

P-03-150 National Cancer Standards – Correspondence from the Petitioner to the Clerking Team, 04.03.2014

Kayleigh Driscoll
Petitions Committee
4/3/14

Hi Kayleigh,

Petitions Committee 11/3/14

I refer to your Email received 26th February, 2014 and the attached document from Public Health Wales.

The petition has always been about improving services, support and information for people affected by cancer and those who care for them. This was initially progressed by seeking compliance of Health Boards with the patient centred Cancer Standards and subsequently the Cancer Delivery Plan.

Information

First, I will comment on the response from Public Health Wales (PHW) to inform us and the minister about their involvement in providing information for people affected by cancer.

We are informed that a key function of PHW is to provide public information that will protect and improve health in Wales. We can see from their correspondence that specifically regarding cancer this information has been extremely limited, excluding the needs of people re. early detection (signs and symptoms) , GP referral, diagnosis, treatment, side effects, re-occurrence, rehabilitation and/ or palliative care , support organisations etc,

I am very pleased to be informed that the [Wales National Strategic Cancer Patient Information Project](#) was set up when in 2010 the Health Minister supported a proposal by Macmillan to explore how tailored cancer information could be developed in Wales through a national strategic information project hosted and delivered as a partnership arrangement between Macmillan Cancer Support and Public Health Wales. Unfortunately the project **does not** encompass public awareness of pre- diagnosis information on signs and symptoms. The project commenced in September 2012 and will end in March 2015.

- *Just a recap for new members, I came into the cancer arena in 2001 when ignorant of all cancer matters, my daughter aged 25 found a lump. It took a year to diagnose and two more years for her to die. Rhondda Breast Friends was set up in her memory, to strive to ensure information and support was available from prevention & early detection onwards, allowing patients to make informed choices that were right for them. Our conference and subsequent Charter of Rights formed the basis and evidence for this petition.*
- *In 2007 I approached the Cancer Network regarding information provision and I was told there was an information project underway only it was on hold as the co-ordinator had resigned.*
- *Then the North Wales Cancer Network came up with their information portfolio for all newly diagnosed patients which was held as best practice and the two Macmillan Nurses responsible were appointed to look at information throughout Wales on a three year project...*
- **November 2008...Enter [The All Wales Patient Information Project](#)** funded by Macmillan Cancer Support and supported by the three Cancer Networks across Wales. The result was draft information pathways (Eg [Breast Cancer pathways](#)) which were circulated in 2013 to Macmillan Information Facilitators within each Welsh Cancer Network for consultation with patients and carers.

October 2010...Enter the [National Strategic Cancer Information Project 2012-2015](#) (see above)

My point? 2001.....2015.

Fourteen long years will have passed since I first looked for information. The Government is committed to providing patient centred information as shown in the Cancer Standards(2005) but it is taking its time to reach patients. More people are receiving good quality information, but there are still gaps and inconsistencies.

[2013 Wales Cancer patient Experience survey](#) showed that although patients

are happy with the clinical care they received, they do not feel they are receiving the emotional, practical and financial support and information they require.

I applaud the Government, Cancer Network, PHW and Macmillan for all their work in this area. The two national strategic projects together provide recommendations for a national, tailored cancer information service in line with the Cancer Delivery Plan. Questions still have to be answered on how the projects recommendations will be implemented and funded? Will it be left up to individual Health Boards? Or lottery funding? Or will the government allocate additional money? How will compliance be measured?

What is the **timescale** for the promised tailor made patient information? How long will it take to make a difference to the people currently being diagnosed and those down the line? Those without key workers or Cancer Nurse Specialists? Those supported (or not) by a patchwork, postcode lottery of Charity Information professionals, trained benefits advisers, Counsellors, therapists etc. without the guarantee of sustainability. These questions still need answers and I believe the answer is that ultimately more professionals will need to be employed and funded.

Part 2: Early detection & waiting time to treatment.

(This area is not covered by the new partnership project).

The earlier cancer is detected and treated the better the outcome. People diagnosed at stage 1 and 2 have a better chance of survival. Waiting time targets aim to expedite the time from referral of Urgent Suspected Cancer to starting treatment.

The Together for Health – [cancer delivery plan – annual report 2013](#) highlights the progress the Welsh Government have made in cancer services over the past 12 months and identifies areas for future improvement. Whilst many improvements have been shown, Wales's cancer survival is lagging behind a number of other European countries. Performance against the 62 day target, for urgent suspected cancer patients referred and diagnosed to start of treatment, remains an area of concern as this target has not been met consistently across Wales for some considerable time.

As a delay in diagnosis and starting treatment can affect outcomes, I am also concerned about how long someone who has been referred for non urgent cancer has to wait for a consultation. I cannot find a maximum waiting time target or statistics. This would include those people referred by their GP as urgent suspected cancer and then downgraded by the consultant to non – urgent, often because of age.

As an illustration, I include a case study I have received in a request for help from a panic stricken 34 year old young lady who has given me permission to use her story.

Case Study

Face Book message , **Thursday 27th February 12:37pm**

1. Hi Diane I'm sian. Ah where do I start I'm having hell, I've had the pain for just under a year but had 4 miscarriages in the last year also so put the pain down to hormonal changes so many times in the past year, I have 4 children breast fed them all and had mastitis, blocked milk glands, cysts etc over the years and pain is nothing like the above, anyway after my breast hurting so much one day around 6 weeks ago I began massaging it to ease the pain and that's when I found the lump about the size of a 10p not sore to touch but horrendous pain in my back behind the breast, armpit, neck, also discharge from the nipple. I went to an appointment for my gyni problems and explained these pains to the consultant and she referred me as urgent to breast clinic while I was there, hadn't heard anything off them so rung to be told I'm not deemed as urgent because of my age even though my symptoms are alarming, I was told to go to my doctors for them to "bump" up my appointment. After examination my doctor saw for for an urgent mammogram within 10 days having not heard anything I rang them yesterday to be told that doctors surgeries are not allowed to refer anyone under the age of 35 so I'm now back in the same boat of being on the waiting list for 8 weeks in, now on week 3 of waiting and pain is horrendous the last 5 days pain is going into my kidney and more up my neck I'm going out of my mind and just don't know what to do I'm contemplating going to a&e this evening to be seen as I cannot handle the pain anymore, I have family history of breast cancer (nan and aunt) and cancer of the cervix myself. Any advice would be fab.x

2. **Thursday 8:32pm**

3. **Friday 12:21am**

4. Well u dont do things by half do you?
5. Not sure what Mags has told you but my daughter had a late diagnosis at 26 after being told the previous year she was too young to get breast cancer. First, how old are you?
6. Second, please disregard the comment GPs cannot refer anyone under 35. They should refer anyone that fits the guidelines for referral for breast cancer recommended by NICE and the Royal College of Surgeons.
7. Check out the following guidelines from Nice:

8. Referral Guidelines for Suspected Cancer in Adults and Children [Internet]. Show details NICE Clinical Guidelines, No. 27. Clinical Governance Research and Development Unit (CGRDU), Department of Health Sciences, University of Leicester. London: Royal College of General Practitioners (UK); 2005 Jun. Specific Recommendations 5. A woman's first suspicion that she may have breast cancer is often when she finds a lump in her breast. The primary healthcare professional should examine the lump with the patient's consent. The features of a lump that should make the primary healthcare professional strongly suspect cancer are a discrete, hard lump with fixation, with or without skin tethering. In patients presenting in this way an urgent referral should be made, irrespective of age. [C] 6. In a woman aged 30 years and older with a discrete lump that persists after her next period, or presents after menopause, an urgent referral should be made. [C] 7. Breast cancer in women aged younger than 30 years is rare, but does occur. Benign lumps (for example, fibroadenoma) are common, however, and a policy of referring these women urgently would not be appropriate; instead, non-urgent referral should be considered. However, in women aged younger than 30 years with: [C/D] • a lump that enlarges, [C] or • a lump that has other features associated with cancer (fixed and hard), [C] or • in whom there are other reasons for concern such as family history. [D] an urgent referral should be made 8. The patient's history should always be taken into account. For example, it may be appropriate, in discussion with a specialist, to agree referral within a few days in patients reporting a lump or other symptom that has been present for several months. [D] 9. In a patient who has previously had histologically confirmed breast cancer, who presents with a further lump or suspicious symptoms, an urgent referral should be made, irrespective of age. [C] 10. In patients presenting with unilateral eczematous skin or nipple change that does not respond to topical treatment, or with nipple distortion of recent onset, an urgent referral should be made. [C] 11. In patients presenting with spontaneous unilateral bloody nipple discharge, an urgent referral should be made. [C] 12. Breast cancer in men is rare and is particularly rare in men under 50 years of age. However, in a man aged 50 years and older with a unilateral, firm subareolar mass with or without nipple distortion or associated skin changes, an urgent referral should be made. [C] Go to: Investigations 13. In patients presenting with symptoms and/or signs suggestive of breast cancer, investigation prior to referral is not recommended. [D] 14. In patients presenting solely with breast pain, with no palpable abnormality, there is no evidence to support the use of mammography as a discriminatory investigation for breast cancer. Therefore, its use in this group of patients is not recommended. Non-urgent referral may be considered in the event of failure of initial treatment and/or unexplained persistent symptoms. [B (DS)] .
9. In Wales it appears to be under 35 not 30 as shown above. It gives the symptoms for urgent referral you can check against to see if you comply. As far as 8 weeks is concerned that is a long time even if they meet the limit. What consultant have they referred you to? I will see if I can find the waiting time standard for non-urgent referrals. I understand your concern and it is frightening facing the waiting game but if you fit the bill you can go back to your GP /consultant with the evidence from official guidelines to get you in. let me know how you get on.

10. Friday 8:38am

11.

12. Hi Diane thank you for the info I'm 34, my gynaecologist referred me from her clinic as urgent 4 weeks ago I rung to find out after 2 weeks as I thought 2 weeks was the urgent time scale to be told because of my age I wasn't deemed as urgent urgent and had to wait 8 weeks and told to go t Back to my doctor to see if they could bump up my appointment which I did and after my doctor examined me he wanted and urgent mammogram done and faxed it to then while I was there and said I should be seen within 2 weeks the 2 weeks were up on weds so I rang to find out what was happening to be told my doctors can't refer me for a mammogram because I'm under 35, I took myself to a&e last night because the pain is unbearable only to be told again they can't do anything because I'm under 35 and no breast doctor was available to see me and to go back to my doctors but what's the point if they can't refer me it's ridiculous I'm now on week 4 of waiting I'm not sure who I was referred to only that it's to breast clinic in royal glam??

13. Friday 3:15pm

14. Stop concentrating on the mammogram. You may not be eligible for a mammogram but even under 35 the guidelines suggest that urgent referral is recommended: if you have a hard lump or one which has got bigger, have symptoms present for several months (pain), family history of bc, bloody nipple discharge. The first step is to get an appointment. It is then up to the consultant to decide investigations. The standard says a triple assessment is recommended – 1. Physical examination, 2. Imaging, could be ultrasound, mammogram, MRI etc. 3. Biopsy. I have been speaking to a young lady today , same problems as you, downgraded to non urgent by consultant. Went back to GP who was angry and referred her to another hospital who diagnosed her bc. She thinks this has to be in the same health board so perhaps your GP could try referring you to Merthyr if willing? (or perhaps another consultant in RGH, I believe you have the right to choose your consultant). I am not a medical professional but you can speak to a cancer nurse on tenovus cancer support line 0808 8081010 who can also counsel you (over phone). Breast cancer care helpline 0808 800 6000 Macmillan helpline 0808 808 0000 If you want to ring me –01656 783241

15.

16. I don't care what I have done to me I just need a specialist to look at me 3 doctors have examined me, all felt the lump and all know my symptoms all have sent referrals to breast clinic in royal glam in the last 4 weeks, I've apparently been down graded and been told the waiting list is 8 weeks. My doctor has today faxed an expedite letter to the breast clinic so I will again ring Monday morning to see what's being done. So the young lady is a typical example that age is not a factor. I will let you know my out come on Monday thank you for your help.

17. I am quite angry about your experience. How would you feel about me using your experience as an example of the hurdles younger women (and GPs) have to get an urgent referral for under 35s (I can keep it anonymous). I am about to write to the Welsh Government about cancer standards compliance. Please don't feel pressurised, it's ok to say no. In the meantime, I hope u get an outcome on Monday. Let me know x

18. And try and find out when u ring who you have been referred to if you can x

19.

20. Yes of course I was going to do something myself but wasn't sure which avenue to go down but yes by all means if it can help and I don't mind you using my name. I sure will

on Monday. Can you tell me how long the other lady had to wait?? If I don't get any joy at the royal then will ask for another hospital. Many thanks again.

21.

22. Oh my gosh how weird appointments have just rung I've got an urgent appointment in llwynypia tues morning with rhodry Williams.

23.

24. I'm so grateful for the advice you gave me I would never have had this appointment sorted without your advice thank you so so much I feel a weight lifted off my shoulders already. Thank you so much. And if you still are going to write to the government then please add my story in so something can be done because by the looks of things It's happening more than it should. Many thanks.xx

25. She had pain & lump. referred to breast consultant, rang after 2 weeks, had been downgraded, she said had to wait months, saw the consultant who prodded around collar bone and told her nothing wrong, no ultrasound or anything. Went back to doc who made new referral to another hospital urgent. Saw & diagnosed with bc.!!! -So don't forget the triple assessment. fingers crossed it's all sorted out, but yes, it is a huge weight to carry until it's sorted.

26. Let's hope it's just something minor hey. Thanks again Diane.x

My concerns are that in the above 2 cases and my daughter's, it is concerning that the reason for downgrading appears to be age rather than symptoms. As a mammogram is not usually given under 35 then the medical staff appeared to disregard the symptoms and the GP's opinion. It is also interesting that one hospital downgraded and another accepted as urgent. I can't help thinking it could be a capacity issue. With breast screening, referral is to a shared a pool of consultants from neighbouring hospitals and Health Boards.

The questions the case study poses is as follows:

- What information and procedures are available to inform the public of signs and symptoms for referral to the GP, (including under 35s) and empower them to know their rights to referral as urgent suspected cancer,
- Is there a protocol for these people to be notified that they have been downgraded and a reason given, not just left glued to the phone. They already know the GP has referred them urgently so the psychological effect and fear is massive.

- Is there a maximum waiting time for non-urgent suspected cancer and /or those downgraded to non urgent? I cannot find one.
- Are the number of non-urgent cancer cases and waiting times collated?
- If urgent suspected cancer waiting time targets are persistently being missed and the consultant has more patients than (s)he can deal with, what then?

Is there a procedure for referral of patient overflow to other hospitals?

What rights does the potential cancer patient have regarding changing consultant and or hospital and finding out about consultant's waiting lists /waiting times and capacity. What information is routinely available to the public regarding signs and symptoms to referral and their rights along the way. Cancer is still a fearful business and the psychological distress and support needed should not be underestimated.

Part 3 – Matters outstanding

Cancer Nurse Specialists and/or Key Workers

A number of issues have been previously raised regarding the fact that not everyone has a Cancer Nurse Specialist and/or Key Worker and that the key worker's role had yet to be confirmed. As major providers of information and support, this leaves some patients unsupported.

In the 2013 cancer patient experience survey: 88 per cent of respondents were given the names of their clinical nurse specialist, 66 per cent of patients confirmed that they were given contact details of their key worker and 58 per cent of patients said they had been offered the opportunity to discuss their needs and concerns. There was wide variances and inequalities across cancer sites from 30–70%.

Care Plans

The Cancer Delivery Plan has set a target that everyone with a diagnosis of cancer should have a care plan. The 2013 Annual report showed only 22% of patients had been offered a written care plan.

Part 4 – Summary

I have to praise the Government and Macmillan for the amount of work it has carried out in partnership to put in place the strategic plans and service recommendation for a tailored patient information service as promised in the Cancer Delivery Plan. This has been done with the consultation of cancer professionals and patients to highlight good practice and identify shortfalls for future action.

Support NOW

I still have my reservations that the information service has to be set up and delivered and the timescale and funds needed for this to happen. Meanwhile, as shown in the patient survey, there is currently inequity and inconsistencies across cancer sites and many people are not receiving the promised information and support, key workers and care plans promised and this is needed NOW, as people are being diagnosed on a daily basis. A phased implementation is needed to provide at least a basic information and signposting to a support service for everyone, now.

Early detection – urgent / non-urgent and/ downgraded urgent suspected cancers.

I ask that any information available on the questions posed on page 5 be provided .

Once again thank you for your time, understanding and patience. So much good work is going on and it is humbling that we are able to help so many people across Wales because of the work of the Petitions committee.

It is hard to keep up with all the developments but I have tried.

Best wishes,

Diane Raybould

Rhondda Breast Friends