

## Summary Report – experience of cancer patients in the Isles of Scilly

**Date:** 13/08/15  
**Title:** Report to Andy Wood, Cornwall and Isles of Scilly Cancer Patient and Carer Group  
**Report of:** Healthwatch Isles of Scilly

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### Background

Healthwatch, and previously Link4Scilly, has been collecting community feedback about health and care services since 2009. Isles of Scilly has a small population (approx. 2,200) and 'our' patient numbers are therefore also small, but we have been passing on people's experience and observations and taking up common issues with commissioners and providers over that time.

The overarching theme is about access to treatment and care, and medical travel.

We have a GP Practice, NHS Dentist and Community Hospital on St Marys. The Community Hospital also provides the Community Nursing Service, nurse-led Minor Injuries Unit, and facilities for on-island clinics with visiting practitioners and consultants, where there is a large enough patient list.

Locally delivered diagnostics and treatments are limited, and the majority of patients travel to the mainland for acute and secondary consultation and care.

Healthwatch Isles of Scilly facilitates a joint working group with commissioners and providers to monitor all aspects of medical travel and transport, and to address issues that arise.

### Patients' costs

Provision for IOS patients' travel is made in the NHS 'Help with health costs' scheme (HC11). It states that Isles of Scilly patients will have to pay no more than £5 to travel to hospital; in practice this is accepted to mean the cost of a medical travel warrant for a return trip to Penzance, or Newquay airport. Warrants are only issued for travel for acute and secondary care.

Patients may request an escort warrant. Criteria for an escort generally follow national guidelines, although it is recognised that Isles of Scilly patients cannot easily arrange or afford for a friend or family member to accompany them. In some specific circumstances authorisation for an escort will be automatic, other requests are considered on a case by case basis. Alternatives, such as transport for the mainland leg of the journey, may be offered. The escort criteria and authorisation procedures for Isles of Scilly are currently under review by Royal Cornwall Hospitals Trust.

As elsewhere, patients pay their own onward travel costs themselves. The NHS 'Help with health costs' scheme and the NHS Low Income Scheme detail the help available to people in receipt of a benefit, tax credit or otherwise on a low income.

There is no provision anywhere for reimbursement of additional expenses, for example accommodation costs, for patient or escort.

The time window to complete a journey in a day is restricted by transport schedules, so many patients arrange to stay overnight on the mainland in order to attend at the time given for their consultation, treatment or admission.

Royal Cornwall Hospitals Trust does endeavour, where possible, to offer appointments which can be completed in a day trip. Their figures show that this is achieved for around 55% of all appointments at Treliske.

## Experience of cancer patients

Most people describe the arrangements they must make to travel and stay away as problematic.

Travelling from the Isles of Scilly for an appointment usually takes up a day (see 'journey map' attached); receiving treatment will require at least one overnight stay, and receiving daily treatment requires patients to stay on the mainland for the duration.

Weather related transport disruption is quite common and patients often factor this into their plans by travelling the day before to be sure they can attend. Also, patients may allow themselves 'recovery time' after their treatment.

People report that it is difficult to find affordable accommodation for regular trips or prolonged stays, and that costs soon mount up. Costs of transport to and from hospital must also be factored in.

Isles of Scilly patients may well be unaccompanied.

Royal Cornwall Hospitals Trust's proposed policy for Isles of Scilly transfers includes scenarios where a request for an escort will be automatically approved. This includes:

- 1<sup>st</sup> appointment on a suspected cancer/two week wait referral;
- Attending for results, in line with National Cancer standards.

The policy also states:

- 'For cancer patients travelling to appointments or for treatment after the initial referral, the standard escort criteria are applied.'
- 'For patients attending for chemotherapy, clinical input is sought and where appropriate a recurring escort is approved and this is explained to the patient.'

Some patients report that they find attending for treatment harrowing. They feel ill and unsupported. They worry about the drain on finances.

Some people have said that they are *minded* to refuse treatment because of their previous experience, but no instances of actually declining further treatment have been reported to us.

## What people say would help

- Financial help.  
This is currently limited to travel costs, and beyond the travel warrant scheme there is only help for certain income groups. People are often unwilling to apply for charitable support or can't find any.
- Accommodation: free or affordable accommodation onsite or near Treliske.  
We have discussed this in the past with Royal Cornwall Hospitals Trust and two possible options were identified: use of staff accommodation where available and at no cost; and use of the University owned accommodation at the standard rate, this might be arranged through hotel services where available. Unfortunately there is little awareness of this on the part of ward staff and patients are not offered these options.  
Sometimes patients have been offered a bed on another ward. One patient reported an uncomfortable and sleepless stay in a busy admissions unit during a course of treatment.
- Awareness of Isles of Scilly patients' particular circumstances.  
Most patients report that staff are extremely understanding and go out of their way to provide help and assistance. Difficulties tend to arise around transport arrangements on leaving hospital at the end of treatment, or the need to stay overnight unaccompanied, in a B&B for instance.
- More treatments on-island.  
Arrangements are underway to provide some treatments at St Marys Hospital and it is hoped this can be extended.