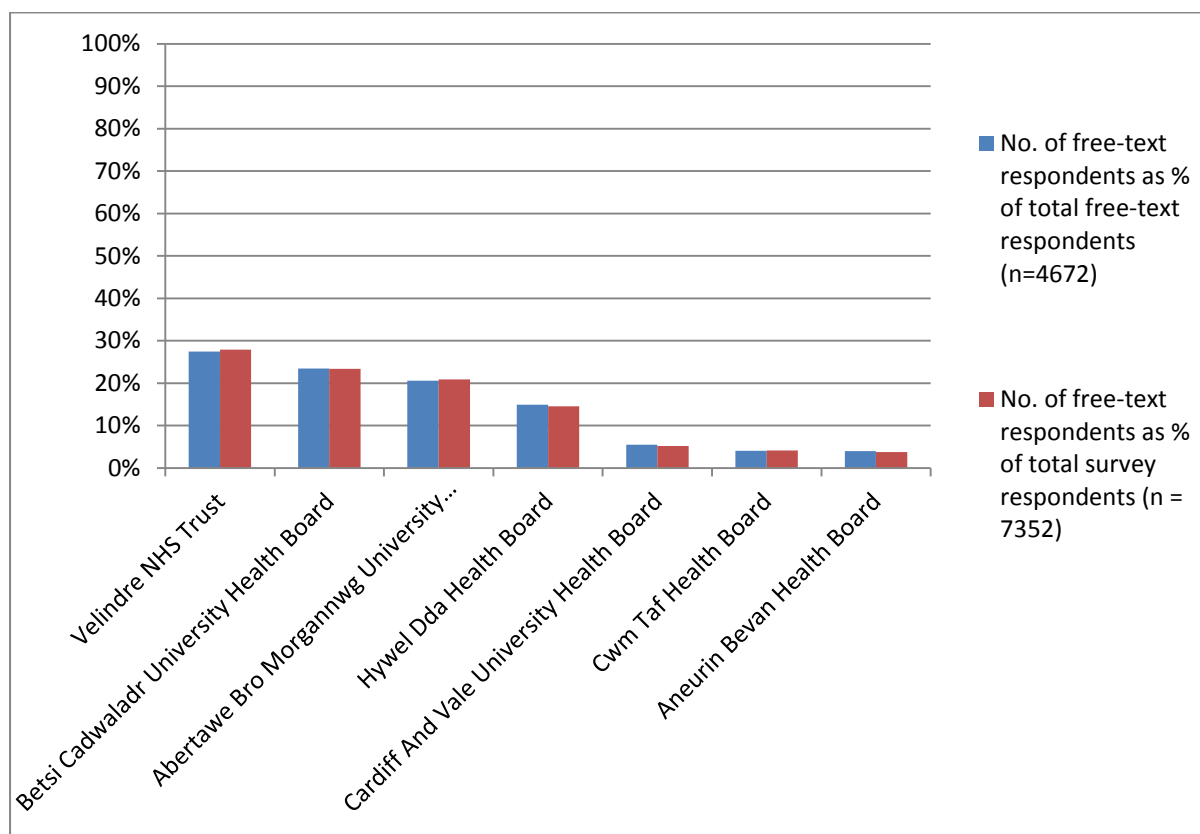


Figure 8 – Percentage of respondents by health board for free-text and total survey respondents.

Health Board	Number of free-text respondents / No. of free-text respondents as % of total free-text respondents (n = 4672)	Number of survey respondents / No. of survey respondents as % of total survey respondents (n = 7352)
Velindre NHS Trust	1283 / 27%	2053 / 28%
Betsi Cadwaladr University Health Board	1097 / 23%	1720 / 23%
Abertawe Bro Morgannwg University Health Board	962 / 21%	1539 / 21%
Hywel Dda Health Board	699 / 15%	1069 / 15%
Cardiff And Vale University Health Board	256 / 5%	384 / 5%
Cwm Taf Health Board	189 / 4%	307 / 4%
Aneurin Bevan Health Board	186 / 4%	280 / 4%

Table 8 – Numbers and percentages of respondents by health board for free-text and total survey respondents.

4 – Findings

Area	Category	Negative respondents	Positive respondents	Total respondents
General comments	Communication between patients and staff (NOS)	287	287	554
	Waiting for appointments (NOS ⁷)	335	249	563
	Communication between staff and/or institutions (NOS)	165	44	206
	Waiting to be seen on the day (NOS)	152	31	181
	Concerns about staffing levels (NOS)	131	-	131
	Out of hours and weekend care (NOS)	60	8	68
	<i>Total respondents giving general comments (NOS)</i>	<i>1223</i>	<i>885</i>	<i>1852</i>
Specific comments	Nursing care	388	785	1074
	Surgery	181	393	541
	Hospital doctors (NOS)	73	411	476
	Consultants and specialists (NOS)	72	408	465
	Investigations and diagnostic services	288	198	475
	GP	246	161	401
	Chemotherapy	85	233	303
	Aftercare	199	97	290
	Radiotherapy	67	191	251
	Emotional, social, psychological support	94	43	132
	Oncology	31	90	117
	Pain management	73	10	82
	Accident & Emergency care	33	8	41
	Urology	7	34	39
	Physiotherapy	12	12	24
<i>Total respondents in specific areas of treatment and care during the cancer journey</i>	<i>1323</i>	<i>1871</i>	<i>2508</i>	
Other comments	Hospital environments	182	53	240
	Travel-related issues during the cancer journey	122	45	161
	Food and catering	128	26	153
	Financial concerns	35	3	36
	<i>Total respondents in other areas</i>	<i>429</i>	<i>116</i>	<i>525</i>

Table 9 - Summary of main categories comprising thematic framework of cancer patient experiences.

⁷ Not otherwise specified.

4.1 – Overview and notes on interpretation of results.

Comment type	Number of respondents	% of total free-text respondents (n = 4672)
Positive	3818	82%
Negative	2313	49%
Positive NOS	1035	22%
Negative NOS	117	3%
Total	4672	100%

Table 10 - Breakdown of total free-text comments as either positive or negative.

4672 participants provided free-text responses. Of these, 2313 respondents provided negative comments on aspects of their care and treatment, while 3818 provided positive comments (a ratio of 0.60 : 1). Of these, 237 negative and 1727 positive comments were general (e.g. ‘my care was excellent’ or ‘poor care generally) or miscellaneous, and these are identified as NOS (not otherwise specified). By comparison, in the closed questions section of the WCPES survey, 58% (n = 4093) of respondents rated their cancer care as ‘excellent’, 31% (n = 2187) as ‘very good’, 8% (n = 595) as ‘good’, and 2% (n = 166) as ‘fair’, and 1% (n = 51) as ‘poor’ (QualityHealth, 2014)⁸.

In interpreting the results of free-text comments, it is important to keep in mind that the majority of respondents provided positive comments about their care; however, a far greater proportion of total positive responses were not identified with a specific area (3% of comments were Negative NOS vs. 22 % of Positive NOS comments). This is indicative of a trend present at all levels in the free-text data, where positive comments tended to be of a more general quality and scope than negative comments. This means that at greater levels of specificity, numbers of respondents providing negative comments may be close to or outnumber those providing positive responses, despite positive responses outnumbering negative responses overall.

All counts relating to comments in this report refer to numbers of respondents providing comments of that specific type and/or area, and **as such negative and positive comments in a given area may not equal the total amount of respondents given** (i.e. because individual respondents may have provided both negative and positive comments). The terms ‘respondents’ and ‘participants’ refer to those who gave free-text comments (unless otherwise specified). Readers are advised to note the limitations of counts in interpreting the data without recourse to the content of comments, as the counts do not take into account the strength of comments or their seriousness (e.g. a comment suggesting that meals could be improved in a specific area would count towards the total in the same way as a more serious complaint relating to care or treatment, and the same logic holds true for positive comments). It is also important to keep in mind that the data discussed reflect patient experiences and perceptions, and that no claims are made regarding the events described beyond reporting these findings as such. Finally, it is important to state that the weight of exemplary comments provided in each section is not intended to reflect the number of comments given, but

⁸ Data were missing for 260 participants.

rather the general content of the areas of comment being discussed (e.g. it may be that four small quotes are provided to illustrate a theme with 100 respondents, while six are used to illustrate a theme with 40 participants).

Description of the findings begins with more general comments, before more specific areas of the cancer journey are explored. This is followed by a discussion of the overarching themes emerging from the data, and areas for further potential future investigation.

4.2 – General Comments (NOS):

4.2.1 – Overview

1428 respondents provided general comments not identified with a particular staff or treatment area, of which 969 were negative and 581 were positive (a ratio of 1.60 : 1). Individual areas with these general comments are summarised in table 1, and discussed in order of number of comments in the sections that follow.

Area	Negative respondents	Positive respondents	Total respondents	Total respondents as % of free-text respondents (n=4672)	Ratio (negative-positive respondents) ⁹
Waiting for appointments (NOS)	335	249	563	12%	1.35 : 1
Communication between patients and staff (NOS)	287	287	554	12%	1 : 1
Communication between staff and/or institutions (NOS)	165	44	206	4%	3.75 : 1
Waiting to be seen on the day (NOS)	152	31	181	4%	4.90 : 1
Concerns about staffing levels (NOS)	131	-	131	3%	-
Out of hours and weekend care (NOS)	60	8	68	1%	7.50 : 1
Total respondents giving general comments (NOS)	1223	885	1852	40%	1.38 : 1

Table 11 - Breakdown of sub-themes within general comments not identified with a specific staff or treatment area.

⁹ Ratios are rounded to three significant figures.

4.2.2 – Waiting for appointments (NOS)

In the closed questions portion of the WCPES survey (question 2), 78% of respondents (n = 5520) indicated that they thought they had been seen ‘as soon as necessary’, with 12% (n = 839) feeling that they ‘should have been seen a bit sooner’ and 10% (n = 685) indicating that they ‘should have been seen a lot sooner’ (QualityHealth, 2014)¹⁰. In the free-text portion of the survey, 563 respondents related general experiences of waiting for appointments, of which 335 were negative and 249 were positive (a ratio of 1.35:1). All negative comments in this section were of a general nature, reflecting concerns over the length of time taken waiting for appointments relating to diagnosis and/or treatment.

Quicker appointments.

I am still waiting for my appointment 6 months after my surgery.

The wait to start treatment is too long. I was initially told I should start treatment by August. I have an appointment for [date removed]. The long delay is disappointing. I was diagnosed in February.

Waiting times for consultancy/results/appointments.

249 respondents related positive experiences in relation to waiting times for appointments, praising the speed of care delivery across their cancer journeys.

My diagnosis to cure all happened within about ten weeks.

On diagnosis (at my first outpatient appointment) I was admitted to hospital on the same day and my treatment was started immediately.

The whole process has been quick and very efficient. All staff and facilities amazing.

I went to my GP on the Thursday and I was seen by the following week. The consultant in the hospital which I had biopsies taken and told that same day I had cancer, and it was dealt with very quickly and I was very happy with the care I was given and how quickly it was treated.

Comments received in relation to appointments suggest that while for a number of participants these happened quickly, there were also a number who perceived delays within the cancer journey.

¹⁰ Data was unavailable for 308 participants.

4.2.3 – Communication between patients and staff (NOS).

554 comments were mapped to this theme, of which 287 were negative and 287 were positive (a ratio of 1:1). Of these, 142 respondents expressed concerns about a lack of information relating to their diagnosis and treatment.

More information on the investigations and outcomes during the interim stages would have been helpful.

An explanation of how severe the long term side effects could be.

More in depth info/discussion regarding the disease at onset and throughout.

As I am a trained nurse, I felt the doctors and nurses assumed I had the relevant information, so did not give me enough explanations of my cancer and treatments.

I have not been given information about future treatments, scan, stoma reversal time scales etc.

Within this group, 60 respondents expressed concerns around information on treatment options, and the impact that this had on their ability to make choices about their care. This included several references to what participants perceived as ‘hidden’ financial or other constraints on the care available to them in Wales.

Treatment option and side effects could have been more fully explained.

Care plan was vague; I didn't realise I would have to decided my course of treatment for prostate cancer

No choice given as to which treatment. Could my cancer have been treated with chemo only?

Cancer treatment choices offers may have been significantly limited by financial constraints imposed. Where this so, it should be made clear to enable other possible options to be considered.

Originally opted for radiotherapy (brachytherapy) but more recently, after learning the effects long term, opted for surgery - robotic prostatectomy being the best option was not

available in Wales, and so had to resort to private health treatment in [hospital removed] at an NHS hospital.

Alongside concerns around information provision, 90 participants expressed concerns about the manner in which they had been dealt with by staff, most commonly in person, but also by mail/email or on the telephone. Of these, 54 people described issues with the manner in which their diagnosis of cancer was provided to them.

I felt I was given \my bad news\" in a rather brutal and unsympathetic fashion. How much training in this particular aspect is given and more inputs in or monitored!"

I was told about my original 'shadow' over the telephone. This really must not happen to anybody.

The manner in which I was informed I had cancer was quite brutal and it took us both a long time to get on an even keel again.

The original time I was told I had terminal cancer and nothing could be done for me was handled very badly. There was no support at all and the doctor was in and out of the room in about 6 minutes. It was as if my life counted for nothing, as if I was being thrown away.

The way I was given the diagnosis of terminal illness.

I feel very disappointed and let down by [hospital removed] and in particular the way in which I was told about having cancer. Ah (jokingly) - you have two tumours the old girl!!!

For others, the news appeared to come from staff who were not aware that the patient had yet to be informed of their diagnosis.

The way my family were told that I had cancer. They were told by a nurse who was taking me to the cancer ward. I don't think she could have known that my family had not been told by a doctor.

The first mention of the word 'cancer' was used by a doctor in the middle of a sentence. It seems that he may have believed that I had already been informed.

Yes, the way that I was told that I had cancer. I had no idea and was put in a room for 2 hours before doctor came in and just told me like I knew, he was quite shocked I had not been told.

For a number of free-text respondents, not having the opportunity to bring family members with them when being told about their cancer was a significant issue.

[A]fter having scan was told I had cancer. Nobody with me when told. It still upsets me.

I took great exception to the manner in which I was told, no privacy, no family member present, and people each side of me could hear.

The initial diagnosis was given from a young doctor and she wasn't very sympathetic to my concerns.

When told you have cancer, family should be present for support.

In the closed questions section of the WCPES survey¹¹ (question 11), 70% (n = 4200) of respondents indicated that they had been told that they could bring a family member or friend with them when first being told about their cancer. This compared with 30% (n = 1761) who stated that they had not been told about bringing a family member or friend. 11% (n = 774) stated that this was 'not necessary', 1% (n = 91) were told by phone or letter, and 5% (n = 337) indicated that they did not know or could not remember (QualityHealth, 2014)¹². In addition, 84% (n = 6073) of respondents indicated that they were informed of their cancer diagnosis 'sensitively', while 11% (n = 757) agreed that it 'should have been done a bit more sensitively', and 5% (n = 360) 'a lot more sensitively'¹³ (QualityHealth, 2014). However, for those who provided negative free-text comments in this area, their responses reflect feelings that both staff and patients themselves could have been better prepared for news of their diagnosis, and in particular, that opportunities for emotional support (whether from staff or from family members) could be increased.

216 participants made positive comments about the manner in which staff interacted with them during their treatment journeys. Of these, the majority (n = 194) highlighted personal qualities (e.g. kindness, empathy, sympathy, respect, compassion) in interactions with staff as positive experiences of their treatment. These experiences were associated with feelings of confidence and safety in relation to patient care and treatment.

Very pleasant. Treated like a person, not an object.

¹¹ Percentages of respondents for particular closed questions within the WCPES survey are calculated using the total number of WCPES respondents (n = 7352) minus the number of participants for which data were not available for that area.

¹² Data were unavailable for 189 participants.

¹³ Data were unavailable for 162 participants.

I was treated with respect, courteousness, understanding. From the receptionist receiving me at entry to the outpatient team as a whole was an excellent experience under a stressful time of treatment.

All of the staff that have treated me over the last two years have been outstanding. They have all showed such compassion and understanding. Nothing is too much trouble.

All the hospital staff were very kind and caring and helped me to be strong. I am very grateful to them.

Staff seemed to care and usually remember you on return and it makes you feel safe.

Everybody treated me well and with respect and this was good for my well-being and morale.

In addition, 74 respondents reported positive aspects of interactions with staff relating to professional aspects of their care (e.g. that staff were helpful, efficient, competent etc.).

Responsive, professional, provided good, clear advice.

Everyone I came into contact with was helpful and friendly, and did their job in a professional and competent way, even when busy.

Staff in the CD Unit were amazing - professional, supportive encouraging, cheerful and friendly.

Professionalism and friendliness of staff.

Staff at [hospital removed] were extremely caring and efficient.

75 respondents indicated that information given to them about their treatment had been a positive aspect of their experience.

Being kept updated as to my treatment and having questions answered fully.

My care and advice were really excellent.

Everything was discussed with me and I was always asked if I had any questions.

Very informative on treatment required.

Of these 77 respondents, 12 also pointed to the availability of information by telephone as important resource during the treatment phase of their journey.

The care was excellent and staff were really helpful, always on the other end of a phone line.

Hot line to [hospital removed] was superb.

Having a 24 hour call helpline very reassuring.

I had to phone [name removed] to ask why I wasn't being treated as I thought early diagnosis gave a better chance of a cure. They explained I was a low risk prostate cancer patient. Very helpful put me at ease.

While negative experiences of interaction with staff were associated with expressions of uncertainty and anxiety, positive experiences whether in terms of their manner, professionalism or the information provided to patients were linked with expressions of confidence in the treatment and care offered. While information provision appears as the most important aspect of interactions with staff, the manner in which this was provided was also significant in respect of building confidence in the care and treatment offered. Timeliness and availability of information is also significant, as seen from positive comments regarding telephone contact during treatment. This is indicative of a theme present across the treatment pathway, where information provision remains significant both as a negative and positive aspect of care for patients.

4.2.4 – Communication between staff and/or institutions (NOS).

206 respondents commented on aspects of their treatment journeys involving communication between staff and/or institutions (e.g. information sharing between specialists and GPs where the latter were not identified as the source of the problem, sharing of notes and/or test results between hospitals/sites etc.). Of these, 165 described negative experiences, while 44 gave positive responses (a ratio of 3.75:1).

165 respondents described poor experiences relating to inter/intra agency communication, almost all of which were general in nature.

[Welsh] At times, a lack of clear communication between different departments/clinics made the situation more and more difficult, eg a number of additional visitors/travellers to the hospital [several words unreadable] because of lack of communication: think beforehand.

Communication/co-ordination on the [unit removed]

Communication between hospital doctors and departments. Speediness of communication between departments and to other hospitals.

Bunker mentality between departments/consultants - emphasis should be on common \team\" approach."

Better communication between wards and doctors

Given that this theme references examples of communication in which patients were not involved directly, the generality of the comments is perhaps unsurprising. However, what they do reveal is that a sizable number of free-text respondents perceived negative aspects of their journeys to have originated from poor communication between staff and/or institutions involved in their care. Further examples of this in relation to specific staff areas are discussed later in section 4.3.

44 respondents reported positive experiences of inter/intra agency communication, and the beneficial impact that this had on their care.

Everything worked well in efficient coordinated way including follow-up.

Good continuity of care received during my chemotherapy at the cancer treatment centre at [hospital removed].

I appreciate the communication between hospital, GP, out of hours etc. It means I don't have to repeat myself so often. It also means I have instant treatment.

The communication between [hospital removed] and [hospital removed] was very prompt and I was treated very quick from when I was diagnosed to the present.

In contrast to more general comments around poor experiences relating to inter/intra agency working, positive comments identified consistently perceptions of good communication between staff and/or institutions as being associated with speediness of treatment, as well as good continuity of care, and this was associated with other positive comments around information provided during the treatment journey, with resulting expressions of confidence in the treatment being received.

4.2.5 – Waiting to be seen by staff on the day (NOS)

Of the 181 participants in this category, 152 related negative experiences of waiting on the day of their appointment, with 31 giving positive experiences (a ratio of 4.90 : 1). Negative experiences almost entirely referred to the additional time taken before being seen by specialist staff.

Sometimes as an outpatient with an appointment, the wait is too long! Eg 1 1/2 to 2 hours, even when you arrive well before time.

I have had two appointments with a cancer specialist, on both occasions I was seen approx 2 1/2 hours after my appointment time; I was told this is \normal\" and nobody seemed to care.

Waited at least 2 hours at outpatient clinic, understand they are very busy but system needs overhauling as can be traumatic.

The timing board could be more accurate (on time/20 mins/40 mins delay). Could lead to problems with the bladder.

Appointment times (4 so far) have all been missed - up to 1 1/2 hour for me as I feel fit but a real trial for some others.

The vast majority of these comments concerned (unspecified) clinic appointments, and within these responses most commonly referred to delays of around 1.5-2 hours beyond their appointed time. While for some participants this extended waiting time was an inconvenience, for others these delays exacerbated existing physical and/or emotional problems. It is also important to note that many respondents providing such comments added qualifications indicating their perception of services being under pressure, as a reason for these delays.

A smaller sub-set of respondents in this theme (31) reported good or acceptable waiting times on the day of their appointments.

[W]aiting times have never been lengthy.

[T]here was minimal waiting around.

No long waits in outpatients.

Well organised with good time keeping.

Appointments have been kept on time and in my view within reasonable waiting time.

Short waiting times.

While for some, waiting times on the day of appointments were not an issue, a greater number of participants reported issues in this area. In addition, for some, protracted waiting times were a source of additional problems and discomfort relating to their condition (e.g. bladder problems). Comments also indicate that while patients are aware of demands on services, there are outstanding unmet needs in relation to discomfort and uncertainty around waiting times on the day.

4.2.6 – Concerns about staffing levels (NOS)

131 respondents described concerns around staffing levels in general, all of which were negative, and appeared in the context of hospital care. These comments reflected perceptions of staff being under pressure and lacking adequate numbers. Some comments were of a general nature, reflecting calls for more staff.

Obviously more staff.

More staff on the wards.

Improved staffing levels are a must.

Staff shortages are always noticeable.

Other respondents linked perceptions of inadequate staffing to positive examples of good care (i.e. in spite of perceived shortages), or as good as could be expected under difficult circumstances.

Wonderful staff, always helpful and friendly even when they were understaffed.

They were all very kind, all the staff were great and I thank them all. They are all overworked; I don't know how they cope every day.

Staffing levels – though I must stress staff always went beyond the call of duty to care for their patients – I never experienced a cross word.

Full marks to NHS. You're doing a great job, but understaffed.

Although the staff were always helpful, at times they were short-staffed and \run off their feet\''''

However, for others perceptions of inadequate staffing levels were linked to a lack of available time to spend with patients.

I had to stay overnight with my husband in [hospital removed] for few nights, he was in for 10 nights, not fit to be left, not enough staff.

Stay on general ward in the [hospital removed] had a few problems and could be improved, short of staff and often 'forgotten' in side ward.

Staff having time to spend with patients just to listen sometimes, wards being understaffed.

More ground staff as no one seem to have any time to do all the things require of them.

Clinic was very friendly and supportive. Ward then was a bit of let down due to them so busy to give too much time.

Other respondents in this area made explicit links between examples of poor care and inadequate staffing levels.

General care, especially for elderly people, seemed pretty bad. I put this down to not enough time or staff... but sooner or later there will be a real disaster.

The [hospital removed] is far too busy and mistakes are obviously being made.

Staff too busy. Hardly saw them, lost 1st 4lb in 13 days!

Had I not been self sufficient following my operation I feel my care whilst in hospital would not have been acceptable. This is not due to the staff competency but due to lack of numbers.

I was in hospital in September and the staff were stretched to the limit. The care in hospitals is very poor, because of the shortage of staff. I have been fighting cancer for [detail removed] and other than short staffed hospital I have no other complaint to make. My stay in hospital was terrible, I was only there 6 days and was glad to come home to be looked after properly.

Respondent comments in this area were typified by recognition of competency and commitment among hospital staff in what were seen as difficult circumstances, as well as examples where inadequate staffing was seen to contribute directly to poor care. These concerns relating to staffing levels not otherwise specified is consistent with those in specific areas of the cancer journey.

4.2.7 – Out of hours & weekend care (NOS).

60 participants provided negative comments regarding out of hours & weekend care not identified with a particular staff or treatment area, while eight provided positive responses (a ratio of 7.5 : 1 – all positive comments were of a general nature, e.g. ‘good care at the weekend’). These comments presented concerns about staffing levels at weekends and during the night in hospital wards, as well as examples of poor care (again, particularly during the night). Noise levels during the night, and difficulties obtaining out of hours advice and/or treatment for problems arising during treatment were also significant concerns. Some of these comments were general, reflecting concerns around quality of care.

Night staff whilst in were remote and unfriendly.

[M]y husband contacted out of hours service, following fall, which came as a result of combination of chemotherapy and oramorph, and found them to be unhelpful, unsympathetic; he made a complaint about this. We both felt abandoned

The night staff were poor to the extent of being uncaring.

I have strong concerns over the diligence of night staff in one of the wards for post operative patients.

Night staff whether due to shortages, not as efficient and caring as day staff. This was echoed by other patients in hospital same time myself

Noise during the night on hospital wards was a concern for a number of participants, many of whom reported difficulty sleeping as a result.

I found that some of the night time staff were very noisy - not all - but certain teams seemed oblivious to the fact that there were poorly patients needing rest...not to hear constant laughing and loud conversation about out of work activities.

Too many noises at night eg moving beds and the ward was next door to a HDU ward which kept many people awake.

The night staff could have been more respectful it was difficult to sleep because of noise from them.

Other participants reported difficulties in accessing specialist support and advice during the treatment phase of their cancer journey.

A cancer doctor available at the weekend.

There are no evening and weekend oncology trained doctors available for patients at my hospital, so ill patients on chemo are seen in A & E; not good enough, high risk of infection.

Contacting out of hours medical staff for advice.

Weekend cover from cancer department. A&E do not have any expertise if taken ill.

Once again, for some participants staffing levels were an issue during the night on hospital in-patient wards.

Level of staffing overnight

More night staff. When asked for attention at night, ie bed bottles, waited till could wait no longer and made unnecessary mess.

Night time on the ward was awful due to it being short staffed.

They tried their best, not enough staff though. Night times very bad.

These comments were not matched by a significant number of positive comments regarding out of hours/weekend care (NOS). While the responses can only reflect the experiences of 60 participants, the specificity of some of the comments (e.g. noise on hospital wards) suggests that there may be specific areas or sites that may warrant further investigation with a view to improving out of hours care.

4.3 – Specific areas of treatment and care during the cancer journey

While a number of participants gave only general comments about their experiences, the majority of respondents provided more detailed accounts of particular areas of their cancer journeys. Once again, it should be noted that negative comments tended to be more specific than positive comments, meaning that the latter tend to outnumber the former as areas become more specific. (in spite of positive comments outnumbering negative in the majority of areas here explored). Specific areas of comment mapped to the topics given in table 12, and findings related to each are now described (areas are discussed by order of number of respondents, largest to smallest).

Area	Negative respondents	Positive respondents	Total respondents	Total respondents as % of free-text respondents (n=4672)	Ratio (negative-positive respondents)
Nursing care	388	785	1074	23%	0.49 : 1
Surgery	181	393	541	12%	0.46 : 1
Hospital doctors (NOS)	73	411	476	10%	0.18 : 1
Investigations and diagnostic services	288	198	475	10%	1.45 : 1
Consultants and specialists (NOS)	72	408	465	10%	0.18: 1
GP	246	161	401	9%	1.53 : 1
Chemotherapy	85	233	303	7%	0.36 : 1
Aftercare	199	97	290	6%	2.05 : 1
Radiotherapy	67	191	251	5%	0.35 : 1
Emotional, social, psychological support	94	43	132	3%	2.19 : 1
Oncology	31	90	117	3%	0.34 : 1
Pain management	73	10	82	2%	7.30 : 1
Accident & Emergency care	33	8	41	<1%	4.12 : 1
<i>Urology</i>	7	34	39	<1%	0.21 : 1
<i>Physiotherapy</i>	12	12	24	<1%	1 : 1
<i>Total respondents in specific areas of treatment and care during the cancer journey</i>	1323	1871	2508	54%	0.71 : 1

Table 12 - Breakdown of respondents by specific staff or treatment area¹⁴

¹⁴ General responses were provided regarding several medical specialties, where significant sub-themes beyond general expressions of dis/approval were not found. To avoid repetition, these comments, identified in the table by their italicised titles, do not have separate discussion sections.

4.3.1 – Nursing care.

4.3.1.1 – Overview

1074 respondents provided comments relating to experiences of nursing care during their cancer journeys. Of these, 388 participants gave negative comments, and 785 gave positive responses (a ratio of 0.49:1). In contrast to the remainder of the data set, negative responses tended to be more general than positives in relation to nursing, with 163 of the former type being general (e.g. ‘nursing care non-existent’), and 74 of the latter classified likewise (e.g. ‘nurses were all lovely’). However, in both the negative and positive comments, several sub-themes relating to nursing specialties emerged, and nursing was by far the largest staff area for which free-text respondents gave comments (the nearest being surgery with 589 participants, less than half the number for nursing). The following sub-themes are ordered by number of respondents (largest down to smallest).

Nursing Area	Negative respondents	Positive respondents	Total respondents	Ratio (negative-to-positive respondents)
General nursing (NOS)	127	402	517	0.25 : 1
Specialist nursing (NOS)	33	92	124	0.36 : 1
District nursing	28	39	66	0.72 : 1
Chemotherapy nursing	-	62	62	-
Breast care nursing	16	33	48	0.48 : 1
Clinical Nurse Specialist (CNS) care	10	29	39	0.35 : 1
Key Workers	20	9	26	2.22 : 1
Nursing NOS	163	74	236	2.20 : 1
Total Nursing	388	785	1074	0.49 : 1

Table 13 - Breakdown of respondents by area of nursing.

Across these areas, several overarching themes emerged:

- **Experiences of nursing care were characterised broadly as positive** – this holds true both in relation to general comments about nursing, and specific areas within this staff area. This is particularly the case with specialist areas of nursing, where the majority of complaints appear to relate to nurse availability, rather than poor care provided. It is also of note that the language used in many of the positive comments conveys strong messages relating to the quality of care and dedication of nursing staff. This is not to diminish the importance of examples of poor care (which were provided), but to acknowledge that the majority of comments given in relation to nursing were positive.
- **Many respondents perceive nurse staffing levels to be a problem** – both negative and positive comments often reflected concerns about nursing workloads and staffing levels. Many examples of positive care were ‘in spite of’ these pressures, while examples of poor care were linked to staffing and resource constraints.

- **Availability of specialist nursing staff for information and reassurance during treatment was important and highly valued** – positive comments about nursing specialties often related to the availability of specialist nurses to give advice or support during treatment, specifically in terms of providing information about treatment and likely side effects. This was associated with increased confidence in the treatment programme, and reduced anxiety around issues such as side effects of radiotherapy and chemotherapy. Conversely, when specialist nurses were not available during treatment, the reverse was often the case (i.e. experiences were linked to increased stress and anxiety).

4.3.1.2 –General nursing (NOS)

517 respondents provided comments relating to nursing that were not identified with a specific area of specialty. Of these, 127 participants provided negative comments, while 402 provided positive responses.

4.3.1.2.1 – Experiences of care provided by nursing staff (NOS)

478 participants provided comments relating to general experiences of nursing care, of which 132 respondents gave negative comments, and 410 related positive experiences. In terms of negative experiences, almost all of these involved examples of poor practical care.

When I had my second operation I was on a surgical ward, I received bad care, resulting in contracting MRSA. I was left to clean myself after a nurse refused to help me; she insisted I went into the shower with an open wound (I refused) and was left with fluid from drain site [word unreadable] - hence MRSA. I put in a complaint to the ward sister and haven't ever received any apology. My treatment was delayed 3 months because of MRSA.

One nurse in chemo unit was always rushing and was very rough when taking out the needle. I ended up with PIC line and was allergic with dressing. I had iodine to clean and one day she used the hand cleaner to clean my PIC. As you can imagine, I became very sore

Care of the ward and more compassion by nurses. I felt some of the nurses left me feeling humiliated when I was in a mess and one nurse in particular made me clean it up myself.

During the period I was there I saw the rules of the ward go out the bathroom window. While I was there someone fell on the floor. He pulled the red [cord] with no response. In the end he sat on a stool, dragged himself to the door, and called for help. He waited more than ten minutes

Nurse care following operation was non-existent. After requesting pain relief I wasn't given any for over 2 hours. The discharge procedure was appalling. I received no advice or given any prior warning before being told I was leaving and before I left the room a nurse came in

to change and clean the bed. I was also left to walk to the car park having only had my operation a few hours earlier

Nurses were incompetent. When removing the meds needle from my hand, tore it out taking the skin with it and just walked away while my blood spurted out. A cleaner lady in dark green ran to me and sorted it out. When I spoke to the nurse concerned, she glared at me and laughed saying \Shame\!"!

A sub-set of negative respondents (24) commented in particular on poor care at night, often linked to perceptions of staff shortages.

The first thing that the night staff did was move my bedside table away so I could not reach the water or the call bell. The lack of care in [ward removed] caused me to have a relapse and I was taken back to HDU.

The ward at night was very noisy and no-one could sleep. Nurses were talking loud and wheeling trolleys about. We were up at six o'clock and no food till 9 o'clock.

Not enough nurses on wards, particularly at night.

Some nurses when on overnight care could not be bothered to help in any way.

The patients were very often looking out for each other. Lack of care and understanding by some night nurses especially dealing with elderly patients with serious illnesses. I felt very vulnerable at times.

I was very disappointed that some of the night staff were extremely noisy, laughing, calling out one to another and when the patients were endeavouring to sleep at night - this seemed very thoughtless!!

In cancer ward [detail removed] in [hospital removed] there is only one member of staff on in the nights. The poor nurse was run ragged and I think there is potential for mistakes to be made.

Despite examples of poor care, a far greater number of participants (410) related positive experiences of nursing care, which tended to be of a much more general nature than negative comments.

[Welsh] I am very grateful for my treatment and care by the nurses and carers

The doctors and nurses were brilliant

[Welsh] More notice should be taken of doctors and nurses and all the staff, they deserve great respect for their work.

The doctors, nurses, and all staff were excellent.

Negative comments in this section point to specific experiences of poor care in relation to general nursing, the vast majority of which were indicated to relate to in-patient care within hospital wards. Notwithstanding the seriousness of these comments, it is also important to recognise that the number of positive comments vastly outnumbered negative responses, while their generality suggests that these positive experiences were stable across the hospital treatment and care stages of participant cancer journeys.

In the closed questions section of the WCPES survey (question 47), 59% of respondents (n = 4302) gave replies relating to confidence and trust in ward nurses. Of these, 73% (n = 3153) expressed confidence 'in all' ward nurses, 26% (n = 1105) indicated confidence 'in some of them', while 1% (n = 44) stated that they did not have confidence in any of the ward nurses (QualityHealth, 2014)¹⁵.

4.3.1.2.2 – Experiences of communication and interaction with nursing staff (NOS).

200 participants provided comments about communication and interaction with nursing staff (NOS), of which 49 were negative and 153 were positive. While four of the negative responses were miscellaneous, the remaining 47 detailed negative experiences of staff manner in patient interactions with nursing staff.

The senior nurse who admitted me to the cancer ward should be ashamed to call herself a nurse, The way she spoke and treated me was disgusting.

Some nurses not nice attitude towards me. Perhaps it's because they are a gynae ward. Not much support there.

The ward nurses showed little care or concern - very, very disappointed.

Some good nurses – but in equal amount, some very lazy, gossiping and bad tempered nurses too.

¹⁵ Data were unavailable for 3055 participants.

As a retired [name removed] I was shocked at the uncaring attitude and rudeness of the nurses - I assume this is due to the change of the training (i.e. university training) being not appropriate to train nurses.

The majority of comments in this section related to what patients experienced as an uncaring or impolite manner in their nursing care on hospital wards. However, 153 participants praised the manner of nursing staff in care given to them during their cancer journey.

[A]ll nurses very pleasant and efficient.

All the nurses and my cancer care consultant have been very kind, informative, and helpful

The nurses are brilliant, understanding, and fighting my case. They are sympathetic and helping wherever they can.

The hospital nurses remember me and chat freely. Lovely!

The nurses were very caring, really good even though they were very busy.

Majority of nurses and staff on [wards removed], and Outpatients efficient, pleasant, and caring.

At both hospitals...the nursing staff were always pleasant and helpful, creating a happy and positive atmosphere, especially the day staff.

The nurses that administer the area and in my case carried out tests were very caring and efficient but very obviously overloaded with work.

Participant experiences in this sub-theme point to a general pattern of positive experience in terms of the manner of nursing staff. This persisted even in cases where patients perceived staff to be under pressures linked to staffing issues.

4.3.1.2.3 – Nursing staff levels and availability.

In the closed section of the WCPES survey (question 49), 58% of total respondents (n = 4287) provided responses relating to whether or not they felt that there were enough nurses on duty to care for them during their time in hospital. Of these, 60% (n = 2580) agreed that ‘there were always or nearly always enough on duty’, 29% (n = 1229) indicated that ‘there were sometimes enough on

duty', while 11% (n = 478) indicated that there were rarely or never enough on duty (QualityHealth, 2014)¹⁶.

In the free-text section, 131 participants gave negative comments relating to nurse staffing levels. These comments were linked to positive experiences (i.e. positive care in spite of what respondents perceived to be a lack of available staff), as well as unmet needs and/or examples of poor care. The vast majority of these comments concerned nursing within hospital in-patient wards.

Sometimes the wards were short of nurses and we had to wait when call bell used.

I always felt that the nurses were under pressure and therefore time allocated to patients was limited which often leads to limited information at times. The Day Unit staff appeared to be 'rushed off their feet'.

Possibly more nursing staff on the wards day and night On some wards the nurses are literally running from one patient to the next.

I think the nursing staff do a very good job but feel there should be more of them. Sometimes they are very stretched to give the right care and treatment needed.

Found some problems on all wards, lack of nurses and communication. Nurses do not have time for the right amount of care. Auxiliary staff are too thinly spread too. My family spend many hours chasing results, appointments and information.

Nurses and other staff - most of them excellent but severely overworked.

More nurses as they couldn't take me to toilet and wait with me as I was having dizzy spells due to low blood pressure. They left me on toilet, only to come back and find me on floor with bloody gash on my head.

At times the ward appeared to be short staffed and the nurses were kept very busy, especially as the ward was very full involving patients who had been moved from other overflowing wards,

The nursing staff on the wards work very hard but are very overworked. Staffing levels need to be improved.

Comments here are part of a wider theme present in other staff areas, where perceptions of staff shortages were allied to both positive and negative experiences of care.

¹⁶ Data were unavailable for 3065 participants.

4.3.1.3 – Experiences of specialist nursing (breast, community nursing specialist or NOS)¹⁷

211 respondents provided comments relating to specialist nurses identified with breast care, community nursing specialists or not otherwise identified with a specific area of speciality. 61 respondents gave negative comments (of which 32 gave responses of a general or miscellaneous nature). 13 respondents commented on the availability of specialist nurses both during and after treatment.

I was given contact details for specialist nurses but could never contact them.

Had only 2 visits from the [specialist] nurse, could have done with more support from her, phoned but calls weren't answered.

I felt I needed specialist nurse support (phone or personal contact) following my 3 operations, especially I experienced difficulty with chemotherapy. Needed emotional support, although I did not contact anyone. I live alone and did ask if there was any advice on home support, no action.

It has been difficult, if not impossible to contact the nurse specialists in both urology and [hospital removed]. This has delayed getting advice and treatment at least twice and caused stress and anxiety.

Eight negative comments contained critical statements relating to specialist nurses in breast care.

It was sometimes difficult in contacting my breast care nurse for advice. I had the impression that her work load was so busy that she did not have sufficient time for patients.

I was refused by the breast care nurse to be seen by her on a number of occasions post-op, which led to me having to attend the hospital 3 times a week for seven months to have my wound dressed. I was treated appallingly only by her.

I have never been assigned a specialist breast care nurse and have not been aware of extra services available to me.

Yes, the time I had to wait to see a breast nurse in the [hospital name removed] was a month!! I waited 6 weeks for operation which caused me great stress.

Eight further negative responses referred to problems with the availability of staff in this area.

¹⁷ In this section 'specialist nurses' have been combined for purposes of clarity and to reflect the organisation of nursing specialities. The separations in this section into breast, CNS, and specialists nurses not specified is reflective of the language used by respondents.

The CNS left after a very few weeks, approx. 3 1/2 years ago and there has not been one since.

I was told that the CNS nurse would contact me. I admit that I did not ask when and in the end tried with difficulty contacting her. In my opinion she should have responded to the first phone message that I gave.

Three weeks waiting for information is too long, especially when in shock. CNS [hospital removed] rely on an answerphone they need mobiles.

I don't know if I still have cancer, I've been waiting 5 weeks for the final CT scan. I still don't have an appointment. Either my CNS has a work load too large to cope with or she is incompetent.

Once again, these comments point to the importance of contact and information during the treatment journey, absence of which was linked to increased stress and anxiety.

169 participants praised the care they had received from specialist nursing staff, of which the majority reflected general comments (e.g. '[T]he specialist nurse [was] outstanding'), while 51 praised specifically the manner in which staff in this area had interacted or communicated with them during their care.

[T]he specialist nurses on the ward were very informative and compassionate.

Specialist nurses were very efficient and helpful. Was nice to be treated by the same nurses every time.

Yes, in the way specialist / consultant special nurses treated you with empathy, not sympathy, giving you confidence and calmness to deal with the illness.

I have found my nurse specialist to be very helpful and always has time to listen to my concerns. She will always do her best to answer my questions. She always returns calls.

The breast cancer unit of [location removed] was a brilliant service. I have to say the nurses there deal with this every day but they remained compassionate and as if I was their first patient.

Excellent follow-up from nurses at breast care [location removed] who phoned and called to see me before my surgery.

I was very impressed with my clinical nurse specialist, she was very caring. Gave me good advice and empathised with me and my family.

The clinical nurse specialist coordinating all of the appointments including scan etc. and always being there if needed.

Once again, in this sub-theme we see positive patient experiences of the manner in which specialist nurses dealt with them, linked to both high quality information provision and confidence in their treatment.

4.3.1.4 – Experiences of chemotherapy nursing

62 participants provided positive responses in relation to chemotherapy nursing, reflecting general satisfaction with this area of nursing (e.g. ‘The chemo nurse care’), as well as more specific comments relating to communication and interaction with staff.

My chemotherapy nurse was patient, caring, understanding, knowledgeable and extremely professional, and made me feel treated as an individual.

The care and treatment I had from the chemotherapy nurses on [ward removed] at [hospital removed] was excellent, they were very kind and caring and any problems I had I could telephone them anytime to discuss.

The nurses were very good on the chemo ward and radiotherapy unit, I was treated with compassion and I am able to ring the ward at any time which is a great comfort to us as a family.

Patient responses in this sub-theme indicate the importance of specialist nursing support and its link with information provision, not only during treatment but also through out of hours telephone contact. The comments indicate that this combination of factors was helpful to patients during treatment.

4.3.1.5 – Experiences of district nursing.

66 respondents provided comments relating to experiences of district nursing, of which 28 were negative and 39 were positive. Of the negative comments, 18 were general (e.g. ‘[T]he district nurse let the side down’) or miscellaneous, while a further 10 provided complaints about district nurse

availability during or after their treatment, many of which referred specifically to implications for wound/dressing care.

When I was discharged I was told my district nurse (in my GP practice) will change and keep an eye on my dressing. When they were approached they said they were too busy so I ended up with a really bad infection, and had to change my dressings myself.

We needed a district nurse to call to change dressings but was refused one. My partner ended up changing dressings under guidance from nursing staff at [hospital removed].

I was given a letter when I left hospital for the attention of \district nurse\". I never had one come to see me. Was I entitled to any financial support? Because no one has said anything!"

[A]s for the GP and district nurses which immediately after my discharge I would have been grateful to see because of the pain and dressing change which was left to unqualified family and friends...\Care in the community\" ??"

Of the 48 positive comments, 38 were of a general (e.g. 'My district nurse was fantastic') or miscellaneous nature, while a further 10 praised the manner in which they had been dealt with and informed by district nursing staff.

District nurses were very caring and patient with my three young children.

The district nurses that called after my op. were excellent. They reassured me and answered all my questions.

The district nurse team were excellent. Their support following discharge really helped, from the first visit they listened to my problems and found solutions. They were professional friendly and very caring.

The comments indicate that for participants in this study, good care and access to district nursing was an issue for some, particularly in relation to wound care. Taken together, both negative and positive responses again underscore the importance of compassionate and caring manner on the part of staff, as well as timely information provision, in patient experiences during the treatment journeys.

4.3.1.6 – Experiences of care from Key Workers.

26 respondents provided comments relating to care from staff identified as Key Workers. Of these, 20 were negative and nine were positive. Of the 20 negative comments, two were of a miscellaneous nature, while the remaining 18 regarded either the lack of a Key Worker during the cancer journey, or difficulties in getting in contact with those that had been assigned.

Contacting keyworker. Usually one has to leave a message on the answer machine and due to being very busy key workers don't pick up these messages until end of day. It would be nice if some how worries could be picked up quicker just for the patient's peace of mind.

I did have a name of the key worker but they did never speak to me, when my family spoke to her they were told to speak to the hospital that is not acceptable. There were times I needed somebody to talk to.

I am concerned that my key contact worker is becoming more overloaded with work. I have noticed the signs over last few months.

I have not noticed the list of a named nurse or key worker, because the support available from any of the haematology ward nurses has been wonderful.

The nine positive comments regarding Key Workers tended to focus on information provision and support, as well as coordination of care.

My key worker was the most important person on the planet during and after my treatment, she always clearly followed up what was said in clinic and still answers emails and chats on the phone even though I know she is so busy. Thank you [name removed].

The support from the key worker nurse at [hospital removed] is fantastic and could not have coped without them.

My key worker, [name removed], has always been exceptionally helpful and always able to answer questions at the other end of the telephone which puts my mind at ease.

Key Worker system with specialist nurse very good; reduces the amount of chasing around. Excellent way of getting information, as often don't want to take up too much of doctor's time.

In comparison with the full WCPES survey (question 25), 24% (n = 1792) respondents indicated that they were given the name and contact details of a Key Worker that was not their CNS, 29% (n = 2162)

had been given the name and details of a Key Worker who was their CNS, 28% (n = 2059) did not have anyone named as their Key Worker, while 10% (n = 188) stated that did not know/were not sure (QualityHealth, 2014)²¹. Of those who were given the name of a Key Worker (whether or not this was their CNS; question 26; n = 1879), 82% (n = 1652) found it 'easy' to contact their Key Worker, 16% (n = 268) found it 'sometimes easy, sometimes difficult', 2% (n = 36) found it 'difficult', and 10% (n = 188) had 'not tried to contact her/him' (QualityHealth, 2014)²².

Although negative free-text comments marginally outnumbered positive responses in the Key Worker area, it is important to note that many of the negative comments referred to issues with availability or provision of a Key Worker, rather than the care provided by them per se. The positive comments indicate that for those respondents who did have a Key Worker and chose to make comment, care was good, particularly in terms of aspects relating to information provision and care coordination. Taken together, the responses indicate that Key Worker provision was a valuable but limited resource in terms of availability, for these participants.

²¹ Data were unavailable for 602 respondents.

²² Data were unavailable for 5473 respondents.

4.3.2 – Surgery

541 respondents provided comments on experiences of surgery, of which 181 were negative and 391 were positive (a ratio of 0.46:1). 18 negative and 190 positive comments that were of a general (e.g. ‘surgeon was a total failure’ / ‘surgery excellent’) or miscellaneous nature. Surgery was the second largest staff area by weight of comments, and revealed a number of sub-areas that are now discussed.

Surgery Area	Negative respondents	Positive respondents	Total respondents	Ratio (negative-to-positive respondents)
Communication and interaction with surgical staff	67	62	124	1.08 : 1
Patient experiences of post-operative hospital care	53	46	97	1.15 : 1
Speed of surgical treatment	18	78	96	0.23 : 1
Conduct of surgical procedures	15	61	76	0.25 : 1
Pre-operative care	17	20	37	0.85 : 1
Total surgery	181	393	541	0.46 : 1

Table 14 - Breakdown of respondents by area of surgical care

4.3.2.1 – Communication and interaction with surgical staff.

124 respondents gave comments relating to communication and interaction with their surgical staff, of which 67 were negative and 62 were positive (a ratio of 1.08:1). Experiences of interactions with surgical staff related to the manner of interactions, and also the information provided during treatment. 54 participants gave comments about the information they had received from surgical staff during their cancer treatment, of which 35 were negative and 19 were positive. The negative comments reflected a combination of poor or absent information provision, primarily around what to expect during and after the procedure, as well as availability of surgical staff to answer questions.

Better information given to the patient. If you know what's coming, you're better prepared for it, not knowing creates anxiety.

If I had been told how long before my surgery- it would have saved a great deal of worry for my family.

I should have received more information about side effects after my operation.

Information on what to expect after op. More time talking to surgeon/consultant.

Post op explanation was poor - English was not good. Spent night worrying about what was said. Only when I asked further questions the next day was I satisfied with what had been done, after clarification.

When I had a biopsy and a lymph gland removed on the neck; more information could have been given on the after efficiently and length of after effect e.g. numbers on the neck.

While lack of information and time to discuss treatment with surgical staff was a significant issue for a number of participants, 19 respondents of related positive experiences of information provision by surgical staff.

The surgeon rang my partner immediately after surgery.

24 hour care, even phoning Mr [name removed] up at home.

Surgeon was very sensitive and kept me well informed.

After the operation the surgeon made several personal visits checking progress and problems which was very thoughtful of him.

Very informative and explained everything about my operation before and after.

The doctors / surgeons at [hospital removed] were excellent and caring, explaining all that was happen[ing] or about to happen

My surgeon was excellent and provided very good information about my treatment throughout.

In the closed questions section of the WCPES survey (question 37), 53% of total respondents (n = 3885) provided information on pre-operative explanations of surgical procedures. Of these, 87% (n = 3316) indicated that their procedure had been explained 'completely', 12% (n = 439) stated that it had been explained 'to some extent', 2% (n = 59) indicated that it had not been explained and that 'they would have liked an explanation', 1% (n = 50) 'did not need an explanation', while a further 1% (n = 21) did not know or could not remember (QualityHealth, 2014)²³. In addition, 53% of total respondents (n = 3876) gave comments on post-operative explanations of procedures. Of these, 78%

²³ Data were unavailable for 3467 participants.

(n = 2952) agreed that their procedure had been explained 'completely' in a manner that they could understand, 17% (n = 652) stated that this had been done 'to some extent', 5% (n = 191) indicated that this had not happened but that they would have liked an explanation, while 2% (n = 81) (QualityHealth, 2014)²⁴.

Respondents providing positive free-text comments about the information given during surgery emphasised the value of being kept informed at every stage of their surgical care (i.e. 'what was happening and what was about to happen). Once again, when comparing negative and positive experiences the importance of information provision (particularly around post-operative experiences) in this area is clear. In particular, the positive comments above detailing examples of post-operative contact with surgeons indicate the link between information provision, and the manner in which that information is provided.

61 participants provided comments relating to the manner of surgical staff, of which 16 were negative and 46 were positive. For participants providing negative comments in this area, problems with the manner of interactions were linked to availability and willingness, particularly of surgeons, to answer questions regarding procedures and their after-effects.

The attitude of the surgeon...had no compassion with the patient. Surgeon not approachable to ask emotional questions. Surgeon always appeared too important and too busy for each patient.

Very brusque, blunt, uninformative attitude of [hospital removed] consultant surgeon.

Surgeon was very casual about what he was going to do and after op was only interested in getting me discharged.

Consultant breast surgeon, did not see him until I complained, and then his comments made me feel as if I was going to die.

The treatment after surgery was a disgrace. Whenever I asked a question it seemed very much as if I was a burden.

These comments stand as equal and opposite reflections of positive responses provided by (46) others in this area. Here, positive experiences of staff manner in interactions relating to surgical care often went hand-in-hand with good information provision, and were linked to patient confidence and reassurance in this phase of their care.

Surgeon was very sensitive and kept me well informed.

After the operation the surgeon made several personal visits checking progress and problems which was very thoughtful of him.

²⁴ Data were unavailable for 3476 participants.

Doctor who performed op and told me all about it very patient and reassuring.

My surgeon was fantastic. The way he explained operation and his optimism helped me a lot.

The consultant who carried out my operation (prostate removed) was so helpful. He gave me complete confidence before surgery, and even phoned me at home to have a kind discussion.

Surgical consultant was excellent with a reassuring manner.

Both negative and positive comments in this section indicate the manner in which information is provided, as well as the content, is vital for building patient confidence. Conversely, absence of these factors can result in increased stress to patients during this phase of their treatment journey.

4.3.2.2 - Patient experiences of post-operative hospital care.

97 respondents provided comments regarding their experiences of post-operative care, of which 53 were negative and 46 were positive (a ratio of 1.15:1). While nine respondents gave negative comments of a general or miscellaneous nature, remaining responses described areas of poor care in hospital during the immediate post-operative recovery period.

While I was recovering from the operation on the ward, no one would assist me out of bed. It was not a modern electric bed and each time I needed to get up I hurt my stomach. I slept in the chair at the side of my bed on 3 occasions, I was told there was no-one who could help me, I would need to do it myself.

[S]ome of the staff at ward [name removed] in [hospital removed] did not treat me very kind. I had my operation on the Tuesday, on the Saturday I asked the doctor if I could go home. He said to go home when I was ready, later on that day when I told the nurse I was going home, they told me to get out of bed at 6:30 in the morning and wait for my husband to collect me. They cleaned my bed and remade it up so I could not get back into it - and I had to wait till 1:30 pm for my husband to come, when I was very ill. I was very upset about it.

I had a malignant melanoma of the rectum. The complete rectum was removed and I found it extremely uncomfortable/painful to sit. Some nurses insisted I sat in a chair even when I said I was in a lot pain. As a result I told my surgeon I had to go home on Day [number removed]. I was not in a fit state to travel/go home but felt I had no alternative as I could not stay in hospital any longer with nurses insisting I sat in a chair. At home I was able to lie down most of the time. After 17 weeks I still cannot sit comfortable for a long period! I believe the nurses on [name removed] ward were not accustomed to this type of operation.

I was in severe pain after my op and spoke to a number of people who said it was nothing to worry about. I became wheelchair bound and it turned out I had caught MRSA. The pain was truly excruciating and my concerns were ignored.

Though not all experiences of poor care were attributed to low staff numbers, the issue of time and resource constraints was raised once again in relation to immediate post-surgical care. For others in this group, poor care was linked to a lack of specialist knowledge on the part of staff.

[A] designated surgical breast care ward would have been beneficial. The ward I was on was a gynae ward and the nurses trained for that speciality.

If you go for an operation for any type of cancer, a cancer ward should be available, as they understand what treatment plan you are to have. Surgical wards did not understand my care or what I had already been through, resulting in a complete lack of care.

My breast care nurse was new in post and was unable to answer questions I asked, I had to suggest she went and found out the information. Both pre and post op care was poor, for example when I complained of pain she told me to 'get through it' not what I expect to be told.

In particular, respondents highlighted understanding and management of post-operative pain as a negative aspect of care in the surgical phase of their journeys.

Earlier diagnosis needed. More empathy from consultant. Very little info given re post-operative problems. Consultant, when told I had pain, told me it was not pain!! It was a funny sensation, but not funny for me!!

Pain relief after operations - what I was given did not relieve pain; asked for something else and was refused.

While recovering after my operation I was in a lot of pain and staff were too slow in giving me pain relief. I was left in pain for many hours.

For patients experiencing issues with immediate post-operative pain relief, this was attributed to a variety of causes, including poor knowledge of their condition, lack of staff and also a lack of compassion and/or understanding of post-operative pain.

46 respondents provided positive comments about the post-operative care they had received, although these tended to be more general in nature than negative comments, and were often referenced (whether implicitly or explicitly) as part of the wider surgical phase of treatment/care.

I had a very good surgeon and his team who looked after me while I was in hospital. Also the specialist nurses on the ward were very informative and compassionate.

Everything was excellent from the moment that I arrived to the time that I left. I did have a problem that was picked up on immediately and dealt with. 24 hour care, even phoning [surgeon name removed] up at home.

After the operation the surgeon made several personal visits checking progress and problems which was very thoughtful of him.

The surgeon and his immediate team were excellent. The individual units within the breast clinic were exceptional in providing a relaxing and comfortable environment in which to recover from a stressful operation.

This reflects a trend, observed elsewhere in this report, of positive comments tending to be of a more general quality than negative comments. While this makes it difficult to present direct and detailed examples of the specific processes underpinning good care, comparison with the negative comments suggests that staff awareness of post-operative conditions, increased availability of ward staff, as well as timely and effective pain relief are important factors in post-operative experiences.

4.3.2.3 – Speed of surgical treatment

96 respondents gave comments relating to how quickly they received their surgical treatment, of which 18 were negative and 78 were positive (0.23:1). The negative comments were characterised primarily by accounts of cancellations and delays to surgical treatment.

If I had been told how long before my surgery- it would have saved a great deal of worry for my family.

I was diagnosed with suspected cancer in May 12. It was confirmed by biopsy in July 2012. It was several months later in January 2013 before I received the operation to remove tumour. This was much too long a wait - and caused me severe anxiety. My consultant surgeon was aware of my feelings - but he was at the mercy of hospital managers.

The nurses and staff were excellent when on 3 times I was sent home for 1 reason or another, I am on Warfarin and [detail removed] for a long time. So I had to start it all over again. It was upsetting for my wife when they would phone her to come and get me when I should have had my op. Put a lot of stress and worry on all the family.

During chemo I was offered an operation to my liver at [hospital remove]. After several months I received a phone call from a clinical nurse at [hospital removed] that the operation would not now be done (no explanation given.)

I was of the opinion that anyone booked in for an important cancer operation would not find themselves on the actual day of the operation, being faced with cancellation due to lack of

beds, even though only being a day patient. It was total chaos to say the least - not enough space here for the details.

Delays in surgery, too longer wait between surgical consultation and surgery. Being bowel prepped for theatre and then told surgery cancelled, due to lack of HDU bed and asked to go home.

The waiting times for surgery are totally unacceptable, people are dying while waiting for surgery and this problem is totally unacceptable and needs to be addressed.

Patients in this area often experienced what they considered to be extended waiting times for surgery, in some cases attended by repeated cancellations, in several cases on the appointed day of the procedure. Once again, as with other areas of treatment, delays in treatment were associated with stressful experiences, and also with perceptions of poorer outcomes due to delays. It is also notable that in two of the cases cited above, some participants separated the care provided by staff from what they perceived to be systemic issues causing the delays. While delays and cancellations were significant issues for 18 of the respondents in this area, a further 78 praised the speed with which they had received surgical treatment.

A short time between diagnosis and surgery. Surgical team performed a difficult procedure with success.

I had my tests and my surgery in a little over two months after my diagnosis, I was very grateful for that.

I was impressed with the speed of my diagnosis and treatment - it was only ten days from first visiting my GP to having the diagnosis and treatment required, then another 3 weeks until my operation.

From the first appointment with the hospital doctors to operation, things moved very fast. Less than 3 weeks!!!

The speed with which my diagnostic test, scans and surgery were organised. All the doctors exuded a sense of urgency which I found reassuring

I was seen by a doctor in the morning and was given an appointment the same afternoon to have surgery. After 3 weeks I was given the results which meant I needed more surgery this was done in a matter of weeks. It was all done very quickly. Excellent service.

For patients praising speed of surgical treatment, this was linked to expressions of satisfaction with their care and confidence in the overall process. Taken together, both negative and positive comments in this section point strongly to the importance of speed and predictability, in the surgical treatment phase of the cancer journey.

4.3.2.4 - Conduct of surgical procedures

76 participants provided comments relating to the conduct of surgical procedures, of which 15 were negative and 61 were positive (a ratio of 0.25 : 1). In terms of negative comments, these reflected miscellaneous comments regarding perceptions of poor surgical practice and conduct of theatre staff.

Surgeon [name removed] made a total mess of my colostomy by laparoscopy. It became necrotic in two days and he had to do an emergency ileostomy which had a [details removed].

Two consultants were involved in my surgery, but my main consultant didn't agree with the amount of lymph nodes removed out of my left arm, it still doesn't feel like my own arm.

The operation was for a [procedure removed]. Unfortunately my left [body part removed] was cut which caused months of hospital visits, blood infections and stent removals and replacements and weight loss over 8 months.

The district nurse who visited me before my readmission joked about the bruising evident, which was infection, telling my wife that the surgeon sometimes put their feet there when stitching! A disgrace!!!

Sewing lessons for surgeons - scar tissue very lumpy!

One operation removing a basal cell cancer had to be repeated because it was not all removed.

You don't mention theatre staff in your questionnaires. Talking about holidays, rotas etc. whilst one is under their care - does not give one confidence that they all paying attention to you.

Elsewhere, a greater number of participants (61) provided comments praising the conduct of surgical procedures.

Very high skill level of surgeon who performed the prostate surgery.

The treatment and the operation from staff and doctors was particularly good.

The obvious skill of the surgeon [name removed] and my very neat scar!

Excellent surgery from [surgeon name removed] for squamous carcinoma.

Surgery excellent. After care in hospital exemplary. Oncology team outstanding.

Comments in this area tended to reflect relatively straightforward statements regarding perceptions of poor/good surgical conduct, of which the majority were positive. Nevertheless, it is important to note that confidence in the conduct of surgical procedures affected overall perceptions of the treatment journey.

4.3.2.5 – Pre-operative care

37 respondents provided comments on pre-operative care, of which 17 were negative and 20 were positive (a ratio of 0.85:1). The majority of negative comments focused on waiting times on the day of surgery, often attended by complaints about the waiting environment and a lack of contact with staff prior to the operation.

Not have to change for theatre in toilets. Waiting from 8 am to 4 pm to go down to theatre, twice this happened.

Overheard conversation re: lack of ward space and \Don't know if there's a space\" - does not help when just had op. Signed consent to op form 2 minutes prior to op which doesn't allow time to read."

On my second follow-up operation I had to sit in an open waiting room from 0800hrs to 1700hrs with no food or drink. Nobody said I could have a light snack at any point of the day, nor a drink.

For day surgery - had to wait 8 hours (on one occasion) in an old stock room in the ward before having to get changed for operation (the room was very small, had seats around 'no sir' and full of patients, no TV or magazines, bed was available, only after operation. I did write a letter of complaint to [detail removed] but failed to get a reply.

The day of the operation I and several people waited for hours before we knew we had a bed and the operation. No food from 12am the night before, operation 4:30pm on the day.

The only complaint I have is that when booking in for my op in [hospital removed] it was terrible. Just felt like a number and was pushed into a very small room with 5 other people. Feel an overnight bags because room was so small and were there for hours. I booked in at 7:30am, went to a bed about lunch time and had op about 3:30pm by which time my nerves were in shreds and I couldn't stop crying. Nurses were so busy there was no one to talk to. I felt very alone.

Once again we see in these comments expressions of stress relating to uncertainties around waiting times, as well as the waiting environments themselves and a lack of communication/access to staff.

In terms of positive free-text comments, once again these followed a similar pattern to other areas of surgical comments in their general nature.

I was very pleased with the treatment I received before and after my operation.

Very informative and explained everything about my operation before and after.

I found the enhanced recovery programme very useful, in particular the information given beforehand with relation to the operation, e.g. anaesthetic, physio, etc. I felt I know what to expect.

Access to professionals, prior to, during and following my mastectomy has always been easy.

The nurses on [ward removed] at [hospital removed] also gave excellent care both prior to operation and after. They were professional, compassionate and treated me with dignity and respect.

Overall, free-text comments regarding areas of immediate pre-operative care reflected similar areas of importance to other areas in the surgical phase, these being information provision and the ability to access staff with knowledge of the patient's condition and likely needs.

4.3.3 – Hospital doctors (NOS).

4.3.3.1 – Overview.

467 respondents provided comments relating to hospital doctors that did not fall into a specific area of specialty (e.g. oncology) and where the object of comments was not specified as either a specialist or consultant by the respondent. Of these respondents, 73 provided negative comments, while 411 gave positive responses (a ratio of 0.18:1). Once again, the majority of positive responses were of a general or miscellaneous nature (e.g. 'wonderful doctors' etc.), and approximately one third of the negative comments were of a similar nature (e.g. 'ward doctors not really involved'). However, there was a sub-theme present relating to aspects of communication and interaction with hospital doctors.

4.3.3.2 – Participant experiences of interaction and communication with hospital doctors.

48 respondents gave negative responses in relation to interactions and communication with hospital doctors during their cancer journey, of which 32 related to experiences of interacting with their doctor. These comments conveyed perceptions of a lack of concern on the part of doctors, as well as a general sense of not communicating or ‘knowing how to talk to people’, in particular when delivering news about cancer.

Doctors didn't seem to care less. I have a fear of hospitals I never used to have.

Attitude of ward staff and medics at [hospital removed] was very cold. I did not have a good experience with my operation or stay there. I would never wish to be treated at that particular hospital again.

As a former employee of NHS, I have the greatest respect for the ward staff who work exceedingly hard, but the attitude of some of the medics and other disciplines need to be visited. Sometimes I felt I was treated like a piece of meat or idiot as medics discussed me with colleagues, without ever talking to me directly.

Although my doctor might be good technically he has no idea at all how to talk and deal with patients. I found his manner very strange indeed.

Doctors listening to me when telling them about side effects getting worse and still carrying on treatment regardless.

The original time I was told I had terminal cancer and nothing could be done for me was handled very badly. There was no support at all and the doctor was in and out of the room in about 6 minutes. It was as if my life counted for nothing, as if I was being thrown away. So sad to treat someone like that.

25 respondents also gave negative comments about the quality of information that they had received from hospital doctors, the majority of which related to vague or inaccurate information, or a lack of willingness to provide this to cancer patients.

Hospital doctor was too circumspect in telling me I had cancer (or he strongly suspected it, based on initial tests). I felt I had to ask the right questions to figure out what was happening.

Sometimes it feels like you have to tease information out of doctors - it doesn't seem to be given readily, you just have to ask the right questions.

Difficult for relatives to get information from nurses and doctors on ward.

When I went to have fluid drained I was seen by a junior doctor, who spent most of his time \chatting up\" the nurse. So did not answer my questions fully or at all."

Only basic information given by doctors. questions were always answered, but as a patient it isn't always easy to know what to ask. Still feel I don't know as much as I should about what it happening to me.

These concerns reflect those appearing across many staff areas with regard to provision of information; however, 11 respondents in these areas praised the information given to them by hospital doctors during their treatment journey.

The doctors / surgeons at [hospital removed] were excellent and caring, explaining all that was happening or about to happen.

I have had and still receive first class treatment from all doctors and nurses concerned at the chemo clinic at [hospital removed]. It is impossible in my opinion to improve any information and treatment I received.

My doctor and key worker are excellent in explaining about my treatment and would answer any question that I have with great care.

Although often long wait at [hospital removed] in outpatients I'm given as long as I need when I see a doctor - I don't feel rushed. All my questions are answered.

The doctor that I saw before and after my operation was so, so kind, caring and informative.

In the closed questions section of the WCPES survey (question 42), 58% of total respondents (n = 4263) gave indications of whether or not they were able to talk to their doctor as often as they would have liked (QualityHealth, 2014). Of these, 54% (n = 2065) stated that they had been able to do this 'all or most of the time', 37% (n = 1440) indicated that this had been possible 'most of the time', for 9% (n = 336) this was 'rarely or never possible', while 11% (n = 485) stated that they did not ask questions (QualityHealth, 2014)²⁵.

By far the largest area of free-text comments in relation to communication with hospital doctors related to positive experiences of the manner in which respondents were treated by this staff group. Once again, terms such as 'compassion[ate]', 'friendly', 'professional' and reassuring featured

²⁵ Data were unavailable for 3048 participants.

prominently among these comments, and in particular respondents linked many of these qualities to increased confidence in their care.

[T]he doctor ... was very, very good. I had faith in him, he did everything to help me feel calm etc.

[D]octors are always reassuring and compassionate.

Doctors and specialist nurses of [hospital removed] were very good, and easy to speak to them.

Dr [name removed] should have been offered a permanent position at the hospital, he is an excellent doctor who instilled confidence into me and made me feel very positive.

[M]y doctors were fantastic, I felt very safe, and well cared for. They made me feel very special...the confidence I had in the team really helped.

This continues a theme present across other staff areas i.e. that the manner in which patients experienced communication and interaction with hospital doctors was linked to more general feelings of positivity about their treatment. Thus the overall profile of comments received in relation to hospital doctors (NOS) suggest strongly that the majority of patients in this study felt well-treated and cared for by this staff group.

4.3.4 – Investigations and diagnostic services.

4.3.5.1 – Overview

475 respondents provided comments relating to experiences of investigations and diagnostic services, of which 288 were negative and 198 were positive (a ratio of 1.45:1). Of these, 101 negative and 81 positive comments were of a miscellaneous nature. The remaining comments broke down into the areas given in table 15, and are discussed in subsequent sub-sections.

Area of investigation/diagnosis	Negative respondents	Positive respondents	Total respondents	Ratio (negative-to-positive respondents)
				2.32 : 1
Speed of diagnosis	132	57	189	-
Waiting for results	76	-	76	-
Screening	-	62	62	-
NOS	102	81	181	-
Total	288	198	475	1.45 : 1

Table 15 - Breakdown of respondents providing comments about investigations and diagnostic services by area.

4.3.5.2 - Speed of diagnosis

As with comments around GP services, responses in this theme also reflected substantial concerns around speed of diagnosis. Here, the concern was related primarily to waiting times for diagnostic services, and the implications of this for care, treatment, and wellbeing. 132 respondents gave negative comments regarding delays relating to initial diagnostic procedures. Of these, 94 were general or miscellaneous comments regarding delays and/or access to diagnostic services in the initial stages of their cancer journeys.

There was a long delay between GP's first referral [date removed] endoscopy/scan appointments and eventual appointment with consultant to start treatment [dates removed].

A quicker diagnosis - as I was in severe pain for many months prior to receiving a PSA test.

Once I was diagnosed with cervical cancer my care was excellent. But before that I had abnormal smears and several colonoscopies. It took nearly a year before I was diagnosed, which I feel was too long.

A simple colonoscopy at the \early stages\" would save a lot of pain and suffering and a much cheaper option.

Once I was having blood in the urine there was obviously something wrong but my appointments were delayed and even cancelled, so the diagnosis took a lot longer, in which time the cancer had developed more.

36 respondents providing negative comments made specific reference to what they described as inaccurate or mistaken diagnoses.

After a fall, I was x-rayed and the cracked ribs not seen! For 22 months I was told I was getting old. The pain grew so bad I could not work. My consultant told me the cancer was caused by cracked ribs.

I believe the cancer was missed in earlier mammograms.

I'm glad I didn't listen to radiologist who didn't think anything to worry about when I decided to go ahead with biopsy - that is all.

My cancer was not picked up soon enough by for doctor in ENT. Sent to speech therapist. Voice got gradually worse. Then 8 months later paid to see consultant who pulled out all the stops and told me I had a growth on my voice box, I then received first class service.

I initially saw hospital doctor in August after having a mammogram and scan and was told lump was just fibrous tissue but a follow up appointment would be sent for a 3 month check. I did not receive an appointment and was worried as lump becoming larger so I took it upon myself to ring hospital and had an appointment for [date removed]. It was after this appointment was a biopsy carried out and I was diagnosed with cancer.

I was seen 3 times in casualty before being admitted to hospital. This was over a period of 8 weeks. I was told it was pleurisy - it was myeloma.

My colon tumour was diagnosed in a [detail removed] hospital and not recognised by Hospital, when I took a constipation problem there, 3 days before.

Original diagnosis received after an ultrasound in my local hospital was for a benign fatty lump that then developed into malignant sarcoma! I feel I was misdiagnosed as there was a delay of 4 months before the correct diagnosis which might have prevented such an invasive and serious operation resulting in secondary tumours that need further surgery.

Clearly, delays in both waiting for diagnostic services, as well as the accuracy of diagnostic services, were of concern to a number of respondents. However, 57 other respondents praised the swiftness of their diagnosis, including the speed of both access to and provision of services for investigation.

Thank goodness for mammograms, I was diagnosed very early.

It is thanks to the radiographer in [hospital removed] that my cancer was found after having pneumonia, I had no other symptoms so would never have known it was there.

I was very lucky to have been seen and diagnosed so quickly following my GP appointment when I told him I had found a lump.

I had early diagnosis which meant my treatment helped having had an early start (13 years)

All tests and treatments carried out promptly and staff on the whole were very good.

The speed with which my diagnostic test, scans and surgery were organised. All the doctors exuded a sense of urgency which I found reassuring.

As with other areas in this survey, speed of diagnosis was highly significant to many respondents' experiences of their cancer journey. In addition to concerns around progression of cancer over time and implications for treatment response, swiftness of diagnosis was associated with feelings of satisfaction and confidence in the process. Conversely, delays in investigations (whether attributed to waiting times or inaccuracies in diagnosis) were linked to perceptions of poorer outcomes and additional suffering.

4.3.5.3 - Waiting for results

76 respondents gave negative comments relating to waiting times for results of investigations. Of these, 35 were of a general nature (e.g. "waiting for results" etc.), while a further 41 referred to waiting for results of diagnostic investigations prior to beginning treatment.

Time waiting for diagnosis, from April 2012 to March 2013. Four cancelled operations and biopsy.

Long waiting between assessments such as blood, x-rays and scans before getting results

The wait for test results to be passed from one hospital to another is too long. Two tests took 4 weeks, which means surgery has been delayed.

I was a long time waiting for results of mammogram

From biopsy...to getting result...5 week...MRI scan ([date removed]) to MRI result...3 weeks.

Waiting for results is the worst point of the process. Managing patient expectations is vital. Telling the patient the results would be in a week when realistically it's two weeks isn't helpful. Also - why does it take so long to get results?

[R]esults are very slow following endoscopes. Need results much quicker than months waiting for results.

The waiting time between tests and their results was tedious and stressful for me and my family.

As indicated in the comments above, waiting for results at or around the diagnostic stage of their cancer journey was associated both with perceived delays to treatment, as well as additional stress. This was of particular note in comments where patients described either not being given an estimate of time taken to get their results, or being given waiting times that turned out to be inaccurate.

4.3.5.4 - Screening

62 respondents gave positive comments relating to their experience of screening services, of which 10 were general comments (e.g. 'my cancer was detected through screening'). 28 of the remaining respondent comments related to positive experiences of breast screening.

Thank goodness for mammograms, I was diagnosed very early.

Breast Test Wales diagnosed my cancer from a mammogram in [month removed]. By [date removed] I was having the operation.

DCIS was originally picked up after my visit to the mobile van for a mammogram.

Mammogram in mobile unit, then recall at [name removed] breast care. Complete confidence in unit and [hospital removed].

Spotted early at the mobile mammogram van, so it was a small lump. Dealt with early.

I was lucky my cancer was picked up at my 3 year mammogram, and was in the very early stages and had not spread from the neck glands (all contained).

24 further participant comments related to positive experiences of bowel cancer screening.

Screening for bowel cancer is excellent, received on my 60th birthday which was lucky.

The BSW screening programme diagnosed my early symptoms of bowel cancer, for which I am truly grateful.

I did not know that I was ill, until I went for bowel screening, I had no symptoms at all, I would advise anyone for to do the test if it was available to them.

I cannot praise the NHS treatment I received highly enough. Following a bowel screening, I had an emergency op (I did not have any symptoms).

In both areas of screening, where participants chose to elaborate beyond most general positive comments, screening services were linked to recognition of problems hitherto unrecognised and/or at an early stage of development. In many cases, this was linked to comments indicating prompt treatment following recognition of their cancer.

4.3.5 – Consultants and medical specialists (NOS)

4.3.4.1 - Overview

465 respondents provided comments relating to experiences with consultants and specialists, where these were not identified with a particular area of specialty. Within this group, 72 participants provided negative comments, while 408 provided positive comments (a ratio of 0.18:1). Negative comments tended to be more specific than positive responses, with 34 of the former being miscellaneous, while over three-quarters of the latter were of a general (e.g. 'excellent consultant') or miscellaneous nature. Other comments in this category related to communication and interaction with consultants and specialists, once again focused on the manner of staff as perceived by respondents, as well as the quality of information provided.

4.3.4.2 – Experiences of communication and interaction with consultants and medical specialists (NOS)

25 respondents gave negative comments regarding the information provided by consultants and /or specialists during their journeys, the majority of which referred to lack of information provided by staff about their diagnosis and treatment.

[C]onsultant offered little advice re: possible treatment and was confused how to deal with anything out of the norm.

They should give the patient time to ask questions, not to be so arrogant as to walk into an appointment following test, say what was wrong and promptly walk away ending the appointment in about two minutes. Felt I was forced to leave without the chance of asking my questions let alone get any answers.

I felt that the diagnostic test carried out by the first consultant, was very brief and little discussion and I felt it was not thorough enough.

My initial diagnosis at [hospital removed] was not dealt with very well by my consultant. I felt he was unable to tell me I had cancer unless prompted by me. I appreciate it is not easy to do but I could have walked away with the wrong impression. There was no written information at all and the nurse said she knew nothing about that type of cancer. The consultant's initial response meant I felt no confidence in asking or returning to him.

The ... specialist in [location removed] has been very disappointing in comparison with [location removed] - duff advice, duff information, and not in the least proactive. Consultant's appointments are often a complete shambles with waiting times far too long.

22 respondents also criticised the manner in which specialists or consultants had interacted with them, and these comments were also often linked to issues around information provision, including how the initial diagnosis was presented.

The second consultant had poor English and very poor communication skills, he did not look at me once! This was a very bad day for me and he did not help at all.

I felt that my first male consultant was rather abrupt and could have been more sensitive and optimistic.

After my initial diagnosis a further scan showed a metastatic mass in my liver. This had to be confirmed by ultrasound guided biopsy which was done by a consultant radiologist at [hospital removed]. His behaviour was extremely unprofessional and nothing short of negligent. He breached his duty of care. He was not only rude but undermined what Mr. [name removed] had told me. He showed me what he had taken from my liver by waving the sample pot in front of my face. He reduced me to tears and ruined any confidence I had in my treatment plan. Dealing with cancer is difficult enough without senior consultants throwing their weight around. I am aware I am still within the legal time frame to make a formal complaint and take action, so this doesn't happen to further patients.

The consultant was unfeeling toward my reaction when he informed me about my cancer by prodding my throat saying \it's cancer and it's there\"

The initial outpatient appointments left a lot to be desired, from the way in which I was told I had cancer (absolutely disgraceful experience) that was for a consultant in [hospital removed].

The importance of how respondents perceived staff manner was also indicated in the positive comments, where 101 respondents praised this area of consultant/specialist care. Terms such as 'caring', 'kind', 'considerate', 'attentive', 'dedicated', 'compassionate' and 'professional' appeared frequently in these comments, and were linked to expressions of confidence in the treatment offered.

Consultant [name removed] very considerate and explained in a no nonsense way.

The team of professionals who treated me, were kind, caring and attentive. Each individual from the consultant's secretary, who showed great patience and kindness to my daughter. The consultants who respected my opinions and valued my input on my treatment, the nurses who were compassionate, dedicated and extremely professional at all times.

Excellent care. Ease of communication with specialist doctors and nurses. In fact I was most impressed with their sincere [2 words unreadable] any worry, and above all courtesy and compassionate at all times.

I was particularly impressed by Mr [name removed] the urology specialist. I thank him for his professionalism.

Dr [name removed] at [hospital removed], the most professional but caring approach doctor I have ever met, all my confidence was with him

My consultant was absolutely fantastic. At no time did he attempt to change my decision, and this meant I had total confidence in his handling of my care.

Comments in this section point to the importance of how consultants and specialists deal with patients during diagnosis and treatment, and its implications for the confidence of patients during their journeys. In addition, 45 participants praised the information they had received from consultants/specialists, and many of these comments were once again linked to increased confidence in the treatment received.

The consultant and his team are very efficient and understanding. By their care, one gets informed when the next treatment is due. One can trust to remain on their records.

Yes, my specialist is informative and discusses my operations which have been ongoing for 5 years. I can ring the nurse or secretary at any time.

He is very approachable and easy to talk to Mr. [name removed] and explains things in a manner easy to understand.

All the nurses and my cancer care consultant have been very kind, informative, and helpful.

The consultant and registrar are most informative and to the point. They always discuss the outcome of my [word unreadable] and the way forward with my treatment. I have every confidence in them.

Overall, comments in this sub-theme provide further evidence of the importance of information provision as well as the manner in which it is provided, and the implications of this for confidence in care provided by consultants/specialists. In terms of accounting for experience, these findings suggest that the vast majority of respondents have had positive experiences of consultant/specialist care, both in general terms and in terms of communication and interaction with them.

4.3.6 – GP care

4.3.6.1 – Overview

401 participants gave responses relating to aspects of GP care. Of these, 246 were negative and 161 were positive (a ratio of 1.53:1). Of these, 33 negative and 70 positive responses were of a general or miscellaneous nature (e.g. ‘my GP is rubbish’ / ‘GP excellent’). The remainder of the comments broke down into two main areas; *care in the initial diagnostic phase* and *post-diagnostic care and support*.

Area of investigation/diagnosis	Negative respondents	Positive respondents	Total respondents	Ratio (negative-to-positive respondents)
Care in the initial diagnostic phase	154	51	204	3.02 : 1
Post-diagnostic care	69	43	111	1.60 : 1
NOS	33	70	103	0.47 : 1
Total GP	246	161	401	1.53 : 1

Table 16 - Breakdown of respondents providing comments about GP care by area.

GP services were one of the few staff areas where numbers of respondents providing negative comments outweighed those giving positive responses. The most prominent concern in this area was around the speed and quality of response by GPs during the initial stages of the cancer journey. The majority of participants providing comments in this section did so in relation to the speed and willingness of GP services to refer for further investigation, and concerns around misdiagnosis with the attendant delays to treatment that this involved. Concerns around GP knowledge also continued into the post-diagnostic phase of the cancer journey, where concerns were raised around GP understanding, both in terms of cancer conditions and of individual patient histories.

These concerns are, in places, attended by expressions that indicate lack of confidence in GP services on the part of some respondents. While we do not have corresponding positive comments for all sub-themes in the GP area, what is present indicates that speed of action and familiarity with patient conditions is linked to confidence in this area of care. It should also be noted once again that many of the positive comments were of a general or miscellaneous nature that did not map to specific sub-areas of GP care.

4.3.6.2 - Experiences of GP care in the initial diagnostic phase.

204 respondents gave comments relating specifically to GP care in the initial diagnostic phase of their cancer journey. Of these, 154 provided negative responses and 51 gave positive comments (a ratio of 3.02:1; 14 negative and 11 positive responses were of a miscellaneous nature). 80 respondents described delays in referral by their GP for further investigation of their symptoms, most of which were of a general nature.

I feel I should have been referred to hospital for a scan more quickly than I was by my GP. It took over two months between him knowing I had a lump in my chest and getting a scan.

Although I had seen my GP with my symptoms, I don't know how long it would have taken me to get my biopsy if I had been referred by my GP rather than the hospital dermatologist.

I only wish that the cancer was diagnosed sooner and my GP had sent me for thorough investigations sooner, rather than trying different medication which was clearly not helping. This would have given me a better chance and prognosis and a far earlier diagnosis avoiding months of suffering.

...There was nearly a years delay from when I initially contacted / visited my GP to when he eventually referred me to the cancer service.

I had to bypass my GP to get an endoscope test, after numerous requests explaining how ill I felt. The endoscopy dept. discovered the cancer.

16 respondents made specific reference to a lack of willingness to refer for further investigations, in some cases accompanied by perceived disinterest in and/or dismissiveness of their symptoms by GPs.

Not one of the 5 GP[s] in practice were willing to make further appointments at hospital.

[Welsh] The family doctor was reluctant to send me for a bowel cancer test, and did not do an audit of it in the surgery. I had to ask to be able to go to the hospital for tests.

My GP should have acted sooner. He kept on insisting my back pain was due to old age. I was told to go home and take painkillers. I pleaded for an MRI scan, but insisted I did not need one. 18 months along with chronic pain I was given physio on a [word unreadable]. 5 months later no referral to a spinal doctor until my wife rang and insisted to see a spinal specialist.

I changed my original GP because of the long delay in him listening to me and getting me referred to hospital first seen Jan, diagnosed May.

The time it took to get a hospital appt from GP who dismissed my worries.

GP's listening to patients, sending patients for tests much earlier. I had to wait 8 months before my doctor agreed to send me for a scan, because he diagnosed I had swollen glands. He just would not listen.

My local GP told me not to pursue the biopsy I wanted for prostate cancer. I had to insist on this procedure.

A GP at local practice would not send me for a third investigation at the hospital when I went back to see him. Hence there was a delay in my diagnosis of cancer by GP responsible so left practice before I was told I had cancer.

A further nine respondents described initiating private investigations, due to perceived delays in referral to NHS services through their GP.

It is my view that the GP in [address removed] did not act quickly enough to help diagnose my cancer and that had I not instigated a private MRI scan I might have been affected by secondary cancer.

My GP surgery doctors completely misdiagnosed my condition and did not send me for an endoscopy early enough. I went private to initially get into the NHS \system.

When I first found a lump in my breast my GP referred me to hospital who did tests and said it was benign. 1 year later exactly it had turned to cancer, after treatment and taking [detail removed] everything was alright. After 5 years they wanted me to stop taking [detail removed]. I stayed on it for 2 more years then stopped. I have severe back pain. My GP diagnosed bed rest for sciatica for two months and had a private MRI scan which showed a tumour on my spine. I was told in hospital that a breast cancer patient there is 75% chance of a return of cancer. Therefore I blame my GP for his negligence.

Concerns were also raised by 35 participants, who described being given a diagnosis by their GP that was later found to be inaccurate upon discovery of their cancer.

My...GP...told me I had cervical erosion and it was nothing to worry about. If I had listened to him and not trusted my instincts and got a second opinion, I would be dead by now.

The GP got my condition completely wrong. He had it fixed in his mind that I had haemorrhoids. Finally my daughter took me to A&E, where they discovered an obstruction.

The following day I had an endoscopy, which revealed a tumour. That day I had the colostomy.

[E]ducate the GP's. I was diagnosed wrongly 3 times. My husband twice, he died last year. If the GP's got it right, cancer...results would be greatly improved.

Yes, before I was told by...had cancer I had complained to my GP.. I had a sore throat for well over 1 year he treated me for thrush!

GP kept saying I had sciatica but after having scan was told I had cancer.

The GP's need more training on ovarian cancer. As prior to diagnosis (it was found by default, as I was having a scan for my hips.) Prior to this, I was diagnosed with irritable bowel syndrome, a hernia and received treatment for polyps.

Recognition by GP that cancer could be present. First GP seen recommended physiotherapy without any thought of scan or possible existence of cancer.

While the majority of responses in this area were negative, 41 respondents praised the speed with which they were referred by their GP for further investigation and/or treatment.

The cancer was suspected on a routine visit to my GP and no time was wasted in arrang[ing] for me to see consultants. Their early diagnosis followed by an early operation has been successful. I'm grateful for all the care and attention received from my GP, hospital doctors and nursing staff.

I would like to thank the doctor at my surgery for arranging an appointment within the weeks to see a cancer specialist at [hospital removed]

GP - as soon as I went to see him and he realised I needed treatment he instantly referred me to a consultant.

The speed at which my GP referred me to a specialist was phenomenal! It gave me a feeling of confidence in the NHS service at a time when I was very frightened.

Quick referral from GP to [hospital removed] was seen in the rapid access skin cancer care clinic, treatment given in a short period of time.

In the closed questions portion of the WCPES survey, 78% (n = 5520) of respondents in this area thought that they had been seen by a hospital doctor as soon as necessary following referral, 12% (n = 839) felt that they 'should have been seen a bit sooner', while 10% (n = 685) indicated that they

should have been seen 'a lot sooner' (QualityHealth, 2014). In the free-text comments, many respondents demonstrated acute awareness that cancer treatment is time sensitive, and the importance of this is reflected in both the negative and positive comments. Of particular note is that, in addition to general comments about speed of referral, a number of participants wrote specifically about what they perceived to be a lack of willingness and/or interest in their symptoms. Those reporting inaccurate diagnosis also pointed to a lack of knowledge about and/or willingness to acknowledge the possible presence of cancer. Conversely, when participants perceived referrals to have occurred in a timely fashion, this was associated with confidence in the service.

4.3.6.3 - Experiences of GP care post-diagnosis.

In the closed questions section of the WCPES survey, 97% of total participants (n = 7154) provided answers to as to whether or not (as far as they knew) their GP had been given enough information about their condition and treatment in hospital. Of these, 92% (n = 4874) indicated that their GP had been given sufficient information, while 8% (n = 440) stated that this had not been the case (26%, n = 1840, did not know or could not remember) (QualityHealth, 2014)²⁶. In addition, 96% of total respondents (n = 7063) provided responses (question 69) as to whether they believed that GPs and nurses at their general practice had done everything they could to support them during cancer treatment. Of these, 67% (n = 3157) reported that staff in this area had 'definitely' done all that they could to support them in this phase of their journey, while 22% (n = 1046) stated that this had been the case 'to some extent', 11% (n = 515) indicated that staff 'could have done more' (33%, n = 2345, indicated that their general practice had not been involved) (QualityHealth, 2014)²⁷.

In the free-text section, 111 respondents provided comments on GP care after their initial cancer diagnosis, of which 69 were negative and 43 were positive (a ratio of 1.60 : 1) . Of these, 44 negative and all 43 positive comments were of a miscellaneous nature. However, 18 respondents did provide negative comments highlighting specifically a lack of GP knowledge of their condition, following their cancer diagnosis. Once again, responses here were in some cases linked to perceptions of disinterest on the part of the GP.

Communication between hospital doctors and GP's. You are told to see your GP for advice and treatment, for chemotherapy side effects, yet they have no information on what treatments you are receiving, or given any blood test results.

My GP's have been far from helpful and I have felt they do not know or care about me as a person or a patient. I have just had major surgery because of the side effects of cancer treatment and feel the GP don't even know...

My local GP seems totally unaware I was ill until 6 months after my initial operation and subsequent chemo.

Lack of coordination between GP and hospital services. Mainly lack of interest and knowledge by GP.

²⁶ Data were missing for 198 participants.

²⁷ Data were unavailable for 289 participants.

I expected some kind of review with my GP but this hasn't happened. They don't seem to be aware of my treatment.

GP did not read up on notes before my appointment and seemed shocked that cancer had been found.

Lack of knowledge here concerned general knowledge with regard to different aspects of cancer, and more specific knowledge about details (e.g. of treatment) pertaining to specific participants. In both cases, perceived shortcomings in knowledge were associated with a lack of confidence in care provided.

4.3.7 – Chemotherapy

4.3.7.1 – Overview

303 participants provided information on experiences relating to chemotherapy. Responses in this category included 85 negative and 233 positive comments (a ratio of 0.36:1). 61 negative and 177 positive comments were of a general (e.g. 'poor chemo care' / 'Chemotherapy team were outstanding'). Remaining comments concerned aspects of communication and interaction with chemotherapy staff.

4.3.7.2 – Interactions and communication relating to chemotherapy.

88 respondents gave comments relating to communication and interaction with staff during the chemotherapy phase of their journey. Of these, 26 participants provided negative comments regarding information provided during treatment.

I felt the less senior oncologist did not give sufficient information about triple negative breast cancer and how it responds to chemotherapy.

Sometimes it feels like you have to tease information out of doctors - it doesn't seem to be given readily, you just have to ask the right questions. Better attention should be given to less common side effects that arise from chemo treatment.

Longer term symptoms of chemotherapy treatment could be discussed and followed up.

Communication often poor, e.g. not told I was having chemotherapy until I arrived for follow-up.

While having chemotherapy I had a bad reaction to one of them and it had to be stopped. This left me with some problems with breathing. This is being monitored, but it was not clear

whom I should speak to when I needed advice regarding this as I did not like to phone the oncology consultant and my clinical specialist nurse said she did not know much about the chemotherapy side of things.

Not much feedback from oncologist during chemotherapy.

15 further participants gave positive comments relating to information provision during chemotherapy.

I was able to contact the sisters in charge of ward when I needed information, as well as for chemotherapy.

I always had direct access to my oncologist's secretary or chemo wards and have never experienced any problem at [hospital removed] with communication.

I have had and still receive first class treatment from all doctors and nurses concerned at the chemo clinic at [hospital removed]. It is impossible in my opinion to improve any information and treatment I received.

People treating me in chemotherapy and radiotherapy were excellent in giving me the attention, info and treatment.

The chemotherapy unit was a very relaxed place and all of the staff were very caring, understanding and informative of my condition.

50 participants also praised the manner in which staff had interacted or communicated with them during cancer treatment (e.g. that staff were compassionate, kind, positive, humorous etc.).

During ...chemotherapy...treatments nurses and staff were always polite and approachable

The staff on the chemotherapy day unit and also in the clinic could not be faulted. They are all very caring and could not do enough for you

The staff were very helpful and caring at the daily chemotherapy cancer unit.

I found the staff at the chemotherapy day centre at [hospital removed] very good. They put me at ease and were always prepared to talk.

Very grateful to have been treated with such prompt attention and compassion from the doctors and chemotherapy nurses.

The chemotherapy nurses were very efficient and understanding.

These findings suggest that for those providing comments about chemotherapy, staff manner in terms of how they interacted and communicated with patients was a significant positive aspect of their experience (it is also worth noting that the data did not include a significant number of negative comments about this area). Once again, however, despite positive comments outweighing negative comments overall, information provision was an issue for a number of participants (a theme seen in other areas of treatment). Comments suggest that information given prior to, and during chemotherapy, as well as on after-effects may be areas for improvement.

4.3.8 – Aftercare

4.3.8.1 – Overview

In this investigation, aftercare is defined as care that was indicated to follow main phases of treatment. Comments were coded to this node where they were identified with the term ‘aftercare’ by participants, or where their comment indicated experiences relating to care following the treatment phase. One exception to this was immediate post-operative recovery in hospital, to which comments were coded if the content described this phase of treatment, even if the respondent referred to it as ‘aftercare’. 290 participants provided comments relating to experiences of aftercare. Of these, 199 were negative and 97 were positive (a ratio of 2.05:1).

In comparison, 69% of total respondents (n = 5047) in the closed questions section of the WCPES survey (question 61) provided answers to the question of whether they were given sufficient care and help from health or social services after leaving hospital. Of these, 59% (n = 2305) stated that they had ‘definitely’ been given sufficient care and help, 20% (n = 794) agreed that this had been the case ‘to some extent’, while 21% (n = 806) indicated that they had not had sufficient care and support (38%, n = 2450, did not require help from health or social services after leaving hospital; 1%, n = 64, stated that they did not know or could not remember if they had received adequate care/support) (QualityHealth, 2014)²⁸.

Area of investigation/diagnosis	Negative respondents	Positive respondents	Total respondents	Ratio (negative-to-positive respondents)
General	157	82	234	1.91 : 1
Follow-up investigations	26	17	43	1.53 : 1
Total	199	97	290	2.05 : 1

Table 17 - Breakdown of areas of aftercare by number of respondents.

²⁸ Data were unavailable for 933 participants.

4.3.8.2 – General comments.

157 of the negative comments were general, referring to lack of aftercare services, rather than poor quality of services actually provided.

I got no after care and would have liked some.

I would have liked a bit more back up when I came home.

The immediate home aftercare could have been better

When discharged from completing radiotherapy I felt quite alone as there had been so much support before.

In hospital NHS care was good but no aftercare when returned home.

Excellent care, but once treatment finished, poor follow-up and family had to do everything.

Follow up care has been mediocre.

82 participants also gave general comments about positive experiences of aftercare, in most cases situating this within an overall experience of good care across their cancer journey.

Good home assessment and aids following discharge from hospital.

[T]hroughout treatment and aftercare I received the best treatment I believe I could

Follow-up care after surgery has been excellent, both nurses and consultant.

[V]ery happy with care and treatment received at hospital and follow up care.

From visiting my GP to after care - all excellent.

When cancer was found I was treated very quickly and my consultant was excellent in my treatment and aftercare.

These comments, while positive, offer little insight into the specific aspects of aftercare that were beneficial to participants. In contrast, the negative comments may be more instructive *because* of their generality, as this content reflects an absence of information and understanding of what patients could expect following conclusion of their treatment. Lack of clarity, in addition to practical support, was associated with experiences of uncertainty and stress in the post-treatment phase. Better information about aftercare and provision of related services could therefore help to meet this need.

4.3.8.3 – Follow-up investigations.

While most comments focused on a general lack of aftercare without reference to specific services, two areas were identified by smaller sub-sets of respondents. The first of these related to the availability of follow-up investigations following treatment, where 43 participants provided comments (26 of which were negative and 17 positive – a ratio of 1.53 : 1). Negative comments referred to failure to conduct what respondents saw as important follow up observations, often with an attendant lack of information as to how they would be monitored for recurrence of their cancer.

Would have liked a scan at the end of treatment. Felt very isolated and don't know what to expect or what is happening now.

Yes. I had a [detail removed] removed from my forehead and this operation went well. But no scans were carried out for checking for [detail removed]. Two months later I found a malignant tumour in my [detail removed] whilst shaving. I was lucky I found this early. A scan would have shown this tumour during my initial treatment.

The care I received was tremendous and I thank all, from the porters and cleaner to the consultants, but with cancer more scans should be taken to check for spread or additional tumours.

Felt should have had closer monitoring and regular blood tests while on the [detail removed] prescribed after cancer treatment. Was only when I started to feel ill was it realised that cancer had spread.

I would have liked a CT scan following the chemotherapy. I would have been happy to pay for this to give me greater peace of mind.

At the end of my first course of chemo, I asked if I would have a scan to ascertain whether the chemo had been successful. I was told I would not as a scan would not necessarily pick up any remaining cancer. I was told that the way they would know if the chemo had been successful would be by \how I felt\". When I began to feel unwell again a scan was carried out which showed that the cancer had spread and I feel that if a scan had been done at the end of my first course of chemo.

My original breast cancer was [time removed]. [Time removed] I returned to normal really for mammogram. Because of radiotherapy my breast was over lumpy and so I requested yearly mammogram but was refused. After [time removed] a mammogram revealed a tumour which should have detected earlier given my history.

Some participants in this sub-theme described a lack of availability and/or willingness to conduct some follow-up investigations, which several linked to delayed diagnosis of cancer recurrence and/or spread. Lack of what participants considered to be adequate follow-up investigation was also associated with anxiety around fear of recurrence. 17 further respondents provided comments relating to positive experiences of investigations following their treatment.

I am clear and no cancer. I go every three months for check-ups. I am [age removed] and have never been in hospital before and cannot speak highly enough of the swift treatment and care I had from all concerned. My grateful thanks.

The surveillance of the cancer by the professionals has been good since 2009 [detail removed] and 2011 [detail removed]. I have very regular hospital appointments.

On the day it was found. One clear check since. Continue to monitor me. My experience of NHS and my GP is all very good.

I get check-ups every six months, which gives me plenty of ease.

I am being monitored regularly and feel \looked after.\ " The specialists are very professional and I felt confident in their care. "

Where negative comments about post-treatment investigations as an aspect of aftercare revealed feelings of apprehension and uncertainty associated with fear of recurrence, in the positive comments regular monitoring was associated with increased confidence that the patient conditions would continue to be managed effectively.

4.3.9 - Radiotherapy

4.3.9.1 - Overview

251 participants provided comments on experiences relating to radiotherapy treatment. Of these, 67 gave negative responses, and 191 provided positive comments (a ratio of 0.35:1). 40 negative and 120 positive comments were of a general or miscellaneous nature (e.g. 'I struggled with the radiotherapy care' / 'The staff at the radiotherapy department in [hospital removed] were

excellent.'). However, a further 101 participants related experiences of interactions and communication with staff in radiotherapy treatment.

4.3.9.2 – Experiences of communication with staff in radiotherapy treatment.

24 respondents described negative experiences of information provision from staff during the radiotherapy phase of their cancer journey. Comments here related to all stages of treatment (i.e. prior to beginning, during treatment itself, and in the immediate aftermath). Areas of concern related to inadequate information about waiting times for treatment, waiting on the day of the radiotherapy appointment, and lack of information on possible side effects.

I would like to have been told at the beginning that I would be waiting a few months before radiotherapy was started.

I felt the radiotherapist's main concern was administering treatment and the effects of this treatment on myself was not taken seriously by them. The information given to me stated I should raise any concerns regarding radiotherapy with the radiotherapist. My side effects were ignored - so feel this should be changed in the information leaflet. Any side effects should be raised with a nurse or doctor.

We should have had a carer nurse right at the beginning. We just contacted the Radiotherapy Dept with a question. Have just been given a name we can contact, nearly one year on.

Any delays on the machines whilst having radiotherapy should be made clear to the patients before they drink the water 3/4 hrs.

Information regarding radiotherapy outdated and of poor information quality. Radiotherapy staff should have the knowledge and skills to recognise early sign of radiotherapy burns and initiate a plan to support patients.

20 further respondents provided positive comments on information given during this phase of treatment. In this group, comments were focused on the availability and willingness of staff to explain procedures and answer questions, as well as the quality of the information provided.

I was fully informed and supported from the time of diagnosis, through radiotherapy etc. I was impressed with the information provided and the support given.

The specialist nurse in [hospital removed] radiotherapy was very helpful with diagnostic and care information.

My radiotherapy oncologist Mr [name removed] at [hospital removed] was a very open and informative doctor. It was a pleasure to talk to him and I come away with all the information I needed and with my mind at rest.

Radiotherapy and chemo nurses explained all procedures and could not have done more to make me feel at ease!

Staff at radiotherapy, cancer centre [hospital removed] were very friendly and put me at ease and gave me advice about skin care during treatment sessions.

65 respondents related positive experiences of staff manner in interactions and communication during to this phase of treatment. Once again, terms such as 'friendly', 'compassionate', 'professional' and 'caring' were often used to describe patient experiences of dealings with staff in the radiotherapy phase.

The staff at the radiotherapy unit at [hospital removed] were fantastic, so helpful and sympathetic.

I was particularly impressed with the radiotherapy staff [word unreadable] very competent, caring and professional.

Staff at the Radium department were very helpful and caring. They always ask if I was in pain; when I said I was they made me an appointment with my specialist for medication to help me.

The radiographers were particularly kind and caring. I went for 40 treatments and it was an honour to be treated by such lovely people. Many, many thanks.

Care, support and attitude of the staff at the radiotherapy dept. of [hospital removed] was excellent. They were very positive and showed concern for me as a person.

Once again, respondent experiences of radiotherapy reflect themes present across the wider treatment journey. The majority of participant responses convey general satisfaction with their treatment, and in terms of sub-themes, communication remained a significant issue in both negative and positive comments. Despite the majority of communication related comments being positive overall, 24 respondents provided negative comments around information provision (compared with 20 giving positive reflections). The majority of negative comments here referred to lack of information around waiting and potential side effects, both before and during treatment. In the positive responses, participants conveyed a sense of being well-informed of potential side effects.

These comments often appeared alongside more general positive comments about their experience of treatment across the journey. Overall, comments suggest that for participants in this study the manner in which staff dealt with patients was a strength of the service, while experiences of information provision were a mixed experience. This may be an area for further attention with a view to future service development.

4.3.10 – Emotional, social and psychological support during treatment

In the closed questions section of the WCPES survey (question 31), 69% of respondents (n = 3278) reported that they had been 'given information about emotional support, such as support or self-help groups for people with cancer', 8% (n = 294) had been given such information but 'would have liked more information', 23% (n = 1099) had not been given this information and would like to have received it, 27% (n = 1882) stated that this was 'not necessary', while 5% (n = 374) stated that they did not know or could not remember (QualityHealth, 2014)²⁹.

In the free-text responses, 136 participants provided comments relating to emotional, social and psychological support during the treatment phase of their cancer journey. Of these, 94 respondents provided negative comments, while 43 provided positive responses (a ratio of 2.19 : 1). Of the negative responses, most did not identify a specific mental health diagnosis or morbidity, but instead referred to feelings of 'isolation', 'loneliness', as well as 'emotional' needs during treatment that were not addressed.

Maybe more emotional support. Cancer is one of the hardest diseases to live with. The waiting time to see a counsellor is far too long, and maybe we need more of them.

Would like to meet people with myeloma for their point of view regarding side effects from this treatment in the hospital that I visit and receive treatment for myeloma.

I felt and still feel lonely and vulnerable. Would have been nice to have had some emotional support.

Emotional support – most hospital staff were quite sympathetic, but never had time to talk to me when I was upset. I had no idea I would be quite so ill from chemotherapy.

I have not been offered a \care plan\" ever or asked about my emotional needs or asked if I needed help with anything. "

I feel as if I have been left to die. Sorry but that is how I feel.

²⁹ Data were unavailable for 325 participants.

Isolation. Especially living alone, trying to deal with side effects, often effects from the treatment. No follow up nursing care at all being house bound. Depression, unable to move on in a positive way.

The emotionally part of it. A cancer patient needs people to talk to, and to be listened to.

Comments in this section reveal unmet needs for some patients around emotional and social support during the treatment phase of respondent cancer journeys. In some cases, patients felt that these needs were not factored into their overall framework of care, and/or that staff did not have sufficient capacity to address them in situ. Several participants also requested more information about where they may be able to discuss their experiences with other cancer patients/survivors. Particularly for those who reported living alone, issues around lack of support for emotional issues relating to treatment were linked to feelings of isolation.

43 participants provided positive comments relating to emotional, social and psychological support during the treatment phase of their journey.

Dedicated, integrated team that looked after your health, well-being, and emotional needs.

Back up of [hospice removed] invaluable in helping with coming to terms with diagnosis and treatment.

The treatment I received from all the staff involved was excellent. Everyone was very positive and helped me get over the shock of having cancer.

Since my op I have had advice and help from my nurse. This has been a great help as my confidence has been up and down over many changes to my body.

My cancer came as a terrible blow and I was so afraid! My continuing support, treatment and care has been so good that I am no longer afraid.

Sessions with...counsellor very helpful with personal issues before treatment began. Made hospital visits and treatment easier to manage.

Unsurprisingly, support for emotional needs (articulated primarily as fears around diagnosis and treatment) were linked to decreased stress and anxiety, and indications that patients felt better able to cope with their condition. However, it is interesting to note that while a number of participants gave positive comments relating to secondary or support services, the majority of respondents in this sub-theme reported that their emotional needs were most effectively met in situ by staff involved in the main treatment phases of their cancer journeys. Recognition of emotional needs and provision of reassurance by staff was associated with positive experiences in terms of meeting emotional needs during treatment. This should not be interpreted as suggesting that other areas of

support such as specialist counselling are less important (particularly as need for these services is indicated by negative comments), but rather serve to emphasise the vital role that staff in the main diagnostic and treatment phases of the cancer journey play in meeting emotional, social and psychological needs.

4.3.11 – Oncology

117 respondents gave comments relating to care received from staff identified with oncology, of which 31 were negative and 90 were positive (a ratio of 0.34 : 1). Of these, 18 negative comments were miscellaneous and 77 positive comments were of a general nature (e.g. ‘oncologist fantastic’). The remaining 13 negative respondents described poor information provision, communication by and contact with oncology staff.

Contradicting statements between surgeon and oncologist.

My oncologist during my first treatment (chemo) I found very ignorant and unapproachable. He would not answer many questions, telling me not to worry about it, which I found demeaning. He would walk out of the room before I had finished my questions and leave nurse to continue. This made me feel he had better things to do and I was a nuisance. I dreaded my appointments and came away frustrated. Took no notice of my concern that treatment not going well due to [word unreadable] results rising. Refused a scan at end of treatment, so had no idea if treatment works. I was given no choice in this decision.

Time spent with oncologist was rushed and had to ask for second appointment so I could ask questions.

Insufficient information at pre-treatment appointment with oncologist.

Not much feedback from oncologist during chemotherapy.

While communication and access was an issue for a minority of respondents in this section, in the positive comments a number of respondents (13) praised these same areas as positive areas of their care.

My current oncologist was very efficient at treating my cancer and treated me in a humane manner.

My new oncologist does listen and makes me feel more confident in my care and has time to answer questions. He treats me as an individual.

[M]y oncologist explained in detail about my operations which made me feel better in myself, was very kind told me I am on remission with my cancer, hopefully I can look to the future which makes me and my family very happy.

Yes. Dr [name unreadable] (oncologist) has been excellent and has explained everything to me in a way I can understand. I don't think I could have anyone better!!

I always had direct access to my oncologist's secretary or chemo wards and have never experienced any problem at [hospital removed] with communication.

My oncologist is usually available, via her secretary, if necessary during the week and will ring me if she thinks it necessary.

Both negative and positive comments show that, once again communication with staff was a key factor. In particular, the quality of information provided by the staff, the manner in which this is communicated, and how readily respondents were able to access staff were all important aspects of care for participants responding in this area of treatment

4.3.12 – Pain management

In the closed questions section of the WCPES survey (question 56), 57% of total respondents (n = 4165) gave responses to the question of whether they believed that hospital staff had done all they could to help control their pain. Of these, 86% (n = 3187) stated that this happened 'all of the time', 13% (n = 482) indicated that this had been the case 'some of the time', while 13% (n = 580) reported that staff had 'not at all' helped to control their pain (13%, n = 580 reported that they did not have any pain) (QualityHealth, 2014)³⁰.

In the free-text responses, 82 participants provided comments relating to pain management during their cancer journey. 73 respondents provided negative comments, while 10 related positive experiences of pain management (a ratio of 7.30 : 1). Of the negative comments, 54 were of a general (e.g. 'I was in severe pain after my op') or miscellaneous nature. Within the remaining negative comments, 19 referred to what participants viewed as excessive waiting times or restricted access to pain relief in hospital, in many cases within in-patient wards. Once again, experiences of waiting for pain relief were linked to difficulties with staffing levels.

Wing [name removed] needs more staff. Outpatients always congested; it took more than 8 hours before I was given pain relief and a hospital bed. I had to go several times to the receptionist to find out when I would be seen to.

³⁰ Data were not available for 3053 respondents.

Pain relief. What is the point of having specialist pain relief nurses when the drugs cannot be given you on time because there are not the staff nurses available.

[W]hen I was in a lot of pain I never got my painkillers until late on only a few occasions though, also the staff at night times on their rounds were late due to the giving out of tablets and more people to look after.

Medication rounds done at midnight, pain relief not administered on time.

When needed could not get contact with any staff to relieve my pain.

One ward sister dismissed my plea for pain relief. One ward nurse rationed pain relief medication. I was not offered or given morphine prescribed by anaesthetist. A nursing assistant took an doctor role and told me I didn't need pain relief - claimed that consultant had said so. They should have felt my pain, it would have changed their mind.

My neck needed dressing none supplied. Extreme pain and no analgesic supplied.

The [hospital removed] had no time for me at all. They delayed giving me pain relief and was going to send me home after one day in hospital.

Pain relief and catheterisation more quickly, would be appreciated.

10 participants also gave comments reflecting positive experiences of pain management during their journey.

Staff at the Radium department were very helpful and caring. They always ask if I was in pain; when I said I was they made me an appointment with my specialist for medication to help me.

[Hospital removed] was especially good to me, re: pain relief.

In control of pain control.

When I did attend the pain clinic - the treatment was excellent.

Once again, participant concerns speak to several themes present across different areas of the cancer pathway, specifically issues regarding staff shortages and out of hours/weekend care. While the vast majority of negative comments in relation to pain relief involved waiting times, there were

also indications that some participants perceived a lack of willingness on the part of some staff to provide pain relief. Though far fewer in number and of a much more general nature, positive comments suggest that in addition to timely administration, proactive pain management by staff (i.e. asking if the patient is in pain) and feelings of control over pain relief on the part of patients were associated with better experiences in this area.

4.3.13 – Accident and Emergency (A&E) care

41 respondents provided comments relating to care in A&E departments, the majority of which involved incidents occurring during the treatment phase of their journey. Of these, 33 respondents provided negative comments, while eight related positive experiences (a ratio of 4.12 : 1). In relation to negative experiences, the vast majority of comments involved waiting times on occasions when patients had attended A&E during their treatment. These comments were also attended by a number of accounts suggesting respondent perceptions of A&E staff as having insufficient knowledge to deal with their condition. In addition, concerns about waiting times were allied to fears around increased infection risk from spending long periods in A&E, during a treatment phase where participants may have been at increased risk of infection.

Service provided by A & E when taken in as an emergency. Wasn't seen for 5 hours.

I had the misfortune to be admitted through A & E in one episode of extreme fever (neutropenic sepsis) and was appalled at the length of time held in this unit (14 1/2 hours). Staff were fine but A & E is not a place to remain as a patient on a trolley!!

Delays when presenting at [hospital removed] A & E during chemo treatment were appalling, same on admissions ward.

One experience of having to be admitted through A & E via triage on [name removed] ward. A & E staff had very little knowledge of the specialist treatment required and how to manage it. It was not a very pleasant experience.

A & E for hours, nowhere to put me in isolation.

[unit removed] closed for the weekend - when you need care after 5 pm on a Friday you have to go to A & E. I have had 2 bad experiences at the hands of the doctors at [hospital removed] A & E. They do not know what to do with you - they do not have enough information on cancer drugs - when something goes wrong - more interaction is needed between the two units for out of hours treatment.

Yes. Instances when circumstances required attendance at A&E were dealt with poorly by staff. No facilities when immunity was low to be isolated from others while awaiting treatment. Long delays and poor communication.

In terms of positive responses, the eight participants who highlighted positive care in A&E focused on the speed in which they were dealt with, and the 'caring' manner of staff.

The way the A&E department (unreadable word) quickly.

The staff in A&E were very good and very kind, and jolly on the two occasions I had to be admitted during chemo. So busy in A&E but excellent staff, very patient and caring.

Made 2 emergency visits to A&E in connection with treatment - excellent and caring treatment.

A&E were quick to see me.

In this area, speed of treatment was especially important in both the negative and positive comments. The negative comments (comprising the majority of responses in this area) also point to perceptions of problems around infection risk during treatment, and lack of knowledge displayed by staff as to particular issues associated with their condition.

4.4 – Other areas

525 respondents provided comments that did not relate to treatment or care related aspects of their cancer journey. These broke down into the areas summarised in table 18, and are discussed in order of number of total comments.

Area	Negative respondents	Positive respondents	Total respondents	Total respondents as % of free-text respondents	Ratio (negative-positive respondents)
Hospital environments	182	53	240	5%	3.43 : 1
Travel-related issues during the cancer journey	122	45	161	3%	2.71 : 1
Food and catering	128	26	153	3%	4.92 : 1
Financial concerns	35	3	36	>1%	11.7 : 1
Total respondents in other areas	429	116	525	11%	3.70 : 1

Table 18 - Breakdown of other areas of interest in free-text responses.

4.4.1 – Hospital environments.

240 patients provided comments relating to aspects of the physical environments in hospital settings during their cancer journeys. Of these, 182 were negative, while 53 were positive (a ratio of 3.43:1), with negative comments tending to be of a more specific nature than positive comments. 80 negative and 34 positive comments were of a miscellaneous nature, while the remainder mapped to the sub-themes discussed below.

Area	Negative	Positive	Total respondents	Ratio (negative-to-positive respondents).
Availability of hospital beds.	58	1	59	58 : 1
Cleanliness of hospital environments.	22	18	40	1.22 : 1
Concerns about privacy in hospital settings.	22	-	22	-
Total hospital environments	182	53	265	3.43 : 1

Table 19 - Breakdown of comments about hospital environments by sub-theme.

4.4.1.1 – Availability of hospital beds.

58 participants provided negative comments regarding availability of beds in hospital settings. Most of these comments were general; however, in some cases these were linked to more specific experiences such as cancellation of surgical procedures, and what some patients considered to be rushed discharge following their operation, in order to free up beds.

Being bowel prepped for theatre and then told surgery cancelled, due to lack of HDU bed and asked to go home.

Had breast operation cancelled on day due, as no beds available. When I eventually had operation and put on ward, old people in beds waiting for social to make arrangements for them to leave.

There should be more beds as my operation was postponed which was very traumatic and emotional.

There are not enough beds and you don't know where to will land up after your op.

Yes, no bed available had to walk to operating theatre for my op.

The day I went into hospital there was no bed for me until 7pm that evening. I was on tenterhooks all day waiting to go to be admitted to hospital.

Respondents also linked lack of bed availability to increased stress and anxiety surrounding surgical treatment. Viewed in the context of the wider treatment pathway, this can be seen as part of a set of issues around ambiguities in the treatment journey (e.g. poor information provision) that appear to have increased stress experienced by participants.

4.4.1.2 – Cleanliness of hospital environments.

40 respondents provided comments relating to cleanliness of hospital environments, of which 22 were negative and 18 were positive (a ratio of 1.22:1). While six of the negative and all of the positive comments were of a general nature (e.g. 'There was in my mind a general cleanliness problem / "Very clean environment)'), 16 participants provided negative comments relating specifically to cleanliness and availability of toilet facilities on hospital wards.

I was on a bowel cancer ward and felt that the toilets were not cleaned or replenished, restocked with loo rolls etc often enough, considering the usage from both men and women. There just seemed a shortage of cleaners. The toilets were often in an unhygienic condition.

The toilets in the ward were filthy. When I was able to walk I went to the public toilets in the hospital. Toilets and shower were given a cursory clean once a day whereas the public toilets appeared to be inspected and cleaned regularly.

The toilet and bath / shower facilities were not clean and could have been a hazard.

Poor hygiene in wards and toilets.

More toilets in the Ileostomy Ward.

[T]he toilets and showers were in a poor condition and the cleanliness often left much to be desired.

Of note within these comments is the observation by some participants that public toilets tended to be cleaner than those on hospital wards, and this may indicate an area for further exploration with respect to service improvement.

4.4.1.3 – Concerns about privacy in hospital settings.

In the closed questions section of the WCPES survey (question 53), 59% of total participants (n = 4305) provided information relating to privacy when discussing their condition or treatment in hospital settings. Of these, 83% of participants (n = 3592) agreed that they had ‘always been given enough privacy in these situations, 13% (n = 540) stated that they had ‘sometimes’ had adequate privacy, while 4% (n = 173) stated that they had not been given sufficient privacy (QualityHealth, 2014)³¹. In addition, 59% of total respondents (n = 4315) provided answers relating to whether or not they had been given enough privacy when being treated or examined (question 54). Of these, 94% (n = 4046) stated that they had ‘always’ been given enough privacy in these situations, 5% (n = 224) indicated that this had ‘sometimes’ been the case, while 1% (n = 45) stated that they had not been given sufficient privacy (QualityHealth, 2014)³²

22 participants provided free-text comments relating to issues with privacy in hospital environments. The majority of these comments referred to privacy in the ward environment, with respondent concerns reflecting a lack of private spaces for discussion of their condition, as well as for washing and toileting.

There were no shower facilities and it was difficult to have any privacy.

The privacy when checking wounds could be improved.

³¹ Data were unavailable for 3047 participants.

³² Data were unavailable for 3037 participants.

More provision should be made for private discussion of patient's condition and care to improve confidentiality.

There is a huge privacy issue in the wards, you can overhear conversations and treatment.

Perhaps it's because they are a gynae ward. Not much support there. Not very private.

Privacy issues relating to discussion of patient conditions appeared in some comments alongside other concerns relating to communication with staff regarding treatment and care, and can, therefore, be seen as part of a more general set of potential stressors relating to information provision.

4.4.2 - Travel-related issues during the cancer journey.

161 respondents provided comments relating to aspects of travel during their cancer journey. Of these, 122 were negative and 45 were positive (a ratio of 2.71:1).

4.4.2.1 - Experiences of distance travelled for cancer treatment/care.

Of the negative comments relating to travel, the vast majority (85) were general responses regarding distance of travel to receive treatment and/or care, and experiences of discomfort and/or inconvenience associated with this. Some also expressed worries around expenses associated with travel connected to their cancer treatment.

Long journey both in time and distance - 64 miles each way - made for a tiring day. Could cancer treatment be made available at [hospital removed]?

[S]everal 40 mile round trip journeys in pain for out of hours treatment.

It was a round trip of 107 miles per day. Borrowed money for travelling, worried don't know how to pay it back.

In spite of having to travel the 60 miles round trip almost daily for 2 months to [hospital removed].

I tried to get help with travelling expenses from various sources but to no avail. I found there was one who could help me in this area.

Only complaint would be having to travel to [hospital removed] everyday apart from weekends. 130 mile round trip, every week day can be exhausting.

In addition, 20 respondents also provided positive comments relating to the availability of treatment at a local hospital, or facilities for patients to stay near to treatment centres if coming from further afield, precluding the need for daily travel.

[Welsh] There was no need for me to travel at all to get chemotherapy.

Able to have chemotherapy at my local hospital.

[H]aving a hospital close by where I can receive treatment.

Staying in the hospital for 3 weeks while I had radiotherapy saved me driving for every day for 3 weeks.

The ability to have treatment in my local hospital.

In both the negative and positive comments, distance travelled was the main issue, and in particular several positive comments indicate that provision for local overnight stays during treatment was of significant benefit to several participants. In terms of negative comments, for those who were compelled to make regular extended journeys, financial worries attend those relating to discomfort and stress associated with travel.

4.4.2.2 – Experiences of hospital car parking.

A subset of respondents (28) also provided negative comments regarding hospital car parking facilities, the majority of which were of a general nature (e.g. 'More car parking facilities when attending appointments'). However, several respondents also linked poor facilities to other stresses such as having to walk further in bad weather during treatment, increasing the stress of this phase of their journey.

Parking is a major problem at [hospital removed]. You are supposed to arrive at the chemotherapy unit warm. Often (particularly during winter) you have to walk from the overflow car park and you arrive frozen. My wife has had to miss appointments and stay with the car.

Parking facilities. Treatment took place over a fair period of time and difficulties were experienced during the inclement weather.

Car spaces are reserved for cancer patients at the cancer day unit for cancer patients. But we find them taken up by staff who have their own care park, which means patients have a long walk from the main car park.

Parking at the [hospital removed] is horrendous. I have got out of the car in the road outside, walked to outpatients and seen the doctor, waited 5 minutes for my husband and walked slowly back to car park to find he had just parked.

Parking was a real problem for my visitors. My parents are pensioners and had to park miles away on more than one occasion.

Comments in this section suggest that for some participants, existing car parking facilities were inadequate, and/or that extra steps that could be taken to make this process easier for patients especially for those whom extended walking journeys to and from their cars may be a challenge.

4.4.3.3 – Experiences of non-emergency ambulance transport.

29 respondents provided comments relating to experiences of ambulance transport, including hospital car services, of which nine were negative and 23 were positive (a ratio of 0.39 : 1). All negative comments were miscellaneous; however, the positive comments highlighted both general satisfaction with the service, and also positive experiences of ambulance staff in terms of their manner and helpfulness.

I would like to mention the ambulance staff who were always very helpful, who gave excellent care and consideration to the patients they had to transport from their homes and back.

Ambulance service very helpful.

[T]he hospital transport all wonderful people.

5 week, 25 days I was taken and returned home by the truly impressive ambulance car service.

The ambulance car service was first class for my 36 treatments at [hospital removed].

The car service could not be faulted - to and from [hospital removed] for 3 weeks. All the drivers were courteous and most of them comical so that I never even thought any day I was going for treatment. They are worth their weight in gold.

For these participants, both the service and also the manner in which staff interacted with patients were positive aspects of this area of provision. In the context of negative comments given in relation to other areas of travel relating to cancer treatment, it appears that this service helped to mediate some of the other difficulties associated with journeys to and from hospital. Therefore, this may be an area to explore in terms of the availability for those who were not able to access the service.

4.4.3 – Food and catering.

153 respondents provided comments on experiences of food and catering in hospital settings, almost all of which referred to food served in hospital in-patient wards. Of these, 128 were negative and 26 were positive (a ratio of 4.92 : 1). Of the negative comments, the vast majority reflected experiences of poor quality food served in hospital in-patient wards, and in a number of cases this was linked to poor choice of food and lack of fresh produce.

Food given to patients unsuitable as all offered was re-heated processed food (microwaved).

[Welsh] The choice of food was not good, and not suitable for someone with cancer. I felt there was no understanding in the hospital, nor in the Red Cross, cafes, WRVS etc, of a suitable diet for cancer care.

Yes – buy fresh food! The food was disgusting. After 3 days of sipping water I was offered my first meal of powdered soup (minestrone) which had not been stirred with tepid water. All the food horrible.

Food in hospital was inedible. Too much reliance on powdered and processed food, not enough fresh provided.

The only thing to be improved upon would be the disgusting food. Cancer patients due to nausea etc. have very little appetite anyway. To be served partially cooked fish, half baked potato served up cold, followed the following lunch time by cold chicken and pasta bake, is not going to make any cancer patient regain lost weight or help with loss of appetite.

Food. People serving the food were marvellous, very friendly and helpful, but the food was close to inedible - very salty. I survived by people bringing in food for me. Food is such an important part of healing and really needs improving.

Patients with or recovering from cancer need a light diet, not tough [several words unreadable], potatoes, cabbage and baked beans.

The hospital food was appalling. I was offered corned beef pie which I thought might be ok, but it comprised of gluey mashed potatoes containing a hint of corned beef, baked beans and

another dollop of glue-like mashed potatoes. I refused a second lunch but if this is an example of normal patient food - it is a disgrace and really lets the hospital down.

A number of patients described having others bring food into the ward due to poor quality provision from the hospital. Several respondents also linked their concerns about food quality to implications for post-operative recovery (i.e. that poor quality food would impede their healing). In a minority of cases, patients voiced concerns over the appropriateness of food on offer for their particular condition.

Of the positive comments (26), roughly half appear to relate to those staying in specialist/hostel accommodation while undergoing chemotherapy or radiotherapy treatment, while the other half applied to hospital in-patient wards.

All meals were very good.

I stayed in the hostel during the week, the care and food was excellent.

Do not close the kitchen on [ward removed]. The food and staff there are both excellent. The cook was unwell for a week whilst I was undergoing radiotherapy and we had to have food from the main kitchen - it was inedible.

Kind and caring nurses, comfortable surroundings; they also offered marvellous food if anyone wanted it.

I had a three week treatment for radiotherapy and stayed in the hostel. It was like a five star hotel, beautiful food

The meals in the dining room were excellent. There was a choice of menu + vegetarian all so plenty of food, there as well was supper brought up to hostel by the chef each day. Marvellous!!!

Comparing negative and positive comments, it appears that while food within specialist cancer treatment settings attracted only positive comments, experiences of catering within non-specialist wards tended to attract negative responses from those who commented in this area. Concerns around the appropriateness of food available and its role in recovery during cancer treatment also remain present in both the negative and positive responses. Improvements to food served to cancer patients in non-specialist wards may, therefore, be an area for further investigation with regard to service development.

4.4.4 – Financial concerns.

In the closed questions section of the WCPES survey (question 33), 44% (n = 1715) of respondents stated that they had been given information about financial help and benefit entitlements, 7% (n = 259) had received such information but would have liked more, 49% (n = 1918) did not receive this information would have liked to, 41% (n = 2897) stated that this was not necessary, while 3% (n = 198) did not know or could not remember (QualityHealth, 2014)³³.

In the free-text section, 36 respondents provided comments regarding financial worries during their cancer journeys, of which 34 were negative and three were positive (a ratio of 11.3 : 1). Specifically, respondents highlighted the need for greater advice and provision to address extra costs associated with cancer care (e.g. transport), and to ease the more general financial burden of their illness.

I had one visit when I came out of hospital, when I was told I could claim for help with heating and other things, which I never had. That was 12 months ago.

Presently I have to travel a round trip of 20 miles on public transport to the hospital three days before treatment. I have to pay for carers to sit with my mother for 3 hrs at a cost of £15 x 3 = £45. Just because the GPs refuse to do this test. I feel very isolated with no-one with the same type of cancer to discuss it with.

More information provided on emotional support (1:1) and financial support given to support this, ie petrol expenses to speak to someone (physiotherapists) - as limited to talk to anyone as [word unreadable] money.

Cancer is a total life danger, so much so that I am wondering how I can carry on financially. I do not think there is enough aftercare, I mean significant help in the healing!

Yes, help straight away with benefits. I lost 6 months financial help. Also, I am receiving treatment weekly 40 miles away and find it difficult to claim traveling expenses. The Macmillan website is very difficult to get to the information I require to get help with heating and other concerns I have. There needs to be someone there, at the time you are told you have cancer, that help is available. I had to find out from other cancer sufferers as I did not know how to go about claiming.

No one told me when I had developed secondary bone cancer, I could have applied for A/Allowance. I pay [detail removed] a week for care package and cleaner as I am single. Surely the info should be forwarded to people especially frail and single.

In this area lack of support for financial worries was linked to other failings in provision, such as information about support during and after treatment, suggesting that this may have contributed to more general negative experiences and uncertainties. It may, therefore, be advisable to explore

³³ Data were unavailable for 365 participants.

areas from which financial advice on benefits and services may be obtained, and for this information to be relayed to patients at earlier stages of their cancer journey where this is not already in place.

5 – Summary of findings.

The findings of this report present a range of experiences from 4,672 cancer patients in Wales which provide many examples of positive care but also areas of concern. This section explores the general themes that emerge across different areas of the findings discussed in previous sections. The discussion within individual sub-sections follows the general form of the findings session, where negative experiences are discussed first, followed by paired examples of positive experiences. These contrasting elements are then synthesised into recommendations for future service improvement.

5.1 – Care across the cancer journey: areas of positive experience – areas for improvement.

5.1.1 – Diagnostic phase

5.1.1.1 – GP

Concerns were raised by a number of participants in relation to GP care in the pre/diagnostic phase of the cancer journey, particularly around speed of GP reaction to presenting symptoms. This was the main factor in GPs being the only staff area in this investigation for which negative comments outnumbered positives. Speed of action was the most common area of comment relating to this phase of the cancer journey, and the majority of responses in this section were negative. Many respondents felt that their GP was slow to act in relation to their presenting symptoms, and linked this to delays in diagnosis and beginning treatment. These comments link with patient responses to Q2 of the section of WCPES survey where over a fifth (22%) of respondents indicated they felt they should have been seen by a hospital doctor a bit sooner (12%) or a lot sooner (10%).

Some participants observed what they considered to be a lack of willingness to refer for further investigations on the part of some GPs, and a smaller number also voiced concerns about GP knowledge of some cancers. Of particular concern was a subset of respondents who described inaccurate diagnosis of their cancer as another condition prior to the correct diagnosis. This was seen to delay diagnosis and treatment often by months, and in some cases a year or more. Comments of this type were often allied with expressions suggesting a lack of confidence in this stage of the cancer journey, and in some cases feelings of disinterest on the part of GPs in their symptoms. In contrast, positive comments in relation to GP care tended to be of a more general nature, but crucially almost all commented on the speed with which their presenting symptoms had been investigated, including referral for further investigations. This was often allied with more general comments expressing feelings of satisfaction and reassurance in terms of the overall care and treatment received during the cancer journey, suggesting that the GP represents an important starting point for building confidence.

5.1.1.2 – Investigations and diagnostic procedures

Speed of diagnosis and treatment was the most important feature of comments about investigations and diagnostic services. The majority of comments relating to investigations and diagnostic procedures at this stage were negative, and reflected general concerns around waiting for investigative procedures. A smaller sub-set of respondents providing negative comments expressed concern over the conduct of investigations (i.e. that their cancer had been missed in earlier investigations). In terms of positive comments, these related almost entirely to the speed and accuracy of diagnostic procedures, and, once again, often appeared within the context of general comments regarding treatment across the cancer journey. These comments suggest that waiting times for investigations may be one area for further investigation with regard to improving care at this stage of the cancer journey.

One area of investigations comprised exclusively of positive comments was screening. Respondents praised both the bowel and breast screening programmes for having detected their cancer, which in many cases had presented no discernible symptoms. Early detection through screening was linked to perceptions of better likely outcomes and increased confidence in the effectiveness of subsequent treatment, and underscores the value of screening programmes to patients.

Investigations and diagnostic services were two of the few general areas in which negative comments outweighed positive responses. The main reason for this relates to waiting times for investigative procedures, rather than poor provision or conduct of investigations per se. Waiting for investigations will have contributed to the delays in diagnosis noted above, that were often described as running into many months, and sometimes a year or more. The majority of comments regarding speed of treatment not mapped to the GP were of a general nature, and as such it is difficult in many cases to identify if this was the result of waiting times for investigations after referrals had been made.

Waiting for the results of investigations was an area in which only negative comments were provided, although it must be acknowledged that the lack of corresponding positive comments may be due to their implicit inclusion in more general responses about speed of care and treatment across the cancer journey. Awaiting results of investigations was indicated to be a time of great anxiety for many participants, and for many this had been exacerbated by extended waiting times, and poor communication regarding timescales for results. Experiences of having to chase results (often repeatedly) with staff were common in this area, indicating the importance of timely communication with patients during this phase of the cancer journey. The data discussed here does not allow us to explore the reasons for these delays in terms of the processes affecting provision. When delays occurred on the day patients often reported not having been kept sufficiently informed.

5.1.1.3 Initial disclosure of the cancer diagnosis.

Some patients described the way that the news of cancer was delivered by staff as insensitive or dismissive, with little time allocated to discuss patient needs or help manage their reactions. This reflects responses to Q12 of the closed questions section of WCPES survey where over a 16% of patients felt the way they were told they had cancer should have been done a bit more sensitively (11%) or a lot more sensitively (5%). Brief visits by doctors who left the patient alone soon after

delivering the news, disclosure of the cancer diagnosis by telephone, and also delivery of the news within public spaces of the hospital were cited as examples of poor management of this event. In addition, the manner in which this information was provided was significant for a number of participants, who described insensitive disclosure, which damaged confidence in their care. Responses to Q11 of the WCPES survey indicated that almost a third (30%) of respondents had not been told they could bring a family member with them when they were told they had cancer. Comments indicate that some patients who were given their news alone expressed a desire that they should have been advised to bring someone with them for support. One other area of significance was inadvertent disclosure of a cancer diagnosis of which the patient had been unaware hitherto. Patients reporting such experiences tended to associate these events with poor communication between staff.

Once again, it is difficult to find in the data direct parallels regarding delivery of the diagnosis in the positive comments due to their comparative generality. What can be said, however, is that a greater number of participants praised the sensitivity, attentiveness and emotional support given by staff throughout their cancer journeys, which would appear to incorporate initial disclosure of their diagnosis. Participants giving positive comments of this type tended to describe their staff as being sensitive and responsive, available to give advice and support when needed, and to taking time to listen to their concerns. These are factors that are identified explicitly as lacking in those for whom disclosure of their diagnosis was handled poorly.

5.1.2 – Treatment phase

5.1.2.1 - Speed of treatment and management of delays

The data considered here indicate that many participants experienced delays in relation to their diagnosis and commencement of treatment. The information given allows only for identification of this as an experience, and provides little direct insight into the processes behind these delays; however, participant comments do identify perceptions of financial constraints, poor inter/intra-agency communication and shortages of available beds as factors that have delayed their care.

What is clear from the comments is that where delays do occur, timely and accurate communication with patients is essential for minimising the stress caused. Participants have reported difficulties in contacting specialist staff, failure of staff to honour promises to return phone calls, and lack of clear timescales for completion of their treatment. Conversely, in the positive comments, clear and accurate communication often went hand-in-hand with speed of diagnosis and treatment, with attendant expressions of confidence in the treatment and care given.

Another area of concern involves patients who appear to have been sent home on the appointed day of their surgical procedure due to a lack of available beds (in some cases, on multiple occasions). This is an area that appears to warrant further investigation as a matter of urgency, as multiple respondents linked this to bed availability as well as poor communication around these resource constraints.

5.1.2.2 - Information and support during treatment

The opportunity to discuss and be informed about the impact of cancer and treatment, including likely side effects and the support that is available to mediate them, was the subject of many patient comments. This reflects concerns indicated within the closed questions section of the WCPES, where almost a quarter (23%) of those patient responding felt they did not receive any information concerning emotional support (Q31), and almost a third (32%) felt they had not had information regarding the impact of cancer (Q32).

For those receiving treatment such as chemotherapy and radiotherapy, information and support can continue as treatment progresses through a central point of contact such as a key worker or member of specialist nursing staff, or contact with consultant through their secretary. Being prepared for the challenges ahead, and the confidence that, should difficulties arise, support will be available in a timely manner (especially out of hours) is important for building confidence in treatment and care. Those who reported limited opportunities to discuss treatment and side effects, as well as difficulties in contacting specialist staff for support, reported additional stress during the treatment phase of their cancer journey. Conversely, those who reported good and clear communication with staff during their treatment, especially in relation to a central point of contact for advice and support, gave explicit indications that this had helped them.

Limited opportunities for contact with specialist nursing staff were a significant source of negative comments in this data set. Such comments often linked to inadequate staffing levels and perceptions of staff in this area being overburdened, and thus not able to respond in a timely manner. Findings from the closed WCPES questions found that 12% of respondents indicated they had not been given a named clinical nurse specialist CNS and over a fifth (22%) had found it sometimes difficult (19%) or difficult (3%) to contact their CNS. While CNSs were more often than not identified as the patient's key worker, over a third of patients (34%) nevertheless indicated that they didn't have a key worker, and 11% did not know.

There were comparatively far fewer attributions of such negative experiences to shortcomings in staff per se, and where specialist staff were available the value of having a central point of contact for meeting needs during treatment (commonly through a Key Worker or specialist nurse) was emphasised heavily in the positive comments. This reflects the finding from the WCPES report of the closed question that found that 74% of patients without a CNS reported excellent or very good overall care, but that this rose to 91% for those who had a CNS.

In relation to surgical care, timely information provision and the availability of specialist staff to answer questions was closely linked to quality of patient experiences at all stages of surgical care. For those providing negative comments, lack of information and contact in the pre-operative phase was linked with experiences of confusion and anxiety in relation to their care. In the post-operative phase, lack of contact with staff and, in particular, lack of opportunity to ask questions about the outcome of procedures and likely experiences during recovery were associated with increased difficulties during recovery from surgery. For those recovering on wards where staff were described as not being trained in their particular area of care, lack of contact with specialist staff could compound feelings of isolation and distance during recovery. Conversely, those who provided positive comments often did so as part of general reflections on good communication and access to specialist staff at all stages of their surgical treatment and care. These positive experiences were

associated with feelings of confidence in the care provided, and statements indicating better ability to cope with the challenges of recovery from surgery as a result.

As the data indicates, for some patients and their families cancer treatment can involve a significant financial burden, both in terms of income lost through inability to work (for both patients and those caring for them) and also in relation to expenses incurred through, for example, travel to and from treatment sites. A number of participants identified information and support for accessing benefits and services as an area of improvement during the treatment phase. For those living alone in particular, the social and financial burdens of cancer can be additional stressors that exacerbate the already considerable challenges of living with and beyond cancer. Within the WCPES closed questions section, almost half (49%) respondents indicated they had not had information regarding financial help or benefits but would have liked such information (Q33).

5.1.2.1 – Nursing care

Overall comments relating to both general and specialist nursing reflect high levels of satisfaction, as well as several areas for potential service improvement.

5.1.2.1.1 – Specialist nursing

Findings relating to specialist nursing care reflect high levels of satisfaction with all nursing specialities. In only one area (i.e. Key Worker) with a relatively low number of associated comments did negative responses outnumber positives, and the cause of this was availability rather than the standard of care provided per se (see above). In cases where actual care was provided, responses were overwhelmingly positive, praising the dedication and skill of specialist nursing staff and their responses to patients' needs during treatment. Where negative comments did arise in relation to specialist nursing, these were almost entirely with regard to the availability and/or ability to contact specialist nursing staff during the treatment phase of the cancer journey. Once again, both negative and positive comments were attended by observations of inadequate staffing levels and/or staff commonly under pressure due to resource constraints. These findings suggest that while care provided by specialist nursing staff perceived to be of a high standard generally, staffing and resources levels constitute one area for further investigation with regard to service improvement.

5.1.2.1.2 – General nursing care (NOS)

As with specialist nursing care, the overall weight of comments relating to this area of nursing were positive and reflected what were often high levels of satisfaction with both the practical aspects of care, and the manner in which this was provided. However, general nursing did attract both a greater number and proportion of negative comments relative to positive responses. The majority of these negative responses appear to relate to instances of poor care within hospital in-patient wards, particularly those identified as non-specialist. Examples of poor care were often (but not always) attended by concerns about staffing levels. This was particularly notable in relation to night

time care. The majority of comments relating to nursing were of a positive or very positive nature, and often appeared as part of more general expressions of good care across the cancer journey. However, general nursing was the area within which concerns about staffing levels were present most strongly, especially at night, both in weight of comments and in the depth of concern caused to participants. In addition, concerns around extended waiting for pain relief in hospital in patients wards was linked frequently to issues with staffing levels, although some of these comments also attributed such difficulties to individual staff unwillingness to provide pain medication. Nurse staffing levels were also highlighted as an issue of concern by patients in the closed questions part of the WCPES, where 40% of respondents indicated that there were not always enough nurses on duty to care for them.

5.1.2.2 – Treatments

5.1.2.2.1 - Surgery

Comments relating to surgery were to a large degree positive, with participants praising the speed of surgical treatment received, and the conduct of procedures (although there were some negative comments in each of these areas). The majority of negative comments centred upon information provision relating to surgery and access to surgical staff for information and support. In terms of negative comments, of particular concern were a significant number of responses detailing experiences of poor care during post-operative recovery, the majority of which referred to nursing care in hospital in-patient wards. Within this group, a number of participants contrasted perceptions of good nursing care on specialist wards, where staff were familiar with their condition, with non-specialist wards where problems were encountered. Notwithstanding issues with staff knowledge and staffing levels, it must also be acknowledged that some negative experiences were identified with shortcomings in the staff themselves, although such comments were fewer in number.

5.1.2.2.2 – Chemotherapy

Participant experiences of chemotherapy were in the main positive, and the content of comments (especially those relating to specialist chemotherapy nursing) reflect experiences of efficient, committed staff who very often went to great lengths to ensure patient wellbeing during treatment. Respondents praised both the professionalism and efficiency of their treatment, and the sensitive and caring manner in which they had been dealt with by staff, linking this to reductions in stress associated with chemotherapy. The few negative comments that were provided tended to focus on lack of opportunity to discuss side effects with staff during the initial stages of treatment, rather than the care provided per se. The findings here suggest that for respondents their cancer care was of a high standard that met their needs during treatment.

5.1.2.2.3 – Radiotherapy

The majority of respondents who commented on the care and treatment provided during radiotherapy, praised both the conduct and the manner in which staff had treated and cared for them. Where negative comments were received, these related almost entirely to information about and opportunities to discuss side effects of radiotherapy. While the majority of comments indicate satisfaction with care and treatment received here, a need was identified for better preparation and increased opportunities for communication with specialist staff during radiotherapy for some patients.

5.1.3 – Aftercare phase

Aftercare is one area of the cancer pathway for which it is very difficult to provide more specific insights involving actual care from this data. This is due to the generality of both negative (which comprise the majority of responses) and positive comments, the former indicating a general absence of provision in this area, and the latter giving only broad comments as part of more general positive reflections on care across the treatment journey. Nevertheless, it would seem that aftercare remains an area where further service improvement is required.

5.2.2.3.1 – Continuity of care and support following treatment.

Following the completion of treatment, whether chemotherapy, radiotherapy, surgery or other treatment programmes, participants giving both negative and positive comments identified a lack of general aftercare provision. The generality of negative comments here appears indicative of a profound gap in services after treatment has finished. Support from specialist medical and nursing staff, as well as emotional, social and psychological support while recovering from cancer treatment, were unmet needs reported by many participants in this data set. Where communication and support had been absent during the treatment and diagnostic phases, patients related a continuation of fears, uncertainty and isolation associated with these negative experiences. For those whose contact with staff had been positive during treatment but had fallen away following completion, feelings of confidence and security often gave way to anxiety regarding the immediate and long-term future. In addition to general comments regarding a lack of aftercare, a smaller subset of respondents gave more specific comments around follow-up investigations. Fear of recurrence was a significant factor in these responses, which conveyed a lack of clear plans as to how the success of their treatment would be confirmed, and if found to be successful, how their condition would be monitored over the longer term. The lack of such plans was a source of considerable anxiety for these participants, extending fear and uncertainties around having cancer into the post-treatment phase. Several participants described actual recurrence of cancer, and reported that its discovery was delayed due to failure to conduct what they considered to be appropriate follow up investigations.

Conversely, for the smaller group of respondents who provided positive responses relating to aftercare, the majority of positive comments reflected the security provided by a clear programme

of regular check-ups following completion of treatment. This helped participants to manage the fear of recurrence that can accompany successful cancer treatment, and once again this shows the importance of clear and consistent communication and staff availability at this stage of the cancer journey. Aftercare was one of the few areas of treatment where negative responses greatly outnumbered positive ones, and it is notable that these in some cases accompanied otherwise positive comments praising many or all other aspects of their cancer journey.

5.2.2.3.2 – Emotional, social, psychological and financial support after treatment.

For some of those moving out of the treatment phase, the **sudden disappearance of sources of support can come as a shock**, bringing **emotional problems** linked to **uncertainty about the future** and **loneliness** (particularly for those living alone) as patients look to move on with their lives. Beyond overcoming fear of recurrence, challenges can include **rebuilding social aspects of life**, coming to terms with **stressors and emotional or mental health issues** that may have arisen during treatment, and addressing financial problems incurred during treatment. This is an area in which a **broad range of support services may be necessary**, and for which **provision at present appears lacking for many participants**. Just as at the start of treatment it may be necessary to **explore what needs individual patients may face**, and what services may be available to meet them, so too might this be **an appropriate step following the end of treatment**.

6 – Discussion and key messages

Analysis of free-text comments within the CPES (Wales) survey complements the formal closed questions by allowing patients to indicate the issues most important to them and provides important insights of the experience of patients. The high response rate to the free-text question (64% of those who returned questionnaires) indicates that patients actively engage with the opportunity to provide comments relating to their experiences. The preceding sections have identified several themes that emerged from the comments. Most of these are not new, but their prevalence in the data and their persistence amongst a large population of patients with cancer indicate they remain issues of concern. Many of these issues seem to be inter-dependent, and from these related themes the following recommendations can be made.

Staff should communicate with patients with compassion, courtesy and respect

Previous research has indicated the importance of the quality of interactions between health professionals and patients for much of the success of healthcare provision (Drew et al 2001), and being treated with courtesy and respect is one of the most important predictors for cancer patients' perception of quality care (Sandoval et al 2005). It is also extremely important for ensuring patients have confidence in the rest of their care. Patients responding to this survey attest to these findings by choosing to describe the impact, both positive and negative, that interactions with staff members have had upon them. These interactions occur across the treatment pathway, beginning in the GP surgery where patients' concerns should be treated seriously, to being given a diagnosis in a sensitive manner with due concern for privacy and emotional support, and being treated with compassion and respect by medical, nursing and allied staff during treatment and post-treatment.

Treating patients respectfully extends to keeping them informed when there are delays waiting for appointments, administrative staff returning phone calls when promised, and nurses ensuring as little noise at night as possible.

Delays to diagnosis, investigations and treatment should be minimal

Any delay to diagnosis and treatment of cancer has the potential to impact negatively on patient outcomes (O'Rourke et al 2000). For patients who suspect they might have cancer and conscious of the risk of progression of the disease, delay also causes psychological distress, which has been shown to correlate positively with the length of that delay (Risberg et al 1996). Nevertheless, despite the NICE guidelines on patients suspected of cancer (NICE 2005), delays in referrals, investigations and diagnosis continue to occur. Previous research has found that patients are often not satisfied with the time it took for the GP to identify their problem and for a diagnosis to be reached (Davidson et al 2005). Delays for investigations and referral are often caused through 'misdiagnosis' with GPs either treating patients symptomatically or relating symptoms to a health problem other than cancer, while for some cancers this could also be linked to inadequate patient examination, use of inappropriate tests or failing to follow-up negative or inconclusive test results (Macleod et al 2009). Previous studies have also found large variations in GP referral rates of patients with suspected cancer to specialist care (O'Donnell 2000), with two-thirds of this variation remaining unexplained (O'Sullivan 2005). Our findings from patient comments would indicate, therefore, that some of this delay may partly be addressed by GPs more often taking patients' concerns seriously and acting on them swiftly.

Patients should be prepared for what they face

Recent evidence suggests that patients want more information concerning effects of treatment and self-management strategies (Rutten et al 2005), but research also indicates that cancer patients continue to receive what they perceive as sub-optimal levels of information and preparation (Ayanian et al 2010; Harrison et al 2012). A wider range of unmet needs have been identified for those post treatment or in survivorship relating to emotional and social support, quality of life, long term functioning and finance (Roberts et al, 2008; Girgis et al, 2000; Llewellyn et al, 2006). A lack of clarity regarding the process of care has also been identified as an issue for survivors post treatment, in part associated with less contact with services (Pollock et al, 2008).

The need for patients to be prepared for the potential impact of their diagnosis and treatment thus pervades the patient journey, and includes: available treatment options and the relative advantages and disadvantages for the individual; information concerning possible physical problems, how to manage them, when they might resolve, what to do if they don't; emotional and psychological issues, such as fear of recurrence and other anxieties and how to find support should this be needed; managing financial and other practical problems, such as returning to work and benefit applications. Such support and guidance have previously been found to be important factors in patients' satisfaction with their quality of care (Davidson et al 2005), but it requires sufficient and accessible specialist staff for its provision. Nevertheless, while there is a clear and consistent finding that information directly from health professionals, during the consultation is the preferred source of information for patients, there is also evidence of a recognition of the workload of health professionals, the needs of other patients who are waiting and these factors influence whether further information is sought or requested (Bungay & Capello, 2009; Leydon, et al., 2000; Manning & Dickens, 2007). This finding is important when considering the utility of information provision interventions based in alternative approaches using video, print material or interactive electronic

sources. The potential role of clinical staff in advocating for alternative sources of information, e.g. recommended websites or referrals to information centres, may help bridge this issue. Finally, as patients do not always want information at the same time or at the same level (Leydon et al 2000), patient preparation should be tailored to the needs of individuals.

Patients should experience good continuity of care

Continuity of care has been defined as one patient experiencing care over time as coherent and linked (Reid et al 2002), and has become one of the key policy themes in cancer care (WG 2012; DH 2008; Freeman & Hughes 2010). Continuity of care incorporates three components: informational, management and relational (Haggerty et al. 2003). Informational continuity links one provider to another and one healthcare event to another so that aspects of a patient's medical condition, preferences for treatments and the context of their illness are accounted for; management continuity is the delivery of health care by several providers in a complementary and timely manner through shared management plans that are consistent and flexible; relational continuity bridges past and current care while providing a link to future care, achieved through a core of consistent staff working together with the patients on their treatment plans (Nazarath et al. 2008). Evidence indicates that higher experienced continuity of care amongst patients and their families is associated with lower future needs for supportive care and better psychological outcomes (King et al. 2008; NCCDSO 2007). Thus, if patients receive adequate preparation for what to expect with regards treatment side effects and self-management strategies, and then experience good continuity of care, their post-treatment needs may be reduced. In the free-text comments, this was supported by frequent references to both positive and negative experiences of care continuity across all stages of the cancer journey. In particular, concerns exist over transitions from primary to secondary care at the diagnostic stage, and then from secondary to primary care in the post-treatment phase.

Key workers should facilitate holistic care planning

Fundamental to continuity of care are holistic assessment and care planning and the development of a key worker role to facilitate these processes (NHS Wales, 2010). Key workers, usually a clinical nurse specialist, should be responsible for coordinating treatment and care during active treatment to ensure good communications between the healthcare team and the patient and their families and to act as their point of contact. Post-treatment this role should be transferred to GPs or their practice nurses. A full holistic assessment should be undertaken and a written plan of care developed. However, it appears that this is not occurring in many instances and very few patients' comments referred to care plans or used the phrase 'key worker', possibly indicating these are not terms with which they are familiar.

Many patients did refer to their clinical nurse specialist (CNS), and almost always described them as ensuring a more positive experience of care: the main criticisms being difficulties with accessing or contacting them. Specialist nurses play a key role in the coordination of care and provision of emotional support, information and supportive interventions and are central to improving the quality of nursing care (NICE 2009; Lancet 2011). However, many patients did describe uncoordinated and interrupted care, especially during the transition between secondary and primary care at the end of treatment. This finding indicates that there is still work to be done to implement and ensure consistency of care planning and continuity of care.

Staffing levels should be adequate - There has been much recent discussion regarding safe staffing levels in hospitals, particularly of nursing staff (RCN 2012). Growing international evidence indicates

that lower ratios of nurses to patients are associated with both poorer outcomes for patients and greater job dissatisfaction for nursing staff (Needleman 2002; Aiken 2002a; 2002b; Rafferty et al 2007). It is probable that inadequate levels of staffing will also contribute to other problems experienced by patients, such as instances of uncoordinated care, lack of individualised care and waiting for treatment and pain control (both significant sources of concern for patients in this study). In particular, inadequate staffing levels were perceived as a problem at night by respondents providing free-text comments. Accessibility of specialist nurses was also an issue.. Recent evidence shows that care coordination and emotional support and support for the control of side-effects are better in Trusts / Hospitals with more specialist nurses (Griffiths et al 2013). Nevertheless, significant variations across Trusts / Hospitals remain in patient access to specialist nurses (Trevatt & Leary 2010).

Patients should have access to adequate post treatment services - Patients often feel 'cut adrift' by the health system after the period of hospital treatment and are left feeling vulnerable and isolated (Armes et al 2009; Penny et al 2000). The transition from secondary to primary care can also mean patients need to adapt to the changed care setting, where they obtain prescriptions from different prescribers and sometimes find it difficult contacting appropriate health professionals for guidance (Coleman & Berenson 2004). Evidence indicates that approximately 30% to 50% of cancer survivors have unmet needs, mainly for psychological support and coping with fear of recurrence (McIllmurray et al 2001; Boberg 2003; Hodgkinson et al 2003). While unmet needs reduce for some patients in the months following treatment, one study found that for 60% of these patients the situation did not improve over a six month period (Armes et al 2009). Patients' comments within the WCPES often did not describe specific issues related to aftercare, other than to describe its lack, which reinforces findings from previous studies.

7. Limitations to the study

Data were volunteered by individuals and were not systematically recorded according to a structured list of topics of areas and, therefore, are not necessarily representative. Recall and response bias may also be present. In addition, though the free-text respondent demographics mirror closely those of total survey respondents, our ability to judge representativeness in relation to the survey population is constrained by the data collected (for example, no data were available for exploring deprivation or differences in socio-economic status). However, the fact that the free text comments reflect scores from the WCPES measures suggests that these are a valid representation of the views of participants. Strong themes emerged from the data, with clearly inter-related associations, that enabled the development of a framework encompassing all responses. The resulting findings complement the findings of the quantitative survey by providing further detail on specific experiences of diagnosis, treatment and aftercare. Themes emerging across individual accounts also help to illuminate processes at play across individual cancer journeys, and also offer insights into more detailed experiences and concerns of patients, some which may not be visible in responses to closed questions.

8. Conclusion

The free-text question incorporated into the Wales CPES survey allowed patients to describe the issues most important to them, and has provided important insights into their experiences of the care they received. The high response rate indicates that patients actively engage with the opportunity to add their own comments, and those who did so were highly representative of the total patients who completed the survey with regards their socio-demographic backgrounds, tumour sites and the treatment centres from which they received treatment.

Analysis of the themes that emerged from these comments found that for most issues described by patients positive experiences far outweighed negative experiences. Most patients reported being happy with the services they had received. Nevertheless, while negative comments were less frequent they tended to be more detailed, and indicated the predominant areas where patients perceived service improvements to be still required. The areas patients valued most included: courteous and effective staff communication and interaction with patients; prevention of delays to diagnosis and treatment; ensuring adequate patient preparation for potential treatment side-effects and sufficient information regarding self-management strategies; good continuity of care, to be facilitated by key workers; adequate staffing levels; improved translational care between primary and secondary sectors; and sufficient support provision post-treatment.

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