



# **Cancer Services for Isle of Wight residents: Experiences of patients and families**

**June 2016**



## How to contact us

Visit us in person at the IsleHelp Hub:

7 High Street  
NEWPORT, I.W.  
PO30 1SS

... or online – [www.healthwatchisleofwight.co.uk](http://www.healthwatchisleofwight.co.uk)

Phone us – 01983 608 608

Write to us - FREEPOST RTGR-BKRU-KUEL  
Healthwatch Isle of Wight  
Riverside Centre, the Quay  
NEWPORT, I.W.  
PO30 2QR

E-mail us - [enquiries@healthwatchisleofwight.co.uk](mailto:enquiries@healthwatchisleofwight.co.uk)

Facebook - [www.facebook.com/HealthwatchIOW](http://www.facebook.com/HealthwatchIOW)

Twitter - @HealthwatchIW



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# 1 - Acknowledgements

**Healthwatch Isle of Wight would like to acknowledge the help of all who contributed to the compilation of this report.**

**Most importantly, thanks are extended to those people affected by cancer who took time to share their experiences in the survey carried out in December 2015. Their openness, and the level of detail they contributed is much appreciated.**

**Thanks are also extended to all professionals from the local NHS, local authority and Third Sector for helping provide background information to assist with this piece of work.**



## 2 - Summary

Healthwatch Isle of Wight carried out a survey about the experiences of people who had used cancer services over previous two years. The survey took place in December 2015 and 220 people participated.

Responses to the survey indicated the very high importance attached to the diligence and manner of professional staff, whether in NHS or other organisations. A majority of feedback about this was positive.

Concerns were expressed about the effects of crossing the Solent for certain treatments and services. Participants highlighted specific points that could be addressed to reduce the more severe impacts.

A number of issues emerged around co-ordination of services. Clinical updates were not always available to professionals, and patients could find themselves passing on this information. Case co-ordination tended to falter if a key individual professional was absent from work. The process of moving from one NHS Trust to another was not always smooth.

Moving through the process of diagnosis and treatment, there was a mostly positive picture. However, outpatient appointments, support from Accident & Emergency and in-patient admissions, all raised their own areas of concern. The process of discharge from mainland hospitals was also highlighted.

Participants could not always recall being given information on sources of support. Overall, a lack of coherence was found in access to information. There were specific gaps around information on financial help.

This report includes recommendations made by Healthwatch Isle of Wight in the light of the survey findings.



## 3 - Background

Healthwatch Isle of Wight\* is the independent “consumer champion” for local health and social care services. It began in 2013 when legislation brought in a Healthwatch organisation in every local authority area in England. Feedback is received from local residents on a range of services. Each year a small number of topics are chosen for more detailed examination.

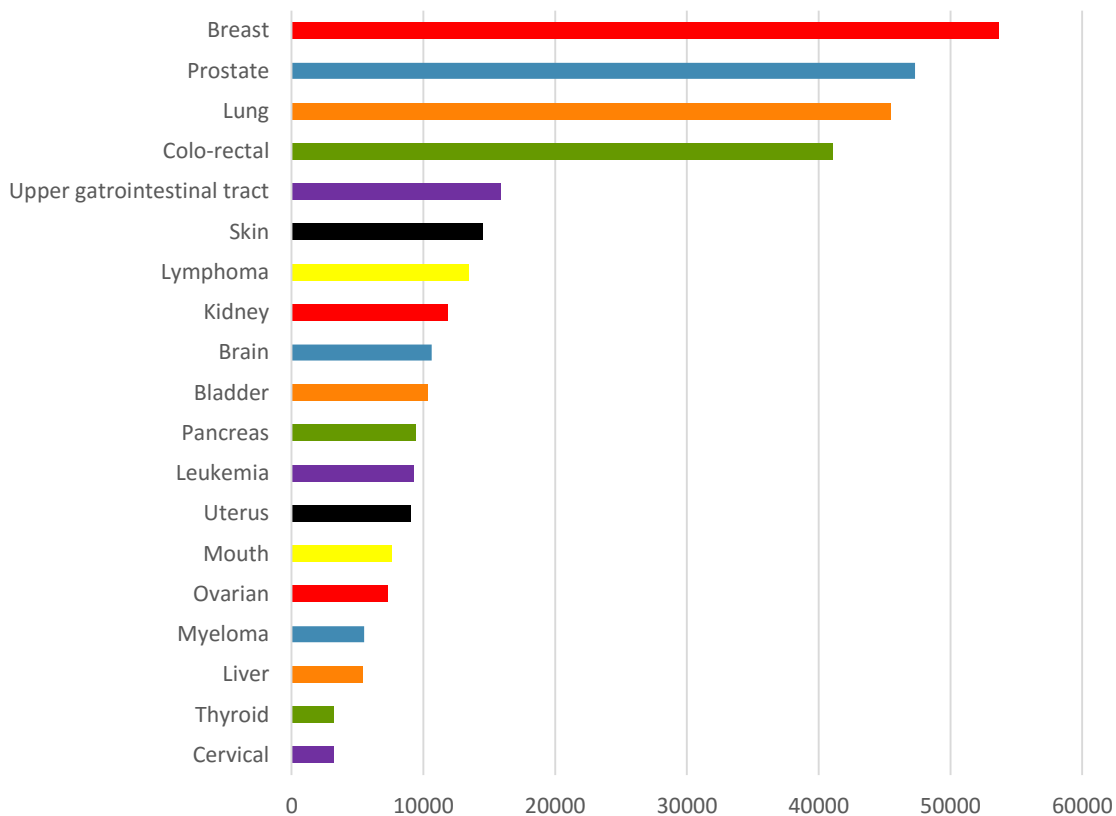
Amongst Healthwatch Isle of Wight topics for 2015 – 16 was the cancer service provided for Island residents. This had been identified separately by the Isle of Wight Clinical Commissioning Group\* (CCG) as the subject of its own independent review. Healthwatch Isle of Wight kept in contact with the CCG when compiling the questionnaire, and the broad findings of the Healthwatch survey were shared with the CCG review team, to help them further in understanding patients’ experiences.

Figures indicate 1,138 Isle of Wight residents were diagnosed with cancer in 2013, which is proportionately higher than England overall<sup>1</sup>.

Table 1 shows the prevalence of the most common forms of cancer at U.K. level in 2013<sup>2</sup>. Of the most common forms of cancer, 167 women on the Isle of Wight were diagnosed with breast cancer that year (slightly higher than England overall) and 290 people diagnosed with urological cancers, including prostate\* cancer, (higher than England overall). In the same year, 120 people were diagnosed with lung cancer<sup>1</sup>.

Numbers of deaths from cancer on the Isle of Wight have shown a steady fall over the last twenty years, in line with national trends. The rate of deaths is slightly lower than the overall level for England, according to figures published in 2013<sup>3</sup>.

Table 1: Cancers, most common - U.K. new cases 2013



Some cancer services are provided at St Mary’s Hospital, with NHS Trusts on the mainland being commissioned to provide treatment for specific forms of cancer. Radiotherapy is not available on the Isle of Wight. Of the mainland hospitals treating Isle of Wight residents for cancer, NHS Trusts in Southampton and Portsmouth are the most often used. For certain forms of cancer and for some specific treatments, NHS hospitals further afield are used, including Salisbury, Oxford, Winchester and London. There are also some services run on the mainland by private providers.

The Isle of Wight Clinical Commissioning Group (CCG) chooses the providers for some cancer treatments. Other treatments, including chemotherapy, radiotherapy, and those for children and young people are commissioned by NHS England.

**NOTE: Throughout the report, terms marked with an asterisk (\*) are further explained in the Glossary section on page 54.**



## 4 - What Healthwatch Did

Healthwatch Isle of Wight carried out a questionnaire survey between 30<sup>th</sup> November and 24<sup>th</sup> December 2015. People who had used cancer services within the past two years were invited to take part; responses were also received from family members and friends. Questions were asked about various stages of cancer treatment and recovery.

A total of 220 responses were received, 207 of those electronically and 13 in hard copy. Details are given in Appendix 1 of the age, gender and home area of people who took part.

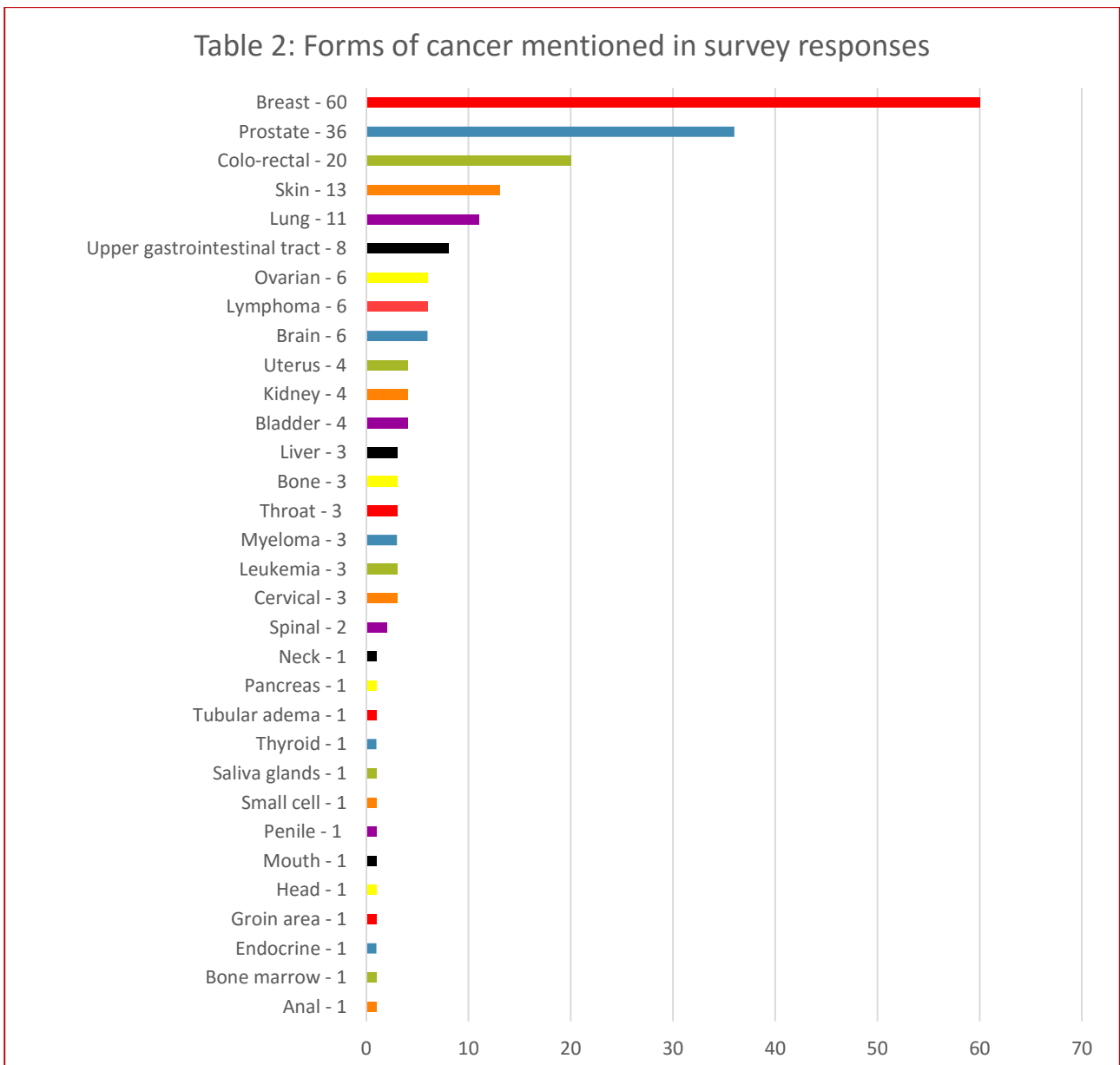
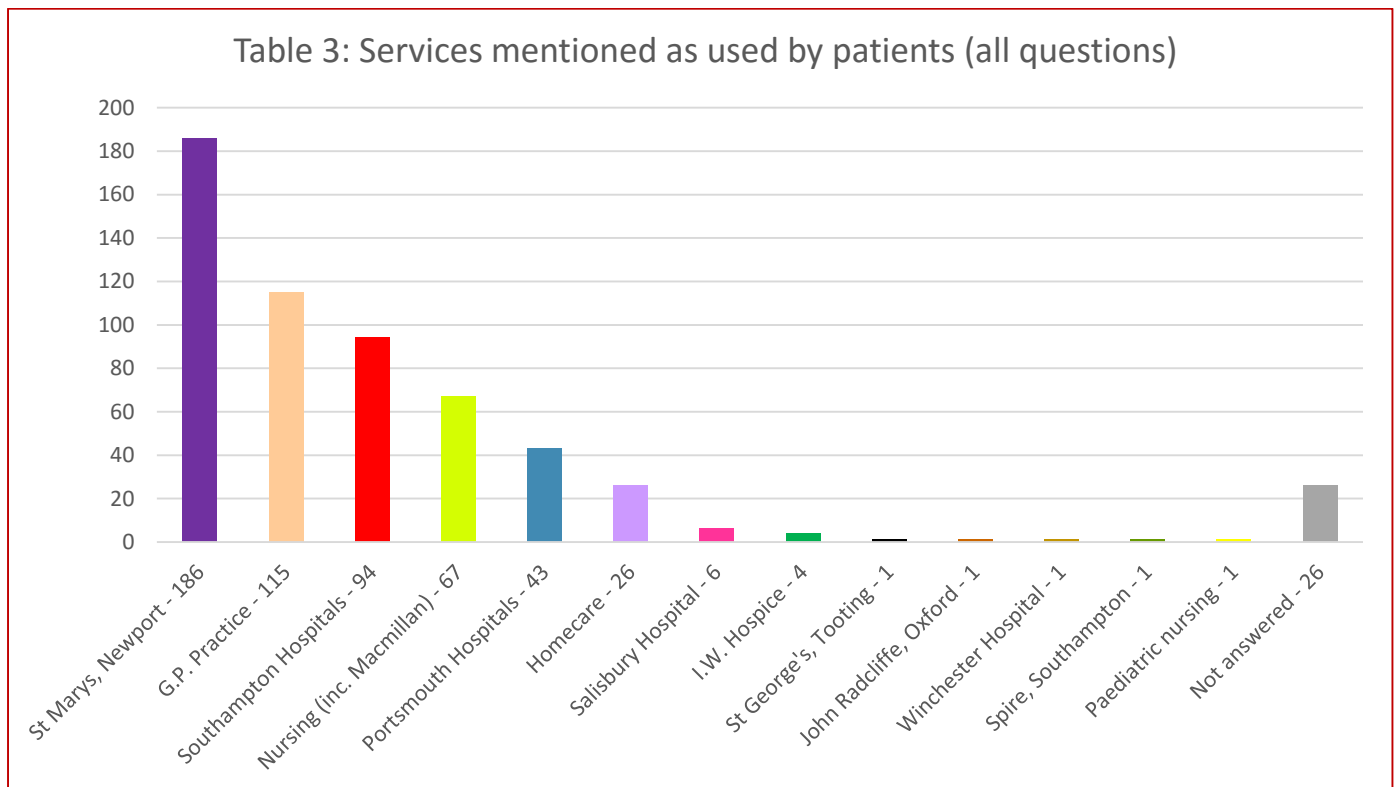




Table 2 summarises the forms of cancer mentioned by people who responded. The forms of cancer mentioned most often correspond broadly with the most numerous nationally in Table 1. However, on the Isle Wight numbers of those with breast and prostate cancers are closer than at national level<sup>1</sup>.



The questionnaire included nine sections in which experiences within a service could be rated as good, moderate, mixed or poor. There was also a space within each section for further written comments. Participants were encouraged to use these spaces, to help ensure the survey gave maximum opportunity to describe a range of experiences.

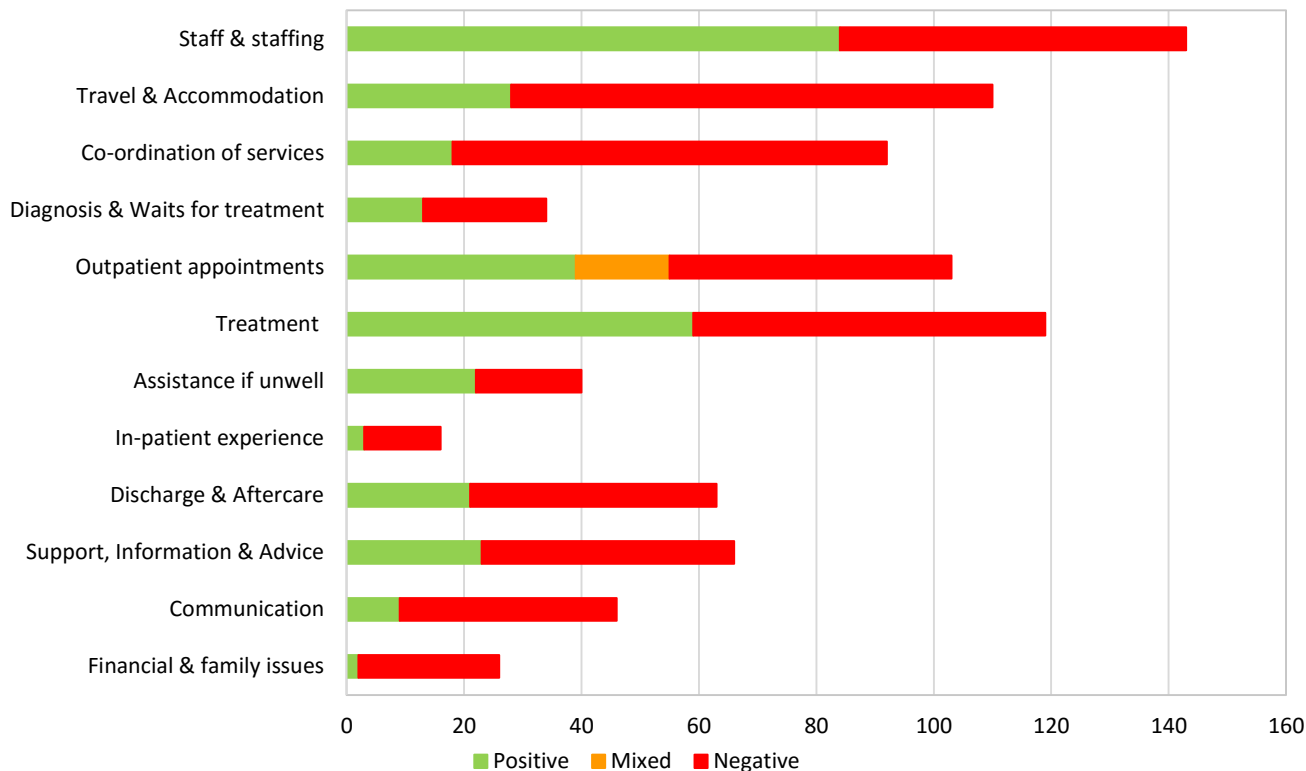
The collection of a large amount of descriptive text allowed for a thematic analysis to be carried out, using the NVivo software programme. The resulting themes form the structure of Part 5 of this report. Some themes correspond with topics outlined in the questions, others emerged from the analysis. Where comments referred to more than one theme, they were included under two or more headings. The volume of feedback on each theme is summarised at the start of the following section.

A copy of the full questionnaire can be found in Appendix 3.



# 5 - What Healthwatch Found

Table 4: Survey - Number of comments per theme



This section of the report is based on an outline of the feedback relating to each of the themes identified in the survey. They are presented in the order listed in the chart above.

The first three themes are the most frequently mentioned of a general nature, and are followed by six themes related to the process through which patients move from diagnosis to aftercare. The final three themes are again more general.

The amount of feedback about specific providers varies according to topic, and depends on location of the various services.

NOTE: Following the outline of each theme are tables giving more detail. The comments for mainland providers relate to the experience of Isle of Wight residents only.

## **a) Staff and Staffing**

This is the theme that came up most frequently in the survey comments, although there was no specific question in the survey about this. It also had the highest proportion of positive comments, across all main NHS and Third Sector providers.

The fact that participants chose so often to mention their contacts with staff members, suggests a high value attached to this, hence the impact of good or bad experiences. Given the vulnerable state of people needing treatment for cancer, this is unsurprising. It was striking though, that comments on the broader health & social care system were at times given a personal slant. Some participants felt that named NHS managers bore personal responsibility for the smooth functioning, or otherwise, of processes affecting patients and their families.

Positive comments often referred to particular health disciplines or staff members. Where individuals were named, this has been passed on to those concerned. Doctors, surgeons and nurses were all mentioned, as were chemotherapy and radiotherapy staff.

*“ There is a huge amount of respect for the surgeon, and the way he runs things ”*

The qualities most often mentioned related to the manner of staff. Participants particularly highlighted qualities of caring, kindness and helpfulness. Also mentioned were experiences of being given time by staff, thoughtfulness and attentiveness. Appreciation was expressed where care had been personalised and well-explained.

*“ ... can't stress enough how very, very kind all staff were ”*

Negative comments related most often to communication, and is discussed in more detail in section K on page 45.

Comments about specific staff related to their manner (most frequently of doctors), rudeness, rushed contacts and what was felt to be a negative attitude. Remarks about capabilities were less frequent, but included reference to poor prescribing knowledge and poor language skills.

*“ I didn’t like the manner of the consultant, who whizzed around the ward having a word with each person, as all their comments were emphasising the negative possibilities of outcomes. ”*

Even where participants had a mainly positive experience, specific unpleasant episodes were recalled vividly, again underlining the increased vulnerability of those affected by cancer.

Moving to organisational matters, comments tended to focus on lack of connection between clinicians, especially due to poor teamwork, or staffing inconsistency. There was concern where cover was not provided during staff absence. Lack of staff consistency in the haematology service was raised in particular, though there was also praise for staff there.

*“ ... there is no chance to build a relationship or rapport with doctors as they are always different – and have a slightly different approach to the subject, depending on what nationality they are. ”*

A number of participants mentioned concerns that staff were overstretched, whether in hospital or community. This sometimes tempered the positive observations about staff, and in some raised a concern that valued staff may not continue in such circumstances.

*“ The staff throughout the hospital are kind, patient, skilled and thoughtful. Please don’t overwork any of them, and do your best to keep hold of them. ”*

## Detail of comments on Staff & Staffing

### St Mary's (Isle of Wight)

#### Positive comments

Doctors and surgeons	14
Breast care nurses	12
Oncology nurses	7
General comments	6
Caring staff	5
Helpfulness	5
Kindness	5
Chemotherapy staff	4
Efficiency	3
Time given to patient	3
Expressions of thanks	2
Personalised care	2
Surgical teams	2
Thoughtfulness	2
Admission admin staff	1
Atmosphere	1
Explanation of care	1
Reassurance	1
Seeing same staff	1
Thoroughness	1

#### Negative comments

Poor communication	10
Manner of doctors	8
Changes of staff	7
Lack of teamwork	3
Manner of nurses	3
Overstretched staff	3
Rudeness	3
Lack of cover (leave, staff vacancy)	2
Lack of follow-up	2
Lack of weekend treatment	2
Lateness of doctors	2
Negative attitude	2
Poor prescribing knowledge	2
Rushed conversations	2
Staff shortage	2
Incomplete information	1
Lack of I.W. - based consultants	1
Poor assessment	1
Poor language skills	1

### Portsmouth

#### Positive comments

Doctors and surgeons	4
Radiotherapy staff	2
Attentiveness	1
Explanation of care	1
Oncology team	1
Surgical teams	1

#### Negative comments

Poor communication	2
Manner of doctors	1
Poor language skills	1

### Southampton

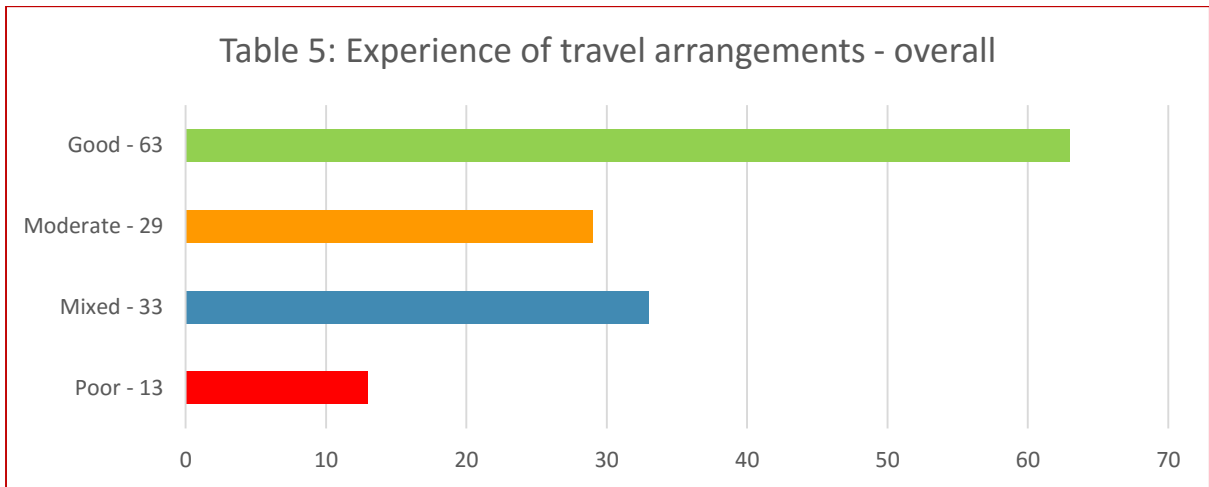
#### Positive comments

Doctors and surgeons	6
General comments	3
Expertise	1
Expressions of thanks	1
Kindness	1
Radiotherapy staff	1
Seeing same staff	1
Time given (anaesthetist)	1

#### Negative comments

Lack of information	1
Manner of doctors	1
Overstretched staff	1

## b) *Travel & Accommodation*

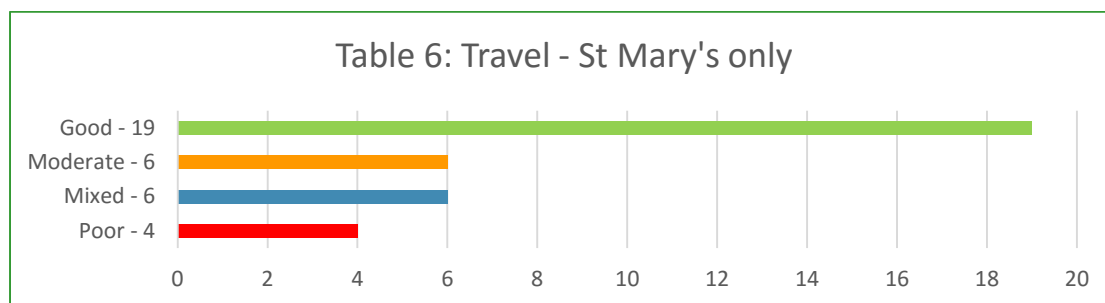


Travel experiences figure largely for many Isle of Wight residents using cancer services. Due to the base of some specialties, and because of the location of certain treatment centres, sea travel is essential for many. As experiences differ for those travelling only on the Island and those crossing the Solent, they are described separately in the following pages.

It is important to emphasise that examples quoted here came at a time when individuals were unwell and particularly vulnerable to fatigue, stress, infection and financial hardship. The impact of travel was therefore magnified, to become a genuinely gruelling experience.

Several comments were received suggesting that some patients find the prospect of travel so off-putting that they do not seek treatment, or decline it when offered.

## - Travel: St Mary's Hospital -



NOTE: Due to the larger number of patients, it is valid to present responses separately of those attending only St Mary's. This has been done in the above table.

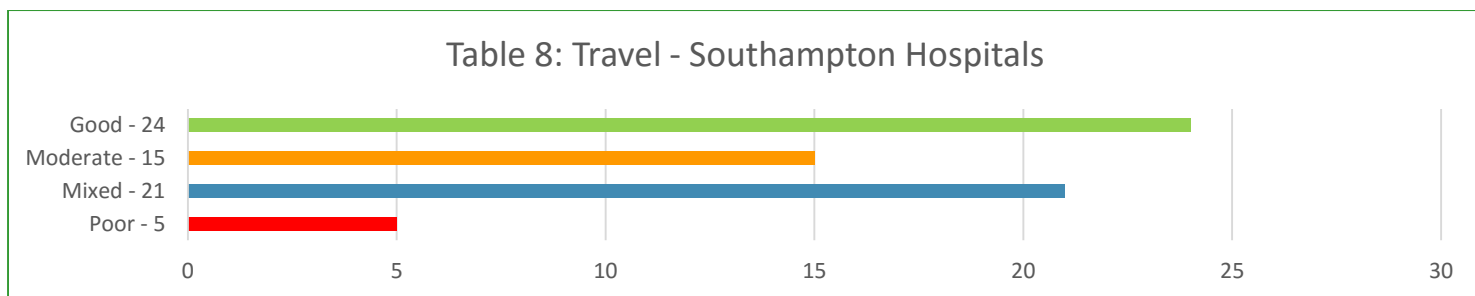
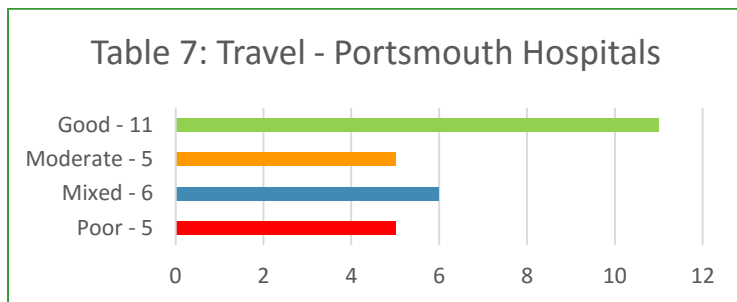
Positive feedback centred largely on appreciation of an Island-based facility for chemotherapy, and for the specific arrangements around parking for patients using this treatment.

The largest number of negative comments related to the absence of radiotherapy on the Isle of Wight. There was also mention of other treatments and consultations not being delegated locally, despite facilities existing at St Mary's. Some participants referred to being called for appointments for communication they felt could be done equally well over the phone or by video conference.

There were a number of remarks about car parking. Although some participants said this had improved, others spoke of lack of space on days when outpatient clinics were busy. There was particular mention of a lack of certainty about how much to pay for parking. Whilst special arrangements existed for chemotherapy sessions, this was not the case for outpatient appointments, the timing of which could be unpredictable. Participants mentioned paying for three hours, though the actual time could be less than an hour. One suggestion was for a system of payment on leaving the car park area.

Other comments referred to lack of information about reasonably-priced transport options, and poorly co-ordinated hospital transport on discharge.

## - Travel: Portsmouth & Southampton Hospitals -



NOTE: The above tables summarise the responses of any patients who attended the above hospitals. As virtually no patients attended only these hospitals, responses refer to other hospitals also, hence the level of “mixed” experiences.

Some participants spoke positively of travel discounts on ferries, and of charitable help with overnight accommodation during long courses of treatment, where this had been available. Much appreciation was also expressed about the transport arranged between ferry and hospitals by the Wessex Cancer Trust. Others spoke of appointment staff being helpful by timing appointments to dovetail with transport needs.

Negative feedback was dominated by the need to travel to the mainland for radiotherapy. Many patients had crossed the Solent daily for extended periods of treatment. Participants highlighted the difficulties inherent in this when not feeling well, and the onerous nature of travelling alongside other passengers. There were several comments about the length of time spent travelling, often a round trip of five to six hours, and in some instances up to eight hours per day.



Lack of dependability of ferries was mentioned, due to severe weather, or large-scale entertainment events. High cumulative costs were an issue, for some people exceeding £1,000 at a time when inability to work may cause a reduced income. For more on the costs of travel see page 48.

Alongside comments that travel was unavoidable, some felt there was a lack of awareness of the impacts of such journeys. One participant recounted alerting appointment staff about a ferry delay and being advised to attend nonetheless. On arrival the clinician had left, so the trip had been to no avail.

Others spoke of extreme early appointments, for example one at 7.00 a.m., entailing a 5.10 a.m. ferry departure. Late appointments also presented difficulties; one suggestion was for early afternoon as the latest appointment time, allowing travel home before becoming exhausted.

A number of comments mentioned previous scheduling of radiotherapy appointments in a single block of time for Isle of Wight residents being treated for prostate cancer. The possibility of travelling as a group had allowed valued mutual support, until this option was abruptly withdrawn.

There appeared to be a lack of choice, with people obliged to travel to a mainland centre that was more difficult to reach than an alternative with better transport links for the individual.

Whilst specific transport was appreciated, patients could be given appointment times not dovetailing with periods they ran, or hearing about transport services only by accident or when too late.

Where usual patterns were disrupted at hospitals, for example by building alterations, participants described being left without explanation about alternative arrangements. One patient using specified hotel accommodation discovered their access needs could not be met due to temporary structural work. Another participant attended radiotherapy at a time when clinics were being held during evenings, finishing too late for mealtime at the accommodation, thus affecting nutrition.

## Detail of Comments on Travel & Accommodation

### St Mary's

#### Positive comments

Car parking provision (general)	3
Chemotherapy parking provision	2
Local chemotherapy provision	2
Pick-up point	1

#### Negative comments

Lack of local radiotherapy	6
Car parking provision (general)	4
Car parking, payment system	4
Advised not to drive	2
Lack of locally-delegated treatment	2
Lack of other options, e.g. Skype	2
Transport poorly organised	2
Bus travel not straightforward	1

### Portsmouth

#### Positive comments

Hotel provision appreciated	2
Clear directions available	1
Easy route from Ryde	1
General comments	1
Good discussion of options	1
Reduced ferry fares	1
Support of fellow patients en-route	1

#### Negative comments

Onerous process when ill	5
Financial issues	4
Group scheduling unavailable	4
Extreme early appointments	2
Deterrent to seeking treatment	1
Ferry delays, missed appointments	1
Lack of choice (e.g. Southampton)	1
Lack of concern/support	1
Lack of information	1
Lack of other options, e.g. Skype	1
Machine broken, wasted journey	1
Wait for return transport	1

### Southampton

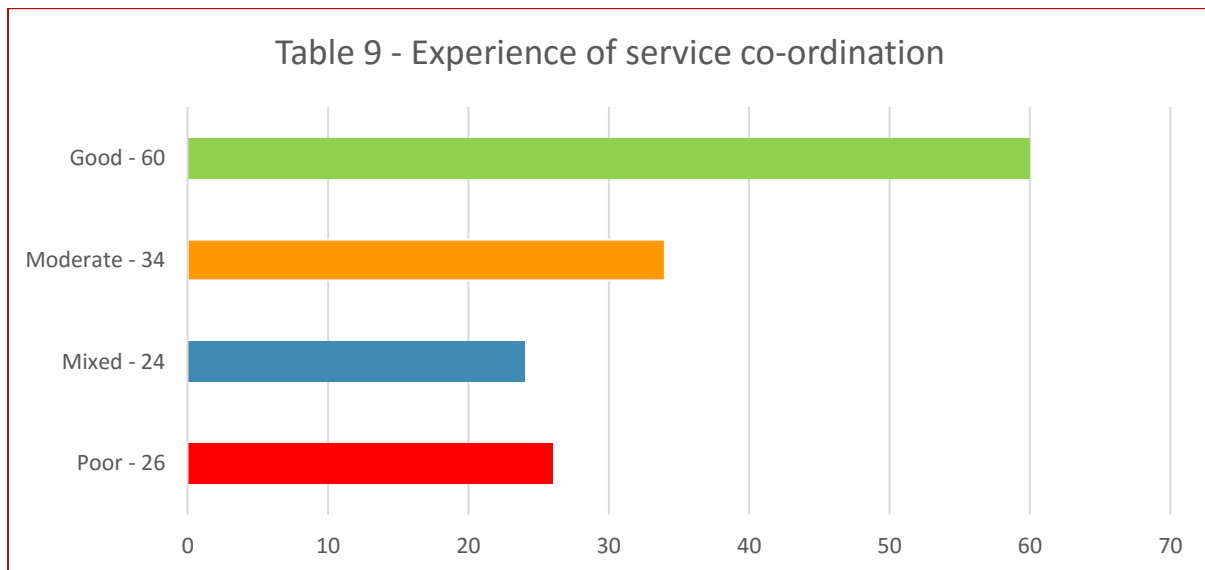
#### Positive comments

Wessex Trust transport	6
Appointment times well-tailored	2
Car parking (general)	1
Ferry ticket provision	1
General comments	1
Hotel provision appreciated	1
Well thought-out	1

#### Negative comments

Onerous process when ill	15
Poor communication of process	7
Travel / appointment co-ordination	6
Financial issues	5
Excessive overall travel time	4
Accommodation issues	3
Family issues	2
Lack of directions around hospital	1
Group scheduling unavailable	1
Wessex Trust bus logo - stigma	1
Deterrent to seeking treatment	1
Issues at busy times, e.g. festivals	1
Ferry delays in winter	1

### c) *Co-ordination of Services*



Participants were asked specifically in the questionnaire about their experience of service co-ordination. The number saying they had a good experience was lower than for any other question. Of those who chose to add comments, this theme yielded amongst the highest percentages of negative experiences (see Appendix 2).

Comments of a positive nature tended to be quite general, mentioning good liaison between hospitals, between GP and hospital, or moving from another geographic area to the Isle of Wight.

Negative experiences encompassed several areas. There were descriptions of test results and scans not being communicated, diagnostic records not being available to clinicians, and patients being “forgotten about” with delays leading to spread of cancer. More than one participant felt the “process” had taken precedence over individualised care.

*“ There was a Wessex Pathway to follow, which made me feel the focus was on systems, not on my unique situation.”*

### **- Case co-ordination -**

There were a number of comments about a lack of case co-ordination, with participants unclear about who might be in a co-ordinating role for their care. A repeated theme was that patients found themselves updating clinicians rather than the other way around.-

*“ I seem to be the one chasing people on the phone. I feel very alone, and services I require are not responding to me – which when you are ill and in pain is very distressing.”*

### **- General practice and community NHS -**

Where case co-ordination is lacking, the GP is likely to be the patient's main source of assistance. More comments were made about poor liaison between specialist services and GPs than any other aspect of service co-ordination. There were many descriptions of the GP not being kept informed of major milestones of treatments, and unaware of results, even where the test had been requested by the same GP.

One respondent mentioned repeated requests from a particular hospital for patient consent before sharing information with the GP. This was puzzling, given moves nationally for smoother information-sharing between NHS services where the patient has once given consent.

Co-ordination between hospitals and community nursing were also highlighted. One participant made daily trips for blood tests, risking infection in a busy hospital setting when immunity was reduced. Only later was it discovered that community nurses could carry this out.

## - Within and between hospitals -

Within hospitals, a number of participants were surprised by a lack of information if a specific member of the clinical team was absent on the day they attended. Other staff members did not appear to be informed about the patient's needs, or have access to the required information.

Some participants spoke of hospital departments not making them aware of important services within the same hospital. An example was given of the chemotherapy department apparently not making a patient aware of the NHS Trust's in-house wig service, entailing a long search for a suitable head covering.

Given the use of mainland hospitals for specific treatments, liaison between hospitals is especially vital. Participants mentioned problems with contact between all hospitals when moving from one service to another. Differences of approach were also experienced between services, with one comment being made about a sense of "professional tension".

Where equipment is needed in small volumes, but on a repeated basis for individuals, generic departments at St Mary's did not seem in a position to stock small amounts of a particular item. One laryngectomy patient described having to make trips to Portsmouth for this reason.

## Detail of Comments on Co-ordination of services

### St Mary's

#### Positive comments

Liaison with other hospitals	4
Appointment arrangements	2
Liaison within professional team	2
Transfer of care from another area	1
Liaison with GPs	2
General comments	1
Progression through treatment	1
Seeing same staff	1

#### Negative comments

Liaison with GPs	11
Liaison with other hospitals	9
Liaison within professional team	7
Info unavailable to specialist staff	6
General comments	5
Poor follow-up	5
Appointment arrangements	4
Clinicians contradicting each other	3
Lack of locally-delegated treatment	3
Patient left to chase things up	3
Handovers between clinicians	2
Transfer between hospitals	2
Unaware of important services	2
Tensions between hospitals	1
Messages not answered	1
Not seeing same staff	1
Relevant clinician not contacted	1
Responsibility for care unclear	1
Sickness/leave – info inaccessible	1

### Portsmouth

#### Positive comments

Liaison with other hospitals	2
Appointment arrangements	2
Liaison with GPs	1
General comments	1

#### Negative comments

Liaison with other hospitals	5
Clinicians contradicting each other	2
General comments	2
Liaison with GPs	2
Patient left to update clinicians	2
Appointment arrangements	1
Lack of link to benefits service	1
Lack of locally-delegated treatment	1
Liaison within professional team	1
Medication mix-ups	1
Tensions between hospitals	1

### Southampton

#### Positive comments

General comments	2
Liaison with GPs	2
Progression through treatment	2
Liaison with other hospitals	1
Seeing same staff	1
Transfer between hospitals	1

#### Negative comments

Liaison with other hospitals	7
Liaison with GPs	2
Appointment handling	1
General comments	1
Handovers between clinicians	1
Inter-departmental communication	1
Messages not answered	1
Sickness/leave – gap in contact	1

## d) *Diagnosis and Waits for Treatment*

### - **Diagnosis** -

There were no specific sections in the questionnaire on diagnosis, so comments on this theme were made on the initiative of participants. Although general practice does not have a formal role in cancer diagnosis, responses underlined the GP role in identifying concerns and referring on. Positive remarks about diagnosis highlighted timely action of particular GPs in this respect.

Negative comments on diagnosis also centred largely on the GP role, especially where participants felt their own concerns had not been appropriately acted on. This was most often the case with regard to bowel symptoms. Screening services had not always been found to call patients for follow-up, where results had indicated a concern at an earlier stage.

Once referred to hospital services, experiences included a delay in diagnosis of three months due to being referred between various departments, difficulty in arranging an appointment to be given results, and incorrect diagnostic tests being used for the medical situation of the patient. Concern was also expressed about a particular specialist's terminology being unduly alarming.

*"...would have been much more re-assured had the St Mary's Consultant mentioned PRE-cancerous rather than just "cancer"*

One comment described an unduly reassuring assessment by the 111 telephone service, when the symptom in question had indicated a major problem.

## Detail of Comment on Diagnosis

### St Mary's

#### Positive comments

Discovered early	1
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#### Negative comments

Delay to test results	1
Unclear info – prompted anxiety	1
Incorrect diagnostic tests	1
Passed between departments	1
Appointment delay, inflexibility	1
Delay to follow-up scan	1

### Portsmouth

#### Positive comments

	0
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#### Negative comments

Travel deterrent to seeking help	1
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### Southampton

#### Positive comments

	0
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#### Negative comments

Passed between departments	1
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### GP Services

#### Positive comments

Arranged testing promptly	2
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#### Negative comments

Not investigated (bowel cancer)	2
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## - Waits for Treatment -

There were a number of positive comments about the swiftness of treatment, and where this was the case, participants were very appreciative.

Some participants spoke of needing to “push” to produce a prompt response, with mixed results.

*“It was first suggested it might be about 6 weeks further delay....but on reminding admin staff this could be cancer they said they would do their best.... I later learned a slot was available about a week later”*



*“3 months between GP referral and seeing the specialist... my [relative] tried to get it moved forward but told this was impossible. Then panic ensued as the consultant recognised cancer, and operated within a week”*

One participant related the experience of an older relative who had waited five months for surgery, during which time a well-contained cancer spread so much that the eventual treatment was in vain.

## Detail on Comments on Waits for treatment

### St Mary's

#### Positive comments

General comments	5
Responsive staff	2

#### Negative comments

Appt. delays led to deterioration	4
Had to “push” to be seen sooner	2
Barely within guidelines	1
Poor communication of urgency	1
Staff shortage, causing delays	1
Wrong treatment tried, so delay	1

### Portsmouth

#### Positive comments

General comments	4
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#### Negative comments

	0
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### Southampton

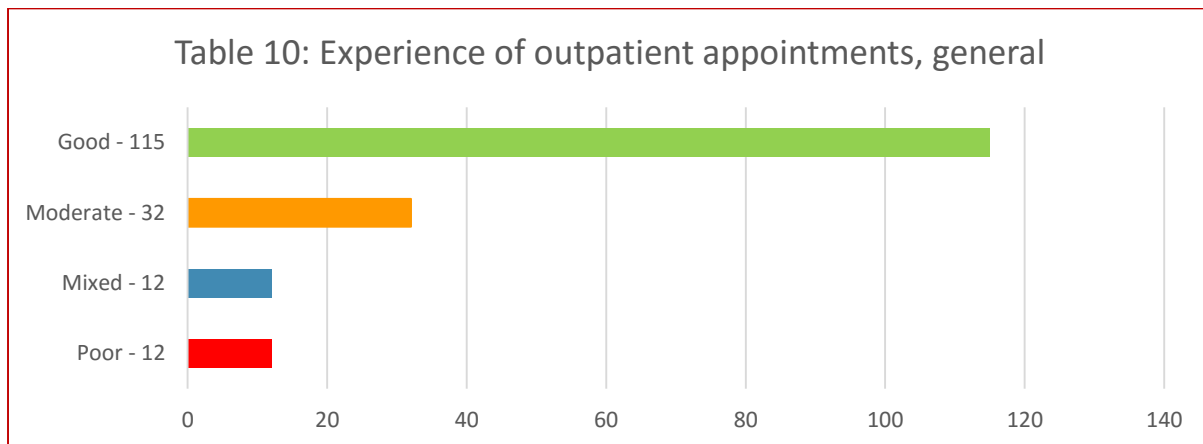
#### Positive comments

	0
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#### Negative comments

Appt. delays led to deterioration	2
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## e) *Outpatient Appointments*



Comments on experiences as an outpatient may refer to a range of specialities, as other hospital specialties are involved as well as specialist cancer services at certain stages of the process.

Positive comments praised the qualities shown by clinicians during their appointments, notably those of honesty, thoroughness and warmth. The Maxillofacial clinic and the incontinence service were mentioned for particular praised by individual participants.

Those who commented negatively highlighted clinicians who were felt not to have empathy, or who “spun the monitor” without looking at the patient. One participant spoke of feeling “bombarded” by attempts to promote a particular piece of equipment, whilst another spoke of an arriving to find an appointment had not been booked as previously stated. There was one comment about a consultant apparently phoning the evening before a planned appointment to change its timing.

One participant felt that the visits to St Mary’s Hospital of a particular oncologist only once a week had led to delays causing a relative’s cancer to spread, whilst several comments revealed a feeling that follow-up and final appointments tend to be rushed.

## Detail of Comments on Outpatient consultations (general)

### St Mary's

#### Positive comments

General comments	6
Given enough time	3
Caring staff	2
Efficient	1
Good information	1
Helpfulness	1
Honesty	1
Nurse input helpful	1
Thoroughness	1
Thoughtfulness	1
Warm atmosphere	1

#### Negative comments

Rushed approach	2
Changes of date	1
Doctor poor rapport	1
Frequent change of doctor	1
Infection concerns, low immunity	1
Limited no. of date changes	1
Notes not available	1
Nurse input unhelpful	1
Pressurised to accept equipment	1
Too frequent	1

### Portsmouth

#### Positive comments

General comments	1
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#### Negative comments

	0
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### Southampton

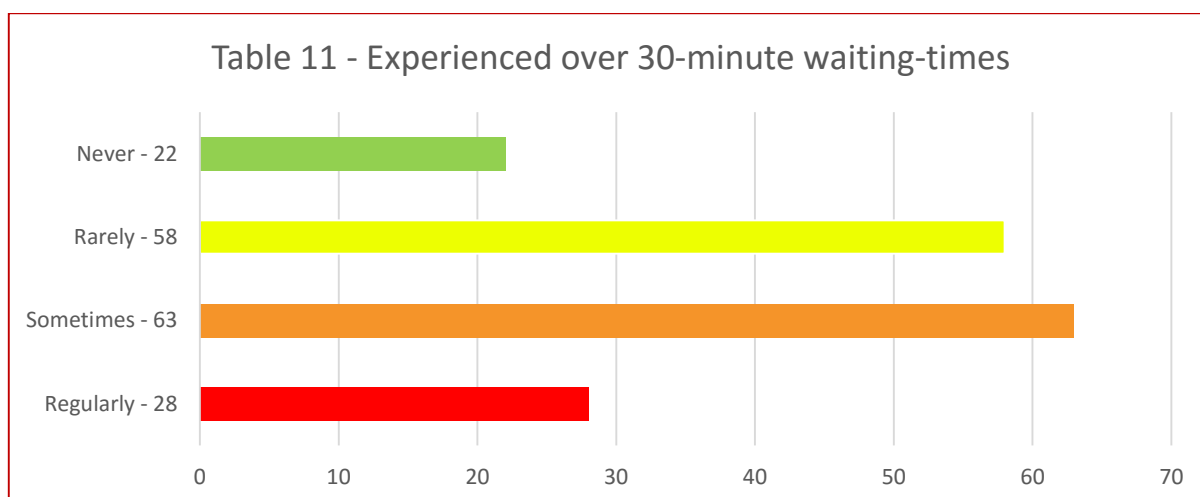
#### Positive comments

General comments	3
Given enough time	1
Travel arrangements	1

#### Negative comments

Travel arrangements	2
Overcrowding	1

## - Outpatient waiting times -



The questionnaire asked about waiting times when arriving for appointments. 53% of those who answered reported experiencing a wait of thirty-minutes or more “sometimes” or “regularly”. 13% stated they had never waited this long.

Strikingly, comments show not all participants saw long waits in a negative light. 16% of comments were upbeat about long waits and are categorised as “mixed” in Table 4 on page 10.

The most frequent reason for being relatively unconcerned about waiting times, was that having received attentive and unhurried appointments themselves, participants assumed that any wait was due to other patients being given plenty of time if needed.

*“I did have a very long wait a couple of times – over an hour – but if that means someone else needed that time, then that would have been important for them. You can’t rush these things sometimes”*

Some participants mentioned being glad to be kept informed when a delay occurred, and of being given a reason – for example someone else needing to be seen on an emergency basis. Others said they had not thought to keep track of waiting times, so could not recall length of wait.

Where concerns arose these usually had a specific cause. Reasons included anxiety before receiving a diagnosis or test result, and the risks of longer exposure to infection at a time of lowered immunity. One participant described being required to have a blood test an hour before the appointment time, which itself was then delayed. Eventually this patient felt too ill to stay in the waiting area and missed the appointment.

Some participants described feeling rushed in the appointment itself, “to make up time” in the words of one response. This was especially noted at the end of the working day. One patient reported overhearing a nurse outside the room being asked to “chivvy up” the clinician, the consultation then being interrupted with a reminder of the time.

Lack of explanation or update on delays prompted negative comment, as did experience of doctors arriving late at the start of a clinic session. One participant felt this applied specifically to Island-based consultants.

The current payment system for parking at Mary's Hospital prompted specific concern about the variability of outpatient waits (see page 15).

## Detail of Comments on Outpatient waiting times

### St Mary's

#### Positive comments

General comments	4
Kept informed if long wait	3
Improved since location move	1
Oncologist appointment prompt	1

#### Mixed comments

Didn't mind – patients given time	6
Only if emergency took precedence	2
Didn't matter – came prepared	1
Ran well despite clinician overload	1
Varies according to time of day	1

### Portsmouth

#### Positive comments

Kept informed if long wait	1
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#### Mixed comments

Didn't mind – patients given time	1
Only if equipment not working	1
Only if appointment time adjusted	1

### Southampton

#### Positive comments

Kept informed if long wait	2
General comments	1
Oncologist appointment prompt	1

#### Mixed comments

Didn't mind – patients given time	1
Varies according to time of day	1

#### Negative comments

General comments	11
Doctors arriving late at outset	3
Car parking issues	2
Longer wait at end of day	2
Anxiety increased awaiting results	1
Clinicians appear overloaded	1
Excessive overall if blood test first	1
Infection concerns, low immunity	1
Lack of apology/update	1
Rushed by staff at end of day	1

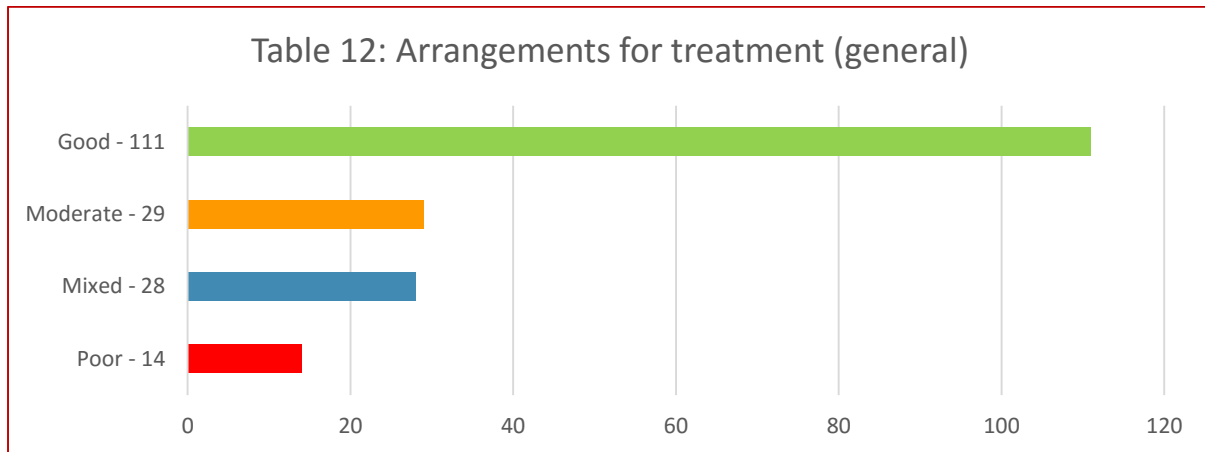
#### Negative comments

General comments	1
Felt rushed, to make up time	1

#### Negative comments

Lack of apology/update	2
Return transport missed	2
Anxiety increased awaiting results	1
Excessive wait at pharmacy	1
Only experienced at Southampton	1
Usually experienced at Piam Brown	1

## f) *Treatment*



There were positive comments, largely of a generalised nature, on all providers. The small number of participants commenting on treatment at Salisbury Hospital were especially appreciative of care there. Overall, value was attached to being informed of a range of treatment options, and being given enough time to talk through the implications of each.

Lack of information to make an informed choice was a large source of negative feedback. One participant felt an unduly off-putting picture had been painted of a certain treatment – only after declining the treatment and being adversely affected, was that treatment given without problem.

Instances were given of treatment not being sufficiently thorough, leading to spread of cancer, and of particular procedures being undertaken where consent had been specifically withheld.

Experiences were quoted of a promised pre-med\* not being given, and of post-operative painkillers not being given due to the pharmacy being shut. Poor prescribing practice was cited by several participants, and in one instance a clinician's later account of treatment that diverged radically from the patient's recollection.

## Detail of Comments on Treatment (general)

### St Mary's

#### Positive comments

Quality of care	4
General comments	3
Communication & information	1
Day surgery	1
Diagnostic tests	1
Doctors and surgeons	1
Home visits	1
Nurses	1
Standard of advice	1
Surgery	1

#### Negative comments

Pharmacy delays	2
Prescribing practice	2
Agreed treatment not provided	1
Day surgery issues	1
Diagnosis communication issues	1
Extent of disease not identified	1
Lack of choice in treatment options	1
Lack of pain relief	1
Treatment arrangements	1
Pros and cons not explained	1
Queried record of treatment	1
Rushed into decision on treatment	1
Treatment given without consent	1

### Portsmouth

#### Positive comments

General comments	2
Cleanliness	1
Competence	1
Staff ratio (post-operative)	1
Efficiency	1
Well-coordinated	1

#### Negative comments

Process prior to treatment	1
Dentistry treatment	1
Physical examination, discomfort	1

### Southampton

#### Positive comments

General comments	4
Anaesthetist, re-assurance	1
Appointments (pre surgery)	1
Efficiency	1
Well thought-out	1

#### Negative comments

Pharmacy waiting times	2
Appointment handling	1
Diagnosis communication issues	1
Fragmented service	1
General comments	1
Long travel time, short treatment	1

### Salisbury

#### Positive comments

General comments	5
Supportiveness	1
Surgery	1

#### Negative comments

	0
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## - Chemotherapy -

There were several appreciative comments about the chemotherapy unit at St Mary's Hospital. Some mentioned the thoughtfulness of staff, one participant said what a difference it had made to be greeted by first name.

*“ The IoW should be proud of the chemo service.... any mistakes are explained and rectified. Staff and volunteers are always willing to discuss any problems”*

Other feedback included a request for clearer information about the longer initial appointment, and a comment on problems experienced from having received too much chemotherapy treatment.

A view was also expressed that chemotherapy treatment “could probably be delegated” to St Mary's more often where currently carried out at mainland hospitals. Participants who had experienced this noted how tiring the additional travel had made the overall process.

## Detail of Comments on Chemotherapy

### St Mary's

#### Positive comments

Care shown by staff	3
Car parking arrangements	2
General comments	2
Local provision appreciated	2
Mistakes explained/rectified	1
Preparation of drugs	1
Soothing atmosphere	1

#### Negative comments

Discouraged from receiving	1
Insufficient local delegation	1
Lack of nutritional advice	1
No info on wig service	1
Organ damage due to too much	1
Poor communication	1

### Portsmouth

#### Positive comments

	0
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#### Negative comments

	0
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### Southampton

#### Positive comments

	0
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#### Negative comments

Insufficient local delegation	1
Lack of nutritional advice	1
Long waiting times	1
Organ damage due to too much	1



## - Radiotherapy -

Positive comments referred to the efficiency, friendliness and caring quality of staff, appreciation was also expressed for a punctual service where this occurred.

After the issues around travel (see pages 16 - 18), the most frequent negative experience was that of machinery being out of action, leading to delays. One suggestion was for tattoos marking sites for treatment being a colour more visible than black, to ensure they could be found.

One comment advocated more information about side-effects of radiotherapy, whilst one participant expressed regret at receiving this treatment, having “not been well since”.

## Detail of Comments on Radiotherapy

### Portsmouth

#### *Positive comments*

General comments	1
Travel arrangements	1

#### *Negative comments*

Clinician language skills	1
Machinery malfunction	1
Poor documentation	1
Travel arrangements	1
Visibility of targeting tattoo	1

### Southampton

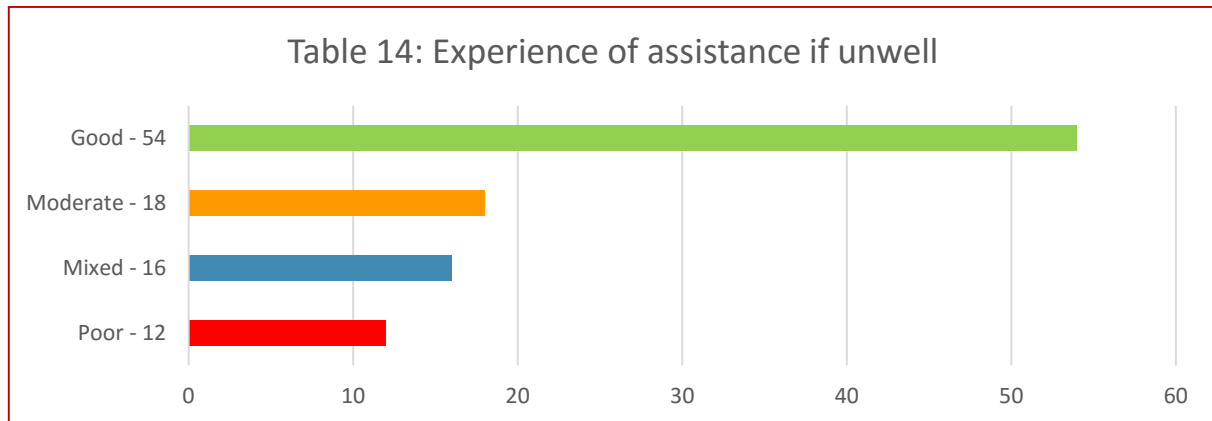
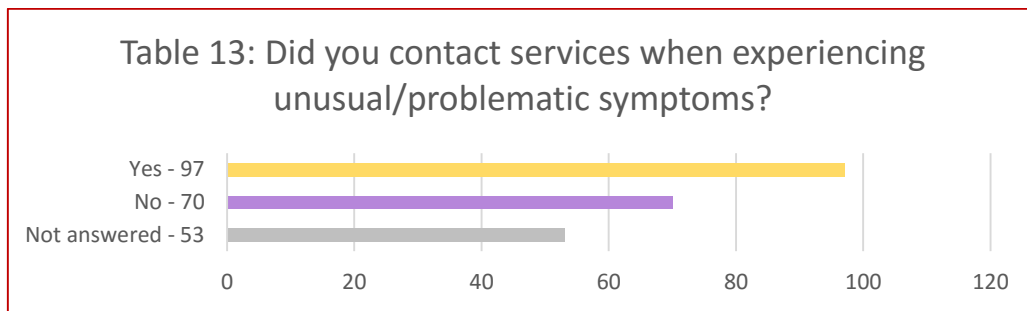
#### *Positive comments*

General comments	4
Efficiency	1
Punctuality	1

#### *Negative comments*

Travel arrangements	11
Accommodation issues	3
Machinery malfunction	3
Scheduling issues (evening)	2
Regret receiving treatment	1
Punctuality	1

## **g) Assistance if Unwell**



Of those who had called for help due to unexpected or sudden health issues, experiences were predominantly good. There were comments about timely help from the Accident & Emergency department at St Mary's Hospital and the Beacon Centre, also the 111 service. The Isle of Wight Hospice was mentioned, as were GP practices. One participant mentioned arrangements being made promptly to see a consultant, others appreciated help given over the telephone.

Of those who had a negative experience, comments ranged from a suggestion of receiving literature beforehand of what to expect, to a poor out-of-hours service for people who are terminally ill. Other comments referred to a lack of specialist care for patients unwell at the weekend, and to promised ring-backs that never happened.

One participant described being at St Mary's A&E Department for five hours with a high temperature attached to a drip on a trolley – without a check or offer of a drink. Another patient recalled the poor diagnosis of an infection by an A&E doctor being followed by complex treatment at another hospital for resultant tissue damage.

Whilst negative comments on the 111 service were fewer than complimentary ones, their content was particularly scathing.

*“111 told me it was normal to be nauseous after chemo (which I knew), when I was concerned it was more than just nausea (which it was)”*

## Detail of Comments on Assistance if unwell

### St Mary's

#### Positive comments

A & E / Beacon Centre	4
Promptness	2
Confident to approach	1
Efficiency	1
General comments	1
Self-referral welcome	1
Telephone response	1

#### Negative comments

A & E / Beacon – waiting times	3
Inpatient issues	2
A & E / Beacon – limited help	1
Misdiagnosed infection	1
Not informed who to contact	1
Unplanned less good than planned	1

### Portsmouth

#### Positive comments

Good communication	2
Confident in contacting	1

#### Negative comments

	0
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### Southampton

#### Positive comments

Open accessibility	1
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#### Negative comments

	0
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### GP Services

#### Positive comments

General comments	2
Good call-out	1
Good prescribing practice	1

#### Negative comments

Concern over getting appointment	1
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### 111 Phone Service

#### Positive comments

Prompt response	4
Urgent treatment arranged	1

#### Negative comments

General comments	1
Poor assessment/advice	1

## ***h) In-patient Experience***

Positive comments were of a general nature, but included one mention of helpfulness of staff on a particular ward at St Mary’s. Positive feedback about a high-dependency ward at Southampton was balanced by concerns at inadequate levels of staffing on a more generic ward there.

Negative experiences quoted by participants centred largely on a feeling that staff on general wards were not equipped to cater for the specific needs of people with cancer, and chemotherapy patients in particular. An incident of poor nursing practice at Portsmouth was mentioned, as were specific wards at St Mary’s where experiences had not been good. These ranged from comments of neglect or a poor attitude, to reports of incorrect medication or clinical procedures being administered.

*“On the ward I asked for pain relief .... was told “In a minute” and made to feel a nuisance”*

### **Detail of Comments on In-patient Experience**

#### **St Mary’s**

##### ***Positive comments***

Helpfulness	1
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##### ***Negative comments***

Poor practice, chemo patients	2
Quality of care	2
Abrupt staff manner	1
Conduct of doctors	1
Neglect	1
Unpleasant incidents	1

#### **Portsmouth**

##### ***Positive comments***

	0
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##### ***Negative comments***

Poor nursing practice	1
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#### **Southampton**

##### ***Positive comments***

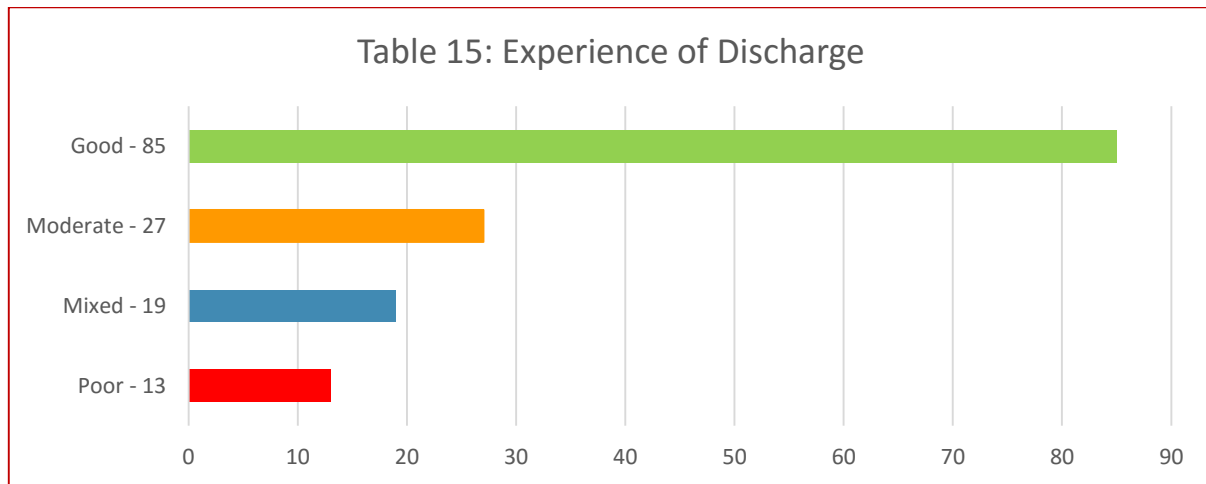
High dependency ward	1
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##### ***Negative comments***

Generic ward – poor experience	1
Staff overstretched	1

## i) Discharge & Aftercare

### - Discharge -



Positive comments on discharge centred on good practical arrangements and provision of helpful advice.

Negative experiences were often connected to timings of discharge. Long waits for pharmacy services were mentioned by several participants, meaning delays of several hours before a patient could leave the hospital. When returning from mainland treatment this added a layer of practical issues for both the patient and supporting family or friends.

A number of participants mentioned early discharge and being left to their “own devices”, in some instances experiencing re-admission to treat infection or other complications. Others spoke of the stress of ferry travel for patients very soon after surgery, and practical issues for people leaving mainland hospitals with little warning and without someone who could help at short notice.

At St Mary’s also, discharge at short notice caused issues. One participant admitted for complications following treatment was informed they had to leave as staff needed the bed “freed up”. Without no-one able to assist at such short notice, the patient relates waiting at reception for a taxi, in nightclothes, without advice or support from ward staff.

## Detail of Comments on Discharge

### St Mary's

#### Positive comments

Quick discharge for death at home	1
Good pick-up point	1

#### Negative comments

Ambulance transport did not arrive	1
Delays waiting for pharmacy	1
Discharged in nightclothes	1
Discharged too soon, re-admitted	1
No follow-up in place	1
Pharmacy closed, no painkillers	1
Prepared before all results to hand	1

### Portsmouth

#### Positive comments

Good discharge advice	1
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#### Negative comments

Abrupt end to support	1
Delays waiting for pharmacy	1
Incorrect advice given	1

### Southampton

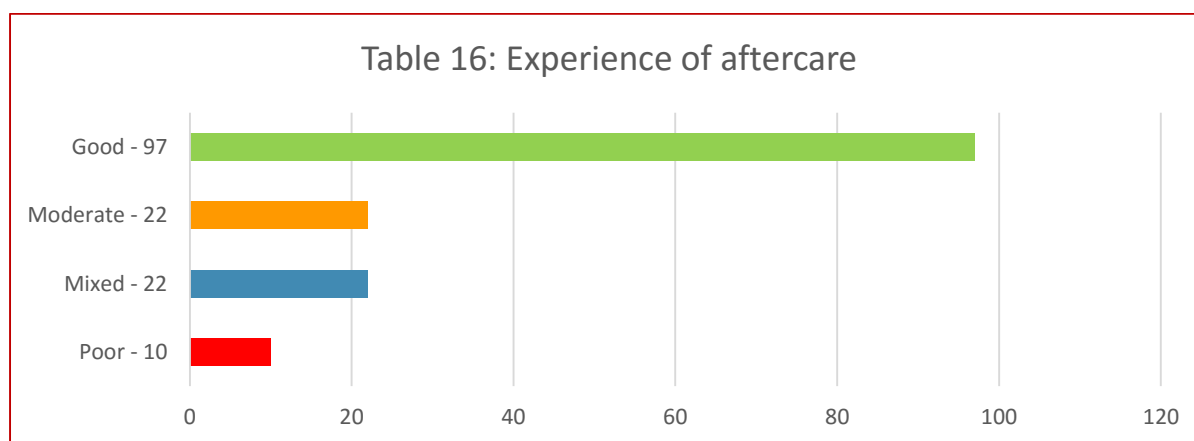
#### Positive comments

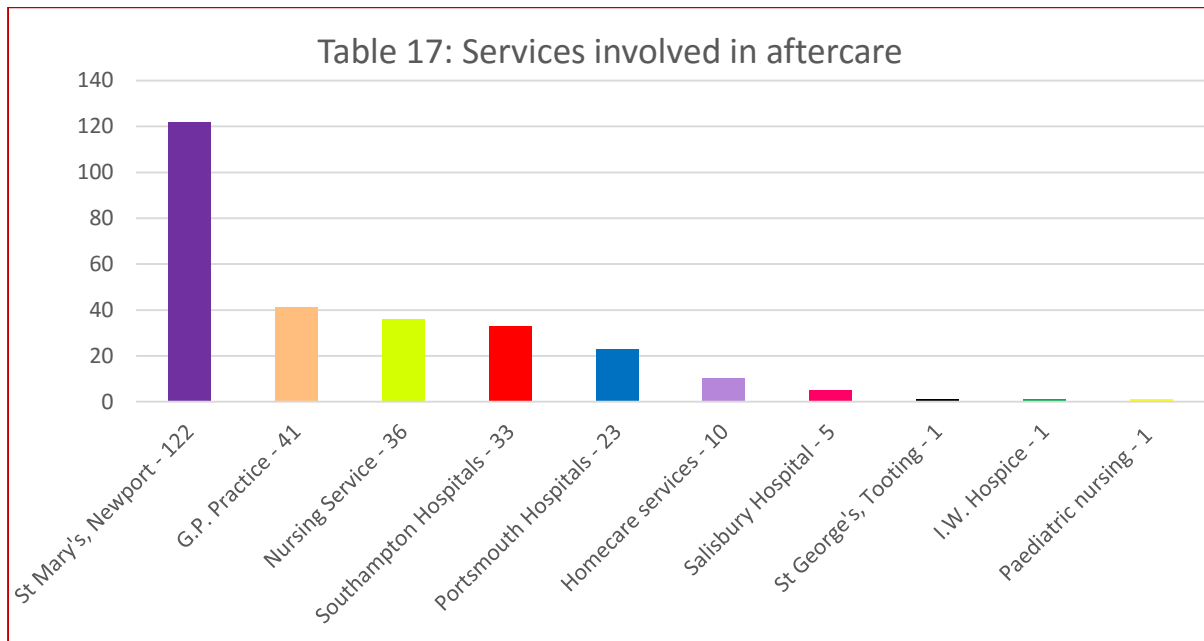
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#### Negative comments

Transport issues	3
I.W. NHS not informed of discharge	1
Abrupt early discharge, no help	1
Delays waiting for pharmacy	1
Waiting time before leaving	1
Discharged too soon, re-admitted	1

## - Aftercare & Follow-up -





Positive experiences of aftercare included informative follow-up letters and appointments and good support from a range of services. Particular mention was made of the GP role and of district nurses. The Isle of Wight Hospice and Macmillan nurses were also mentioned.

Where concerns arose, this was often due to a lack of clarity about who was responsible for what areas of support, and a feeling of having to chase things up and take the initiative. Experiences seemed to vary according to the form of cancer involved, some participants feeling there had been little or no aftercare.

With the role of the GP and district nursing mentioned frequently in connection with aftercare, the level of support here was a big factor in the quality of participants' experience. Management of dressings was mentioned by a number of participants, with wound infection sometimes requiring a convoluted series of contacts between services.

Some participants spoke of feeling isolated following treatment, having no-one to discuss concerns with. Contact phone numbers had not always turned out to be correct. One person felt that help with the after-effects of surgery and radiotherapy had evaporated after a couple of months.

Specific concerns were mentioned by individuals about support from Portsmouth hospitals over erectile dis-function and with the level of service at St Mary's Hospital for patients with secondary breast cancer.

## Detail of Comments on Aftercare and Follow-up

### St Mary's

#### Positive comments

General comments	3	
Breast care nurses	1	
Doctors	1	
Follow-up letters	1	
GP practice	1	
I.W. Hospice	1	
Macmillan	1	
Phone-calls	1	
Thoroughness of staff	1	
Three-monthly checks	1	
Well-explained	1	

#### Negative comments

Lack of aftercare	6
Follow-up appointments rushed	2
More follow-up needed (BCN's)	2
Not called for follow-up	2
Dressings support insufficient	1
GP practices	1
General comments	1
Lack of home visits	1
Lack of info on district nursing	1
Patient left to chase things up	1
Timetabling issues	1

### Portsmouth

#### Positive comments

General comments	1
Good advice given	1
Well-explained	1

#### Negative comments

Not called for follow-up	1
Poor follow-up	1

### Southampton

#### Positive comments

General comments	2
------------------	---

#### Negative comments

Lack of follow-up	1
Liaison took time	1
Patient left to chase things up	1

### Salisbury

#### Positive comments

General comments	5
Supportiveness	1
Surgery	1

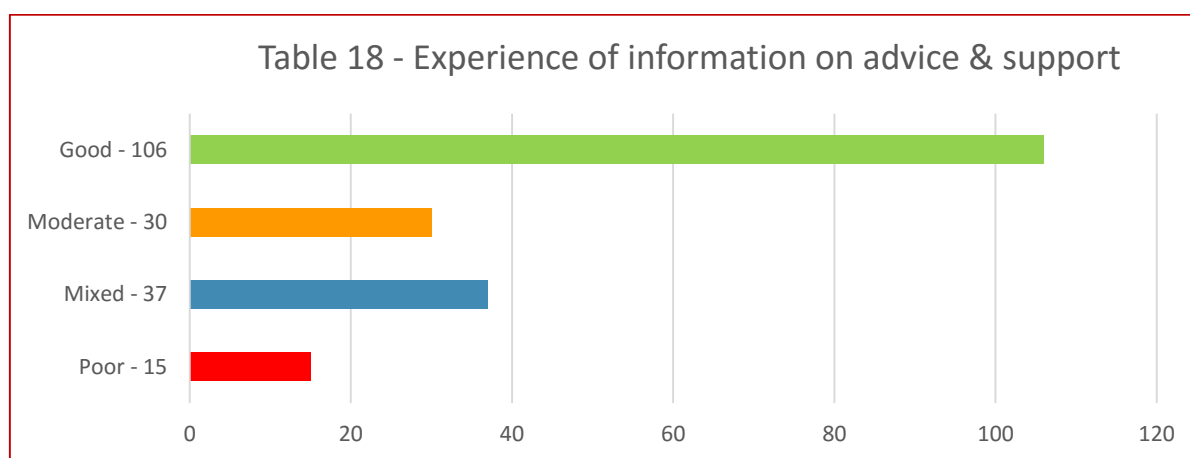
#### Negative comments

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## j) Support, Information & Advice

### - Support -



Comments about good support centred largely on the attitude of clinical teams, those at St Mary's, Southampton and Salisbury being particularly highlighted. The Breast Cancer team was mentioned most frequently. The services offered by the Isle of Wight Hospice were much appreciated, along with Macmillan and the Wessex Cancer Trust. Peer support groups were much valued for opportunities to speak to people going through similar experiences.

*"Sometimes all we need is re-assurance. Appreciate staff are very thorough..."*

Negative feedback often centred on an absence of structures enabling support, and not made aware of where it might be found. There were also comments about a perceived lack of counselling. Several comments referred to support being completely missing, or "promised but not given".

*"Cancer nurses rely on patients to inform them of their treatment. And only respond to requests. No time to offer proper support.... Not professionals fault, but the lack of funding and time."*

One participant mentioned a peer support group they felt to be unwelcoming.

## Detail of Comments on Support

### St Mary's

#### Positive comments

General comments	2
Applegate	1
Breast care team	1

#### Negative comments

Poor support	5
Gap during staff vacancy	1
Lack of counselling	1
More re-assurance needed	1
Only respond to requests	1
Support for relatives lacking	1

### Portsmouth

#### Positive comments

Support from fellow-passengers	2
--------------------------------	---

#### Negative comments

Group sessions unavailable	1
Support for relatives lacking	1
General comments	1
Only respond to requests	1

### Southampton

#### Positive comments

General comments	3
Hectic but good	1

#### Negative comments

Wait whilst staff on leave	1
Lack of counselling	1

### - Information -

Feedback about information centred largely on the way it was given, as well as its quality and scope. One participant spoke of being “bewildered and bombarded by leaflets”, whilst others struggled to know what information to request.

*“Treated very well, but sometimes finding out about information after the event. When you are in this position, you don't know the right questions to ask any more”*

On the other hand, where information was given during an unhurried conversation, some found a greater capacity to take it in.

*“The information personally given by the Macmillan and liaison nurses was easier to take in, as they would patiently let you talk around in circles until you got it, and answer any questions.”*

Amongst those noted by participants as giving useful information were district nurses and breast care nurses, as well as Macmillan.

Views were expressed that information was “poorly-presented and out-of-date”, and that an information centre at St Mary’s Hospital would help.

Some feedback related to areas of information found difficult to get hold of locally, despite patients’ best efforts. Some participants would have welcomed more preparation on the effects of treatment. Others would have liked to know more about complementary therapies, and using nutrition to best advantage during cancer treatment

## Detail of Comments on Information

### St Mary’s

#### Positive comments

Breast care team	1
------------------	---

#### Negative comments

General comments	1
Hard to take info in - bombarded	1
Incorrect contact numbers	1
Info discovered too late	1
Info on compl. treatments lacking	1
Info on condition lacking	1
Info on financial help lacking	1
Info on nutrition lacking	1
Info on provider transfer lacking	1
Info on side-effects lacking	1
Info on symptoms lacking	1
Info on treatments lacking	1

### Portsmouth

#### Positive comments

	0
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#### Negative comments

Travel information lacking	1
Radiotherapy information poor	1

## Southampton

### Positive comments

	0
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### Negative comments

Poor timing of financial info	1
Transport information	1
Hard to take info in - bombarded	1
Incorrect contact numbers	1

## - Advice -

There were several positive comments about the level of advice provided by all services. As well as the three main hospitals used, Wessex Cancer Trust, the Isle of Wight Hospice and Macmillan were all mentioned.

Some participants felt they could have benefited from additional advice. There was one comment that the level of advice varied according to the form of cancer, and another on the Internet being a major advice source.

*"It would have been useful to have had the Macmillan booklet about feelings after the end of treatment... I was surprised by my feelings that I have since found to be common amongst survivors."*

## Detail of Comments on Advice

### St Mary's

#### Positive comments

General comments	6
Macmillan advice	1
Nurse advice	1

#### Negative comments

Lack of advice	3
Contradictory advice given	1
For some forms of cancer only	1
Lack of access to advice, relatives	1

### Portsmouth

#### Positive comments

General comments	3
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#### Negative comments

	0
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## Southampton

### Positive comments

Good Macmillan room	1
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### Negative comments

Lack of advice/signposting	1
Fragmented approach	1
Travel advice lacking	1

## k) Communication

Good communication was much valued by participants where it had occurred. Most comments were general in nature but spoke predominantly of promptness and responsiveness. Resolution of appointment and medication issues were appreciated, medical secretaries and GPs were amongst those to be mentioned.

Negative experiences of communication often centred on a lack of answers to questions, and the need for repeated “chasing”. Non-arrival of letters from clinics was a concern, as were receiving conflicting appointment notices from different NHS Trusts, or being called for an appointment that had already taken place. All of these examples had caused raised levels of stress. Incomplete information was also a source of puzzle and worry.

*“ [I was] told a second biopsy was needed, but the results from the first biopsy were not made available to me”*

A number of participants mentioned how important they found being given a sense of the longer term time-span, rather than being updated in an abrupt or fragmented way. An example given several times was of a changed of specialist doctor without warning or introduction.

*“Informed about what was happening a week at a time, so no ability for [patient] to live her life to the fullest”*

## Detail of Comments on Communication

### St Mary's

#### *Positive comments*

General comments	3
Follow-up phone-call	1
Given time	1
Kept informed	1
Responsiveness	1

#### *Negative comments*

General comments	4
Patient left to chase things up	4
Communication of results	2
Doctors - rapport with patient	2
Complaints handling	1
Information on changes, staff etc.	1
Nurses	1
Partial information, anxiety raised	1
Response to questions	1

### Portsmouth

#### *Positive comments*

Promptness	2
Responsiveness	1

#### *Negative comments*

Clinician language skills	1
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### Southampton

#### *Positive comments*

General comments	1
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#### *Negative comments*

General comments	2
Correspondence not sent	1
Doctors - rapport with patient	1
Information on changes, staff etc.	1
Late appointment arrangements	1

## **I) Financial & Family issues**

### **- Financial issues -**

Almost all of the feedback on financial issues was negative, with the majority being about the cost of travel. This is described in more detail on pages 16 - 18. Other comments related to the availability of information, and experience of acute stress in sustaining family finances after the onset of illness.

Comments mentioned practical issues around information, such as not being made aware beforehand that the claims office at St Mary's Hospital is open on certain days only. Timeliness and clarity of information on finance came across areas for improvement.

*"It would be helpful for patients to be told about financial issues before treatment starts. I attended the SCIP\* sessions, and the finance week was held a bit too late."*

Fact-finding for this report suggested that patients and families could be helped by bringing information together to a much greater extent, as arrangements for financial help involve multiple agencies and are complex. Finance-specific written guidance for people affected by cancer would be invaluable, to give a clearer idea of which avenues to explore in changed circumstances. Face-to-face sessions are available to people to navigate possible help, via the Wessex Cancer Trust and Citizen's Advice, but are not currently widely-publicised.

*"Again communication of all travelling.....and reimbursement of expenses very confusing and staff not available to assist."*

Reimbursements direct from the NHS are available to people on certain named benefits. There is also a nationwide NHS Low Income Scheme which involves an application to a national office. Local printed information directs people to national sites to find leaflets and forms, which are not cancer-specific and may not be straightforward to interpret<sup>4</sup>.

Currently, the availability of travel claim forms is variable. For example, the local authority provides grant funding for a “Cross Solent Travel Scheme” managed and administered by the NHS Trust. It is understood that claim forms are available only from oncology nurses at St Mary’s Hospital, and information about the scheme appears not to be included on the Isle of Wight NHS Trust website. It would be helpful for venues which stock any kind of cancer travel claim form to stock all varieties of form, along with the specific information suggested above.

For working people with cancer some specific finance issues were raised. A sudden change of financial circumstances will often result from the onset of cancer, with self-employed people amongst those with particular issues. One participant gave a vivid account of repeating detailed medical information to the Department of Work and Pensions that had already been supplied to them by the GP and then being allocated a weekly allowance that did not even cover the travel costs to treatment.

*“Nobody is linking with the impact on health by other systems and environments – we are nobody’s problem once they have done their bit...”*

## Detail of Comments on Financial issues

### St Mary’s

#### Positive comments

	0
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#### Negative comments

Lack of information, general	2
Lack of information, travel	2



## Portsmouth

### Positive comments

Help with ferry costs	2
-----------------------	---

### Negative comments

Travel expense	4
DWP – severe issues	1

## Southampton

### Positive comments

	0
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### Negative comments

Travel expense	3
Lack of information, general	1
Lack of information, travel	1

## - Family issues -

Issues affecting families were not the subject of a specific section in the questionnaire, but the impact of an experience of cancer on families was apparent throughout much of the survey. Although the volume of feedback was the least of any theme, the intensity of the comments was high, and all the content was negative in character.

Some comments were about levels of support and access to information on sources of support for families. One participant mentioned being told about a support group, but only after some time of feeling unsupported. Many other general comments spoke of poor levels of support for family in general and partners in particular.

Particular issues affected families of working age with young children. Whether the patient was a child or a parent, there were descriptions of the effects spreading across whole families. Once again travelling was a major factor, and the impact of this in addition to intense treatment.

*“... the fact that [my partner] had to travel so far was awful, very hard for me to give support as we had a young child to look after”*

Levels of specific practical help were also highlighted, where family members became unpaid carers for people needing substantial care.

“... had one visit from Social Services when it was too late. I looked after [my partner] for 15 months and had no help at all at the beginning – the free two-hour help would have been nice to know about.”

## Detail of Comments on Family issues

### St Mary's

#### Positive comments

	0
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#### Negative comments

Support for relatives lacking	2
Mistakes – impact on spouse	1
Lack of co-ordination - impact	1

### Portsmouth

#### Positive comments

	0
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#### Negative comments

Support for relatives lacking	1
Multiple stresses of process	1

### Southampton

#### Positive comments

	0
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#### Negative comments

Travel issues - impact	2
Childcare & family life - impact	1
Lack of co-ordination - impact	1



## 6 - Conclusions

- The quality, consistency and reliability of staff support is a predominant factor in patient experience. Priority should be given to recognising good practice, and working to make this universal.
- When patients travel to the mainland to use cancer services this tends to have major effects. All practicable measures should be taken to reduce the need to travel, and to minimise the effects when this is unavoidable.
- Gaps were identified in the co-ordination of services, both between professionals, and between provider organisations.
- Few obstacles were identified to the swift diagnosis and treatment of cancer, but where these occur they have a huge impact.
- Outpatient appointment schedules need to reflect the reality of the time needed to effectively support patients. Good practice needs to be upheld to ensure consultations are not rushed.
- Treatment generally prompted positive feedback, particularly of chemotherapy provision at St Mary's Hospital. However, the need to cross the Solent for radiotherapy caused major concerns.
- The fitness for purpose of generic services supporting cancer patients experiencing unexpected acute symptoms needs a thorough review, with remedial measures implemented speedily.
- Arrangements for discharge from hospital need to be improved, especially when cross-Solent travel is involved.
- The availability, clarity and navigability of patient information needs an urgent review, with meaningful input from patients. Information on financial issues needs particularly urgent improvement.



## 7 - Recommendations

### INTEGRATION

Cancer services for Isle of Wight residents should undergo a radical programme of integration to enabling the following:

- Greater flexibility of service provision, allowing the most accessible location of treatment, whilst ensuring the best possible clinical input
- Provision of treatment involving the least travel, not precluding the development of radiotherapy services on the Isle of Wight, should this become practicable in the future.

### SOLENT TRAVEL

A Charter is needed, setting out what patients have a right to expect from providers. To be devised by the Isle of Wight Clinical Commissioning Group and NHS England for adoption by all relevant providers. To include

- Scheduling of appointments and treatments
- Arrangements for admission to and discharge from in-patient treatments, especially the predictability and practicality of timings
- Processes for making changes to services, both temporary and permanent. Patient involvement should be part of this, including, but not be limited to, contact with recognised peer support groups

### CO-ORDINATION

Key aspects of service co-ordination, affecting the care and treatment of cancer patients need improvement:

- Barriers to communication between hospital departments, G.P. practices and community nursing should be identified and rectified
- Better arrangements to be developed for other professionals to step in, should key clinicians and care co-ordinators be absent from work
- More realistic scheduling for outpatient appointments, to allow sufficient time for consultations, without feeling rushed

## ACCESS

Careful note should be made of any barriers to the timely diagnosis and treatment of cancer, to include:

- Good practice amongst GPs needs recognition in referring patients in the event of concerns, and poor practice needs to be identified and improved
- Organisational barriers to swift diagnosis, including the application of the appointments process, should be identified and addressed
- Further investigation is required as to whether any particular groups are disadvantaged in having access to swift diagnosis and treatment of cancer

## ASSISTANCE

The effectiveness and quality of generic services in supporting cancer patients experiencing unexpected, acute symptoms needs further examination and action:

- 111, Accident & Emergency and generic in-patient wards to be assessed for their ability to support cancer patients
- Specific facilities developed for cancer patients where this is necessary and feasible
- Where specific services are not developed, trainings to be delivered in effective and appropriate support, to be monitored through patient involvement to assess the extent of positive change

## INFORMATION

A review is required for all patient information, and a process put in place for regular updating:

- Patients to assess the usefulness of information provided to them, immediately and then through an ongoing structured process
- Information on financial help should be made clearer, and public access to this information improved and rationalised



## 9 - Glossary

<b>Full title</b>	<b>Abbreviation</b>	<b>Explanation</b>
Chemotherapy	Chemo	Chemotherapy uses anti-cancer drugs to destroy cancer cells. Usually injected into a vein or taken as tablets.
Colo-rectal		Refers to the lower region of the intestine, part of the digestive system
Haematology		Speciality dealing with blood disorders
Healthwatch Isle of Wight		Local “consumer champion” for Health and Social Care services, formed in April 2013
Isle of Wight Clinical Commissioning Group	Isle of Wight CCG	Main organisation that decides which services will be funded by the NHS for Island residents, and how much money will be spent on these services
Maxillofacial		A medical specialty dealing with the head, neck and face and the hard and soft tissues of the mouth and jaws
NHS England		National organisation that makes commissioning decisions on primary care and some specialist health services
Pre-medication	Pre-med	A medication taken before an anaesthetic, to help with relaxation and reduce anxiety
Primary care		Health services that the public has direct access to (not in a hospital)
Prostate		A gland forming part of the male reproductive system
Radiotherapy		A technique that uses high-energy rays to destroy cancer cells, as a treatment, or way to relieve symptoms
Surviving Cancer Information Programme	SCIP	A programme offering information and psychological support at the end of cancer treatment



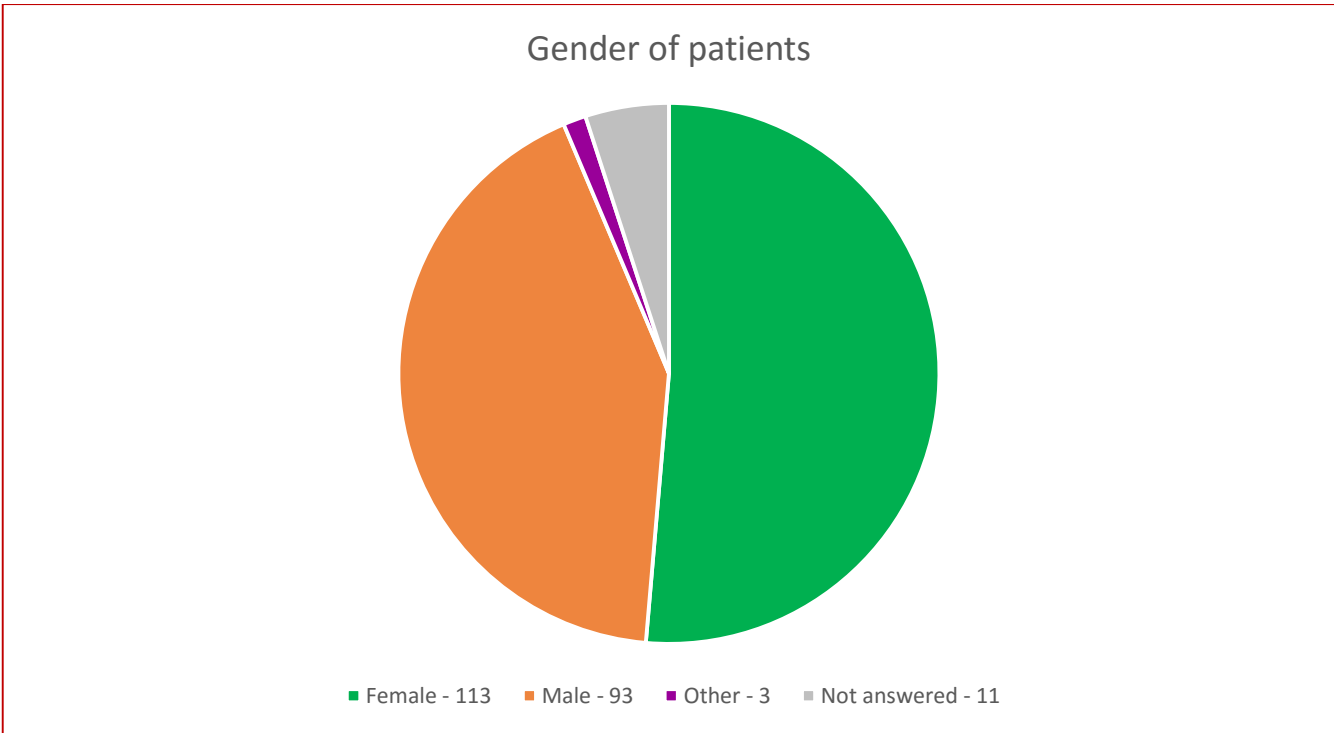
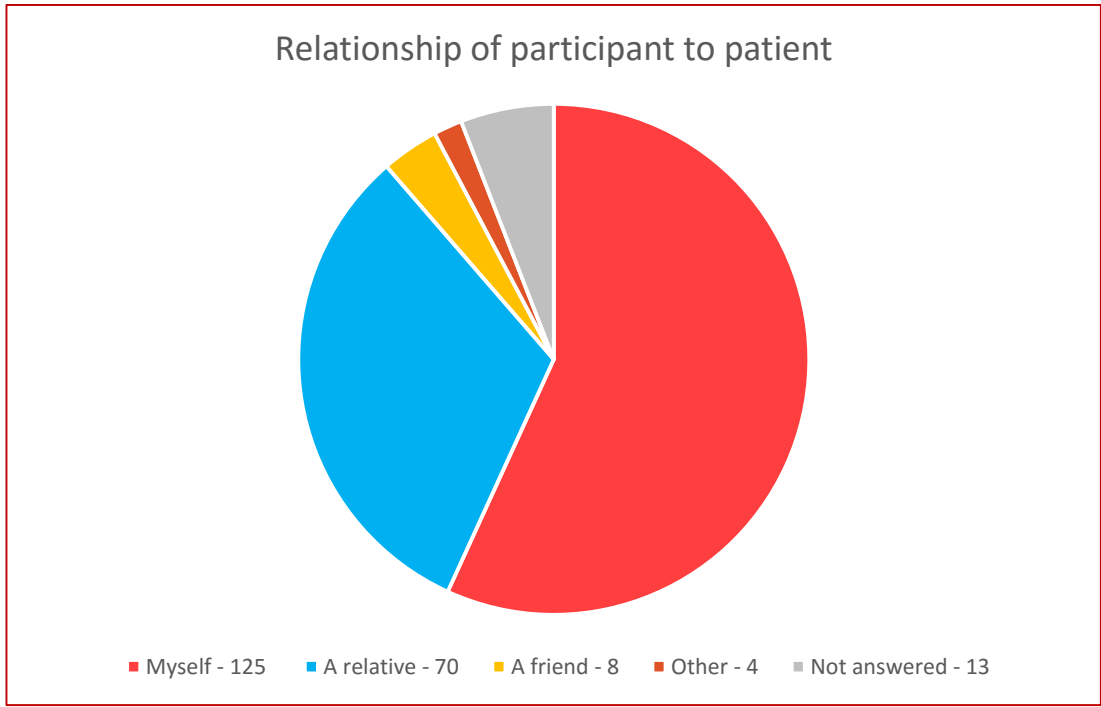
## 9 - References

1. *“Cancer Incidence in NHS Isle of Wight CCG: Local Cancer Intelligence website, Public Health England and Macmillan Cancer Support*
2. *“The 20 Most Common Cancers, UK, 2013”*: Cancer Research U.K. Website
3. *“Cancer Mortality in NHS Isle Of Wight CCG”*: Local Cancer Intelligence website, Public Health England and Macmillan Cancer Support
4. *“Help with Health Costs – HC11”*: Department of Health, Updated April 2015



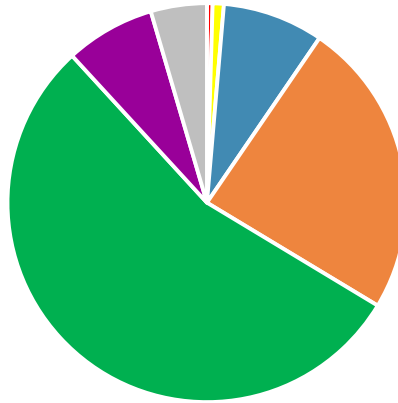
# 10 - Appendices

## Appendix 1 – Outline of Survey Participants & Patients



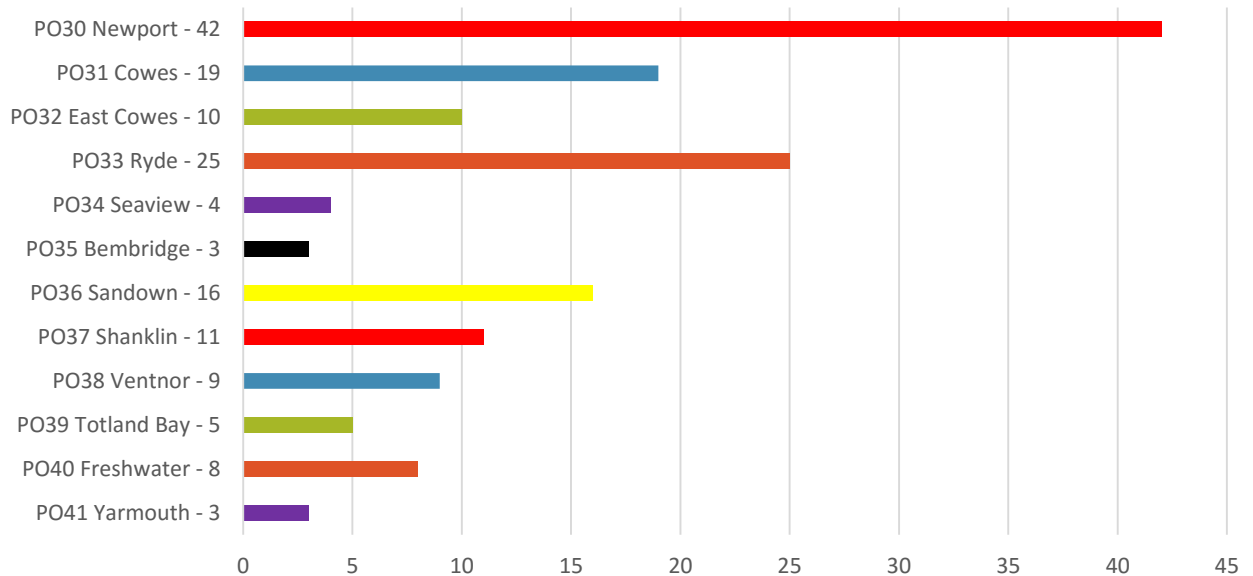


### Age-group of patients

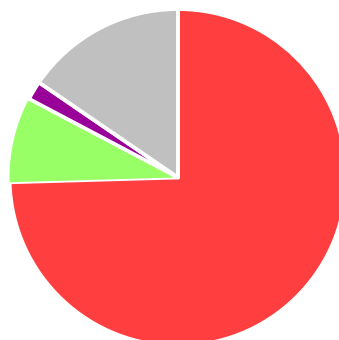


■ 17 or under - 1 ■ 18 to 29 - 2 ■ 30 to 44 - 18 ■ 45 to 59 - 53 ■ 60 to 79 - 120 ■ 80 or over - 16 ■ Not answered - 10

### Home post-code areas of patients

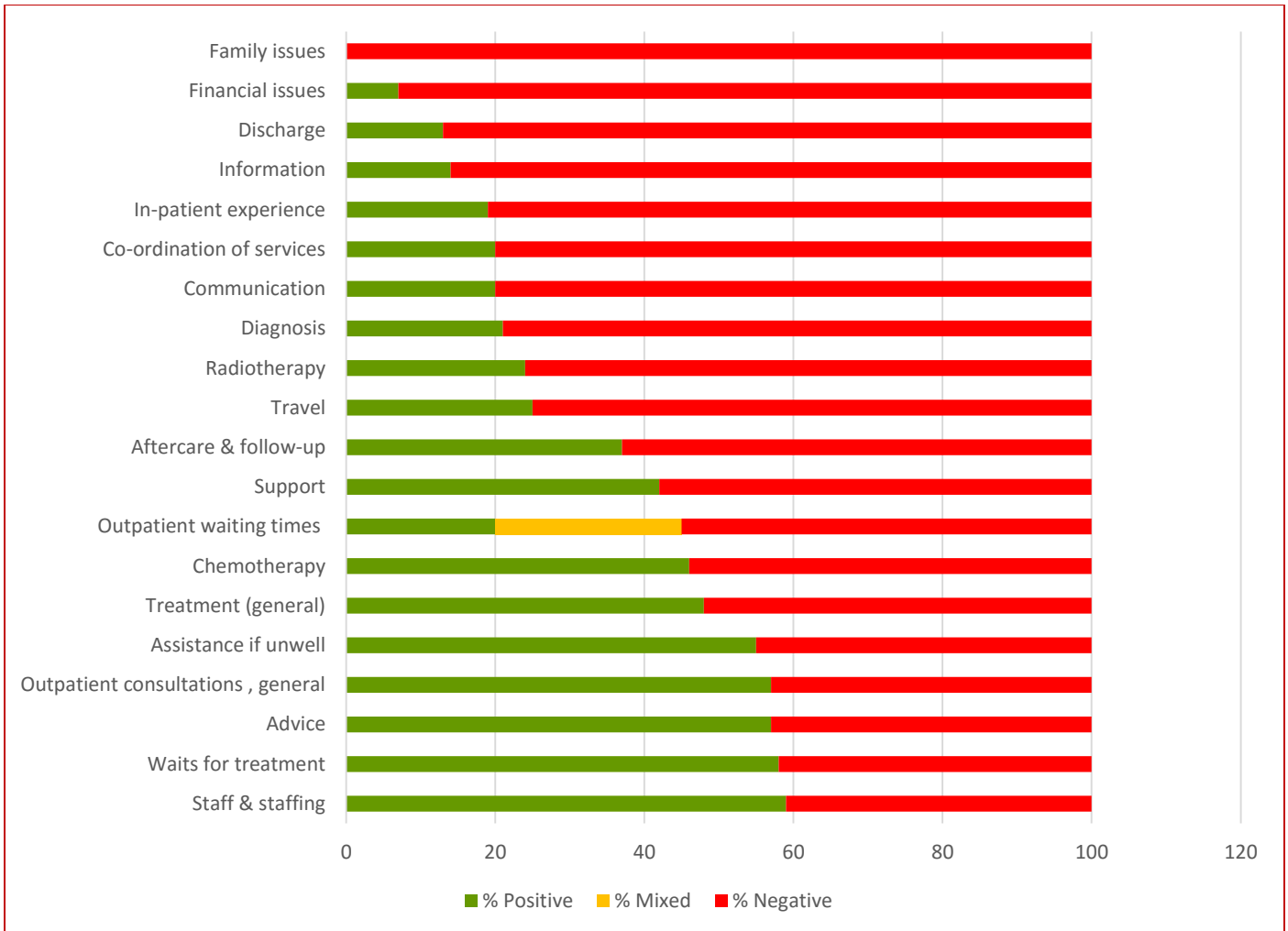


### Number of forms of cancer per patient



■ One form - 164 ■ Two forms - 18 ■ Three forms - 4 ■ Not answered - 34

## Appendix 2 – Percentages of Positive & Negative Comments



## Appendix 3 – Text of the Questionnaire on Cancer Services



### **SURVEY 2015 – Experiences of Cancer Services: including Chemotherapy, Radiotherapy and Hospital stays for cancer or oncology issues**

*Healthwatch Isle of Wight is an independent local “watchdog” and signposting service. It works with decision-makers and service providers to help improve health and social care services on the Island.*

*The Isle of Wight Clinical Commissioning Group is the main body making decisions on which organisation will provide NHS services to people who live on the Island. This includes specialist cancer services.*

Healthwatch Isle of Wight and the Isle of Wight Clinical Commissioning Group are working together to learn more about patient experience of cancer services.

Healthwatch Isle of Wight has adopted cancer services as one of its priority topics for 2015-16 and the Isle of Wight Clinical Commissioning Group is currently reviewing chemotherapy, radiotherapy and admissions to hospital with cancer issues.

Please take a few minutes to fill in this questionnaire, answering as many or few questions as you wish. We want an up-to-date picture, so please answer **only about experiences in the last two years.**

*If you need this form in another format or version, please contact Healthwatch Isle of Wight on 01983 608608 (text 07739 436600) or visit*

The questionnaire should take no longer than 30 minutes to fill in. The closing date is **24<sup>th</sup> December 2015**

**Thankyou**

## **INTRODUCTION**

**Healthwatch Isle of Wight and the Isle of Wight Clinical Commissioning Group realise that people's experiences of cancer services are likely to be complex and intense.**

**This survey is about patient experience of chemotherapy and radiotherapy services and of hospital admissions related to cancer. Some of the questions relate to parts of the patient journey which have attracted most feedback from the public. We want to find out how well services have helped people with cancer.**

**We understand that it may not be easy to sum up experiences in a few words. Where we ask for a one-word answer or a ticked box, this is to help us understand the overall views of larger numbers of people, who we hope to hear from.**

**The comments about your individual experiences are the most important part of the survey, and we really appreciate your willingness to share these.**

**If you wish to share experiences not covered by this survey, you are most welcome to contact Healthwatch Isle of Wight to tell us about these.**

**1 – How have you had experience of the oncology or cancer services?**

**Used Services  
myself**

**A relative  
used services**

**A friend  
used services**

**Other**

Please tell us, if you wish, what form(s) of cancer the services you have told us about relate to:

Please tell us the age-group of the person whose experiences the answers relate to:

- 17 or under**
- 18 – 29**
- 30 – 44**
- 45 – 59**
- 60 – 79**
- 80 or over**

The sex of the person the answers relate to:

- Male**
- Female**
- Other**

## 2 – Advice and Support

How would you rate the experience of services letting you know where to find advice and support?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

### 3 – Arrangements for treatment/care

How would you rate the experience of services making arrangements for, and communicating with you or other about treatment and care?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

#### 4. Overall Experience of Outpatient Appointments

How would you rate the experience of the outpatient appointments with the cancer doctor (oncologist)?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
Nursing service	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	



### 5. Outpatient Waiting Times

How often did you (or other person you are completing the survey on behalf of) have to wait longer than 30 minutes from your appointment time to see the doctor?

<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Regularly</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?  
*(please tick as many that apply)*

G.P. practice	<input type="checkbox"/>
Nursing service	<input type="checkbox"/>
St Marys Hospital	<input type="checkbox"/>
Portsmouth Hospitals	<input type="checkbox"/>
Southampton Hospitals	<input type="checkbox"/>
Other(s), please specify:	<input type="checkbox"/>

## 6. Assistance if Unwell

Did you (or the person you are completing this survey on behalf of) contact any service as a result of experiencing any unusual or problematic symptoms?

Yes

No

If you answered yes, how do you rate the support you received?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
Nursing service	
Homecare service	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

### 7 – Arrangements for travel

How would you rate the experience of travelling to services, and any associated issues (e.g. accommodation)?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

### ***8 – Arrangements for discharge/going home***

How would you rate the experience of completing treatment(s) and returning home?

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

**9 – Aftercare and follow-up**

How would you rate the experience of care following any treatment, and follow-up visits or appointments?

<b>Good</b>	<b>Moderate</b>	<b>Mixed</b>	<b>Poor</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?  
*(please tick as many that apply)*

G.P. practice	<input type="checkbox"/>
Nursing service	<input type="checkbox"/>
Homecare service	<input type="checkbox"/>
St Marys Hospital	<input type="checkbox"/>
Portsmouth Hospitals	<input type="checkbox"/>
Southampton Hospitals	<input type="checkbox"/>
Other(s), please specify:	<input type="checkbox"/>

### 10 – Co-ordination between services

How would you rate the level of co-ordination between services that were used? (Including how well they communicated with each other)

**Good**

**Moderate**

**Mixed**

**Poor**

If you would like to share your experiences or have any other comments, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
Nursing service	
Homecare service	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

### **11 – Any other comments**

If you would like to add any other comments about your experiences of cancer services, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

G.P. practice	
St Marys Hospital	
Portsmouth Hospitals	
Southampton Hospitals	
Other(s), please specify:	

## **11 – About You!**

Please tell us the first line of their postcode of the person whose experiences you have told us about, during the time the answers relate to:

	Please tick one:
<b>PO30</b> (Newport)	
<b>PO31</b> (Cowes)	
<b>PO32</b> (East Cowes)	
<b>PO33</b> (Ryde)	
<b>PO34</b> (Seaview)	
<b>PO35</b> (Bembridge)	
<b>PO36</b> (Sandown)	
<b>PO37</b> (Shanklin)	
<b>PO38</b> (Ventnor)	
<b>PO39</b> (Totland Bay)	
<b>PO40</b> (Freshwater)	
<b>PO41</b> (Yarmouth)	

**Thankyou for filling in this questionnaire!**



**This is an anonymous survey – names of the people taking part will not be recorded.**

**Any comments will be recorded on a secure data system and will be shared with key staff at the Isle of Wight Clinical Commissioning Group and may be quoted in reports to decision-makers and service providers.**

**PLEASE RETURN TO THE FOLLOWING ADDRESS**

**By 24<sup>th</sup> December 2015**

**Healthwatch Isle of Wight  
FREEPOST RTGR-BKRU-KUEL  
Riverside Centre  
The Quay  
Newport, Isle of Wight  
PO30 2QR**