

## Cancer Services for Isle of Wight Residents: Co-ordination, Travel and Urgent Assistance



July 2018



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# 1 - Acknowledgements

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

**Most importantly, Healthwatch would like to thank all of those who took part in our survey in 2017 sharing their experiences of cancer services. Their willingness to share these personal experiences is very much appreciated.**

**Thanks are also expressed to all those from local organisations and community groups who helped provide background information on cancer services, and who distributed copies of the questionnaires to people who might wish to take part.**

**In particular, Healthwatch wishes to thank contacts from other U.K. island communities, who informed us of their own various situations around travel to cancer treatment.**



## 2 - Summary

Cancer Services were identified as a priority topic for Healthwatch Isle of Wight for 2016-17 as a result of engagement with the local community. A questionnaire survey was carried out with local people who had used cancer services since January 2016. Questions concentrated on three topics that had emerged strongly from patient experiences recorded in a 2015 Healthwatch Isle of Wight survey on Cancer Services.

Responses to questions in the more recent survey suggested some decline in the consistency of case management since early 2016. Noticeable differences were described in the level of co-ordination between hospitals when contrasted with co-ordination between hospitals and G.P. practices. Experiences were particularly variable of information on other sources of support, for example community services.

Cross-Solent travel continues to be a source of stress for many patients who make regular journeys. Responses suggested some differences between mainland hospitals in the extent to which they accommodate the travel needs of Isle of Wight patients. Access to information on financial help was variable amongst those who took part, suggesting not all eligible patients were aware of relevant help.

Those needing assistance with unexpected symptoms reported a predominantly positive experience, but concerns remain about the process of admission and discharge when a stay at St Marys Hospital is required.

This report ends with conclusions and six recommendations for practical action.



## 3 - Background

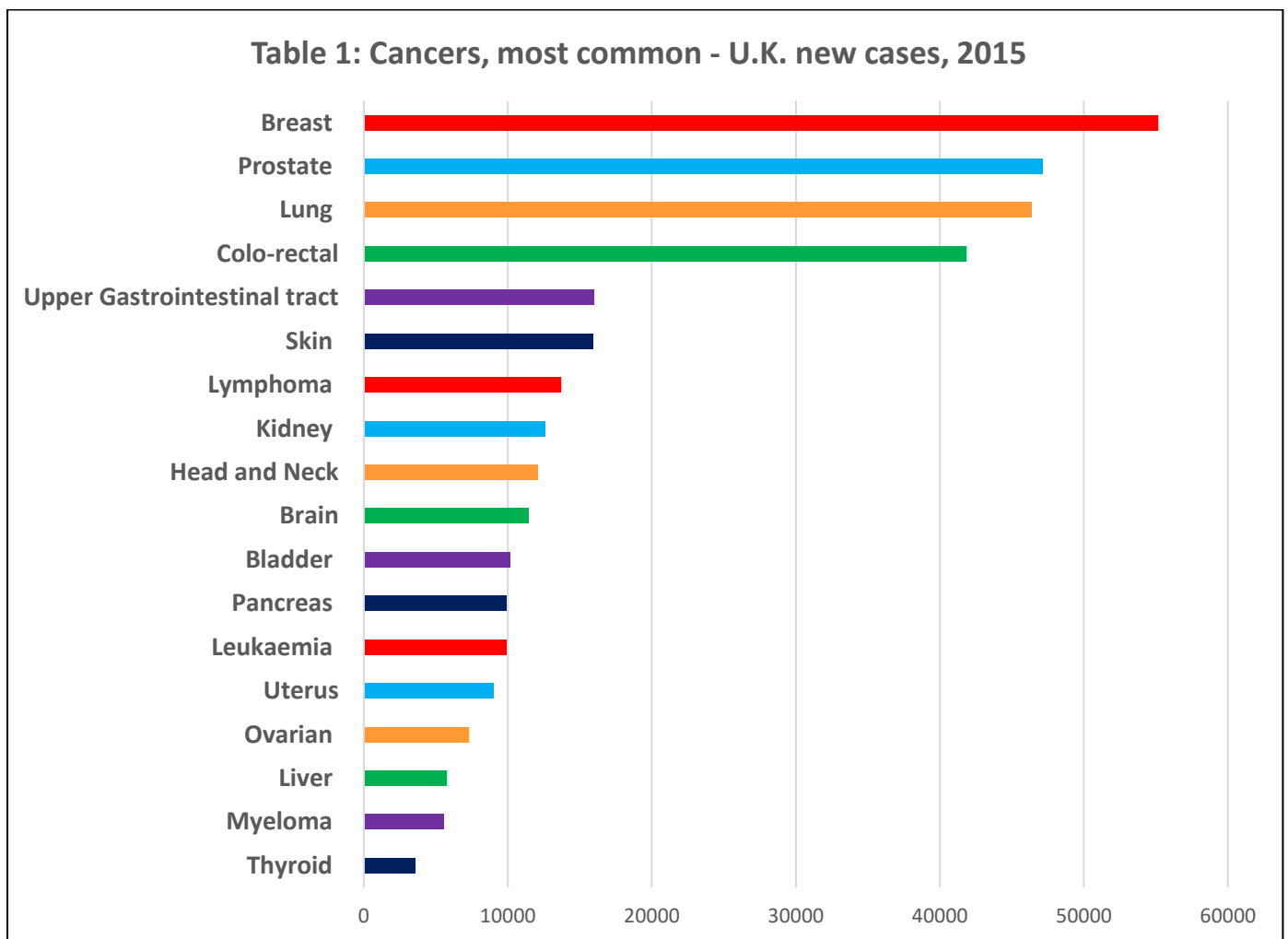
Healthwatch Isle of Wight is the independent “consumer champion” for local health and social care services. It began in 2013 following legislation which introduced a Healthwatch organisation in every local authority area in England. Feedback is received from local residents across a wide range of services. Each year a small number of topics are chosen for detailed examination following a process of public engagement.

Cancer services were identified as a priority topic for Healthwatch Isle of Wight for two years running. In late 2015 a broadly-based questionnaire survey was carried out in which 220 people took part. A report<sup>1</sup> was written which is available from the Healthwatch Isle of Wight website, or by using the contact details on page 2. The greatest number of comments in the 2015 survey related to patient contact with staff, and the majority of these were positive. All comments about individual staff were passed on to the relevant NHS organisations. Having considered all themes raised in the 2015 survey, a report was written which made recommendations aimed at improving the future experience of patients.

In 2016-17 Cancer services were again identified by Healthwatch Isle of Wight as a topic for special attention. In mid-2017 people were invited to take part in a survey if they had used cancer services since January 2016. This time there was a focus on three parts of people’s experience which had featured particularly strongly in responses to the 2015 survey. Accordingly, there were questions on the level of co-ordination between services, on arrangements for cross-Solent travel, and on assistance when help was needed urgently with unexpected symptoms.

Statistics for 2015<sup>2</sup> indicate that on the Isle of Wight a slightly higher proportion of people were diagnosed with cancer (652 per 100,000) than in England overall (605 per 100,000) but that a slightly lower proportion died from cancer on the Island (269 per 100,000) than in England as a whole (275 per 100,000).

The most common forms of cancer in the U.K.<sup>2</sup> are shown in Table 1 (below).



The many and varied forms of cancer are reflected in a range of different NHS treatment provision. The Isle of Wight NHS Trust offers a number of services, including an outpatient chemotherapy unit, and has a team of clinical nurse specialists for ten of the more common forms of cancer. Where a more highly specialist service is needed, a referral to an NHS Trust either in Southampton, Portsmouth or another mainland centre may be made. Where radiotherapy is required, this is always provided in one or other of the specialist mainland centres.



## 4 – What Healthwatch did

A questionnaire survey was prepared, which was available direct from Healthwatch Isle of Wight and also distributed more widely with the help of patient groups and local NHS organisations. The survey was open for responses between 28<sup>th</sup> July and 29<sup>th</sup> September, 2017. Participants were asked to answer only in relation to experiences since January 2016.

A total of 113 responses were received; 105 of those electronically and 8 in hard copy. Details are given in Appendix 1 (page 37) of the age, gender and home postcode area of people who took part.

Three sections of the questionnaire included questions on the themes of Co-ordination of Services, Travel to Appointments & Treatment and Assistance if Unwell. Each of these sections contained questions in which participants could rate the quality of their experience on various matters, and then gave an opportunity for further comment. Each of these questions picked up on specific areas raised in the 2015 Healthwatch Isle of Wight survey.

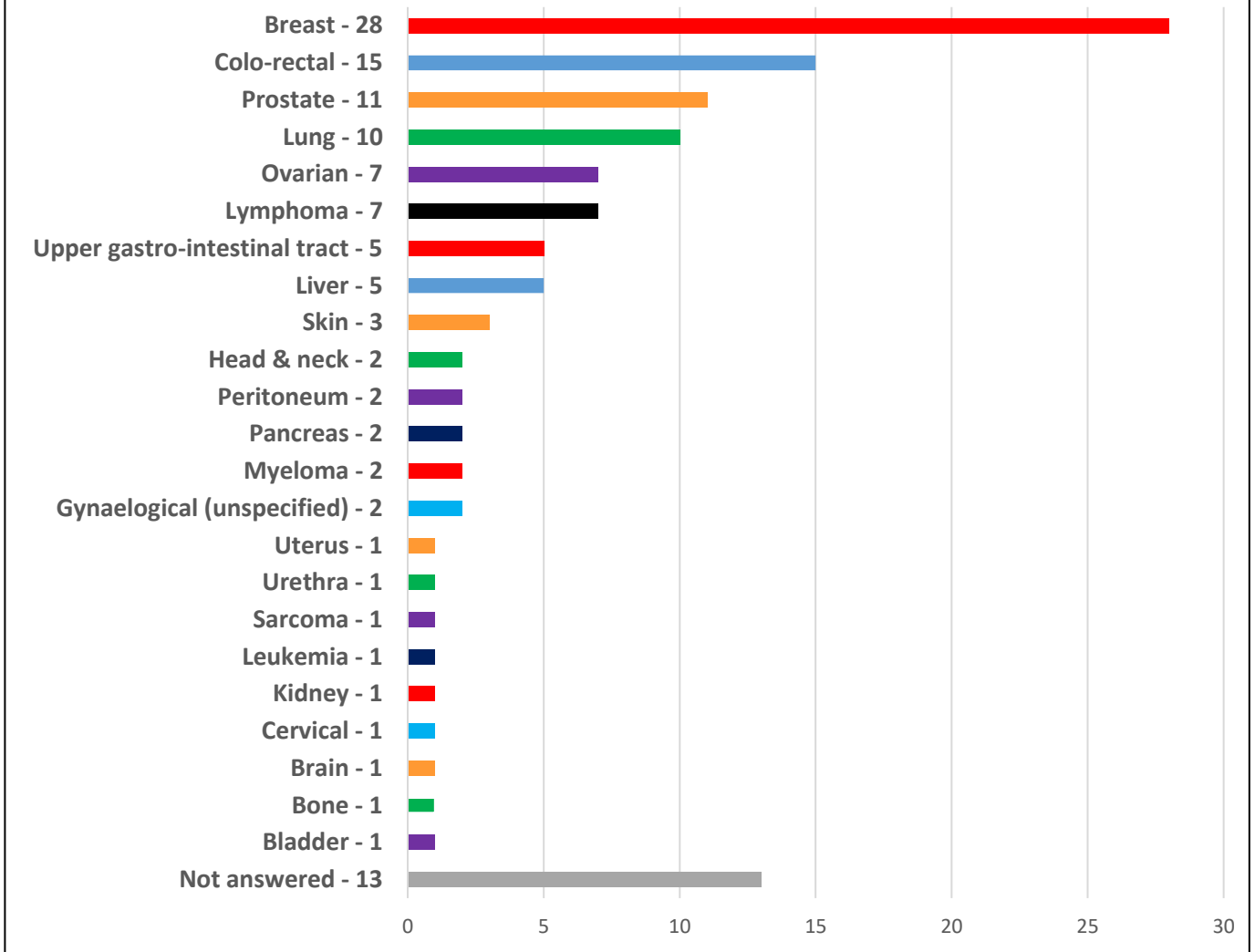
Two further sections of the questionnaire gathered more general but anonymous information about the participants.

A copy of the full questionnaire can be found in Appendix 2 (page 39).

Table 2 (page 9) summarises the forms of cancer mentioned by people who took part in the survey. The four most common forms of cancer at national level (see Table 1, page 7) were also the four mentioned most often within the survey, though in a different order.



**Table 2: Forms of cancer mentioned in survey responses**



An analysis of the survey responses forms the next section of this report, followed in turn by conclusions and recommendations.



## 5 – What Healthwatch found

### A - Co-ordination of Services

During the 2015 Healthwatch survey a majority (60%) of those taking part indicated they had a good experience of service co-ordination. However, Those where experience was less good people spoke of inconsistent case management, patchy communication between different parts of the NHS, and delays in access to community support. The 2017 Healthwatch survey therefore asked about each of these areas in detail.

Healthwatch Isle of Wight has kept in touch with local NHS organisations on the extent of change since 2015. Issues of consistency in case management have been recognised by the Isle of Wight NHS Trust, with an additional support nurse appointed in 2016 and another due to start during 2018. The Isle of Wight Clinical Commissioning Group has given news of various meetings to help solve issues of co-ordination, and an intention to improve information-sharing in future re-organisations. However, practical impact achieved so for patients remains unclear.

“Care from all levels of clinicians and other health care professionals has always been wonderful. Management of patients' journey through care settings is poor.”

*Relative of patient receiving care between mid-2016 and mid-2017*

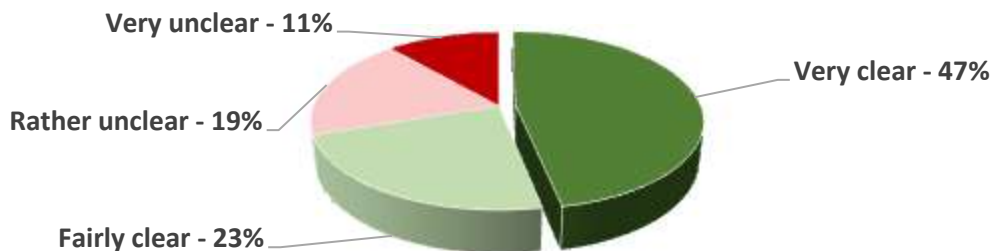
#### *Case co-ordinators*

Overall 70% of those who answered (Chart 1, page 11) had felt very or fairly clear about who their case co-ordinator was, with 65% of those who answered reporting a very or fairly good level of consistency if their usual case-co-ordinator was absent (Chart 2, page 11)

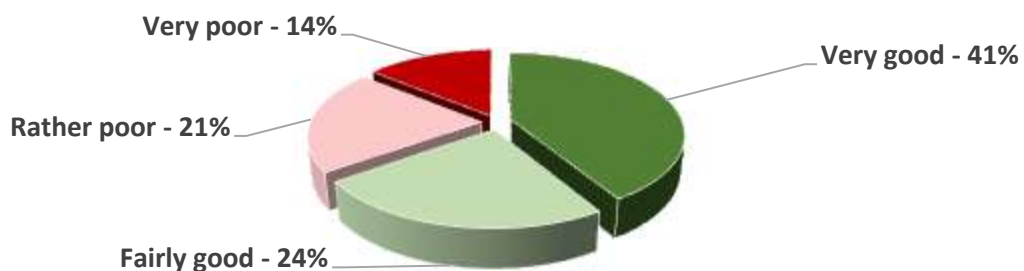
Of the four most common forms of cancer, over 50% of those who answered said they were very or fairly clear about their case co-ordinator, rising to 96% for those being treated for breast cancer.

With regard to continuity when the usual case manager was absent, a greater contrast in experiences was noted. 92% of those with breast cancer rated their experience as very or fairly good; with the other three most common forms of cancer this ranged between 42% and 50%.

**Chart 1: Clarity about who was case co-ordinator (96 answers)**



**Chart 2: Continuity when case co-ordinator absent (92 answers)**



Overall, survey responses show a steady fall in those reporting very or fairly good continuity when the usual case co-ordinator was absent - from 86% in early 2016 to 63% in mid-2017. It is not known whether staff absences may have increased, whether there were communication issues, or whether there is some other reason.

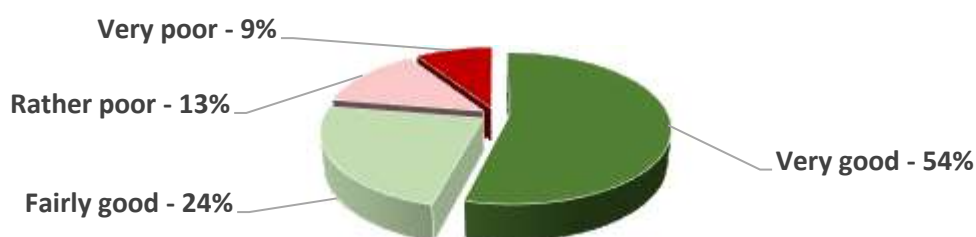
### *Progress of treatment*

When it comes to the progress of patients into treatment and beyond, the quality of co-ordination between different parts of the NHS becomes a vital part of patient experience.

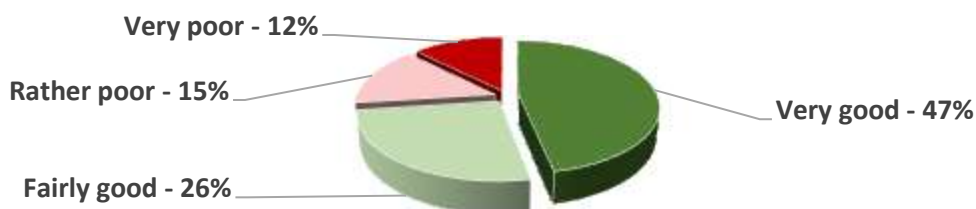
It is pleasing to note that for each the four most common forms of cancer, over 90% of patients reported a very or fairly good experience of appointments and starting treatment. However, an overall figure of 78% (Chart 3, below) points to contrasting experiences amongst the remainder of survey participants.

With regard to receiving test results and updates on treatment, the level of patient satisfaction is noticeably lower, with 73% overall of those who answered reporting a very or fairly good experience, and a lower percentage rating this as “very good”. The ratings for those with the four most common forms of cancer ranged between 60% and 88%.

**Chart 3: Making appointments & starting treatment (98 answers)**



**Chart 4: Test results & updates (96 answers)**

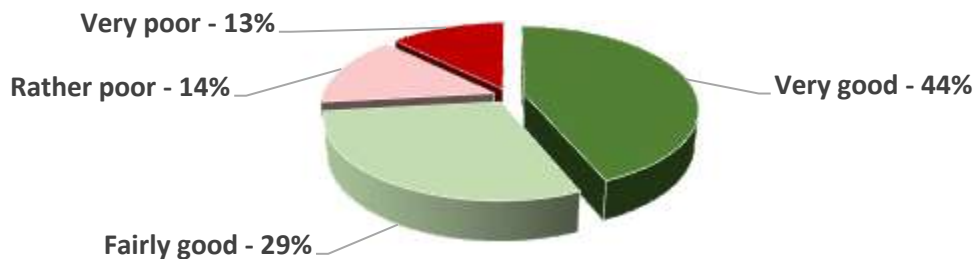


### *Moving between services*

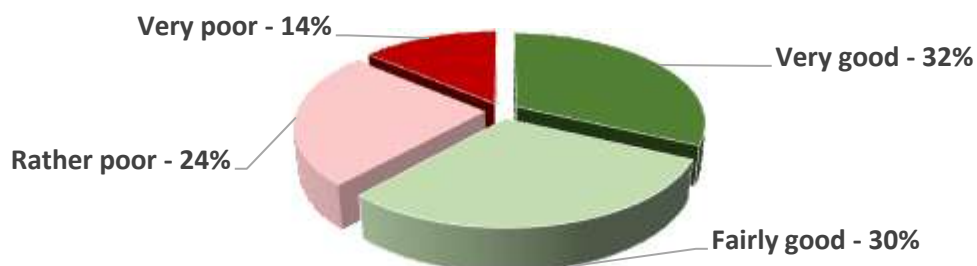
The sharing of information between different parts of the NHS is very important for Isle of Wight residents who often receive cancer services from more than one NHS Trust. This will apply increasingly to people with other conditions as Island and mainland providers work more closely together in future.

The 2017 Healthwatch survey asked about co-ordination from one hospital to another, between G.P. practices and hospitals, and about receiving information on other services, including community support (Charts 5 – 7, below).

**Chart 5: Co-ordination from one hospital to another (71 answers)**



**Chart 6: Co-ordination between G.P. and hospital/s (94 answers)**



**Chart 7: Info. on other services e.g. community support (84 answered)**



The question on co-ordination between one hospital and another did not apply to all patients, and this was reflected in the number of responses. However, a greater percentage (73%) of those who did answer reported a very or fairly good experience than in the question on co-ordination between G.P. practice and hospitals (62%). Positive comments were made about individual clinicians throughout services, not least G.P.s.

“...received a telephone call from the G P to find out how I was feeling and coping with treatment, which I was not expecting”

*Patient receiving treatment between early 2016 and mid-2017*

Some responses from the 2015 Healthwatch survey suggested that issues around patient consent had led to a reluctance on the part of NHS organisations to share information with one another. However, it has since been clarified that patient consent for sharing information is incorporated into the referral process.

It is understood that communication between some parts of the NHS cannot happen until a formally typed-up letter, whereas more rapid channels exist between other NHS organisations. It is possible that this accounts for some of the stories from the 2015 survey of patients knowing their test results before the G.P. or having themselves to update clinicians on key health issues. Where co-ordination is lacking, it can leave a lasting feeling of unnecessary extra stress.

“ ...treatment continued with both hospitals and there have been several re-admissions as the cancer progressed. It's time wasting of everyone's time to have to give the same details again and again to both St Mary's and Southampton. I realise that these are two different locations but surely they can share patient information...?”

*Relative of patient receiving treatment between mid-2016 and mid-2017*

Sometimes it appears that patient access to information is at the clinician's discretion; some patients telling us the level of detail has been inconsistent, depending on which staff member they see.

Answers to the question about information on other services including community support, indicated a lower level (54%) of very or fairly good experiences than the previous two questions. This is of some concern, given the importance to recovery of such services; it is unclear to what extent the complex pattern within cancer services leads to confusion about where signposting or referral to these services should reside.

## *Impact on patients*

In common with the 2015 Healthwatch survey, questions asked in 2017 prompted several comments on the impact of poor service co-ordination on patients.

The importance of the case manager is highlighted by the number of comments on this role (see page 16) and remarks from patients on an of proactive help at an already worrying time. Poor co-ordination of services was described as itself an additional source of stress.

For those with previous experience of trauma, awareness of clinicians was not always felt to be sufficiently high, and communication with mental health services not always adequate.

The centrality of community support in enabling the treatment process to take place was brought to life by a number of comments from survey participants.

When first told of diagnosis [there was] no mention made of support available, we had to make our own enquiries re support and what happened next. Had we not done this radiotherapy would have been delayed.... Having personal experience of how the 'system' works I was able to ensure the right care and support was received - I worry for those people out there who do not have experience of how things should be.

*Relative of patient receiving treatment in mid-2016*

## Themes from comments: Co-ordination of services

### Positive comments

#### Theme

Admin staff helpfulness	1
Appointments (mainland) arranged on one day	1
Chemotherapy arrangements	1
Community support information	1
Co-ordination between hospitals	2
G.P. input (general)	1
Pro-active help from services (GP)	1
General comments	3
Individual clinician input	1
Inter-department co-ordination	1
Radiotherapy arrangements	1
Referral processes	1
Treatment/test results	1

#### Provider

G.P. practice	2
I.W. Hospice	1
Mainland hospital (not sepcified)	1
Portsmouth hospitals	1
Southampton hospitals	2
Unspecified	7

### Negative comments

#### Theme

Aftercare arrangements	2
Availability of local oncologist	1
Communication between hospitals	1
Communication between staff	1
Communication with mental health services	2
Continuity of care	1
Follow-up arrangements	3
General comments	4
GP practice kept informed	4
Individual clinician input	1
Information about choice of provider	1
Information on peer support groups	1
Information on support	1
Information sharing, general	2
Inter-department co-ordination	1
Level of case co-ordinator input	4
Pro-active help from services (general)	4
Referral process to social care	1
Referral process, clarity	1
Referral process, transmission issues	2
Repetition of requests for patient information	1
Senisitivity to past traumatic experience	1
Stress levels around co-ordination issues	2
Transmission of test results	1

#### Provider

MacMillan	1
Portsmouth hospitals	4
Southampton hospitals	5
St Marys Hospital	10
Unspecified	9



## B – Travel to Treatment

For people needing certain consultant appointments or particular treatments in a specialist cancer centre, Cross-Solent travel is required. In the 2015 Healthwatch survey many stories were told of the impact of these journeys, especially when they had to take place regularly.

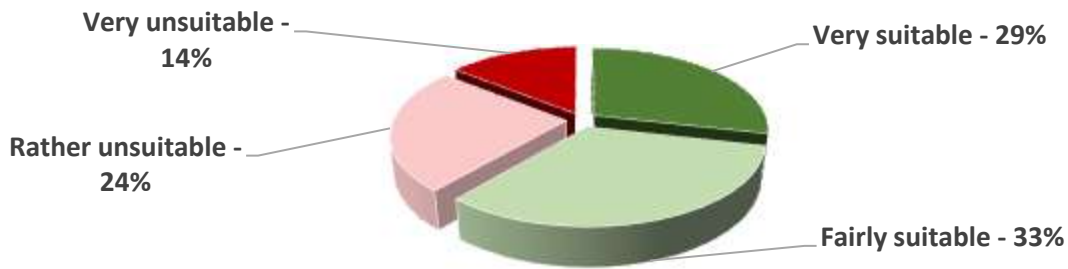
Prior to the 2017 survey, Healthwatch Isle of Wight made contact with key individuals on other island communities around the coast of Britain. Unlike other islands, the Isle of Wight has some cancer services, which are located in the Cancer Unit at St Marys. However, where travel to a specialist Cancer Centre is needed, patients from all U.K. islands are required to travel to mainland hospitals. The Isle of Wight is alone amongst them in there being an expectation of travel each day during extended periods of daily treatments such as radiotherapy.

The geography of many U.K. islands often entails a complex trip to treatment; in places as the Scilly Isles or Orkneys, travel from an outlying island to a larger island may be necessary followed by a further journey to the mainland hospital. The Isle of Arran is more comparable in size to the Isle of Wight, and has a similar duration of ferry crossing, but the onward distance to the Cancer Centre in Glasgow is around 30 miles. Patients are therefore not expected to travel daily from Arran, but in common with those from other Scottish islands, overnight accommodation adjacent to the hospital is funded on weekdays.

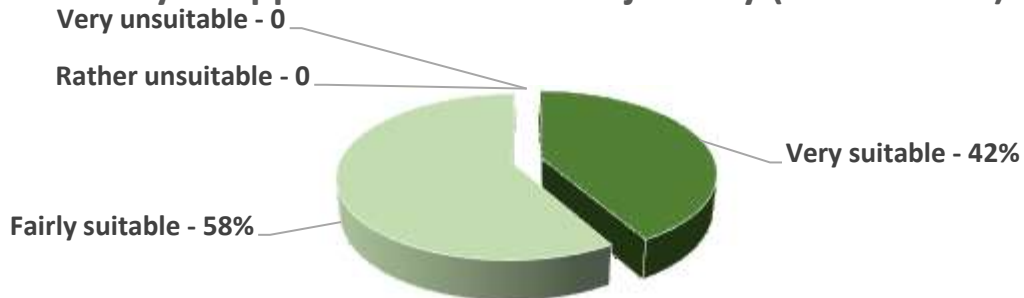
### *Appointment arrangements*

One of the matters commented on in the 2015 Healthwatch survey included the extent to which mainland NHS centres took into account the travel circumstances of Isle of Wight patients when booking appointments, and the proportion of journeys to appointments which patients felt could have been undertaken by methods other than a face-to-face consultation.

**Chart 8: Suitability of appointment times, Southampton (49 answers)**



**Suitability of appointment times to journey (Portsmouth)**

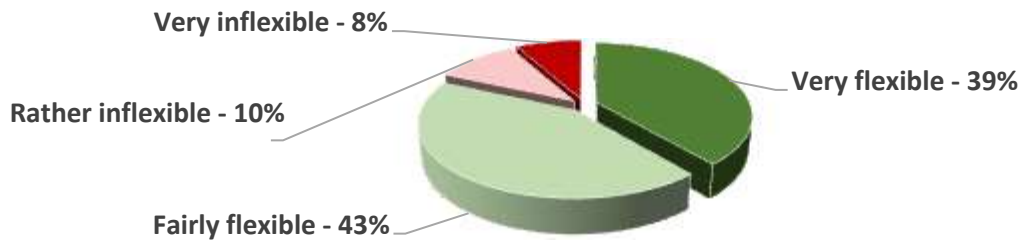


The 2015 Healthwatch survey identified the importance to patients of mainland NHS centres taking into account the travel needs of Isle of Wight patients when arranging appointments. Flexibility once arranged was also highly valued, given the unpredictability of travel services.

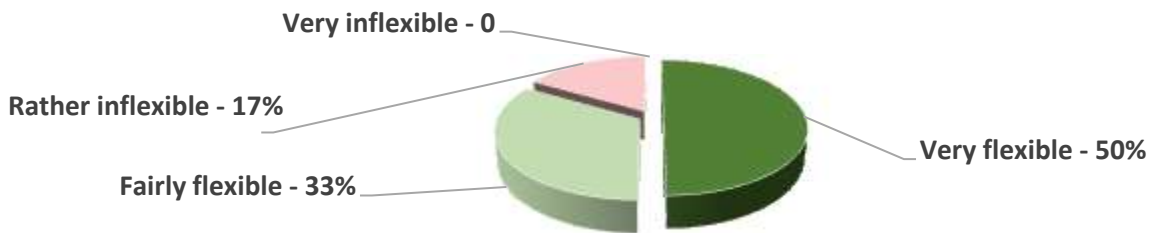
Charts 8 and 9 (above) summarise responses in Healthwatch's 2017 survey on the suitability of appointment times from the two most frequently-used mainland providers. Whilst a majority of those answering found the arrangements very or fairly suitable, for Southampton the percentage was 64% in contrast to 100% of the smaller total of Portsmouth patients.

Regarding flexibility of times once arranged, there was a similar contrast in responses between those treated in Southampton with those who went to Portsmouth, please see Charts 10 and 11 (page 19).

**Chart 10: Flexibility of appointment times, Southampton (49 answers)**



**Chart 11: Flexibility of appointment times, Portsmouth (12 answers)**



“No account is taken of travel difficulties when surgeon’s list is compiled. On two occasions.... I have been left waiting for up to seven hours for a procedure.... meaning that I did not get back home until gone midnight”

*Patient receiving treatment on unspecified dates*

Chart 12 (below) again shows variation in responses of people treated for cancer at mainland centres, this time when asked how often a mainland trip could have been avoided by using another mode of communication. Examples might be a telephone conversation or video link.

**Chart 12: Cross-Solent journey for something achievable by other means (50 answers)**



The report written by Healthwatch Isle of Wight following its 2015 survey included a recommendation that a Charter be devised setting out what patients have a right to expect from providers, including arrangements around appointment times, timings of discharge and patient involvement in any service changes.

In its response to the recommendation, the Isle of Wight Clinical Commissioning Group felt that such a Charter could be considered after services are re-organised at some future date. Another possible approach, however, is to develop a Charter straight away, to assist in giving due weight to issues around travel when future changes happen.

### *Experiences of Travelling*

Many of those who took part in the 2015 Healthwatch survey described their experiences of travel, mentioning the stress of daily travel whilst receiving radiotherapy, the degree to which transport services were co-ordinated, and arrangements for patients offered funded overnight accommodation during treatment.

In the 2017 Healthwatch survey, participants again shared stories of their experiences. The public nature of the travel experience and increased risk of infection were described as sources of stress, as were the physical demands of boarding, disembarking and changing between different modes of transport.

A number of survey participants made a point of saying how much they had valued the transport provided by Wessex Cancer Trust for cancer patients between the ferry ports and hospitals in Southampton and Portsmouth. Shortly after the survey doubt over the continuation of one of these routes; at the time of writing its future remains unclear.

*“Travel became very stressful once the effects of treatments had “kicked in”... the Wessex Cancer Daisy Bus is a fantastic service and life would have been virtually impossible without it”*

*Relative of patient receiving treatment from late 2016 to mid-2017*

It is unclear what consideration is given to the overall experience of patients, including the impact of travel, in making decisions on where and how to provide services. The safety and effectiveness of treatments is of prime concern to all. However, in this and the previous survey responses indicated that some patients opt for whichever treatment entails least travel. Survey feedback on chemotherapy at St Mary's has been very positive, but this may not be the most clinically appropriate for all patients.

“My [relative] chose against radiotherapy chiefly because of complex problems which would have caused great difficulty especially with regards to the ferry crossing and travelling.... and staying over there”

*Relative of patient receiving treatment between early 2016 and late 2017*

Accommodation close to the relevant mainland hospital is funded for some patients, and many find this helpful. The guidance specifies that this should only be agreed on “medical” grounds, and not for what are described as “social” reasons. (The assessment is made by a consultant oncologist or medical staff, nurse specialist or radiotherapy radiographer). It is not clear how consistently this is applied, or to what extent the stresses of travelling are regarded as having a medical implication. Respondents said their stresses increase during the course of treatment.

In both the Healthwatch surveys of 2015 and 2017 there were comments that radiotherapy facilities are needed on the Isle of Wight. There will be no recommendation in this report about this, acknowledging that currently there is little realistic prospect of funding to establish and sustain this. At the same time it is observed that radiotherapy equipment has been recently introduced in Dorchester as part of a wider service based in Poole - this followed a large charitable bequest. It also appears that some small privately-funded hospitals offer radiotherapy services.

### Paying for travel

Cost of travel is of great interest to many, and responses in the 2015 Healthwatch survey described this as a cause of extra stress, with patchy access to information on financial help. The situation on the Isle of Wight

differs from other U.K. islands. NHS regulations specify that Scilly Isles patients pay only the first £5 of travel to any hospital visit<sup>3</sup>. In Scotland those travelling more than 5 miles from an island to treatment pay no more than £10 under the Highlands and Islands Patient Travel Scheme<sup>4</sup>.

The arrangements for the Scilly Isles and Scottish islands are not specific to cancer and apply to medical treatment of all kinds. On the Isle of Wight recognition has been given to the particular needs of cancer patients through funding help for those attending mainland radiotherapy or chemotherapy sessions. This has in recent years been allocated by the Isle of Wight Council and administered by the Isle of Wight NHS Trust. However, at the time of writing funding has only been agreed until September 2018, and its future is uncertain. People on specified benefits or a low income are eligible for a national NHS scheme, which will continue, although under this scheme the lowest cost route should be used, which in some instances may involve a longer duration of journey.

In Healthwatch's 2017 survey, travel costs were again mentioned by participants as a source of stress. Whilst some were stoical about the need to pay for transport, others spoke of the inroads this made into savings, not least those being treated at specialist centres further afield than Southampton or Portsmouth.

“Saving for your old age doesn't pay! BUT [the cost of travel and accommodation] was worth every penny – what are savings for?”

*Relative of patient receiving treatment from late 2016 to mid-2017*

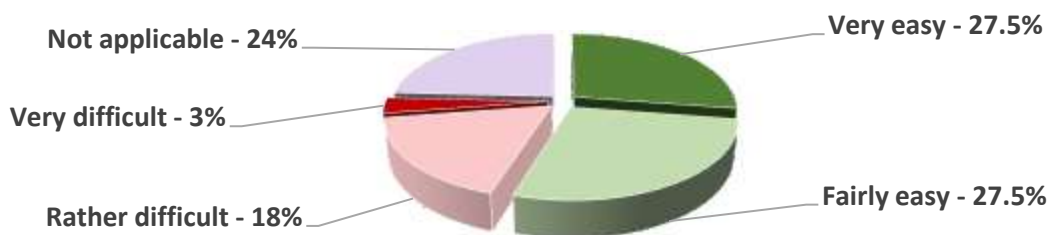
The survey included questions on access to information on help with costs. Something over a half of those who answered, said they had found it very or fairly easy to find information. Whilst a majority said it had been very or fairly easy to obtain claim forms, it is worth noting that only when information was found on sources of help, that patients would be in a position to seek claim forms. A lower total of people gave a rating for this, than for the previous question on finding information.

Charts 13 and 14 (page 23) summarise answers to these two questions.

**Chart 13: Info. on travel & costs, mainland treatment (64 answers)**



**Chart 14: Obtaining claim forms, mainland treatment (62 answers)**



It is worth noting that six of the fifteen people answering “not applicable” to the question about claim forms also marked themselves as having attended radiotherapy on the mainland, suggesting strongly that they were not aware of a travel expense scheme relevant to them, as at the time of the survey all radiotherapy all patients were eligible for assistance with help for Cross-Solent travel costs.

**“Nobody ever told me about claims for travel except booking clerk at ferry”**

*Patient receiving treatment in early 2016*

Indeed, of those receiving radiotherapy or chemotherapy at mainland hospitals, 46% of those answering said they were unaware of the ferry travel scheme specific to them (see Chart 15, page 24).

Chart 16 (page 24) summarises responses to a question on awareness of help, to which 78% of those who answered replying “no” or “not applicable”. At the time of the survey there should not be a need for help from charities to the ferry journey itself. However, it may be a useful form of support for people with a lengthy journey to more distant mainland

**Chart 15: Knew about Ferry Travel Scheme (41 answers)  
mainland radiotherapy or chemo patients only**



**Chart 16: Knew about help from charities (40 answers)  
all patients receiving mainland treatment**



hospitals, or across the Island to the departure port for their allocated treatment centre. For most patients, the mainland hospital for treatment would be decided according to the form of cancer, although one person described a successful request to change to a mainland hospital more accessible from the part of the Island where they lived.

In future, it is likely that people with other conditions, not related to cancer, will travel from often from the Isle of Wight to mainland hospitals. Ferry companies are working with local NHS organisations through a Cross-Solent Operators Group aiming to improve travel advice, broaden travel options to and from ferry ports, and give better co-ordination.

A further aim of the Cross-Solent Operators Group is to introduce a broader use for transport currently used by people with a specific condition. Several of the participants in the Healthwatch survey mentioned the value to them of specific transport. They mentioned the importance of a sense of camaraderie, and of an assurance amongst patients of not having to “explain themselves” to others, as all are going through comparable experiences. It is important that amidst any changes, the particular needs of people with cancer will be given full consideration.



## Themes from comments: Travel to services

### Positive comments

#### *Theme*

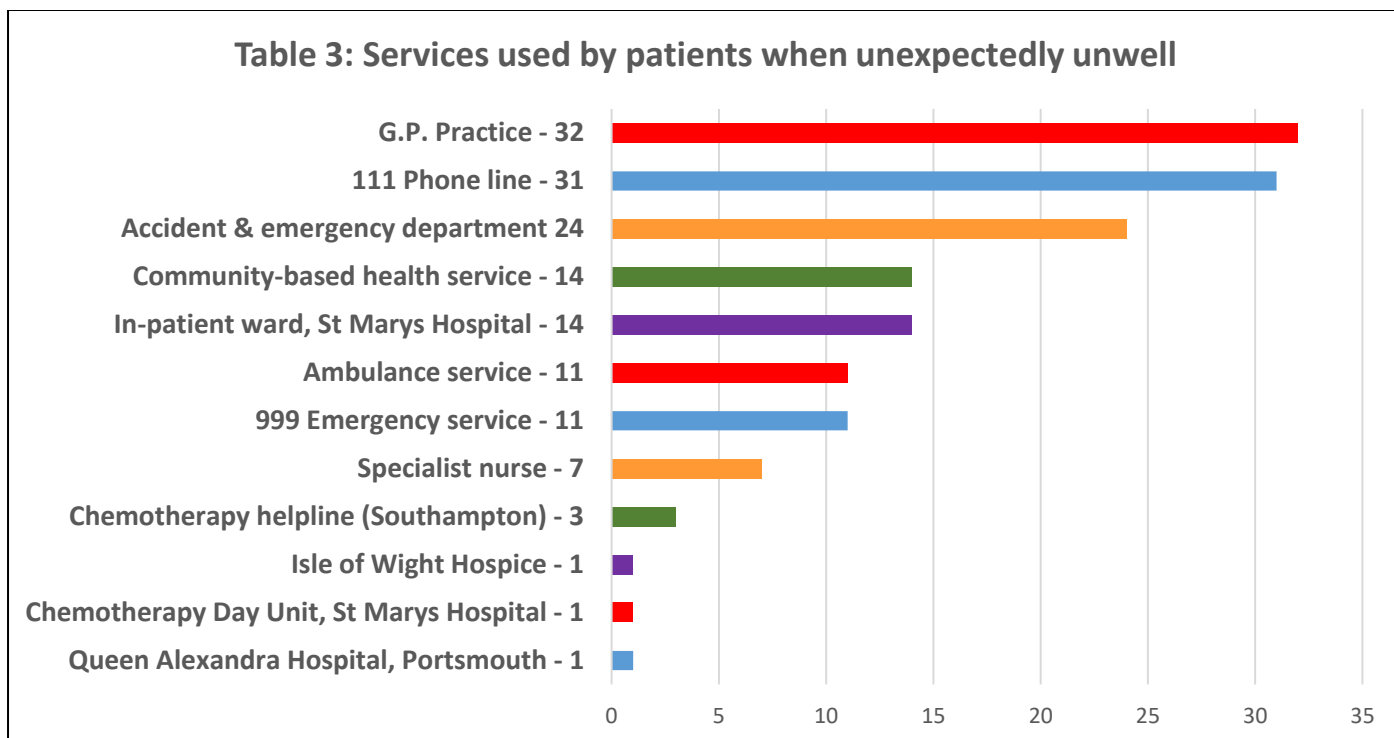
Availability of dedicated transport	1
Daisy Bus, Portsmouth	1
Daisy Bus, Southampton	6
Dovetailing of treatment times to travel needs	1
Ferry companies provision of information	1
General comments	2
Level of explanation on travel	2
NHS Travel scheme	1
Worth travelling further for better service	1

### Negative comments

#### *Theme*

Amount of notice for arranging transport	2
Appointments arranged outside bus pass hours	1
Assistance levels at mainland hospital	1
Chemo drugs unavailable, wasted journey	1
Declining treatment due to travel challenges	2
Erosion of personal savings	2
Lack of toilet facilities, Red Jet	1
Level of clarity about eligibility/claiming	2
Level of information on financial help	5
Payment for chaperone, limitations	1
Risk of infection, public transport	1
Stress levels	1
Synchronising appointments to travel needs	3
Tiredness levels	1
Travel to radiotherapy, general	2
Unfairness of paying when choice unavaible	1

## C – Assistance with Unexpected Symptoms



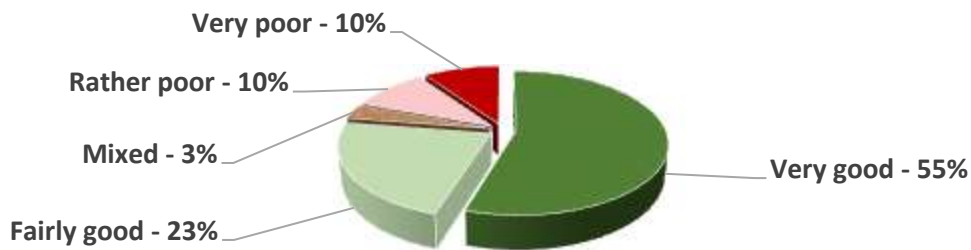
The final group of questions in Healthwatch’s 2017 survey referred to those times when unexpected symptoms occurred during treatment for cancer. The services that people used are shown in Table 3 (above).

Overall, 88% of people who answered, found assistance when unwell very or fairly good. Amongst the smaller number who answered a question about support at weekends, the percentage rating support as very or fairly good fell to 72% whilst the proportion rating it as very good dropped sharply to 31%. See Charts 17 & 18 (page 27) for more detail.

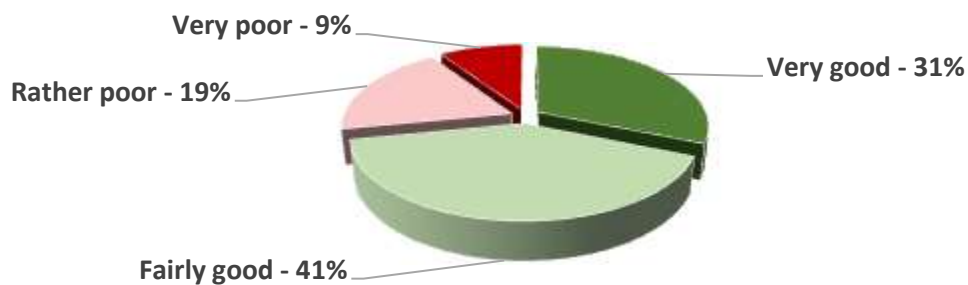
Whilst general practice was mentioned most frequently as the service contacted for urgent support, it is unclear to what extent the lower percentages of positive ratings at weekend are due to decreased access to GP services at that time.

Shortly after the 2017 Healthwatch survey, access was increased to GP services on Saturdays. This is for pre-booked appointments only, so it is not clear to what extent, if any, weekend levels of support to cancer patients with unexpected symptoms may have changed.

**Chart 17: Assistance when unwell, overall (62 answers)**



**Chart 18: Assistance when unwell, weekends (32 answers)**



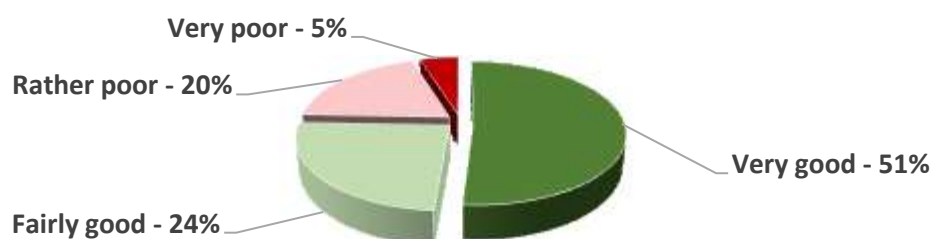
## 111 Telephone Line

Slightly over half of those who answered, rated their experience of the 111 service as “very good” with 75% rating it as very or fairly good. Comments were evenly balanced between those who found the service helpful and those who were unimpressed.

Where necessary, 111 call handlers can “escalate” a call and send out a paramedic team. In contrast to other locations, Isle of Wight paramedic services can be co-ordinated closely with the local cancer unit, as both are part of the same NHS Trust. Paramedics here are thus able to administer “first dose antibiotics” where appropriate, and a system exists to “flag” relevant patients. In principle, the availability of treatment by this means, should reduce the number of occasions where attendance at hospital is required.

The survey did not ask a specific question about paramedic visits, so no overall summary of participant experience can be given. However, one comment did refer to a patient’s experience of call handling not succeeding in summoning this help.

Chart 19: Assistance when unwell, 111 phone line (41 answers)



## Accident & Emergency

Responses to the Healthwatch 2017 survey paint a mixed picture of experiences in Accident and Emergency at St Mary's Hospital. Comments about staff in A&E were amongst the most positive in the survey. One comment particularly praised volunteer support. Overall, 71% of responses rated experiences as very or fairly good.

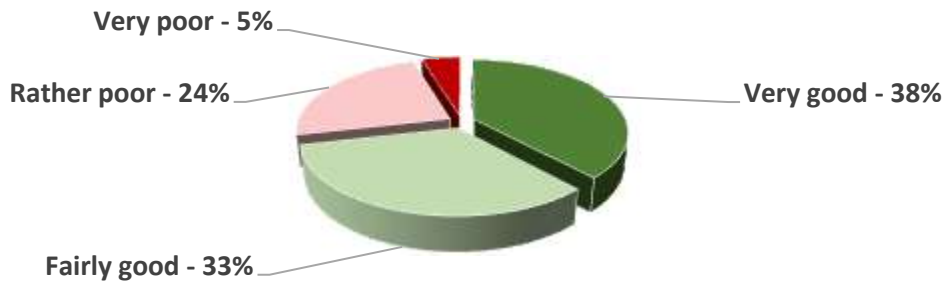
The contrast in experiences stemmed from how busy the A&E department was at the time a particular patient arrived. There is a triage system in place which should help to make the process quicker for those with most urgent need, but one comment referred to a wait for this triage and this a concern of raised risk of infection. Negative comments about waiting times in A&E included one referring to a wait of "several hours" and another to concern at being left unaccompanied during a long wait.

One account mentioned a decision, taken reluctantly, to pay for a private admission, this being seen as the only way to avoid repeating a previous poor experience in A&E.

"Having to go through A&E each time was very disturbing..... There really does need to be a more efficient way of getting cancer patients admitted without having to go via A&E."

*Relative of patient receiving treatment in late 2016 and early 2017*

Chart 20: Assistance when unwell, St Marys A&E (42 answers)



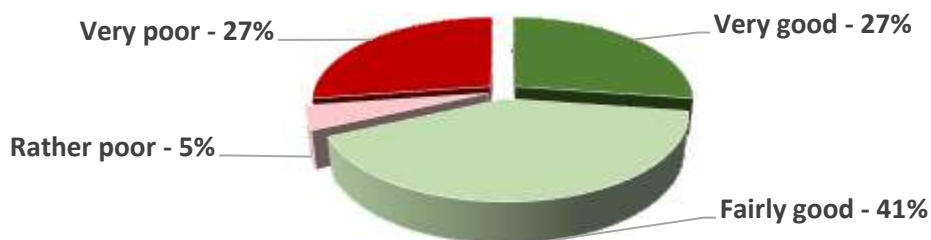
### In-patient admissions

A majority of patients admitted to St Marys rated their experience as very or fairly good, though the 27% noting a “very poor” experience is of concern (Chart 21, below). Some of the comments about poor inpatient experience came from people who otherwise gave positive feedback on services.

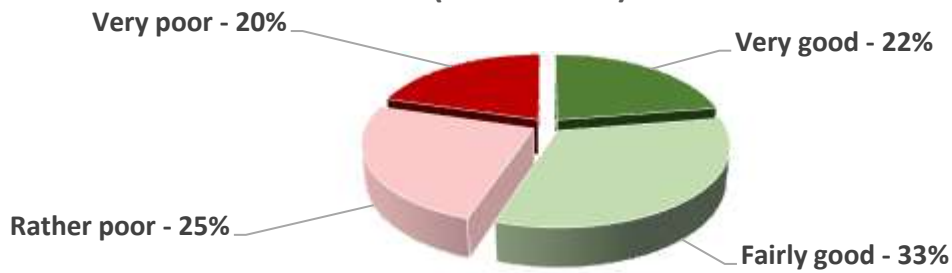
Where experience had been positive, the availability of clear information on procedures and treatment was particularly valued.

Comments expressing concerns, related most often to experiences of being moved from one ward to another or to leaving hospital. One participant mentioned a patient being transferred between wards at 2.30 a.m. after already having a long wait prior to admission. Another comment related described a patient being moved to an area unsuitable for their needs, and then insisting on being discharged before fully ready.

Chart 21: Assistance when unwell, St Marys ward stays (44 answers)



**Chart 22: Assistance when unwell, discharge from St Marys  
(49 answers)**



A survey question on discharge from hospital (Chart 22, above) saw 45% of those who answered reporting a “rather poor” or “very poor” experience. Comments suggest that patients with cancer are not immune from discharge in the early hours; in one instance a departure time of 2.00 a.m. was reported. A comment about daytime discharge mentioned a wait for medication of five hours before being able to return home.

Other comments related to a lack of checking on home circumstances and level of support, or sudden discharge without regard to the patient’s access to travel assistance. A lack of involvement in discharge planning was also raised, and the consequent absence of support once home.

## Themes from comments: Assistance when unwell

### Positive comments

#### *Theme*

111 service, general	2
A&E staff, St Marys	3
Ambulance staff	1
Chemotherapy Unit, St Marys	3
In-patient care, St Marys	1
Patient transport, general	1
Provision of information	2
Southampton hospitals, general	1
St Marys Hospital, general	1
Ward staff, St Marys	2

### Negative comments

#### *Theme*

111 service, general	2
A&E department, waiting times	3
A&E staff, St Marys	1
A&E, waiting time for triage	1
Admission - resorted to private treatment	1
Community nurse availability	1
Discharge at night	1
Discharge, rushed	1
Discharge, wait for medication	1
G.P. symptom screening	1
Home treatment, when cannot leave home	1
In-patient care, St Marys, general	3
Inpatient ward transfer, St Marys	2
St Marys Hospital, general	1
Support after discharge from Hospice	1
Support after discharge from St Marys	1



## 6 - Conclusions

From the 2017 Healthwatch survey on cancer services, it is clear that there is a widespread continued appreciation for the treatments available to Isle of Wight residents, and the skills and attitudes of the staff providing them. There is no reason to doubt the quality of service patients receive within local specialist services.

The areas where the survey uncovered concerns related to the broader patient experience, which is particularly important to people with cancer due to the way people pass between different parts of the NHS. This increases the need for service co-ordination and results in many cases in prolonged travel for patients. Given the many stresses associated with a cancer diagnosis, improving these areas would have a major beneficial impact on patients.

Health services for Isle of Wight residents are entering a period of change in which co-ordination between services and more frequent travel look set to become widespread. Making improvements in cancer services at an early stage would offer a positive model for other specialites to learn from.

The role of case co-ordinators is central to this picture, and the survey responses suggest there remains room to improve consistency of access.

Whilst experience of co-ordination between hospitals was generally positive, co-ordination between NHS Trusts and GP practices was less encouraging, with access to information on other services and community support being decidedly mixed.



Comparisons of travel arrangements with those for other U.K. islands highlighted the unique demands on Isle of Wight residents who cross the Solent daily for extended periods to radiotherapy treatment. Difficulties and risks continue to be experienced by patients as a result. Information on current help with travel costs remains patchy. At the time of writing, future levels of support with travel are uncertain, and any change will have an impact on patient experience.

Assistance with unexpected symptoms is also an area where patient experience ranges beyond specialist cancer services. Whilst paramedic services on the Isle of Wight can give cancer-specific treatments more readily than their mainland counterparts, the effectiveness of “flagging” system for these needs to be examined.

At St Marys Hospital, the route of access through Accident and Emergency gives rise to widely differing waiting times, depending on the department’s workload at any given time. For those who become in-patients, concerns over moves from one ward to another and the arrangements for discharge figured largely in the survey.





## 7 – Recommendations

1. This report to be shared with all managers and clinicians involved with cancer services for Isle of Wight residents. All staff to be mindful of connections between services as well as their own specific contribution. Impact of increased awareness to be monitored through feedback from patients and patient groups.
2. Improvements in co-ordination between cancer services in different NHS Trusts should be implemented without delay. Establishing good practice in cancer services to be used a model for other specialties which become more integrated in future.
3. Barriers to communication between specialist cancer services, general practice and community support services should be identified at an early date with the help of patients and patient groups. Improvements should then be implemented without delay.
4. A Charter should be developed without delay setting out the standards expected of NHS providers with regard to travel needs of patients. To include treatment and appointment schedules, admissions and discharge, and processes for service change. This to be a model for other specialites with regard to cross-Solent travel.
5. Local agencies should no longer take decisions in isolation about financial assistance to people travelling for cancer treatment. Before any proposed change, partners including the local NHS, local authority and voluntary and community sector should jointly explore all options to maintain and improve travel support.
6. Ways need to be found for cancer patients to by-pass the accident and emergency department when admissions to St Marys Hospital occur, and to ensure ward moves and discharge take place at appropriate times, with a suitable level of planning and support.



## 8 – References

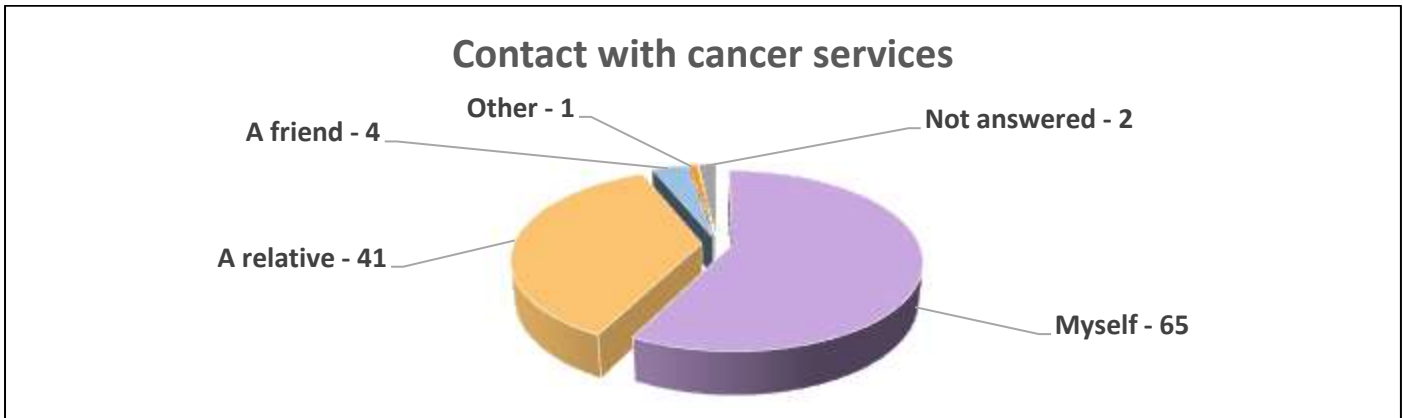
1. *“Cancer Services for Isle of Wight Residents: Experiences of Patients and Families”* – Healthwatch Isle of Wight, June 2016
2. *“Incidence and Mortality statistics for 2015”* – NHS England and Public Health England Cancer Data Website
3. *“Help with Health Costs – Leaflet HC11”* – Department of Health, November 2017
4. *“Are you entitled to Help with Care Costs?”* – NHS Scotland, May 2012



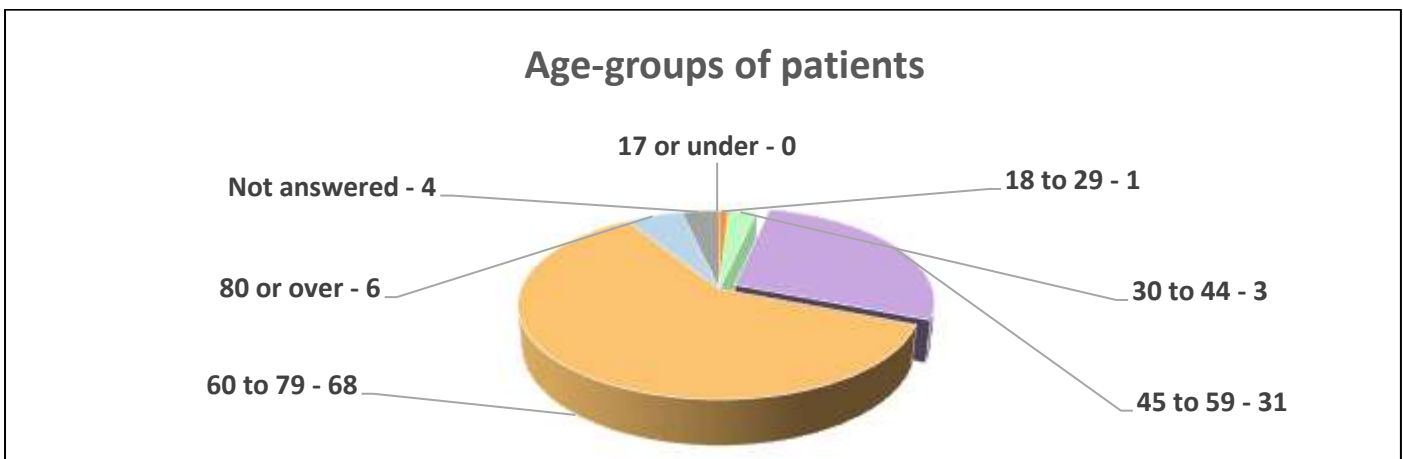
# 10 – Appendices

## Appendix 1 – Profiles of participants

Participants were asked who the experiences related to, as described in their answers:



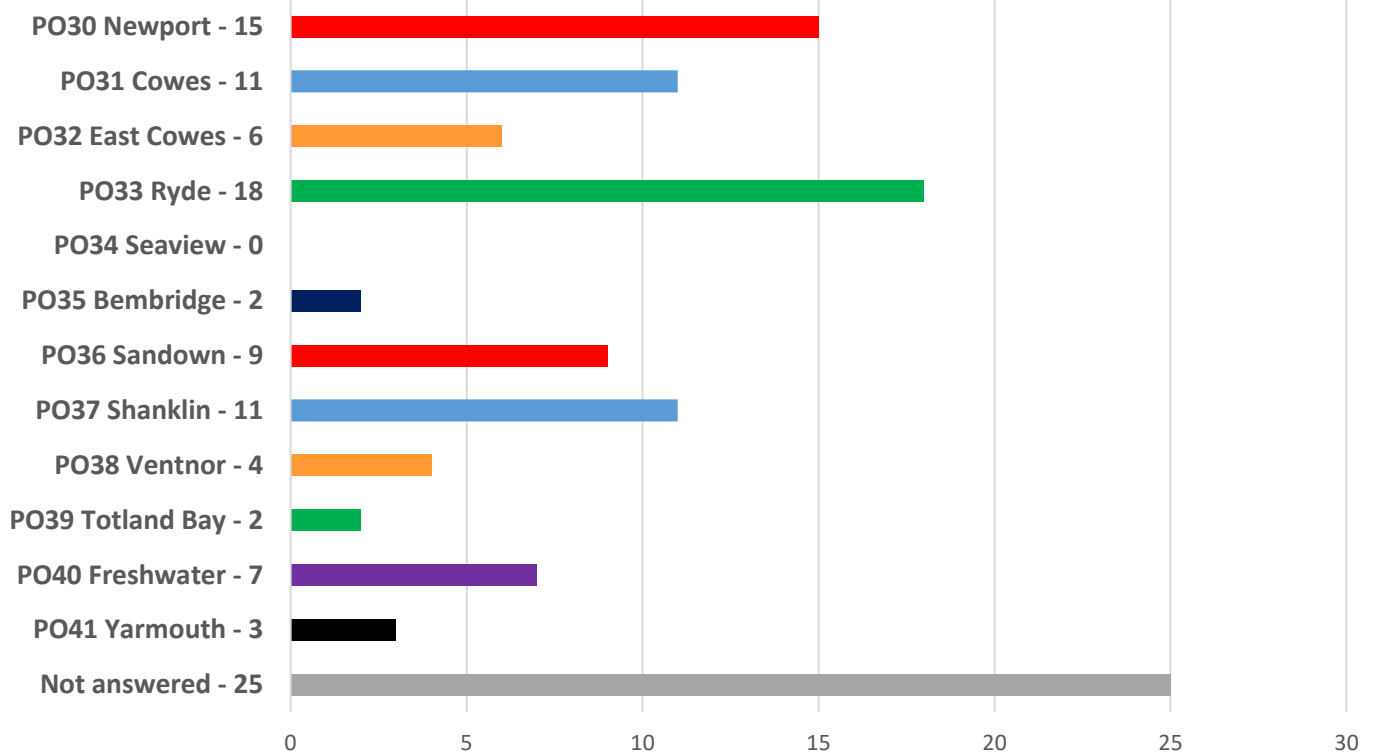
The age, gender and home postcode areas are given below and on page 37 of the people whose experiences were described in the answers:



### Gender of patients



### Home post-code areas of patients





## SURVEY – JULY - SEPTEMBER 2017

### Recent Experiences of Cancer Services

*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.*

Cancer services is a priority topic for Healthwatch Isle of Wight in 2017. It is one of five topics decided through public engagement.

In 2015 Healthwatch Isle of Wight did a survey with local people on their experiences after being diagnosed with cancer.

This is now being followed up with a detailed survey on three areas:

- **Co-ordination of Services**
- **Travel to Treatment**
- **Assistance if Unwell**

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 since 1<sup>st</sup> January 2016**.

*If you need this form in another format or version, please contact Healthwatch Isle of Wight on 01983 608608 (text 07739 436600) or visit [www.healthwatchisleofwight.co.uk](http://www.healthwatchisleofwight.co.uk)*

The questionnaire should take no longer than 30 minutes to fill in. The closing date is **Friday 29<sup>th</sup> September 2017**.

**Thank you**

## **INTRODUCTION**

**Healthwatch Isle of Wight recognises that people's experiences of cancer services are likely to be complex and intense.**

**This survey is about three areas that people told us about in a previous survey in 2015. We would like to hear about recent experiences to get an updated picture.**

**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.**

**Just answer as many questions as you wish, and if any are not relevant please move on to another question.**

**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.**

***SECTION 1 – How have you had experience of 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 are telling 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**

***SECTION 2 – Co-ordination of Services***



How clear was it made which health professional was the **case co-ordinator**?

Very clear

Fairly clear

Rather unclear

Very unclear

How was the continuity of care if the **usual** case co-ordinator was **absent or unavailable**?

Very good

Fairly good

Rather poor

Very poor

Not applicable

How were the arrangements for **making appointments** and **starting treatment**?

Very good

Fairly good

Rather poor

Very poor

How were the arrangements for receiving **test results** and **updates on treatment**?

Very good

Fairly good

Rather poor

Very poor

Was **consent** requested for information to be shared between one NHS service and another?

Yes	No	Previously agreed	Unsure
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How was the co-ordination between the **G.P. and the hospital(s)**?

Very good	Fairly good	Rather poor	Very poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How was the co-ordination **between one hospital and another**?

Very good	Fairly good	Rather poor	Very poor	Not applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How was information about **any other services** (e.g. community-based support) – or how to receive these services?

Very good	Fairly good	Rather poor	Very poor	Not applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you wish to share more detail on experiences of ***Co-ordination of Services***, please do so here:

Which service(s) are your answers about in this section?  
*(please tick as many that apply)*

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

**SECTION 3 – Travel to Appointments & Treatment**

Was travel within the Isle of Wight for the following, or was travel to the mainland also involved?

	Isle of Wight only	Mainland travel
Appointments with specialist	<input type="text"/>	<input type="text"/>
Surgical procedure/Operation	<input type="text"/>	<input type="text"/>
Chemotherapy	<input type="text"/>	<input type="text"/>
Radiotherapy		<input type="text"/>
Other (please name)	<input type="text"/>	<input type="text"/>

.....  
 .....

How suited were the **times of appointments/treatment** to the journey needed to get there?

Very suitable	Fairly suitable	Rather unsuitable	Very unsuitable
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

How **flexible** were NHS services in adapting appointment/treatment times to reflect travel needs?

Very flexible	Fairly flexible	Rather inflexible	Very Inflexible	Not applicable
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

How easy or difficult was it to **find information** about travel and help with travel costs?

Very easy

Fairly easy

Rather difficult

Very difficult

Which, if any, of the following did you **know about** before the first journey?

Yes

No

Not applicable

NHS travel cost scheme  
(benefits recipients)

NHS travel cost scheme  
(those on a low income)

Ferry travel scheme  
(chemotherapy &  
radiotherapy only)

Help from charities

How easy or difficult was it to obtain relevant **claim forms**

Very easy

Fairly easy

Rather difficult

Very difficult

Not applicable

How often was a cross-Solent journey made for something you felt could have been **achieved by other means**?

Frequently

Occasionally

Once or twice

Never

Not applicable

If you wish to share more detail on experiences of ***Travel to Appointments & Treatment***, please do so here:

Which service(s) are these answers about?

*(please tick as many that apply)*

St Marys Hospital	<input type="checkbox"/>
Portsmouth Hospitals	<input type="checkbox"/>
Southampton Hospitals	<input type="checkbox"/>
Salisbury Hospital	<input type="checkbox"/>
Other(s), please specify:	<input type="checkbox"/>

**SECTION 4 – Assistance if Unwell**

Did you (or the person whose experiences you are telling us about) contact any service due to unusual or problematic symptoms?

Yes

No

If you answered “yes” to the above, which of the following were used?  
*(please tick as many as apply)*

G.P. Practice

111 Phone line

999 Emergency Service

Ambulance Service

St Marys Accident & Emergency Dept.

In-patient ward, St Marys Hospital

Community-based health service

Other, please state.....

Overall, how would you rate the **help given** by the above service(s)?

Very good

Fairly Good

Rather Poor

Very Poor

Mixed

How was the **waiting time** before being given appropriate help?

Very good

Fairly Good

Rather Poor

Very Poor

Mixed

If assistance was called for at **weekends**, how would you rate the response?

Very good      Fairly Good      Rather Poor      Very Poor      Not applicable

If the **111 telephone service** was used, how would you rate the response?

Very good      Fairly Good      Rather Poor      Very Poor      Not applicable

If St Mary's **Accident & Emergency** department was used, how would you rate the experience?

Very good      Fairly Good      Rather Poor      Very Poor      Not applicable

If **admitted to a ward** at St Mary's how would you rate the experience?

Very good      Fairly Good      Rather Poor      Very Poor      Not applicable

If admitted to St Mary's, how was the experience of **leaving hospital**?

Very good      Fairly Good      Rather Poor      Very Poor      Not applicable



If you wish to share more detail on experiences of ***Assistance if Unwell***, please do so here:

## **SECTION 5 – About You!**

Please tell us the first line of the postcode of the person whose experiences you have told us about:

	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)	

When were the experiences of cancer treatment which have been described in your answers? *(please tick as many as apply)*

<b>Early 2016</b>	
<b>Mid 2016</b>	
<b>Late 2016</b>	
<b>Early 2017</b>	
<b>Mid 2017</b>	
<b>Late 2017</b>	
<b>Other</b>	

**Thank you 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 may be quoted in reports to decision-makers and service providers.**

**PLEASE RETURN TO THE FOLLOWING ADDRESS**

**By Friday 29<sup>th</sup> September 2017**

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