

## Assembly Communications: Outreach

### Health and Social Care Committee

#### Inquiry into Progress made to date on implementing the Welsh Government's Cancer Delivery Plan

As part of the Health Committee's inquiry into the Welsh Government's Cancer Delivery Plan, the Assembly's Outreach team conducted five regional workshops with cancer patients across Wales. The workshops were conducted for a number of reasons including:

- To provide cancer patients, with first-hand experience of the Cancer Delivery Plan, an opportunity to share their experiences;
- To prepare participants for a focus group with Members of the Health and Social Care Committee;
- To inform the formal evidence sessions with witnesses including the Minister for Health and Social Care.

This document outlines the evidence gathered including the specific contributions of focus group participants.

### Participants:

#### North Wales Cancer Patients Forum

(1 May 2014, Coleg Llandrillo College, Rhos on Sea)

There were 13 participants including patients, former patients, carers, volunteers and the Macmillan User Involvement Facilitator. A mixture of male and female participants from across North Wales were present.

The North Wales Cancer Patient Forum includes three 'locality groups' which are based around the three District General Hospitals in North Wales – Gwynedd, Glan Clwyd and Wrexham Maelor. An over-arching 'Strategic Group' meets in Rhos on Sea. Each group meets to discuss current topics affecting cancer patients in North Wales and ensure that the views of patients, friends and families are being heard.

### NETs Natter Group



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(7 May 2014, conference venue, Manor Way, Cardiff)

There were a total of 25 participants including 18 patients, five carers and three members of staff.

### Singleton Hospital Craft Group

(8 May 2014, Singleton Hospital, Swansea)

The group consisted of four female participants, two of whom have breast cancer, one of whom has lung cancer and secondary breast cancer, and one of whom has HPV cervical cancer.

### North Caerphilly Breast Cancer Support Group

(12 May 2014, White Rose Information and Resource Centre, New Tredegar)

The group consisted of seven participants, all of whom were breast cancer patients. Three nurses/support staff were also present.

### The Bracken Trust Cancer Group

(12 May 2014, Bracken Trust's offices in Llandrindod Wells)

A total of 10 participants took part – one participant spoke on behalf of his partner who has ovarian cancer, one patient had previously had breast cancer, three participants have prostate cancer, and two participants attended with their respective partners. The remaining participants worked for the Bracken Trust.



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### Notes from the Focus Groups

01. Are patients being adequately supported and receiving person-centred care (i.e. access to a Key Worker and a written care plan, access to sufficient information, receiving care in the most appropriate place for the patient)?

Were you supplied with a named Key Worker or Clinical Nurse Specialist?



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### North Wales Cancer Patients Forum

Some participants were unfamiliar with the term 'Key Worker', and did not know what it meant. Participants did not understand whether their clinical worker was their Key Worker, and felt that different terminology was being used by different hospitals, organisations and patients.

One participant, diagnosed with prostate cancer in 2006–07, said that he had been assigned a Key Worker who was very supportive initially during the first couple of months following diagnosis but, as time went on, the Key Worker gradually became more and more difficult to get hold of. He had been diagnosed with cancer again in 2010 and had not been allocated an initial key/clinical worker.

A carer whose husband was a cancer patient in receipt of cross-border treatment at two hospitals, said that the patient did have a Key Worker, but that things did fall through the net between hospitals on occasion, and the Key Worker was not always aware of the patient's treatment and needs. However, the carer emphasised that there was always someone they could talk to, and that the oncologist had given them his personal contact details.

All participants agreed that having a point of contact, whether identified as a Key Worker or not, was very important.

### 'NETs Natter'

#### *Availability of Key Workers*

Of the eighteen patients, nine had been diagnosed with neuroendocrine cancer post-2012. None of the patients had been assigned a Key Worker at any point during their care, although one patient had been assigned a neuroendocrine Clinical Nurse Specialist during their treatment in Liverpool.

#### *Availability of Clinical Nurse Specialists and difficulty in diagnosing neuroendocrine cancer*

The group highlighted that, at present, there are no neuroendocrine Clinical Nurse Specialists in Wales. A significant proportion of the group felt that while the symptoms of neuroendocrine cancer are similar to other cancers that attack the liver and bowel, many nurses and clinicians (especially General Practitioners) have difficulty diagnosing it.

### Singleton Hospital Craft Group



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### *Availability of Key Workers*

Three of the four patients had been allocated a 'Key Worker' or designated Clinical Nurse Specialist. There was some confusion about the role of 'Key Worker' and the meaning of the term. The patients felt that many people contributed to their 'care' experience and noted that the level of care they had experienced in Singleton Hospital was excellent. One patient described personal experience of care delivered elsewhere where she had felt "*cattle-herded*" during her chemotherapy treatment. She said that once at Singleton, she was made to feel important "*and a person again*".

### **North Caerphilly Breast Cancer Support Group**

#### *Lack of person-centred care*

Some patients felt that they had not received person-centred care until they joined the Macmillan North Caerphilly Cancer Support group. Other patients noted that they had received excellent person-centred care and had had a direct link with a Macmillan cancer nurse as soon as they were diagnosed at hospital.

#### *Availability of Key Workers*

Two of the patients had been diagnosed with cancer before the Cancer Delivery Plan's implementation in 2012. The remaining five had been diagnosed post-2012. Two patients confirmed that they had been allocated a named Key Worker; the remainder of the group had been allocated a Clinical Nurse Specialist. One patient had successfully requested a change of Key Worker as she had felt that her initial Key Worker was poor at providing her with support and "feedback" in terms of her treatment and "*lacked any interest [in me]*". The change had been "*simple*" and she was very happy with her new Key Worker. A second participant described the lack of care she had received when allocated a new member of staff when her Clinical Nurse Specialist had gone on maternity leave.

#### *Standards of care*

The patients all agreed that there should not be discrepancies in the standard of care received by different people.

### **The Bracken Trust**

#### *Availability of Key Workers and Clinical Nurse Specialists*

Two of the patients had been diagnosed with cancer pre-2012, and four



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patients had been diagnosed during or post-2012. Three of the patients had been allocated a Key Worker, and one had been assigned a Clinical Nurse Specialist. The group noted that having a Key Worker or Clinical Nurse Specialist improved the patient's experience of treatment, and reassured them that they had a point of contact that they could utilise at any point during their treatment and aftercare. Some patients had had a poor experience of care and support from their District Nurse; while two others had received a high level of care and support.

**Did you have an opportunity to discuss your care needs, and were you given a written care plan? If so, what was the benefit of this?**



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### North Wales Cancer Patients Forum

#### *Lack of awareness of written care plans*

The majority of the group had received treatment either wholly or partially prior to the implementation of the Cancer Delivery Plan in 2012. One participant had received treatment since 2012 and had been given a written care plan.

The group agreed that there was a lot of jargon and unclear terminology. Participants had not been made aware of the purpose of a written care plan.

One participant referred to the Wales Cancer Patient Experience Survey and said that it reported that only 24% of patients of the Betsi Cadwaladr Health Board had a written care plan. The group thought that these figures suggested that awareness of written care plans is poor.

#### **'NETs Natter'**

#### *Availability of written care plans*

One patient who had been assigned a neuroendocrine Clinical Nurse Specialist had been given an opportunity to discuss her needs, in addition to receiving a written care plan.

#### *Lack of opportunities to discuss clinical/care needs*

The remainder of patients had received no appointments to discuss their clinical needs. They cited high rates of appointment cancellations, which resulted in further 4 – 6 month waits that delayed discussion of their future care needs. It was noted that, due to the nature of neuroendocrine cancer, it is difficult to foresee a patient's future care needs until he/she reaches a certain point in treatment.

### Singleton Hospital Craft Group

#### *Lack of written care plans*

One patient had requested a written care plan but was refused. The other patients had not received written care plans. The patients, however, all agreed that their care and clinical needs were discussed often in appointments. Appointments ranged from one a month to bi-monthly and the patients all agreed that they had open access to their designated nurses or clinicians to discuss any issues as and when they arise.

### North Caerphilly Breast Cancer Support Group



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### *Availability of written care plans*

Three of the seven patients had received a written care plan and found that it was an excellent way of discussing their care needs, in addition to obtaining a wider understanding of their disease.

### **The Bracken Trust**

### *Availability of written care plans*

Only one patient had been provided with a written care plan.

### *Differences in information between Wales and England*

One terminally-ill patient said that they had difficulty understanding the discrepancy between services provided through the NHS in England and Wales. The group thought that more information about care needs should be provided, particularly where there are differences in the application of NICE guidance between the Welsh and English NHS, and that this could save patients a lot of disappointment in terms of understanding why they can/cannot receive certain cancer treatments.

**Were you supplied with, or signposted to, sufficient information on your cancer and the effect it could have on your health, home life, work, finances etc.? Was that information accessible and easy to understand?**





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### North Wales Cancer Patients Forum

#### *Good access to information*

In general the group felt that they had been provided with sufficient information about their cancer.

One participant who had been diagnosed with bowel cancer and prostate cancer said that there was sufficient information about bowel cancer but less information available about prostate cancer. One participant said that she had been provided with a lot of information about her husband's cancer and the treatment he would receive, but that they were not provided with information about finances.

#### *Poor signposting*

One participant involved in supporting people in the community stated that people are finding it difficult to get the information they need because signposting is poor. It was noted that, in the last year, the Macmillan Centre in Glan Clwyd Hospital has found that it has had a *huge number* of people wanting information about different aspects of their treatment as they have not been signposted in the first place by the NHS.

The group felt that the majority of people received sufficient information about their cancer and treatment but not enough information about finances.

### 'NETs Natter'

#### *Poor information and poor signposting*

Without the opportunity to discuss their care needs and lack of written care plans, the patients had received little to no information to help them understand their condition. A number of participants described how they had tried to gain a better understanding of the cancer (both as patients and carers) which they found "scary". This self-exploration, and the information gathered from it, was often contradictory and difficult to understand. In terms of coming to terms with the effect of neuroendocrine cancer, patients, carers and nurses stated that they learn by experience "the hard way".

One of the nurses present at the discussion stated that there were not enough Key Workers/Clinical Nurse Specialists with the requisite knowledge and understanding of neuroendocrine cancer to be able to provide sufficient information and support to patients.



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### Singleton Hospital Craft Group

#### *Good access to information*

There was general consensus that patients were signposted to – or provided with – sufficient information about their cancer. One patient had been misdiagnosed for some time and found it difficult to access further information. Whilst it did not prove to be a significant problem for her, she felt that it could (due to the nature and rarity of her cancer) be a problem for other women. The patients also agreed that the majority of this information was provided through charities (like the Macmillan Cancer Support) rather than the NHS.

### North Caerphilly Breast Cancer Support Group

#### *Good signposting*

The three patients who received a written care plan were also supplied with – and signposted to – sufficient information on their cancer.

#### *Inconsistencies with regards to information and signposting*

The remaining patients had had to find this information independently by picking up leaflets and booklets after their treatment. There was a particular lack of information provided about the effect of cancer on the future health, home life, work and finances of patients. The patients agreed that, upon diagnosis, the language used to explain their condition can be overly technical. Some had met with a Macmillan nurse immediately after their oncologist to talk the diagnosis through with them, and the patients agreed that this should be a mandatory part of everyone's care. They also argued that although some of the literature is easy to understand, it is something difficult for you to seek alone, saying that "*support and understanding is key*".

### The Bracken Trust

#### *Good signposting*

The patients had all received booklets on their cancer, and some had been signposted to other information. Patients felt that the Bracken Trust was better at providing this signposting than the NHS. One patient explained that there is more information available now than there was in 2004 when he had been diagnosed. Another participant stated that more information should be given to patients about preventing cancer after recovery (for example, following the correct diet) although he appreciated that some cancers recur without cause. One breast cancer patient suggested that more information about diet and the



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risk of weight loss should be given to those receiving chemotherapy.

**Were your family given the information they needed to help care for you at home?**



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### **North Wales Cancer Patients Forum**

#### *Lack of information for families*

The group generally felt that once treatment stops there is not much information about what the carer should do once a patient is at home. This includes information about all stages of cancer from treatment through to palliative care.

One participant said that psychological care for both patients and carers is lacking.

#### *Lack of support for those without families*

One participant noted that there is a need to avoid assuming that everyone has family around them to support them, and asked where people can access support if they do not have family.

### **'NETs Natter'**

#### *Lack of information for families*

A number of patients stated that some of their family members attended appointments with them, but no specific information was given to help them understand on-going care needs. The participants agreed that more information should be provided to family members, particularly as patients aren't the only people who have to "live with the cancer".

### **Singleton Hospital Craft Group**

#### *Lack of information for families*

Although the patients' families/next of kin all attended their appointments with them, none of them received one to one support or information about how to help care for patients at home. One of the patient's Clinical Nurse Specialists shared her contact details with her family and emphasised that they could contact her at any point should they need to.

### **North Caerphilly Breast Cancer Support Group**

#### *Lack of information for families*

The patients stated that none of their families were given the information they needed to help care for them at home.

### **Bracken Trust**



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### *Lack of information for families*

The patients stated that carers should also have a care plan, in addition to the patient, and noted that there is a lack of support for families across the board (in terms of healthcare) to help them come to terms with a family member's illness. One participant had received advice on financial support during their partner's treatment, but said that they had not needed it.

**If you have any long term side effects as a result of the cancer treatment, have you received the necessary information and support for these?**



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### North Wales Cancer Patients Forum

#### *Lack of information and support for long-term side effects*

One participant felt quite strongly that people do not receive the information they need about the possible side effects of cancer and its treatment.

It was noted that many people have problems following treatment such as chemotherapy and there is very little information available in order to deal with these problems. The group felt that the follow up to radiotherapy was not very good; one participant still suffers from severe side effects following radiotherapy treatment and had not been given any information about this.

#### *Knock-on effects of lack of information*

The group expressed concerns that if people are not followed up after their treatment, health practitioners may not learn about potential side effects of cancer and its treatment. The group was also unclear about how, if at all, lessons learned from their experiences were captured and used to help with the treatment and care of others.

### 'NETs Natter'

#### *Lack of information and support for long-term side effects*

Living with neuroendocrine cancer was compared to suffering from diabetes – the importance of balancing the clinical aspect of the cancer (such as treatment) with the management aspect of the disease (living with the cancer, taking medication and the daily side effects) was noted. The patients stated that they were wholly unprepared for dealing with the psychological effect of the cancer, noting that many of the symptoms discouraged patients from leaving their homes or making travel arrangements.

### Singleton Hospital Craft Group

#### *Information on long-term side effects*

Three of the four patients explained that they were provided with the necessary information and support on the long-term side effects of their cancer treatment.

The remaining patient stated that her district nurse did not have the requisite knowledge to know how to treat her in the community and to provide her with the same level of support provided at hospital. She said that her district nurse had been offered training in order to support her HPV treatment, but that she



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often felt that she was supporting and co-ordinating her own care.

One patient felt that she was wholly unprepared for the psychological and practical effects of her cancer treatment, and felt that she could have received some more support with regards to having to give up her career and the resulting financial implications.

### **North Caerphilly Breast Cancer Support Group**

#### *Good information on long-term side effects*

The patients generally agreed that they have received the necessary information and support about the long term side-effects, and feel that this is provided more than adequately by the Macmillan Cancer Support Group.

### **Bracken Trust**

#### *Lack of information on long-term side effects*

The patients all agreed that they had not received the necessary information about the long-term side effects of cancer and its treatment.

#### *Information about the financial impact of cancer*

Many thought that patients should be able to claim back the costs of travelling to and from hospitals outside of their local health board area. It was also noted that more support is needed for patients to improve their understanding of how they can find funding for prosthetic body wear and wigs.



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02. What actions need to be taken to ensure cancer is detected quickly (for example, increasing the level of uptake of cancer screening services, more direct access to diagnostics for GPs, improved referrals by GPs regarding waiting times)?

What actions need to be taken to ensure cancer is detected quickly?





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### North Wales Cancer Patients Forum

#### *Lack of specialists*

One participant noted the paucity of specialists in certain types of cancer across North Wales, for example skin cancer, for which clinic appointments have been postponed more than once, sometimes at short notice. The participant also felt that there is a discrepancy between services in north and south Wales, and that shortages in north Wales are not being addressed in a timely manner.

#### *Delays and misdiagnosis*

One participant noted that once someone has cancer symptoms they are put on some treatment or medicine and told by the GP to return in a month if the symptoms are not better. They thought that delays such as this could have knock-on effects for referrals further along the line, including waiting for CT scans or relevant screening. Some participants had waited as long as 3 months between presenting themselves with symptoms and getting access to cancer screening.

The access GPs have to screening was deemed insufficient.

#### *Issues relating to gender-specific cancers*

One participant who had been diagnosed with prostate cancer and then bowel cancer said that there is little being done to promote men's health and the screening available to men for things like prostate cancer.

#### **'NETs Natter'**

#### *Delays and misdiagnosis*

The participants felt strongly that GPs should have a greater awareness of the symptoms of neuroendocrine cancer and be more willing to refer patients for scans. One participant said that it took seven years from her initial visit to her local GP surgery to final diagnosis. Participants said that because neuroendocrine cancer does not sit within oncology, it is not within a clinician's radar for detection. It was argued that a more cost-effective method of detection would be the routine use of urine testing.

### Singleton Hospital Craft Group

#### *Quick diagnosis and detection*

The patients all felt that quick detection was key for diagnosis.



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### *Delays and misdiagnosis*

Two of the patients had been misdiagnosed for a significant period of time (up to one year) which had resulted in their cancers being categorised T4<sup>1</sup>. One of the patients suggested that individuals should be given the opportunity to elect and pay for a scan to be carried out, and reimbursed if anything is detected.

Another patient said that dealing with referrals in a timely manner was very important. She noted that her GP had referred her for an urgent appointment at the breast clinic, but that for her own peace of mind she had elected to have a private scan. She received this within two days, but the letter for her urgent appointment did not arrive until 6 weeks later. She felt that more could be done to encourage timely referrals from the GP to diagnostic testing.

One patient felt that more family GPs should be allocated. She explained that most of her GPs were locums and she did not see the same one twice at any point prior to diagnosis. She felt that this may have contributed to the time taken to diagnose her.

### *Issues relating to gender-specific cancers*

As individuals diagnosed with gender-specific cancer, the patients explained that male clinicians only make appointments with them when a female nurse is available to sit-in too. It was suggested that this could contribute to the time delay in diagnosis/treatment. The patients all stated that they would have been comfortable to meet with their clinicians without a female nurse being present.

## **North Caerphilly Breast Cancer Support Group**

### *Delays and misdiagnosis*

The patients all agreed that the age for mammogram screenings should be lowered. One patient had been diagnosed at the age of 40 and would have been a decade away from her first screening. She was diagnosed with a T3<sup>2</sup> aggressive form of breast cancer which, undetected, would have taken her life within 18 months.

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<sup>1</sup> Most types of cancer have a staging system numbered one to four. Category four is given where the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

<sup>2</sup> Category three staging is often given when the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in the area.



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### *Awareness raising*

The patients agreed that more should be done to raise awareness of the fact that cancer is a life-threatening illness, rather than an illness that manifests from smoking or an unhealthy lifestyle for example. Some cancers develop without symptoms and often without reason. As such, they felt that young people should be taught how to check their bodies for lumps.

### **The Bracken Trust**

### *Awareness raising*

The patients agreed that more should be done to raise awareness of cancers at an earlier age, and particular attention should be paid to GP referral times and detection.

### **Did you/do you attend regular cancer screening services?**

Participants in all groups noted that they had participated in screening and continue to do so, but that screening services should be available at an earlier age.

Furthermore, the North Caerphilly Breast Cancer group noted that more awareness should be raised to ensure that patients receiving treatment should continue their screenings in order to ensure that cancer is prevented from developing elsewhere in the body.

The NETs Natter group reported that some patients had waited up to 8 months for lung and heart checks ups.

Participants from the Bracken Trust noted the need to draw attention to the fact that male cancers can request a PSA from the GP at any age.

### **What could be done to encourage more people to take advantage of cancer screening services?**



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### North Wales Cancer Patients Forum

#### *Raising awareness*

One participant said that people need to take more personal responsibility for their health.

The group felt that more is being done now to make people aware of cancer screening services but that this it is still not enough. They felt that we need to talk to children in schools about cancer and we need to speak to them in the way they want to be spoken to. They need to be educated on the information that is available and where they can find it. The group felt that children need to be shown something that will force them to take action.

#### **‘NETs Natter’**

#### *Raising awareness and understanding of neuroendocrine cancer across the board*

There are no screening services for neuroendocrine cancer, and the participants stated that there needs to be a greater understanding and awareness of the condition and the symptoms at all levels of health care.

### Singleton Hospital Craft Group

#### *Raising awareness*

Some of the patients stressed the importance of breaking the “embarrassment and comfort” barrier in order to take advantage of cancer screening services. One patient stated that anyone who is sexually active should be smear tested, as HPV cancer and viruses can be immunised against. It was noted that outside the UK young people are taught to check for breast and testicle lumps; the patients all argued that this should also be the case in our secondary schools. They said that this learning should be visual, and show the effects of cancer. They thought that personal health should be at the top of the agenda, along with nutrition.

#### *Genetic testing*

One patient raised the possibility of introducing more routes to “genetic testing”, to add to the existing routes available to women who come from families with a long history of breast cancer.

### North Caerphilly Breast Cancer Support Group



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### *Raising awareness*

The patients agreed that in order to encourage more people to take advantage of cancer screening services, advertising should be shown during prime time television and targeted carefully to the relevant audiences.

### **The Bracken Trust**

### *Raising awareness*

For more people to take up cancer screening services, encouragement should come in the form of public health campaigns, in addition to services being made available to individuals who come from families who suffer from a high incidence of cancer.

**How proactive and informed was your GP in assessing and referring your symptoms?**



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### North Wales Cancer Patients Forum

#### *Delays and misdiagnosis*

One participant noted that it took 10 months for him to be diagnosed with prostate cancer because his symptoms were initially treated as an infection.

#### *Consistency of GP services*

The group felt that GPs were sometimes proactive, however not everyone has a consistent family GP meaning that the GP is reliant on filed information rather than using first-hand knowledge about a particular patient. Members of the group were worried that seeing more than one GP could result in inaccurate information being recorded or transferred.

Patients' experiences varied significantly, but in general the group felt that a lot needs to be improved in general practice.

#### **'NETs Natter'**

#### *Lack of awareness of neuroendocrine cancer/NETs at GP level*

The patients all felt that GPs lacked the requisite knowledge and understanding of neuroendocrine cancer to be able to assess their symptoms as being synonymous with the disease. This, in turn, had a knock-on effect on referrals. The majority of patients were misdiagnosed when they had presented themselves, and had spent between six months to seven years being treated for conditions such as Irritable Bowel Syndrome.

### Singleton Hospital Craft Group

#### *Delays in being referred for scans*

In general, the patients felt that their GPs were proactive and informed in assessing and referring their symptoms, but the lack of urgency to refer them for scan testing meant that two of the patients' cancers spread. One participant felt that her GP surgery was very poor identifying her symptoms, although the level of care she has received since then had been excellent.

### North Caerphilly Breast Cancer Support Group

#### *Proactive and informed GPs*

The patients generally felt that their GPs were proactive and informed in assessing and referring their symptoms; for one patient the time from screening to diagnosis was three weeks. One patient said it happened "*a little too fast*" for



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her, and said that she had not had much time to come to terms with what was happening to her. On the other hand, she said that the support she had received from the nurses was outstanding and helped put her at ease.

### **The Bracken Trust**

#### *Proactive and informed GPs*

The patients all agreed that their GPs were very proactive and informed in assessing and referring their symptoms.

**03. What improvements can be made so patients receive fast, effective treatment and care (e.g. fast access to appropriate treatment, well-coordinated services, access to clinical trials and research)?**

**Do you have any experience of receiving cancer care across different hospitals or across primary, community, secondary or social care settings, and if so, what is your view on how your care was coordinated?**



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### North Wales Cancer Patients Forum

#### *Poor cross-border coordination*

Some participants within the group had experience of cross-border treatment. They felt that there is a lack of co-ordination between different hospitals. They reported the need to tell the nurses or oncologists at one hospital what had happened in another hospital with paperwork not always passed between them. There was a strong feeling that communication between hospitals is lacking.

#### *Good coordination across care settings*

One participant felt that he had a good experience of communication between his GP and hospital consultant. His consultant sent a review of his condition and his treatment to his GP and he also received a personal copy of this information.

### 'NETs Natter'

#### *Lack of coordination*

The vast majority of participants stated that the care of neuroendocrine cancer should be better coordinated, as they felt that they were asking for treatment all the time rather than receiving it. They highlighted the need to build momentum in treatment from the first test onwards, saying that there were lapses in time between tests and a lack of a sense of urgency by clinicians.

### Singleton Hospital Craft Group

#### *Good coordination*

The patients all agreed that their care was generally well-coordinated. However, they stressed the importance of information sharing and the need to make everything accessible electronically for all medical staff. They argued that clinicians from all departments and approved care settings should be able to access an individual's medical record.

#### *Lack of coordination*

One patient, having received care at two different hospitals, stated that her information wasn't shared adequately between them.

### North Caerphilly Breast Cancer Support Group

#### *Better communication across care settings needed*

The patients all had experience of receiving cancer care across the south Wales





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region. They felt that communication needed to be prioritised in order for care to be better coordinated. They also noted that better communication between the hospital and the aftercare teams is required. Some spoke of experiences where District Nurses showed a “*lack of care and respect*” when visiting, failing to read notes and asking the patients “*what they were there to do*” on occasion.

### **The Bracken Trust**

#### *Better communication across care settings needed*

The patients all had experience of receiving cancer care across different hospitals. The patients agreed strongly that better communication between departments and hospitals is required, and stressed the need to send copies of letters to patients so that they are “kept in the loop” about the discussion of their care.

**Were you approached with regard to participating in a clinical trial, and if so, what was your experience of this?**



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### North Wales Cancer Patients Forum

Many of the participants within the group had been approached about participating in a clinical trial.

One participant said that her experience with clinical trials had been very good and that she believed that they helped to save her life. Her sister was diagnosed subsequently with the same cancer and the drugs from the clinical trial that she had been involved in were then used as part of her sister's treatment.

### 'NETs Natter'

One participant has taken part in three clinical trials: two in the UK, and one pending in Germany. She had enjoyed taking part and welcomed the offer to participate.

### Singleton Hospital Craft Group

None of the participants were approached with regards to participating in clinical trials.

### North Caerphilly Breast Cancer Support Group

One of the patients took part in a five-year clinical trial that compared the effects of Anastrozole and Tamoxifen. The clinical trial came to a close last year. She had enjoyed the experience, and felt as though she had an excellent point of contact throughout her treatment.

### The Bracken Trust

One of the patients was approached to take part in a clinical trial, but his clinician stressed her desire to manage his treatment personally. One participant outlined that clinical trials are only really offered to those where previous treatments had proved unsuccessful.

**04. What improvements can be made to ensure people are aware of, and supported in, minimising their risk of cancer through healthy lifestyle choices?**



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Do you believe the public awareness campaigns about cancer risk factors (for example smoking, alcohol and obesity etc.) are sufficient? If not, why not, and how could they be improved?

Did you access any of the public health services available to promote healthy lifestyles (such as obesity, alcohol or smoking cessation services) and if so, what was your experience of them?



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### North Wales Cancer Patients Forum

The group as a whole felt that the key word to consider when discussing public awareness of cancer risk factors is motivation. They felt that people refuse to take responsibility for their own lifestyle. They argued that making people more aware of the effects of their lifestyle decisions may motivate them to change their decisions. There was recognition, however, that finding ways to motivate people can be difficult.

The group felt that educating people about the risks of cancer from a young age is very important, but there was a feeling amongst the group that there are too many public awareness campaigns about cancer risk factors. The group queried whether people take any notice of them and wondered whether messages were being diluted as a result of the sheer number of campaigns.

One participant noted that changing legislation has an influence from time to time, for example the legislation to ban smoking in pubs. It was noted that being bombarded with campaigns everyday does not have the same effect. The group asked whether any research has been done to see whether these campaigns actually work.

Many of the participants felt that existing initiatives are not used to best advantage for example Flying Start sessions – the Welsh Government’s targeted Early Years programme for families with children under 4 years of age in some of the most deprived areas of Wales – were cited as an opportunity to promote lifestyle decisions and to give people advice about cancer.

### ‘NETs Natter’

The group argued for increased awareness amongst General Practitioners of neuroendocrine cancer symptoms. It was explained that neuroendocrine cancer does not necessarily manifest itself as a result of poor lifestyle choices, but may stem from genetics or hormonal imbalances. It was felt that having specialist neuroendocrine nurses would be the best option for patients and that teaching about this form of cancer should form part of the GP’s Continuous Professional Development.

### Singleton Hospital Craft Group

The patients agreed strongly that cancer campaigns were insufficient for young people and cancer screenings should start at a younger age.

One patient outlined the need to keep educating women about breast cancer:  
*“Breast cancer isn’t just a lump...there are other ways of identifying it through*



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*tissue strands...you need to know your own body, and young women should be taught to explore in order to be able to understand when something's wrong".*

One patient accessed the exercise referral scheme, but it had not been developed fully enough in order for her to take advantage of it. She said that she had received this information at a Cancer Recovery Show and not through the NHS.

### **North Caerphilly Breast Cancer Support Group**

The patients felt that more gender-targeted advertising should be shown on television. Some patients stated that there were too many health campaigns which cause confusion, particularly with regards to "what's healthy to eat". The group had a discussion about the lack of information available in the public sphere about the effect of food and drink additives. As mentioned previously, the group also stated that cancer campaigns should not merely focus on a healthy diet, as many cancers develop without cause or symptoms.

Two of the patients accessed public health services, but these were referred to them through Macmillan as opposed to the NHS. One attends a fitness class which is delivered jointly through Macmillan and the local Communities First scheme. The other utilised a reflexology treatment referral through Velindre which helped her regain focus on her general well-being.

### **The Bracken Trust**

The patients all agreed that public awareness campaigns about cancer risk factors were insufficient. The group noted that there is a lot of competing information, particularly with regards to diet. One of the participants felt that public health messages often "*talk-down to the public which is patronising...people cannot be expected to live up to this high expectation of what constitutes a healthy lifestyle*".

Another participant and patient felt that information should be shared with children of all ages, rather than allowing them to be sheltered from the effects of cancer: "*there needs to be an open conversation about cancer which may in future...encourage them to take up screening*".

