

P-03-150 National Cancer Standards - Correspondence from the petitioner to the Deputy Clerk, 16.04.13

Kayleigh Driscoll
Petitions Committee Deputy Clerk
Committee Service
National Assembly for Wales

16th April, 2013

Dear Kayleigh,

P-03-150 National Cancer Standards

I appreciate your support and revised deadline.

Thank you for the opportunity to comment on the oral evidence from the Health Minister on 20th November and whether the National Cancer Delivery Plan addresses the issues raised within the Petition.

I last commented during the previous government's term of office. At that time the self-reported achievement of gaining up to 90% compliance with the cancer standards across Wales was an outstanding achievement brought about by our tenacity and that of the previous Petitions Committee.

The Cancer Delivery Plan has built on the firm foundations of the Cancer Standards and introduced new population outcome performance measures. How those outcomes will be achieved is the remit of individual Health Boards' Local Delivery Plans.

I think that the evidence session with questions members put to the First Minister was excellent and demonstrated that the new committee members have achieved a good understanding of the issues involved and I make no apology for re-enforcing my opinions on some of the points raised. I have concentrated on what I believe are currently the most important issues for patient centred care.

*Minister[96]: All health boards have committed to achieving the cancer standards by **next year**. The building blocks of the service are in place. However, I do not want to continue to focus **on process**. I would rather focus on **delivering the continuous improvement in quality care that we have seen over the past few years**.*

Cancer Standards

What a wonderful piece of work. How empowering! Including NICE guidelines, it seemed that patient centred cancer care had indeed been promoted to centre stage. It was in the public domain, anyone could go online and know what the minimum expected level of service was, the "process," if you knew where to look! When I came across them I thought this was everything we could ask for, already in print and with implementation deadlines decreed by the Welsh Government. How could it be that compliance was such an issue since 2005 and despite considerable progress we still wait for full implementation "by next year"? or even 2016?

The Welsh Government believes it is not appropriate to continue to monitor 700 plus standards which form the process and mechanics of service delivery.

Each HB's compliance was previously self-assessed and submitted to the government for monitoring. I believe that the Minister has accepted the importance of the cancer standards and their effect in raising the standards of cancer care by requiring 100% compliance by 2013 and ensuring that HBs will continue to monitor the standards. I remain optimistic that the organisational structures in place will allow that to happen. In addition, there will be a system of peer review and audit. I am pleased that the review process will continue, albeit in another format.

Cancer Delivery Plan

I have to congratulate the minister and her team for producing the first comprehensive cancer plan for Wales – it covers every stage of the cancer journey: prevention, early diagnosis, screening, delivering high-quality cancer services, supporting people living with cancer, as well as improving cancer information, and promoting research. The central theme is on outcomes with local cancer delivery plans drawn up detailing how HBs, with their partners, were going to achieve them. National priorities have not been assigned but left to HBs, using national and local indicators to decide their own local priorities but with an overall delivery date of 2016. I think putting the information in the public domain was vital to enable public accountability and inform of progress.

The first local and national annual reports on the delivery plan have been released online. I am “delighted” with Cwm Taf's report which I believe gives a full hard hitting account of local challenges with areas of high deprivation and the lowest life expectancy in Wales, AND.... it included progress against the Cancer Standards with a report of areas of compliance and non compliance, (including Cancer nurse specialists and psychological support) , WHOOP, WHOOP...RESULT!

Cancer has a greater impact in the more deprived areas of Wales and the annual reports will highlight particular challenges faced by these LHBs. Will the government recognise and support those areas and work with them towards solutions? I did a survey a number of years ago comparing an area of Rhondda Cynon Taff (RCT) with a more affluent area in South Glamorgan. At that time it highlighted a greater patient doctor ratio in RCT and with a greater number of people with chronic and life threatening illnesses. So more ill patients per GP, greater strain on the service, not the most attractive proposition for GPs, .problems getting a GP appointment for patients.... Hmmm any changes there I wonder???

Issues raised by the Petition

Overall, I believe that the vision from our original Charter of Rights is reflected in the vision for the cancer delivery plan across the cancer journey. A shared vision is one thing, delivery is another and HBs will have to put the processes in place, implement them and achieve the required outputs. As we have seen from the Cancer Standards this can be problematical.

Patient centred care: Key workers, Clinical Nurse Specialists (CNS), Psychological support, Rehabilitation, Information, benefits advice. Carers & care plans.

1. **The Issue of Key workers and Cancer Nurse Specialists** remain a burning issue for me. I do not believe the minister's response is adequate.

There seems to be some conflict and cross over in the evidence supplied. The cancer rehabilitation standards were released in 2010 and health boards were required to ensure

all key workers were in place by the end of March 2011. We know this has not happened and full compliance with standards is now next year – 2013, but the delivery plan on the other hand sets performance measures that by 2016, 100% of people with cancer will have an assigned key worker and care plan in place?! 2013...2016 exactly when?

I believe it is totally unacceptable that some patients should have to wait until 2016, that means patients passing through the system without support for the next 3-4years,?!

So what is a key worker, what is their role? Is it pivotal, a keystone of care?

- Do patients that *do* have them know their remit?
- Do clinicians and other health and information professionals know for signposting?
- Do they have a national or local remit?
- Does this mean inconsistencies and inequalities?
- How does not having a key worker affect other cancer standards?

Appendix 1 is an excerpt from Macmillan's policy document (1) which the Health Minister frequently made reference to. It briefly explains the role of the key worker based on their research and also their concern that it should be a nationally agreed remit.

During the treatment phase the key worker is likely to be the clinical nurse specialist (CNS) who is: the co-ordinator of care and central point of contact, undertaker of assessments, communicator of care plans to the patient and carers, provider of information and understanding about cancer and its effects, referring and signposting to other support e.g. financial, practical, emotional, psychological, rehabilitation etc. The absence of a key worker could thus leave the patient without vital communication and co-ordination of services and I have witnessed the traumatising of the patient, carer and family members leading to more complex psychological needs leading into rehabilitation.

The Haematology department in Royal Glamorgan had no CNS when one of our clients was diagnosed with Leukaemia last year and had no information or support. "I should have been sat down and discussed what was happening and the side effects. I expected to be back in work within two weeks. The nurse did not even have a leaflet to give me and I did not know how tired and unwell I would be feeling."

I accessed the Macmillan RCT library service for booklets on Leukaemia, side effects, radiotherapy, fatigue and the emotional effects of cancer. He told me, "The books were really good and for the first time I could understand what had happened to me."

The fact that patients are given a name and a number of their key worker I believe is inadequate. A written copy of their remit is needed. I have seen so many people coming for support and when I ask do you have a key worker, or have you been given a phone number to ring I often get blank looks. When I explain they seem surprised and comments like. "On I didn't think of ringing them for that" are often made. Perhaps the significance of the cards has gone undigested due to the impact of the diagnosis and aftermath.

There therefore seems to be a conflict in the Ministers comments that, "It is up to local health boards whether they employ specialist nurses and it is up to them to ensure that they get the right skills mix." If every cancer patient is promised a key worker/ specialist nurse then should not CNS staffing levels be decided by demand?

Action: I believe that all patients have the right to:

- (i) A key worker (with a nationally agreed remit) from the date of diagnosis (**now**) as promised in the cancer standards 2011, not waiting for the delivery plan target of 2016.
- (ii) Receive a copy of the key worker's remit in support and rehabilitation at each stage, not just a name(s) and phone number(s).
- (iii) A personal copy of the care plan in writing.

2. **Rehabilitation Standards and psychological support**

The standards require an assessment of Physical, Nutritional, Psychological, Informational, Practical, Spiritual, Social and Financial needs. My understanding is that again a key worker will be crucial in assessing individual need and some of the above areas like psychological support have very limited services. The voluntary sector may be able to offer some support in some areas and locations but again, inconsistencies and inequalities can mean the needs of a patient can go unsupported on their cancer journey.

3. **Information, including benefits advice & the Voluntary sector**

The All Wales Cancer Information Pathway Project and the new Public Health Wales NHS Trust post, funded by Macmillan Cancer Support, is designed to support each person with cancer being offered, through their care plans, written information about their disease, treatment and supportive care including psychological.

If Key workers /CNS are responsible for agreeing and communicating care plans, and helping with understanding of information, then the lack of a key worker will impinge directly on their ability to make informed decisions and cope with the effects of their treatments.

The Voluntary sector: national and local cancer charities and support groups, age concern, etc., have supported the provision of good quality information to patients, carers and family members close to home, assisting with compliance of information needs. More referrals are being received from health providers. However, this service can be tenuous and sustainability is an issue.

The Macmillan Cancer Information and support in Libraries projects that have been funded across Wales come with a three year funding and the first information co-ordinator is coming to the end of her funding and other projects will follow. Traditionally Macmillan fund for three years with the expectation that the host organisation will take over funding after that time. In the current financial climate that is not happening.

Likewise benefits advisers have terminated when their funding ran out. Other charities I believe have received lottery funding for some of their services which again is time limited. The government and HBs needs to be mindful of this situation which could potentially leave further gaps, inconsistencies and inequality in patient centred information and care. A classic example of this is when Cancer Care Cymru ceased to exist leaving a huge gap with regard to CNSs. LHBs had to employ the nurses over a period of time, some financed by Macmillan but still leaving gaps in provision.

A comprehensive cancer patient information service needs to be seen as a core service within the HB which does not stop it contracting out this service to the voluntary sector.

4. Carers & family support

Carers also need support to look after themselves as well as their loved one, especially in palliative care when the patient is being looked after at home. Carers are often kept in the dark, under huge psychological stress and need to be kept informed and supported. I would like to see specific targets and performance outcomes for carers and family support.

5. Process & Outcomes

The Health Minister commented, “that the cancer delivery plan has overtaken the cancer standards, that there is a change of focus from the process and mechanics of service delivery to delivering continuous improvement in quality care and outcomes. “

The Health Minister has delegated the process, mechanics and monitoring of cancer standards to HBs so they can concentrate on the new population outcomes: incidence rates, mortality, one and five year cancer survival... in effect, how many lives are saved and/or quality of life managed better.

However, I don't think that the process and the mechanics should be undermined as they have been an important part of consistent patient centred care across cancer sites and locations and have improved the patient experience. It is the difference between fearing the unknown and knowing exactly what to expect. I believe that the cancer standards have provided HBs with an excellent platform from which they can work to set up new processes to achieve the new outputs.

6. Patient Power: Continuous improvement in quality care and outcomes

Patient engagement

I believe that the government's engagement with Macmillan on the patient survey will indeed provide valuable information on patients' need for co-ordinated information and support, as did Rhondda Breast Friends' Community cancer conference and leading to the petition.

Patient action: patient power

I believe it is a time for openness, transparency and empowerment and we have seen this reflected in the requirement to publish Annual reports in the public domain.

Informing patients in writing of their agreed care plans and what looks like “excellent service, the best in the world” and getting feedback at various stages in the cancer journey would ensure that “quality and patient-centred outcomes” are evaluated and continuously improved by those using the service.

Action -Patient Power monitoring system

Set up a pilot “Measure your quality outcomes treatment” [MyQoT] feedback system to inform, empower and feed back on the quality of individual cancer care. Patient centred care

feedback systems can be piloted /implemented to replace government monitoring, given at each stage of treatment for monitoring

Examples of patient empowerment – the good practice

The First Minister recently launched Cwm Taf’s bowel cancer DVD that won national acclaim. The DVD was designed to prepare patients for going into hospital and to familiarise them with the diagnostic and surgical procedures and treatment they may undergo while there. It effectively provides a virtual tour for patients and is an excellent example of the vital part played by informing patients of the process and mechanics of their treatment care plan. I believe that the quality of the service will in fact be determined by the process and the trained, experienced, dedicated personnel undertaking the “process.”

Breakthrough Breast Cancer has a brilliant publication, “The Best Treatment: Your guide to breast cancer treatment in England and Wales, (July 2012). (Link provided in reference section).It was first published in 2004 to provide a guide for women during their breast cancer treatment journey. It includes information from documents and official guidelines used by health professionals, with an explanation of what they mean for you, the patient (Cancer Standards, NICE guidelines etc.) It explains why you might be offered certain tests and treatments, and what to expect if you need them. It equips you to have informed discussions with your doctors and nurses, so you are able to play as full a part in decision-making about your treatment as you’d like to. I discovered this book after my treatment and if I had known about a “triple assessment” sooner, I would have pressed for a biopsy which could have potentially saved my daughter’s life.

Examples of patient helplessness - the bad & the ugly

There is a lack of public knowledge regarding treatment guidelines and what is “patient centred care.” Many people come to me because they don’t know where to turn, So much of cancer care seems to rest on the patient asking for answers or help and for those afraid to ask, afraid they won’t understand the answers, afraid of seeming weak and helpless there is ignorance, anxiety, uncertainty and fear.

My husband has recently had bowel investigations at Prince Charles hospital and I was extremely impressed with the service, communication and written feedback supplied to him the next day, I rated it 1st Class. I have supported other patients and I could not believe the differences in experiences ranging from: misunderstanding of diagnosis given, appointment letters not received, referrals not actioned, side effects and after effects of treatment ignored, lack of information, not knowing where to go for help....practical, emotional, financial and other. Patients are often still left in the dark worrying about their condition and treatments.

Action:

- Key workers are this seasons must have -NOW
- Empowerment: Best treatment guidelines –NOW
- Care Plans – NOW

CONCLUSION

When I see how much work has been put into improving cancer services in Wales and how much has been achieved since 2008 I am filled with gratitude, hope, enthusiasm and optimism for full compliance with the standards and evidence of improved outcomes.

Areas of concern noted:

- Key workers, should be prioritised for compliance as without them other patient standards will fail and those people will have a much worse experience than others fully supported with a key worker.
- Carers can often be left out of the support cycle
- The importance of the Voluntary sector in supporting information and support services should be recognised.
- Patient empowerment with treatment guidelines.
- Access to GPs
- Additional support for areas of high deprivation and poor cancer outcomes

Opportunities

- Set up a pilot “Measure your quality outcomes treatment” [MyQoT] feedback system to involve patients in evaluating various stages of their treatment


Thank you once again for giving me the opportunity to comment on the evidence supplied by the Health minister.

Regards,

Diane Raybould

Rhondda Breast Friends

Appendix/Attachment/Links

1. Key worker role _excerpt Macmillan Policy Report 2011
 2. The best treatment: your guide to breast cancer treatment in England and Wales (Edition 2, reprint July 2012) (1191 kb)  (link), or copy and paste ...
www.breakthrough.org.uk/document.rm?id=1924
 3. National Standards for Rehabilitation of Adult Cancer Patients (link)
www.wales.nhs.uk/sites3/Documents/322/National_Standards_for_Rehabilitation_of_Adult_Cancer_Patients_2010.pdf
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APPENDIX 1

CHANGING CANCER CARE IN WALES

A report by Macmillan Cancer Support

March 2011

Access to an identified key worker

Every cancer patient should have access to a named key worker who understands their needs and is able to support them during and after treatment.

In May 2010 the government announced that all people with a cancer diagnosis in Wales would be given a key worker to coordinate their care. The new Local Health Boards were required to implement the policy by March 2011. We warmly welcomed this announcement. We understand the work has begun, but as yet there is no nationally agreed, clear definition of the key worker role. And most planning for the scope and function of the key worker role in Wales is being undertaken locally. This may lead to inconsistency and geographical inequality in the level and quality of service provided.

We believe it is important that the implementation of the key worker initiative in Wales is consistent. Although key workers may be different professionals at different stages in a person's cancer journey, there should be consistency in their functions and responsibilities throughout Wales. With the current approach there's a risk that the type of key worker a person has to support them will depend on where they live rather than on their needs and circumstances.

In developing the role of the key worker, it is vitally important to consider continuity of care. Issues such as access to key workers out of hours, the transition from secondary to primary care and the use of electronic records are all essential to the success of this initiative. In order to ensure consistency across Wales, the role and remit of a key worker must be agreed at a national level by the end of the first year of the next assembly term. By the end of the second year of the next assembly term, we want every person living with or beyond cancer in Wales to have access to a relevant, named key worker.

What is a key worker?

What should a key worker do?

Based on our research, and work carried out by governments elsewhere in the UK, the role of the key worker is to:

- Be a main point of contact.
- Undertake assessments, agree care plans and ensure the details of the care plan are communicated to the person living with cancer and others involved in their care.
- Be ultimately responsible for coordinating care and managing care transitions.
- Provide information about cancer treatment and its effects. Help the person living with and after cancer to understand that information so they can make informed decisions.
- Find out what additional help and support the person needs and make sure they get it. This may mean signposting them to other support services, such as financial advice, practical help and emotional support. Ensure people know who to contact when they have questions or need help.
- Give advice to the person and their carers.

It should be acknowledged that the implementation and coordination of a person's care may be carried out by a number of clinical and non-clinical professionals.

Who will they be?

During the treatment phase, the key worker is likely to be the clinical nurse specialist. After treatment, the most appropriate key worker will depend on the type, severity and advancement of the cancer and the needs of the person. For people living with and after cancer who have complex needs, their key worker is likely to be very involved. For those who have moderate needs, their key worker will be less involved. For people who have no complex needs, they are likely to have more limited contact with their key worker, although the key worker should be available if any issues arise. The important thing is that the person living with and beyond cancer knows who their key worker is, and the key worker knows their responsibilities to that person.