Letter from Minister for Health and Social Services #1

Edwina Hart AM MBE
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/04772/08
Your ref:

21 OCT 2008

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Val Lloyd AM
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

21 OCT 2008

21st October 2008

Dear Val

Thank you for your letter of 6 October on behalf of the Petitions Committee asking for an update on the position of Local Health Boards (LHBs) in delivering the National Cancer Standards by March 2009 and, in particular, the position in relation to Rhondda Cynon Taff LHB. You also ask what sanctions and actions will follow in the light of any non-compliance with the Standards.

At the time the Standards were published in 2005, the Cancer Networks were required to map and assess current services against the Standards and develop formal action plans to map the journey to full compliance. All LHBs have action plans in place and the three regional Cancer Networks are working to support the LHBs to achieve the standards by March 2009. Progress against action plans is monitored carefully by the Regional Offices.

With regard to Rhondda Cynon Taf LHB, it is working with Cwm Taf NHS Trust on a delivery plan which details the remaining gaps and further work required towards compliance with the Standards. This plan should be finalised at the end of the month. The South East Wales Cancer Network is monitoring progress with compliance, providing quarterly progress reports to the South East Wales Regional Office.

The recent merger between the two Trusts will have made some issues more complex for the newly formed Cwm Taff NHS Trust but it is fair to say that the merger will have provided opportunities for some non-compliance issues to be overcome.

My Regional Office officials meet regularly with the Network and key leads in the Trust and LHB to assess progress against the delivery plans.

Regarding your question about the application of sanctions for non-achievement of the targets, I do not believe it is right or proper that I should set out the potential consequences for an LHB in advance of the deadline for implementation of the National Cancer Standards. However, I can assure you that the NHS performance management framework provides me with a wide range of interventions and sanctions that I can use if the required levels of performance are not achieved.

Response from petitioner

Rhondda breast friends

Registered Charity No: 1113717

2nd December, 2008

Dear Gareth,

Petition: National Cancer Standards

Thank you for your feedback from the Petitions Committee received 21st November, 2008.

I read the minister's letter attached but did not quite understand it.

Paragraph 2 states "All LHBs have action plans in place………progress against action plans is monitored carefully by the Regional Offices"

Paragraph 3 gives details of RCT's "delivery plan……should be finalised by the end of the month." (October)

Are these conflicting statements? Is the "action plan" which is apparently in place, the same as the "delivery plan" which is still to be completed?

We set up a Cancer Focus Group in RCT to raise the profile of cancer issues locally when it was felt that the new Health Social Care and Wellbeing Strategy did not address the needs of people with cancer in RCT. A meeting with the Local Health Board on 18th April reported that there was no specific implementation plan for Cancer Standards for RCT and no funding. We were congratulated on our Charter but told not to get our hopes up but that they (our health providers) wished us well!

The Cancer Focus Group adopted The Charter of Rights resulting from Rhondda Breast Friends (RBF) Community Cancer Conference as a local action plan in the absence of anything else. What really worries me and fills me with great sadness is that if an action plan exists, and they have not been able to provide us with one to date, then absolutely no involvement or participation has taken place. The LHB are well aware of the Cancer Focus Group and we now have 2 sub groups for cancer information and cancer carers.

The Information Sub Group, working with the Cabinet member in RCT,

- has succeeded in getting the local authority to agree to extend their chronic conditions library to include Cancer and the LHB have donated £1000 towards it.
- We are working with patient support officers in Velindre, Merthyr and Royal Glamorgan and we have seen many examples of good practice. The North Wales Cancer Network has developed a "Patient Information folder" containing general information for newly diagnosed patients which is supplemented according to individual need and this written information supports the advice given by the cancer patient's team. Well done North Wales……………….so sad it is not available across all Wales.
- The Velindre Patient Involvement group provide basic packs which are sent out to feeder hospitals but we do not know of anyone who has ever received them. This is being investigated by the group.
- When asked about south Wales I am told the "All Wales Information Group" started but was discontinued when the lead left……?

The Cancer Carers sub group have organised a carers' involvement event (see enclosed draft report) and we are meeting with Macmillan this week to discuss possible funding initiatives. The report findings identify a lack of support for carers although they are identified in RCT's strategic Carers plan. I am informed that about 6 out of 37 surgeries in RCT have "Carer Champions". To date approaches to the LHB on this matter has met with a brick wall and we have been referred to other organisations and charities. The Cancer Standards includes information & support for carers, which the report clearly identifies is lacking.

So what is the LHB & Cwm Taff Trust doing????

- At our Cancer Focus Group on 4th September we were promised 2 seats on their Cancer Strategy Group which we took up directly. To date, despite contacting them, we have heard nothing and no notice of dates or meetings given, but can they now report patient involvement because in writing we have been allocated 2 seats?
- They have been unable to give us a copy of their "Cancer Plan" and in their defence I was told that "RCT are not the best, but not the worst in Wales". I took this to mean that other LHB also have not completed their plans.
- And the patient forum of the Cancer Network in Cardiff does not wish to discuss individual's experiences………
- And the Community Cancer Services in Tonypandy is closing………………..

So…….I grow weary. I work late into the night to keep the momentum going with the Focus Groups and all I ask is involvement of those people strong enough to tell of their patient and carer experiences to inform of future service improvements.

At a recent Cancer Network Learning Day it was stated that although there may have been improvements in medicines in the last 10 years, the patient experience is still the same. A GP standing by the side of Dame Ilora Findlay then commented from the stage, "There is no such thing as psychological pain, once the medication is adjusted the pain goes away……………
If you haven't guessed yet, my psychological pain is still here…………………………

So I considered how I would find out about LHB plans and how I could evidence what is happening elsewhere. Do I ask every LHB for a copy? Do I write to AM's asking them to approach the LHBs, or do I do nothing? And will it change anything anyway? No wonder public participation is seen as a waste of time!

In Summary

- The Welsh Assembly Government has invested a great deal of time, effort and money in developing cancer standards which I think are brilliant and address patient centred care.
- This petition has proved invaluable to date and even if we have not received their plan, the LHB are working on it………….that is progress.
- Patient participation is high on the Governments agenda

but

- I am disappointed that our LHB appear not to embrace the ideals of the Assembly Government or the pain of cancer sufferers.
- That good practice with Patient Information is not shared across the whole Cancer Network
- And that I, a mere mortal, on a voluntary basis, have to fight the might of gigantic organisation to get the justice promised by the Assembly Government.

Thank you for your time and consideration to date, Yours sincerely, Diane

Chairman: Diane Raybould, 15 Bronheulwen, Porth, Rhondda CF39 0BJ Tel: 01443 683220,
Email: di.bri@hotmail.co.uk

Prif Weithredwr/Chief Executive: Mr M S Evans
Cadeirydd/Chairman: Dr C D V Jones

Letter from Rhondda Cynon Taf Teaching LHB

Teaching | Addysgu
Bwrdd Iechyd Lleol
Local Health Board
Rhondda Cynon Taf
Rhondda Cynon Taff

Val Lloyd
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Date 22nd January 2009

Our Ref : MSE/RR/VL

Your ref: PET-03-150

30 JAN 2009

Dear Val,

Re: Petition – National Cancer Standards

Thank you for your letter dated 19th January 2009 regarding the petition from the charity 'Rhondda Breast Friends'. I acknowledge the concerns that are expressed in the letter of response from their Chairman, Mrs Diane Raybould, dated 2nd December 2008.

The recent merger between North Glamorgan NHS Trust and Pontypridd and Rhondda NHS Trusts has included the appointment of a new cancer services manager and trust lead clinician. As you will appreciate, the need to gain a full understanding of the current issues and the complexities of providing services across the newly formed Cwm Taf NHS Trust is of paramount importance.

As Local Health boards we are dependant on Cwm Taf trust to provide the operational detail required in the delivery plan. We have now received this document and it is scheduled for discussion at our next scrutiny committee at the end of January.

The Trust has established a cancer strategy group to oversee the delivery of the Cancer Standards. A cancer delivery plan has been developed. This includes as attachments to support its deliver: an action plan to deliver cancer site specific standards, the CANISC Implementation plan and a 2008-11 strategic framework action plan. Some actions identified in the cancer delivery plan are in many cases already being implemented as the target date approaches.

With response to the specific issues raised in the Petition:

The confusion in terminology between 'action plan' and 'delivery plan' in the Ministers letter may be due to the generic use of the term action plan in paragraph 2, whereas the delivery plan in paragraph 3 refers to the Local Cancer Service Delivery Plan in response to the Cancer Standards.

NHS WALES GIG CYMRU
INVESTORS IN PEOPLE

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With regard to the issues raised as part of the consultation on the Health Social Care and Well Being Strategy, a formal response was made to Mrs Raybould. A copy letter is attached for your information.

The LHB is aware of good work undertaken by the Cancer Focus Group and continue to offer their support where ever possible. However, we are not able endorse individual groups and our formal engagement with the voluntary sector in Rhondda Cynon Taf is through Interlink.

Unfortunately, I am unable to comment on information provided by Velindre NHS Trust to their patients, as am I unable to comment on the 'All Wales Information Group'.

The Cancer Strategy Group is a quarterly group, attending by health care professionals and non health care professionals across Cwm Taf. In addition the LHB is invited. As stated in the petition, 2 seats have been allocated to Rhondda Breast Friends.

The last meeting of the Cancer Strategy Group took place 19th December. I understand that Mrs Raybould has been nominated as a representative to attend this group and as such attended. Following concerns in relation to the quality and availability of patient and carer information across Cwm Taf, Mrs Raybould has been asked to participate in a review of patient and carer information available across Cwm Taf.

A copy of the local Cwm Taf Cancer Standards Delivery Plan was emailed to Mrs Raybould 11th December 2008. This included details of our progress against the cancer site specific stands and compliance with CANISC and a summary of our position against the strategic framework

The role of the South East Wales Cancer Network is to provide strategic direction to service developments across south east Wales. Any issues relating to individual experiences should be addressed with the relevant organisation and lead. With regard to the patient forum of the Cancer Network in Cardiff, unfortunately I am not a member of this forum and therefore unable to comment. May I suggest that this issue and the concerns expressed regarding disseminating of patient information across the network, is discussed with Eleri Girt, Macmillan Patient Involvement Facilitator, South East Wales Cancer Network.

The Local Health Board hopes that the response in this letter has answered the petitioners concerns satisfactorily.

If we can be of any further assistance please do not hesitate to contact us.

Yours sincerely,

Mel Evans
Joint Chief Executive / Prif Weithredwr ar y cyd
Merthyr Tydfil LHB and Rhondda Cynon Taff Teaching LHB / BILI
Merthyr Tudful a BILI Addysgu Rhondda Cynon Taf

Letter from Minister for Health and Social Services #2

Edwina Hart AM MBE
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/00634/09
Your ref: PET/03/150

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Val Lloyd AM
National Assembly for Wales
Cardiff Bay
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RECEIVED
-2 MAR 2009

3rd March 2009

Dear Val

Thank you for your letter of 16 February on behalf of the Petitions Committee, asking to be informed of Local Health Board (LHB) implementation of the National Cancer Standards, once the March 2009 deadline has been reached.

LHBs have action plans in place on the implementation of the Standards and are working with the Regional Cancer Networks to achieve these Standards by March 2009. Progress against action plans is being carefully monitored by the Regional Offices.

In April 2009 the NHS will complete a detailed self assessment of its compliance with the National Cancer Standards. Detailed reports on compliance will be provided for the LHBs by the three Regional Cancer Networks, working with the Cancer Services Co-ordinating Group (CSCG), commencing in June. The CSCG will prepare an all-Wales summary report for me in July. I have also asked CSCG to look at how I can present the outcome of this exercise to assess compliance with the Standards to the public in a meaningful way.

RECEIVED
05 MAR

Letter from Minister for Health and Social Services #3

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/07332/09
Your ref: P-03-150

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Val Lloyd AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
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NB AM

8 December 2009

Dear Val

Thank you for your letter dated 26 November on behalf of the Petitions Committee about the outcome of the Cancer Services Co-ordinating Group's (CCSG) all Wales report on performance against the target requiring full compliance with the National Cancer Standards by March 2009.

I have seen this report from my Lead Adviser for Cancer and Director of CSCG, Dr Jane Hanson, which is based on a self assessment by the NHS undertaken in April. After discussing the report with Dr Hanson, I agreed to her suggestion that she ask the NHS to submit reports to reflect all progress and improvements since the April self assessment to provide me with an up to date picture of performance across Wales. I am awaiting formal advice from Dr Hanson and officials on what action I should take and I will write to all AMs on this shortly.

Letter from Minister for Health and Social Services #4

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/00328/10
Your ref: P-03-150

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Christine Chapman AM
Chair
Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

8 February 2010

Dear Chair

Thank you for your letter dated 29 January on behalf of the Petitions Committee asking to be provided with the findings of the Cancer Services Co-ordinating Group's all Wales report and a summary of the progress made by the NHS since the April self assessment.

The results of the April 2009 self assessment against the National Cancer Standards showed areas of non compliance. The update report on the position at the end of October was prepared for me by the Cancer Services Coordinating Group and showed improvement. This information is for use by the Assembly Government for performance management purposes and by the NHS to inform its future planning and delivery of cancer services and is not intended for public consumption.

In the light of the reports on performance, the Assembly Government will write to the Local Health Boards (LHBs) setting a new deadline of the end of September this year to achieve full compliance across Wales. LHBs have been asked to produce action plans by the end of February setting out the action needed in order to achieve this. Each LHB is required to designate a formal executive lead for cancer services.

The Assembly Government is also setting up a Cancer Implementation Group, responsible for overseeing and performance managing this process. This group will report progress to me.

Letter from Minister for Health and Social Services #5

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/01154/10
Your ref: P-03-150

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Christine Chapman AM
Chair - Petitions Committee
National Assembly for Wales
Cardiff Bay
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13 April 2010

Dear Chr,

Thank you for your further letter dated 30 March asking about the work undertaken on the National Cancer Standards and whether action plans have been agreed by Local Health Boards (LHBs) to meet the Standards by September 2010.

The Cancer Services Co-ordinating Group report to me on performance against the National Cancer Standards which was based on the NHS self assessment in April 2009 showed varying levels of compliance across Wales. The updated report on performance in November, however, showed that improvements had been made.

All LHBs have produced action plans and are aware of my expectation that they will achieve the deadline of September 2010 for full compliance with the Standards. One of my senior officials is Chairing a group made up of the nominated executive leads for cancer in each LHB to monitor progress closely.

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/01579/10
Your ref: P-03-150

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Christine Chapman AM
Chair
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17 May 2010

Dear Chris.

Thank you for your further letter of 5 May about the work undertaken on the National Cancer Standards.

Achieving compliance with the National Cancer Standards is the cornerstone of my policy on tackling cancer and improving outcomes for patients. To help the NHS achieve these Standards, I announced an additional £4.5m central recurrent funding in 2007-08.

The Cancer Services Co-ordinating Group's (CSCG) report to me last year on performance against the National Cancer Standards showed that non compliance was for a variety of reasons. In some cases this was due to missing data which is simple to remedy whilst other areas, such as waiting times for radiotherapy, are more challenging.

The Local Health Board (LHB) Executive Leads for cancer are leading the work on compliance with the National Cancer Standards, but each Board is accountable for ensuring cancer services for the LHB's resident population meet these Standards.

I should emphasise that while there is still room to improve cancer services in line with the Standards, our clinical outcomes are good and improving as shown by the regular reports from the Wales Cancer Intelligence and Surveillance Unit, and national clinical audit reports. Services are improving year on year with new technology, latest clinical practice and evidence.

Letter from Minister for Health and Social Services

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/02098/10
Your ref: P-03-150

Llywodraeth Cynulliad Cymru
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Christine Chapman AM
Chair
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National Assembly for Wales
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5 July 2010

Dear Chair

Thank you for your further letter dated 21 June asking how National Cancer Standards performance information is communicated to the public.

The Cancer Services Co-ordinating Group (CSCG) has developed a summary document of the original technical report on cancer standards compliance. This was put on the CSCG internet site on 4 June 2010. The link is:

http://www.wales.nhs.uk/sites3/Documents/322/National_Cancer_Standard_Report_on_Compliance_2009_-_Summary_for_Patients_%26_Public.pdf.

This report is intended to provide the public with an informative picture of cancer services across Wales in the light of the 2009 self assessment process by providing a contextual narrative. Following the end of September this year, there will a further round of self assessment against the National Cancer Standards and CSCG is currently looking at how best to present these results in a way that is meaningful to the public and the NHS.

Response from Powys Health Board

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NHS WALES
Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

Cyfarwyddiaeth Nyrsio
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Nursing Directorate
Phone: 01874 712652
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e-bost/email:: carol.shillabeer@powyslhb.wales.nhs.uk

Our ref: CS/CP/FOI/10.R.106

1 July 2010

Your ref: P-03-150

RECEIVED
06 JUL 2010
[illegible]

Christine Chapman AM
Chair Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF99 1NA

Dear Ms Chapman

Request under Freedom of Information Act 2000

Further to your previous correspondence in respect of your request for information which we originally received on 25 June 2010, I can confirm in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Health Board holds the information you asked for.

I am therefore pleased to enclose the information held by the Board and we will be working with all our providers to ensure the actions within the plan will be achieved.

If you need any further assistance, please do not hesitate to contact us at the address below.

I trust this information is helpful to you. If you are dissatisfied, with the way your request has been dealt with by the teaching Health Board (tHB), you have the right to request a review in which case you should write to:

Andrew Cottom
Chief Executive
Powys Teaching Health Board
Mansion House
Bronllys
Powys
Brecon
LD3 0LS

Bwrdd Iechyd (addysgu) Powys
Y Plasty, Bronllys, Aberhonddu, Powys LD3 0LS
Ffon: 01874 711661 Ffacs: 01874 712554

Powys (teaching) Health Board
Mansion House, Bronllys, Brecon, Powys LD3 0LS
Telephone: 01874 711661 Fax: 01874 712554

NHS GIG

Rydym yn croesawu gohebiaeth Gymraeg
We welcome correspondence in Welsh

POSITIVE ABOUT DISABLED PEOPLE
GADARN O BLAID POBL ANABL

If you are still dissatisfied at the end of the review, you may complain to the Information Commissioner, who can be contacted at the following address:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SH9 5AF

Yours sincerely

Carol Shillabeer
Director of Nursing

Encs

Powys tLHB Achieving National Cancer Standards : Action Plan May 2010

Standard Non Compliance	**Current Position**	**Action required**	**Powys Lead**	**Deadline partner leads**
Non Surgical Oncology:			**VS SC**	
1. Radiotherapy Provision	Radiotherapy waiting times are monitored and reported on by all providers	1. Working with Cancer Networks to continue to monitor waiting times.		1.Ongoing
		2. Agreed in principle support for Radiotherapy unit at Hereford Hospital		2.Awaiting DOH funding agreement to commence build
		3. Received and support in principle Velindre Cancer Centre Business Case to increase Lineacs		3.Ongoing
2. Chemotherapy redesign	Outreach Chemotherapy available in one area only	Audit in progress to assess number of treatments given to Powys residents by post code, the toxicity of the treatments and the feasibility of outreach clinics and their most accessible location determined in partnership with Velindre, ABMU, Bronglais Hospital, SWWCN and the English Cancer Networks.	**VS SC**	July 2010

Service Redesign to achieve 'IOG' for certain cancers	Reconfiguration underway in all Cancer Network areas	1. Support the configuration where appropriate to ensure delivery of care is provided within 'IOG '. 2. Powys tLHB Lead Cancer Clinician to meet all providers to define pathway	**VS SC**	3 CCN area: Head & Neck in consultation Haemo- Oncology: awaiting strategic HA directive GMCN area: agreements in place following outstanding 'IOG' review Nov 2009 Project manager appointed: work ongoing South Wales Cancer Networks: Ongoing
Radiology, Histopathology CNS input to MDTs AHP requirements	Compliance varies widely between Health Board and Cancer site Specific Groups	Powys tLHB Lead Cancer Clinician to meet all providers and will review compliance and discuss barriers to achieving these standards.	**VS SC**	July 2010

Psychology services	Compliance not achieved in all areas	Powys tLHB Lead Cancer Clinician to meet all providers to discuss. Potential for referral to Powys Community Based services where appropriate	**VS SC**	July 2010
GP receipt of patient diagnosis in 24hours	Compliance not reported/ achieved in all areas	Primary Care audit of receipt of information on cancer patients within 24hours of diagnosis to compliment secondary care internal audit of compliance	**VS SC**	July 2010
Improved Audit	Audits are in place but more required to achieve compliance in all areas	Work through the Cancer Network and Health Boards to ensure improved audit activity	**VS SC**	July 2010
Communication policies	Majority of providers have these in place	Powys tLHB Lead Cancer Clinician to meet all providers and will review compliance	**VS SC**	July 2010

Dr Susan Closs MA FRCP FRCPath
Locum Consultant in Palliative Medicine and Cancer Lead Clinician, Powys
Veronica Snow Cancer Network Liaison Manager Powys tLHB

Response from ABMU Health Board

GIG
NHS
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

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30th June 2010

Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Ms Chapman

Petitions Committee: P-03-150 National Cancer Standards

In response to your letter regarding the above I am pleased to inform you that ABMU Health Board is confident that the standards will be achieved by the end of September subject to the successful appointment of a Consultant Oncologist.

Yours sincerely

DAVID SISSLING
CHIEF EXECUTIVE

Response from Hywel Dda Health Board

GIG
NHS
Bwrdd Iechyd
Hywel Dda
Health Board

Dyddiad/Date:	5th July 2010
Ein cyf/Our ref:	PCMH 0701_10
Gofynnwch am/Please ask for:	Mrs Bernardine Rees
Rhif Ffôn /Telephone:	01437 771225
E-bost/E-mail:	bernardine.rees@wales.nhs.uk

[illegible]
1[illegible] JUL 2010

Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
CARDIFF CF99 1NA

Dear Ms. Chapman

PETITIONS COMMITTEE: P-03-150 NATIONAL CANCER STANDARDS

Thank you for your letter of 21 June 2010 regarding the Health Board's compliance with meeting the cancer standards.

We are confident that we will meet the standards which are related to the quality of the service we deliver within the Hywel Dda health community, those relating to communication, information, access to services and the structure and format of the multi-disciplinary meetings.

However, we are currently experiencing significant difficulty in appointing to vacant consultant posts, particularly in key support services such as pathology, which will affect our ability to deliver 100% of the standards.

At this time, we are exploring options for consolidating services and our future clinical strategy where we aim to create a larger mass of service to improve stability and sustainability. This will not be without impact upon patients, some of whom will need to travel further to receive services currently provided locally to them, but if a change is not made, the Health Board will not be in a position to deliver high quality and safe services to its residents.

Cont'd ...

Service reconfiguration will take time and the appointment of clinical staff is not guaranteed, but we will be seeking opportunities to work in partnership with neighbouring health boards to address these areas on a case-by-case basis and the timescale for delivering these solutions will be dependant upon the specific service, the supply of available consultants and the available capacity in neighbouring Health Boards.

If I can assist further, please do not hesitate to contact me.

Yours sincerely

TREVOR PURT
Chief Executive

AM Response from Aneurin Bevan UHB

GIG NHS
Bwrdd Iechyd
Aneurin Bevan
Health Board

Ref: AG/JP/law/AM-MP 199 Direct Line: 01495 765072 22 July 2010

RECEIVED
03 AUG 2010

Ms Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Ms Chapman

Petitions Committee: P-3-150 National Cancer Standards

Thank you for your letter dated 21st June regarding the above.

The Health Board is making every effort to ensure it is in a position to meet the National Cancer Standards by September 2010. Detailed action plans are in place within each of our specialities and additional investment has been made available to ensure our services are able to comply with the requirements of the standards. Periodic reviews undertaken by the National Cancer Standards Co-ordinating Group (CSCG) indicate that we are making good progress and our compliance is improving.

Our commitment to providing excellent care for cancer patients can also we demonstrated by our good track record of performance against the AOF targets for cancer waiting times. In May we achieved 97.2% compliance against the 62-day target compared to an all Wales performance of 90.6%. Against the 31-day target we achieved 100% compliance against an all Wales performance of 98.1%.

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I trust this provides the Committee with sufficient information but if I can be of any further assistance please do not hesitate to contact me

Yours sincerely

Dr Andrew Goodall
Prif Weithredwr/ Chief Executive

cc Mr Duncan Ingrams, Lead Clinician
Mr Mike Hague, Cancer Services Manager

KM

Response from Cwm Taf Health Board

GIG
NHS
Bwrdd Iechyd
Cwm Taf
Health Board

Your ref/eich cyf: PMW/CWHITE/BS
Our ref/ein cyf: SS/MSF/DD.405
Date/dyddiad: 6 September 2010
Tel/ffôn: 01443 744803
Fax/ffacs: 01443 744888
Email/ebost: margaret.foster@wales.nhs.uk
Dept/adran: Chief Executive's Office

Christine Chapman AM
Chair, Petitions Committee
Cardiff Bay
Cardiff
CF99 1NA

RECEIVED
15 SEP 2010

Dear Christine

Re: Delivering Compliance with the National Cancer Standards

Thank you for your letter dated 27 August 2010.

I am able to confirm that Cwm Taf continues to make significant progress towards full compliance with the Cancer Standards but that this will not be fully achieved by the end of September 2010.

Cwm Taf is fully engaged with Network Solutions to achieve compliance in upper GI, Head & Neck and Urology. To achieve compliance these require major patient pathway re-design and are at varying stages of the implementation process, but are all proceeding well.

Cwm Taf has made very significant progress towards compliance for those areas which fall within its own span of control. The outstanding issues involve implementation of guidelines, protocols and audit programmes, most of which will be in place by the end of September.

To achieve full compliance for all Standards within its own span of control, the Health Board must implement structural changes which cannot be implemented prior to the end of September 2010. The organisation has been actively working towards compliance since 2008. A notable example of success in this category is in Breast Cancer. The Health Board continues to work actively with cancer and other clinical teams to maximise usage of human and physical resources including the use of technology to combine MDTs where possible, re-design of pathology, radiology and specialist palliative care services to improve core attendance at MDTs.

The rate of improved compliance for Cwm Taf in both generic and cancer site, specific standards have improved significantly since 2008. By the end of September 2010 compliance levels will be improved further but plans to achieve full compliance will not be fully implemented.

Yours sincerely

Margaret

Mrs M S Foster
Chief Executive

Response from Jan Williams, Cardiff & Vale University Health Board

GIG CYMRU
NHS WALES
Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

BRIEFING REPORT ON ACHIEVING THE NATIONAL CANCER STANDARDS

1. INTRODUCTION

This report has been prepared to present the latest information on progress towards the achievement of the cancer standards in Cardiff and Vale University Health Board (UHB). It highlights the areas of compliance and the areas of risk as well as the actions being taken towards achieving compliance by September 2010.

2. BACKGROUND

As part of the monitoring process, the UHB reviews its progress on a quarterly basis, with submissions made to the South East Wales Cancer Network.

The Cancer Services Team has been collating the recent sets of self-assessment reports at a cancer site level for discussion at the Cancer Management Meeting so that actions such as agreeing guidelines, audit plans etc can be prioritised towards meeting the Standards.

Scores against the Standards have been allocated for each Multi Disciplinary Team (MDT) and these have been provided to the Cancer Tumour Site Leads and the appropriate managers. Action plans for each of the tumour sites have been developed that identify the risks and actions required against each individual standard.

Initial meetings have been held with the Cancer Leads and managers to discuss these reports in detail, and a further meeting is planned with all the Cancer Leads to monitor progress and agree what actions are required to ensure compliance.

In addition to the primary objective of assessing compliance, this process has been particularly useful in identifying where there are still gaps in the provision of information, and also where questions have been misinterpreted.

3. TRAFFIC LIGHT SYSTEM

A “traffic light” system has been adopted as part of the performance reporting in order to ensure that attention and effort is placed on those standard areas where further work in required and actions are prioritised accordingly. This is as follows:

- Green – Low Risk.
- Amber – Medium Risk - Plans in place and on target, or areas where progress is being made but not in line with overall timescales for delivery of the standards; however actions have been agreed to achieve the overall target within agreed timescales.
- Red – High Risk -progress not in line with plan and corrective action has not been agreed/financial implications

4. PROGRESS

Significant progress continues to be made:

- The UHB have processes for internally managing the achievement of Standards including regular meetings with clinicians, and with local commissioners and the Network.
- Continued roll-out of CaNISC across the Tumour site for use of the MDM at the MDT meeting
- Communications Policy, produced by the Network has being evaluated by the UHB for local adoption.
- The UHB has also produced a Communication Strategy for Board approval. The Directors are considering the Strategy's evolution into a Communications and Engagement Strategy. This work is on-going and the final document is due to go to the Board in September 2010. The new document has an extensive evaluation section.
- In an attempt to ensure continuous improvement in patient care – communication the UHB is looking at ways it can work with patients to understand better how their experience was as a patient receiving care. Work in this area includes patent questionnaires. Cancer Services are currently liaising with the Assistant Director of Patient Experience to progress this as a joint procedure.
- There have been improvements in Radiology and Pathology cover for all MDTs in C&V.
- Cancer Intranet site including details of MDTs, contact details for referral, details of End of Life Pathway etc being developed by Cardiff & Vale UHB to aid communications across the organisation.
- New Breast Unit at Llandough on schedule to open October 2010
- Additional MDT coordinators and cancer data clerks appointed for fixed term at Cardiff & Vale. Funding for these posts is non recurring and discussions re funding are ongoing.
- Cardiff and Vale UHB is investigating the use of the WCCG Gateway to improve links with Primary Care, including e-referral, notifying GPs of diagnosis within the required 24 hours.
- Review of MDT administrative support structure to ensure all MDTs at C&V UHB are appropriately supported.
- Role profiles produced for MDT Tumour Site Leads at Cardiff and Vale which strengthen their ability to ensure MDT members undertake their role in compliance with the standards. Also the UHB is reviewing job plans to ensure that MDT attendance for core members is recognised.
- Timed pathways have been developed for all tumour sites and are being used for performance monitoring against the 31/62 day targets. These have been built into a data monitoring tool by the Cancer Services Improvement manager for performance monitoring.

- Providing information on clinical activity such as number of patients, management by team, types of surgery undertaken – is now better available to support MDTs by the increased use of CaNISC.

5 MAIN OUTSTANDING ACTIONS

The main outstanding areas for action against particular cancer standards are detailed in UHB Common Themes Action Plan (Appendix 1) This Action Plan is being used by the UHB to drive the implementation of changes required to ensure compliance with Cancer Standards. The Action Plan has common issues and specific areas within tumour site care are highlighted as being currently none compliant. The plan details action required and identifies responsible individuals as well as expected timelines for completion. Each area is also allocated a risk category as described previously.

In summary the Action Plan has identified the following risks

JACIE Accreditation

It was initially thought that the UHB would not achieve this standard by September 2010 as the Inspection visit for this accreditation will not take place until after the September deadline. A query regarding this was sent to the CSCG and the following response was received.

"The standards do not require that the UHB have gained JACIE accreditation, just that the centre meets the requirements. The questions about participation in JACIE accreditation and the outcome are for information for peer review (as if the centre is JACIE accredited, then peer review does not have to test this standard)"

C&V have passed this standard in 09/10 on that basis.

Dermatology & treatment of BCCs within 5 months

This standard to be transferred and managed under Referral to treatment time (RTT)

Attendance at the Thyroid MDT

The UHB did not meet compliance against this Standard in the November return. However, since that time a Second endocrine surgeon has been appointed at C and V UHB and will be starting on 13 Sept 2010. A Professor of Endocrinology has been appointed and will be the named endocrinologist when in post. Cover to be discussed once in post.

The plan also highlights a number of actions which are required across the tumour sites including

- Cover for oncologists which remains a problem for many teams. Velindre have forwarded a copy of their action plan to C&V for discussion and consideration. This highlights areas where financial investment is required by each of the LHBs, but does not provide the detail on service efficiencies and cost effectiveness required to take commissioning decisions. The UHB Cancer Lead Clinician and Cancer Services Manager meeting with Velindre to discuss oncology issues on the 14th September 2010.

- Clinical Nurse Specialist (CNS) support is not available for a number of the teams. However, there are other nurse specialists that provide adequate and appropriate cross cover. Business case for Skin submitted to Macmillan.
- Ensuring that there is formal recognition of the protocols and guidelines followed by the MDT.
- Development of local audit programmes to ensure compliance with the agreed protocols. Work underway. Head and Neck have submitted their programme
- Access to Psycho-social support in the adoption of the proposed Cancer Network wide service would have additional cost pressure of circa £120,000. However, Cardiff and Vale have access to Psychiatric liaison support and the private sector have support mechanisms that patients can access.
- Cover for key MDT members e.g. CNS, Pathologist, Radiologist – the UHB are reviewing arrangements, and ascertaining where additional resources may be required e.g. palliative care.
- Audits required to evidence many of the standards. A lack of audit support staff has been identified discussions underway to progress this.
- **No skin cancer CNS – the UHB examined the role of the surgical nurse in dermatology to determine whether there is scope for role expansion this is not deemed possible by the Cancer Lead Clinician. The UHB have submitted an expression of interest case for a Skin CNS to Macmillan and the UHB are awaiting the outcome of this. Flexibility in the role of the UHBs Clinical Nurse Specialists is to be reviewed to assess whether there is a possibility of more flexible use of the resource that can encompass cancer care, rather than ever increasing specialisation.**
- Need to ensure that MDT members have had assessment of their communication skills and received training in communication skills where appropriate.
- Cover for key MDT members e.g. CNS, Pathologist, Radiologist – the UHB are reviewing arrangements.

Plans to address a number of these are being taken forward at both the Network and UHB levels. Some of these have financial cost implications that the UHB cannot afford to support in the current financial situation.

6. IMPACT ON C&V UHB OF VELINDRE NHS TRUST ACTION PLAN (Appendix 2)

The Velindre NHS Trust have submitted a high level action plan, with their initial estimates of the costs of meeting the standards. Relevant to Cardiff and Vale are the following two developments, which have investment requirements:

- Need to ensure Oncology support to MDTs across region, and adequate cover (cost £256,000)
- Radiotherapy waiting times – Interim arrangements in place, but requires completion of on-going LINAC schemes to increase capacity (cost circa £5million)

A detailed business case which demonstrates cost effectiveness, efficiencies and honouring of existing service commitments is required by the UHB prior to agreement on the appointment of further oncologists.

In regards to the LINAC business case, the UHB can not afford this development given existing financial pressures and would require full financial support from WAG to support the commissioning of LINACs at additional sites.

Cancer Standards Action Plan – Common issues 2010/11

Area for Action	Specific issue	Affecting which tumour sites	Action required	Responsible person/s	Due date	Action taken to date
Cancer standards objective 2 – Lead Clinician's job plan	Not all job plans specify responsibility for all elements of the Lead Clinician's role	Lower GI	Ensure the job plan includes all elements of the Cancer Lead Clinician's role **LOW RISK**	Tumour site lead / Clinical Director	May 2010	A generic job description has been rewritten and now specifies responsibility for all elements of the Tumour Site Lead Clinician's role. This will aid the job planning process Job Plan review underway to ensure that all elements of MDT work are included for those who undertake MDTs All Consultant Histopathologists have a sessional commitment to attend MDTs in their job plans; we do not however specify which particular MDT. Looking at the wording of the submission "MDT sessional commitment agreed in contract/jobplan as programmed activity" I think we can legitimately answer yes to this question for all Consultant Pathologists at Cardiff and Vale.

Cancer Standards Objective 2.5 – liaising with Primary Care team	No protocol for liaising with patient's Primary Care team	Urology	- Write protocol for liaising with patient's Primary Care team - Devise monitoring process to ensure the policy is adhered to **LOW RISK**	Tumour site lead		Already part of the protocols for rapid access PSA and Haematuria clinics Cancer lead to consider replicating the protocol re liaising with patients' GPs and Primary Care Teams for all tumour types across urology Already part of the UHBs "Breaking Bad News" policy and "Effective Communication".
Cancer Standards Objective 2.6 – communicating with GPs	No protocol for communicating with patients' GPs	Urology	- Write protocol for communicating with patients' GPs - Devise monitoring process to ensure the policy is adhered to **LOW RISK**	Tumour site lead		Already part of the protocols for rapid access PSA and Haematuria clinics Cancer lead to consider replicating the protocol for all tumour types across urology Already part of the UHBs "Breaking Bad News" policy and "Effective Communication"
Cancer Standards Objective 2.7 – admin/secretarial support to the MDT	Cover split between Cancer Services and Directorate. Funding issues	Urology Skin	- Ensure continued funding **LOW RISK**			Urology: One Directorate-funded and one cancer services co-ordinator who provide cross cover. The UHB has underwritten funding for the Cancer Services post for 2010-11. Skin: Cancer Services to provide some support.
Cancer standards objective 3 – Patient/carer survey	No patient/carer survey undertaken	Head and Neck Thyroid Breast and Gynae need to be redone this year	Cancer Services to liaise with Assistant Director of Patient Experience to set up rolling patient survey programme for cancer patients. **LOW RISK**			The UHB has been looking at ways it can work with patients to understand better how their experience was when receiving care. This will include patient/carer surveys. Cardiff and Vale

						Community Health Council undertaking patient survey with Haematology. Head and Neck currently preparing a survey. The Thyroid Advisory Group discussed at their last meeting and Thyroid to undertake survey in October 2010 Breast have undertaken surveys within the last year Discussions are underway with the Assistant Director of Patient Experience to develop process for undertaking such surveys through his department
Cancer standards objective 3 – room for breaking bad news	Several MDTs report either that no dedicated room is available or that it is not fit for purpose	Breast Upper GI Urology	Establish the specific issues: is there no room or is it unsuitable. If the former, the UHB needs to look at options for provision of a room. If the latter the UHB needs to determine what needs to be done to make the room suitable **RISK REMOVED**	Tumour site leads, Cancer Director, Executive Lead		Two dedicated rooms will be available in the new Breast Unit to be operational by Oct 10 Lower GI have private rooms available in the clinic at UHW. At Llandough the room vacated on retirement of the previous Lower GI Lead will be used. All areas will have a suitable room that can be utilised even though not dedicated for this purpose
Cancer standards objective 3 – ongoing follow up and support	Protocol for ongoing follow up and support not written (H&N) and not submitted to the Network (Breast)	Breast Head and Neck	Write protocol for ongoing follow up and support and submit to the Network **RISK REMOVED**	Tumour Site Lead		Copy of both Head and Neck and Breast protocol has been developed and forwarded to the Cancer Network Achieved

Cancer standards objective 3 - Psychiatric/psychological support	No data on number of patients referred	All	A Network plan is to be developed. Paper received Oct 09	Cancer Services		Discuss with UHB service whether it is possible to record this
Cancer Standards Objective 4 – appropriate referral of cases to the MDT	Audit indicates that not all cases are referred to the appropriate MDT for discussion and/or care	Haematology	• Tumour Site Leads to agree actions to be taken upon notification **LOW RISK**	Tumour Site Leads		The MDT co-ordinator highlights to the Lead Clinician any cases she becomes aware of which are not under the care of a Haematologist. This enables the patient to be listed for discussion if appropriate.
Cancer Standards Objective 4.2 – adherence to guidance for number of cases treated by surgeon per year	Need to ensure that all surgeons treat the minimum number of cases	Breast	**LOW RISK**	Cancer Services/Directorate		Weekly monitoring now in place showing the number of cases under each surgeon. This is over a year and is being regularly assessed to ensure that on target to achieve
Cancer Standards Objective 4.2 – job plans	The MDT is not agreed in all job plans as a sessional commitment or programmed activity	All (including support services)	Revise job plans to include sessions for MDT work **LOW RISK**	MDT clinicians and CDs		Job Plan review underway to ensure that all elements of MDT work are included for those who undertake MDTs All Consultant Histopathologists have a sessional commitment to attend MDTs in their job plans; we do not however specify which particular MDT. Looking at the wording of the submission “MDT sessional commitment agreed in contract/jobplan as programmed activity” I think we can legitimately answer yes to this question for all Consultant Pathologists at C and V.

Cancer Standards Objective 4 - MDT attendance and cross cover	Cross cover issues	Thyroid	This is a regional service. Consider seeking cover from participating organisations **RISK REMOVED**	Tumour site Lead		Tumour Site Lead and Cancer Lead to discuss this with sister LHBs Second endocrine surgeon appointed at Cardiff and Vale UHB starting date 13 Sept 2010 this post will provide cross cover
Cancer Standards Objective 4 - MDT attendance and cross cover	Not all MDMs had a Surgeon present	Lung Skin (surgeon who regularly performs excisional surgery)	Ensure adequate cross-cover ***If SpR cover is accepted the rik is removed*** **LOW RISK**	Tumour site Leads		**Lung: SpR cover for Thoracic Surgeon and Oncologist has been suggested. However unsure whether this is an acceptable form of cover. To check with the Cancer Network and CSCG** Skin: absence is rare
Cancer Standards Objective 4 - MDT attendance and cross cover	Issues with cross cover for Radiologists	Breast Gynae Urology	Discuss the extent of Cardiff and Vale's responsibility. Seek help with cover from sister LHBs, particularly for Network MDTs **LOW RISK**	Cancer Director in conjunction with Dept of Radiology		The Breast MDT has 3 named Radiologists cover available. The Gynae MDT now has a second named Radiologist. There is no named cover for the Urology Radiologist. This has been raised with the CD for Radiology who is looking at Radiology support and cover for all MDMs
Cancer Standards Objective 4 - MDT attendance and cross cover	Issues with cross cover for Histopathologists	Breast Gynae Urology	Discuss the extent of Cardiff and Vale's responsibility. Seek help with cover from sister LHBs, particularly for Network MDTs **LOW RISK**	Cancer Director in conjunction with Dept of Histopathology		Gynae now have named cover for Histopathologist Breast and Urology both have more than one named Histopathologist so adequate cover should exist. It is essential that the named individuals are not off at the same time.

Cancer Standards Objective 4 - MDT attendance and cross cover	Issues with cross cover for Oncologists	Breast Gynae Lung Skin Urology	Discuss with Velindre **MEDIUM RISK**			**Lung: SpR cover for Thoracic Surgeon and Oncologist has been suggested. However unsure whether this is an acceptable form of cover.** Skin: Dr Morris to write to Drs Kumar and Gallop-Evans. Included in Velindre Action Plan with cost tag of £256,000. The \UHB does not have this additional funding Breast have cross cover The Cancer Director and Senior Manager for Cancer Services are to meet with A Hague (Velindre) to discuss on the 14 September 2010.
Cancer Standards Objective 4 - MDT attendance and cross cover	No Microbiologist	Haematology	Discussed with Dr Rosemary Barnes. Cross cover being arranged. **NO RISK**	Tumour site Leads		There is now a named cover for Microbiology ACHIEVED
Cancer Standards Objective 4 - MDT attendance and cross cover	Not all MDMs had a Restorative Dentist	Head and Neck	Ensure adequate cover **LOW RISK**			Not a Core Member. There is a named Restorative Dentist but he does not attend the MDM.
Cancer Standards Objective 4 - MDT attendance and cross cover	Not all MDMs had a Dental Hygienist present	Head and Neck	Ensure adequate cover **LOW RISK**			Not a Core Member. The named Dental Hygienist attends the MDM but there is no cover.
Cancer Standards Objective 4 - MDT attendance and cross cover	No named Endocrinologist and no cover	Thyroid	Tumour Site Lead to raise again with UHB **RISK REMOVED**			Professor of Endocrinology has been appointed and will be the named endocrinologist when in post. Cover to be discussed once in post

Cancer Standards Objective 4 - MDT attendance and cross cover	Not all MDMs had a CNS present	Head and Neck	Ensure adequate cover **RISK REMOVED**			2nd CNS now in place
Cancer Standards Objective 4 - MDT attendance and cross cover	CNS: Thyroid and Skin do not have a CNS on site. Lower GI have only one CNS, leading to cover issues	Lower GI Skin Thyroid Gynae	**RISK REMOVED FOR THYROID AND GYNAE** **HIGH RISK for Dermatology**			Thyroid patients have access to a CNS at Velindre. Gynae lost CNS support with the collapse of Cancer Care Cymru but now have some support Dermatology CNS bid in for Macmillan to consider funding for the first 3 years. Review CNS' roles within the UHB.
Cancer Standards Objective 4 - MDT attendance and cross cover	Palliative Care not able to support all MDT meetings	Head and Neck Gynae Lung Urology	• Consider grouping patient likely to require Palliative Care input at the start or end of the MDM and ask a Palliative Care practitioner to attend for that slot only **MEDIUM RISK**			Not a Core Member. There is a named Palliative Care Consultant but she does not attend the MDM
Cancer Standards Objective 4-frequency of MDT meetings	Gold standard is weekly	Skin	• MDMs will be fortnightly from Jan-10 **LOW RISK**			Fortnightly meetings were accepted for Head and Neck
Cancer Standards Objective 4 - support services – psychiatry/psychology	No named contact. Access is via department	All	A Network plan is to be developed. Paper received Oct 09 **LOW RISK**	SE Wales Cancer Network		Named contact now available Cost pressure circa £120,000 if contributing to Network wide service
Cancer Standards Objective 4.2 – support services	No named contacts for Lymphoedema, and social work	Lower GI	**LOW RISK**			We now have a named contact in Velindre
Cancer Standards Objective 4.2 – interventional radiologist	No recorded access or insufficient access to an interventional radiologist	Lower GI Urology	**LOW/MEDIUM RISK**			Requires discussion with Radiology CD

Cancer Standards Objective 4.6 –JACIE accreditation	The centre meets JACIE standards but has not yet been accredited	Haematology	• Complete final submission to JACIE (by end of Mar-10) • Await JACIE inspection – the timing of this is out of our control **RISK REMOVED**	Keith Wilson		JACIE inspection not scheduled before deadline of Standard return Query sent to CSCG response below The standards do not require that the UHB have gained JACIE accreditation, just that the centre meets the requirements. The questions about participation in JACIE accreditation and the outcome are for information for peer review (as if the centre is JACIE accredited, then peer review does not have to test this standard) C&V have passed this standard in 09/10 on that basis.
Cancer Standards Objective 5 – referral pathways	Referral pathways do not detail the patient journey from all points of access	Head and Neck Lower GI Upper GI Urology	Referral pathways need to document the patient journey from all points of access. **LOW RISK**	Tumour site leads		Examples of referral profoma now available. Urology has guidelines for Rapid Access. Lower GI are currently addressing this Head and Neck have produced guidelines based on NICE

Cancer Standards Objective 5 – referral pathways	No audit has taken place to assess adherence to referral pathways	Breast Gynae Head and Neck Lower GI Skin Thyroid Upper GI Urology	Each MDT needs to undertake an audit to assess adherence to referral pathways **LOW RISK**	Tumour site leads		Examples of timed patient pathways now available. Gynae agreeing date to undertake audit. Lower GI are currently addressing this Breast have an audit currently underway Consider auditing 20 referrals per tumour site (all referral sources) Thyroid to undertake audit in October
Cancer Standards Objective 5.4 – appropriateness of USC referral	No audit has taken place to assess the appropriateness of USC referrals	Breast Gynae Head and Neck Lower GI Lung Thyroid Upper GI Urology	Each MDT needs to undertake an audit to assess appropriateness of USC referral **LOW RISK**	Tumour site leads		Gynae to undertake audit. Lower GI are currently addressing this Breast have an audit currently underway and will feed back to Primary Care following completion of the audit Thyroid to undertake audit in October Consider auditing 20 USC referrals per tumour site
Cancer Standards Objective 5.5 – Treatment times for Malignant Melanoma	No routine monitoring of whether MMs referred as USC were treated within 6 weeks.	Skin	Subject to “blue form” **LOW/MEDIUM RISK**			Melanomas are subject to the 31 and 62 day targets with which we are > 95% compliant, the 6 week standard is obsolete
Cancer Standards Objective 5.6 – downgrading of USC referrals	No audit has taken place to assess whether GPs were informed when a USC referral was downgraded	Breast Gynae Head and Neck Lower GI Skin Thyroid Upper GI Urology	Each MDT needs to undertake an audit to assess whether GPs were informed if a USC referral was downgraded **LOW RISK**	Tumour site leads		Gynae to undertake audit by check date Lower GI are currently addressing this The Thyroid Advisory Group is to discuss this at its next meeting on 06/09/10. Breast have an audit currently underway and will

						feed back to Primary Care following completion of the audit
Cancer Standards Objective 5.8-diagnosis to GP within 24 hours	Standard should be 100%	Breast Head and Neck Lower GI Skin Thyroid Upper GI Urology	Haematology runs a system whereby a handwritten proforma (1 side A4) is faxed to the GP on the day the patient is given the diagnosis. If this were faxed to the MDT co-ordinator at the same time they could record the date on Canisc. **LOW RISK**	Tumour site leads		Lower GI:The CNS will fax a proforma to the GP following the Cancer clinic. A document is in preparation specifying which professional is responsible for contacting the GP, depending on where the patient is in the journey. The Thyroid Advisory Group is to discuss this at its next meeting on 06/09/10. Breast will address this as part of changes in process with the move of the service to the new Breast Unit this will be achieved. The UHB GP representative for cancer suggested a copy of a proforma be put onto Clinical Portal
Cancer Standards Objective 5.9 – treatment times for BCCs	Treatment times for BCCs	Skin	CaNISC report needs to be adjusted to allow monitoring **RISK REMOVED**			BCC to transfer to Referral to Treatment Time (RTT)
Cancer Standards Objective 6.1 – locally agreed clinical policies	MDTs should follow clinical policies developed by the Network Advisory Board. If Local Clinical Policies are followed, these should be endorsed by the Network Advisory Board	Breast	Adopt Network Advisory Board Clinical Policies or seek endorsement of local Clinical Policies **RISK REMOVED**	Tumour site leads		Copies of local Clinical Policies have been received. Network representatives have agreed that Breast Services will conform to NICE guidelines.

Cancer Standards Objective 6.2 –written programme of audit	No written programme of audit	Head and Neck Thyroid Upper GI	A programme of clinical audit needs to be written up annually **LOW RISK**	Tumour Site Leads		Check with Directorate Managers the progress to date Head and Neck: programme of audit for 2010 written
Cancer Standards Objective 7.5 – preoperative MRI	Inadequate access to preoperative MRI	Gynae	**MEDIUM RISK**			Discuss with CD for Radiology
Cancer Standards Objective 7.5 – pre-treatment MRI - cervix	Standard should be 100%	Gynae	**MEDIUM RISK**			Currently checking with Radiology/Directorate
Cancer Standards Objective 8.2 - Histopathology	Not all Pathologists reporting on Haematological cancers have participated in an appropriate diagnostic EQA scheme	Haematology	No appropriate EQA scheme available for Lymphoma Histopathologists in Wales ??? Seek advice for SE Wales Cancer Network and CSCG **CENSORED (CSCG terminology)**			No EQA scheme available in Wales Query sent to CSCG Response from Louise Carrington below I have queried this with Haematological advisors and despite no-one ever raising it before, and Haematologists advising us to put it in the standards, Dr Knapper is correct: there are no appropriate EQA schemes available for Histopathologists (anywhere in the UK). My understanding is that C&V were attempting to put one together at some point? But that this fell through? We have therefore censored it from the standards monitoring for the current year (effectively removing it as a standard), and going forward past the September deadline. This standard is then flagged for urgent

						review during the revision next year, at which point I expect it to be removed entirely.
Cancer Standards Objective 9.1 – service model	Network responsibility	Upper GI	Service model has been agreed but not yet implemented **LOW RISK**	SE Wales Cancer Network	Sep-10	Service model to be implemented Sep-10
Cancer Standards Objective 9.3 - surgery	Local MDTs should not be performing complex surgery	Upper GI	Comply with the Network model once it is implemented **LOW RISK**	SE Wales Cancer Network	Sep-10	Service model to be implemented Sep-10
Cancer Standards Objective 9.3 – cases cancelled through lack of ITU beds	Cancer cases cancelled through lack of ITU/HDU beds	Lower GI Upper GI Urology	**MEDIUM RISK**			We are checking current data

APPENDIX 2

Velindre Cancer Centre
Action Plan to Comply with National Cancer Standards

No	Standard Required	Current position	Actions	Lead Person	Action deadline	Funding required
Service Provision Actions						
1.	Provision of radiotherapy within RCR guidelines	Radiotherapy waiting times are monitored on a monthly basis and January's assessment has shown some improvement in waiting times. A detailed action plan has been discussed with Regional Office and WAG in order to secure physical (linacs) and staff resources. Business cases will be developed in line with action plan. Many improvements and extended hour initiatives have been implemented.	1. Monthly monitoring to continue.	Dir of CS, VCC	Ongoing	
			2. Business case for additional capacity currently in WAG process for comments. Negotiations begun with UHB's about revenue implications.		End of March 2010	Capital =£18-22m Revenue = £5m
			3. Business case for additional radiotherapy provision to be submitted in 12 machines by 2017/18		Ongoing	Yes but uncertain at this stage
			4. Extended day initiatives funded by WAG to continue.		Achieved	-
			5. Extended day initiatives funded internally have been submitted to LHB's via AOF for continued financial support (until Nov 2010)		Submitted	£459,000

No	**Standard Required**	**Current position**	**Actions**	**Lead Person**	**Action deadline**	**Funding required**
2.	Provision of specialist psychological care	This action is to be taken forward by South East Wales Cancer Network. Progress is unknown.	Formal feedback to Trusts and LHB's over current status of funding and service provision.	Network Director	Sept 2010	Yes
MDT Actions						
3.	Consultant Oncologist attendance at all MDT's including cross cover if absences	**Consultant** cover at all MDT's. In times of leave etc MDT not covered by Consultant by SpR.	Work with UHB's to identify gaps.	Clinical Director	Sept 2010	£256,000
4.	Development of MDT specific communication policies	The Trust currently operates 3 MDT's on behalf of the Network (Upper GI, Urological and HbP).	MDT leads to develop communication policies to reflect MDT processes.	Oncologists/ MDT Lead	Sept 2010	-
5.	Establishment of Network MDT's such as anal and head and neck cancers	This action is attributable to the Cancer Network. Bids and support to organize these MDT's have been made by the Trust.	**Anal MDT** - fully costed proposal submitted to Network during 2009 but remains unfunded. **Head & Neck MDT** - project manager to be appointed to develop Network wide MDT. Oncologist support provided to support establishment of MDT and associated funding requirements submitted to Network during 2009.	Network Director Network Director	Sept 2010 Sept 2010	2008/09 bid = £100,000 VCC element = £tbc

No	Standard Required	Current position	Actions	Lead Person	Action deadline	Funding required
6.	Provision of Radiology cover for MDT's	Consultant Radiology support not available to all MDT's Current job plans do not allow for consistent attendance and cover during leave periods.	Bid placed as part of AoF process to increase Radiologist sessions.	Clinical Director, VCC		£52,000
7.	Clinical Nurse Specialist attendance at all MDT's	CNS provision at all MDT's has suffered since dissolution of Cancer Care Cymru charity. Also, charitable funds are only available until end of March 2010 for those CNS's formerly employed by Tenovus charity who removed funding in 2009 (?). Internal funding has been used for breast and head and neck CNS and bids are being placed with other cancer charities for CNS roles. Bid also placed as part of AoF to LHB's.	1. Await outcome of AoF process and discussions. 2. Maximise use of current CNS's. 3. Seek all possible funding opportunities to develop and reinstate the CCC roles. 4. Develop CNS strategy to ensure equity across all cancer sites. 5. Work with South East Wales Network on their review of CNS provision.	Director, VCC		£200,000

No	**Standard Required**	**Current position**	**Actions**	**Lead Person**	**Action deadline**	**Funding required**
Audits						
8.	Approved definition of radiotherapy related morbidity	Clinical Oncology Sub-Committee (CoSC) should be requested by Welsh Cancer Networks to develop and agree definitions that are applicable across Wales.		Network Director	Asap	-
9.	Audit of radiotherapy related morbidity		1. Once definitions have been agreed the 3 Welsh Centres can audit in line with standards. 2. Results to be shared with Network Director.	Radiotherapy Services Manager Radiotherapy Services Manager	Sept 2010	-
10.	Auditing of Trust communication policy	The Trust's Equality & Diversity Manager is currently reviewing Trust policy.	Once in place the Information Manager at VCC will ensure in line with Cancer Standards and audit performance against the approved policy.	Director of Nursing	Sept 2010	-

No	Standard Required	Current position	Actions	Lead Person	Action deadline	Funding required
11.	Major morbidity following Chemotherapy in patients treated with curative intent should be monitored	An audit proposal to review performance against Trust's Neutropaenia policy has been approved. Further work required to achieve audit.	1. Chemotherapy Navigator/Specialist Lead to be released in order to undertake audit 2. Results to be shared with Network Director	Dir of Ops, VCC Dir of Ops, VCC	Sept 2010	-
12.	Development of mechanism between VCC and South East Wales Network for sharing audit information and results	Joint meetings with Cancer Managers & clinicians and Network Director reinstated in January 2010. A mechanism for sharing of information will need developing to inform Trusts and LHB's.	Continue to share Annual Audit Report with Network Director.	Network Director and Cancer Managers	Sept 2010	-

Response from Betsi Cadwaladr Health Board

GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Christine Chapman AM
Chair, Petitions Committee
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Dyddiad / Date: 19th November 2010

Dear Ms Chapman

Petitions Committee: P-03-150 National Cancer Standards

Thank you for your letter regarding the above and please accept my apologies for the delay in responding.

I can confirm that the all-Wales Cancer Standards were last reported on a national basis in April 2010 and at that time, the Health Board achieved 80% compliance with the standards, which was the highest in Wales.

As you may know, the standards have been recently re-audited on the basis of compliance by September 2010 and reported to the Minister. I am confident we will improve upon our previous level of compliance and from our own analysis would expect to be between 95% and 99% compliant. We know from our reports that we will not achieve 100% compliance this calendar year, however, there are plans in place to address any areas in need of further work.

In terms of when we might be fully compliant, I would expect the Health Board to achieve this by the end of 2010/11.

I think it is important to note that the All Wales Cancer Standards are far from comprehensive and the committee should be aware that in order to provide good quality cancer services for the population of North Wales, and indeed Wales, a considerable amount of work and activity is required over and above that implicated by the Cancer Standards.

Yours sincerely

pp Grace Lewis Parry.

MARY BURROWS
CHIEF EXECUTIVE

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Response from petitioner

Dear Christine,
Thank you for your feedback on the petitions reading 30/11/10.
I will make a further considered response in due course but my initial response is disappointment. My understanding was that LHBs had to submit their updated performance against the Standards by the end of September 2010 and I was waiting for this result. I believe you have supplied me with the results for 2009? Where is the update for Sept 2010?
Regards,

Diane

Diane Raybould, Chairman,Rhondda Breast Friends

Response from Minister for HSS

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/04080/10
Your ref: P-03-150

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Christine Chapman AM

committee.business@Wales.gsi.gov.uk

6 January 2011

Dear Christine

Thank you for your letter dated 7 December on behalf of the Petitions Committee about compliance with the National Cancer Standards.

I am currently considering the results of the Local Health Board (LHB) self assessment returns following the end of September target date and I will be writing to AMs shortly.

I can say now that compliance rates with the Standards are much improved across Wales and I expect this to be maintained. For those areas of remaining non-compliance, LHBs will need to address these urgently and confirm when they expect to have done so.

Rhondda breast friends

Christine Chapman
Chair, Petitions Committee
Cardiff Bay

11.1.11

Dear Christine,

P-03-150 National Cancer Standards

Thank you for your letter dated 7.12.10 and the chance to support your work on compliance with the Cancer Standards.

PART 1

Overview

Rhondda Breast Friend's petition was submitted on 25th June 2008. At that time LHB's had no plans to implement Cancer Standards by the promised date of March 2009.

Since that time and with the influence of the Petitions Committee, monitoring and peer review against the standards have been introduced and revised time scales implemented which have enabled us to see their progress towards compliance. This has hugely raised the profile of cancer standards and with comparison between LHBs being published, good practice can be celebrated and problem areas highlighted.

Progress

I will give progress against selective areas in which we have been working as an indication of progress towards compliance.

TOPIC: ORGANISATION

OBJECTIVE 2: CARE PROVIDED BY TEAMS SHOULD BE WELL CO-ORDINATED TO PROVIDE AN EFFICIENT, EFFECTIVE SERVICE TO PATIENTS.

The greatest impact for us in Cwm Taff LHB is to see the management of cancer services substantially improved. In 2008 there was one officer part time on cancer services who never returned a phone call or email. At the end of 2010 we had a Cancer Management Team with officers from director level down, to whom we have access and are building up relationships. We also have representation on the Cancer Services Strategy Group.

TOPIC: PATIENT-CENTRED CARE

OBJECTIVE 3: TO ENSURE THAT PATIENTS AND OR THEIR CARERS HAVE SUPPORT AND ALL THE INFORMATION THEY REQUIRE REGARDING THE DIAGNOSIS, TREATMENT OPTIONS AND TREATMENT CARE PLAN.
Rationale: Appropriate information, communication, psychological needs

Information was an issue for us. We have produced an information leaflet signposting to cancer services in Rhondda Cynon Taff supported by patient support officers in Velindre and Cwm Taff which has been approved by our Cancer Services Strategy Group who are assisting us with its distribution within Cwm Taff. We have also been instrumental in introducing the Macmillan information in libraries scheme throughout

Rhondda Cynon Taff. I believe this has helped improve the availability and supply of written information and signposting to other support in our area.

Information on benefits is specifically mentioned in Palliative Care and the Rehabilitation Standards and this information can be provided by Tenovus and Macmillan but is a post code lottery service. The Macmillan service in Rhondda Cynon Taff which consisted of 2 officers has been cut to one and this funding only continues up until next year. Their statistics showed that palliative care patients often missed out on benefits and sometimes only received them weeks before they die. A survey by the Cancer Network showed that information was sometimes given by staff that did not have the requisite training. So is this a requisite of the LHB because if so I question its compliance by all LHBs?

Privacy on wards was another issue for us with diagnosis and test results of inpatients often communicated on open wards with only a curtain separating beds. I am not aware of any improvements on wards as I have been told space does not permit.

Carers was another action area for us and our workshops and the work of the RCT Cancer Focus Group has resulted in Carers champions being promoted in GP surgeries and also in hospital discharge procedures. However, I believe much more work needs to be done to inform carers and provide psychological support, 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 for carers support.

TOPIC: THE MULTIDISCIPLINARY TEAM

OBJECTIVE 4: TO ENSURE THAT BREAST CANCER CARE IS PROVIDED BY A SPECIALIST MULTIDISCIPLINARY TEAM (to include a cancer nurse specialist)

The Demise of Cancer Care Cymru specialist nurses posed a problem with a shortage of Cancer Nurse Specialists which had a knock on with the composition of the MDT. While a number of nurses have been employed my understanding is that shortages still apply.

TOPIC: INITIAL REFERRAL AND TIMES TO TREATMENT

OBJECTIVE 5: PATIENTS WITH BREAST CANCER SHOULD BE REFERRED, DIAGNOSED AND TREATED PROMPTLY.

…"Therefore it is important to support public awareness of symptoms that may indicate cancer and ensure GPs refer promptly to appropriate cancer teams for assessment and treatment if necessary."

This is the area we are currently investigating. Early detection is a priority of the Government to improve outcomes.

Problem no 1…I am not aware of any program by our Cancer Network, LHB or HSCWB team to support public awareness of cancer symptoms. We produced a calendar last year which the LHB promoted, Tenovus are promoting their safe in the sun campaign, what of the statutory organisations? This begs the question as to whether any other LHB in Wales has actively progressed this issue.

Problem no 2… how can we encourage the public to visit their GPs when getting a GP appointment in the valleys is such a problem and often ends up with the person not bothering…….(count me in I'm ashamed to say).

….. How can we ensure GPs refer promptly? How do we know that they are skilled in cancer diagnosis and who has the authority to ensure GPs attend awareness courses and be assessed on their skills? Does the LHB have the authority? Can the government enforce?

PART 2

National Standards for Rehabilitation of Adult Cancer Patients April 2010

This will improve the level of support in the rehabilitation of patients and I believe this Standard will come into force in April 2011.

It includes:

- an integrated continuum within NHS and social care,
- the provision of a Key worker / navigator for all cancer patients,
- assessment of Physical, Nutritional, Psychological, Informational, Practical, Spiritual, Social and Financial needs
- self management training and skills
- etc….

The question arises as to whether the LHBs have the necessary plans and procedures in place for compliance by the due date………..sounds familiar!

Conclusion

I must congratulate the government on its intentions and plans to improve cancer care with the production of the Cancer Standards. I believe that compliance with the Standards has been given its rightful importance with the enthusiasm and tenacity of the Petitions Committee in pursuing this goal. Standards have definitely improved in some areas but there remain challenges in others. The performance “league tables” are a useful tool to highlight poor performance but also to celebrate successes and motivate others.

I believe early detection to be an area of high priority with WAG but I do not see activity around this area?

I would also like you to ask about LHBs plans to implement the Rehabilitation Standards.

Thank you for the opportunity to comment and I look forward to the Minister’s response on implementation timeframe.

Thank You

Yours sincerely

Diane
Diane Raybould
Chairman Rhondda Breast Friends

Response from the Minister for Health and Social Services

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/00389/11
Your ref: P-03-150

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Christine Chapman AM
Chair - Petitions Committee
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10 February 2011

Dear Christine,

Thank you for your letter dated 26 January about Petition P-03-150 National Cancer Standards.

Accurate and timely diagnosis is a core aspect of GPs training and continuing development. GPs are encouraged to reflect on their practice and each must undertake an annual appraisal to review learning needs and define a personal development plan that is reviewed at the next appraisal meeting. Through the Quality and Outcomes framework, GPs are encouraged to review significant events such as late diagnosis, and to identify any change in practice that might be appropriate

It must always be remembered that in the community setting the incidence of many cancers is low and that early presentations may mimic very common, non serious conditions. It is important that GPs and patients discuss likely diagnoses and the risks and the benefits of watchful waiting, investigation or referral. If cancer is suspected then NICE guidance applies but GPs must balance the risks of over investigation and the possibility of delayed diagnosis.

The Welsh Assembly Government, through Health Challenge Wales working with the voluntary sector, has funded work to raise public awareness of, and change attitudes to cancer. This has included raising awareness of testicular cancer and the provision of information through the Health Challenge Wales website.

I have also approved participation in an international project involving a number of countries with the same or better cancer survival rates to try and find out what are the main reasons for the survival differences. This study is looking at awareness and understanding of cancer across the participating countries, with a view to informing future cancer policy.

Response from Cardiff and Vale LHB 150

GIG CYMRU NHS WALES

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Cardiff and Vale
University Health Board

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Jan Williams OBE
Chief Executive

Christine Chapman AM
Chair, Petitions Committee
Welsh Assembly Government
Cardiff Bay
CARDIFF CF99 1NA

Dear Ms Chapman

RE: P-03-150 National Cancer Standards

In response to your letter dated 26 January 2011 regarding the above, please find below information presented, in the order requested. Collaborative Rehabilitation Standards and Implementation of the Key Worker action plans, together with a proposed key worker information card, are also available in detail, if required these.

Q1 Is there a shortage of Cancer Nurse Specialists, and if so, how this impacts on your ability to meet cancer standards;

Answer:

Cardiff &Vale UHB has been and continues to work towards improvements in compliance against cancer standards, including:

- determining ways of obtaining prompt access to psychology services,
- addressing the standards that cannot be met due to the lack of CNS
  - Currently the CNS shortage in Dermatology, Colorectal Tumour and Thyroid sites is being addressed by the UHB Director of Nursing and Medical Director and joint working being considered, to provide cover for the CNS role.
  - An oncology Nurse Specialist is now in post in Gynaecology.
- improving multi disciplinary team attendance and ensuring all specified professions are present including palliative care
- ensuring completion of all the required audits.

Q 2 Do you have staff who are able to give advice on benefits to palliative care patients and whether these staff are fully trained

Answer:

In addition to the information available via the Social Work Department and the Citizens Advice Bureau, six Benefits Officers have been appointed by Tenovus from lottery funding. Discussions have taken place between representatives from Tenovus and the UHB Cancer Services Department to determine how these postholders will best provide information and support to cancer patients. The signposting role of the Key Worker will be valuable in this respect.

Q3 Will you be in a position to meet the National Standards for Rehabilitation of Adult Cancer Patients, which we understand will come into force in April 2011. If you are not in a position to meet these standards, what are the barriers to full compliance?

Answer:
To ensure that patients are treated equitably and consistently across the entire cancer pathway, including secondary, primary and tertiary care, all the Health Boards in South East Wales and Velindre Cancer Centre have worked in collaboration to develop Action Plans for both the Full Rehabilitation Standard for Adult Patients with Cancer and the Implementation of the Key Worker.

As part of this process, a co-ordinating group has been established with appropriate representation from each body, to improve communication and to plot progress on a regular basis, with submissions made to the Cancer Management teams within each organisation.
Initial meetings have been held with the Cancer Leads and managers to discuss the requirements of the Rehabilitation Standards and, in particular, the Key Worker implementation action plan.

Current Status

Many patients are already being supported through their cancer journey by a key worker, or someone they can contact. Some cancer sites already have a key worker system in place, which works well. These systems are now being formalised and documented, with named individuals identified. It will be challenging to implement the initiative at those cancer sites without Cancer Nurse Specialist (CNS) staff. This is currently being addressed.

In most cases the patient journey is identified in the initial MDT meeting. The initial key worker is easily identifiable and is usually a CNS or Allied Healthcare Professional (AHP).

Referring on after treatment is the subject of ongoing discussions with primary care leads to ensure clear definition.

The function of the key worker system is already being practiced in many of the cancer sites within Cardiff and Vale UHB and just needs formalising. The new cancer key worker initiative will support and enhance areas of existing good practice and will build on current practice.

The UHB is developing the organisational relationships between primary and secondary care, with and a greater involvement of community care, to fully support the patient following the acute treatment phase. This will be an area for further evaluation and careful attention during the implementation phase of the cancer key worker.

A paper outlining the role of the key worker has been developed by Cancer Services and has been circulated for consultation to all relevant staff within the cancer care role.

With the work that has already been undertaken, and the planned programme of work, we will comply with the minimum requirement by which every cancer patient will be allocated a dedicated Key Worker at every stage of his/her patient journey. Each patient will have contact details for his/her Key Worker on how to contact them.

I hope that this information is of assistance.

Yours sincerely

Jan Williams

Jan Williams
Chief Executive

Response from POWYS LHB

GIG
NHS
Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Y Prif Weithredwr | Chief Executive
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Ref: AC/CH/sj

23rd February 2011

Ms Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Pier Head Street
Cardiff Bay
Cardiff
CF99 1NA

Dear Ms Chapman

I write in response to your letter of the 26th January regarding further information about the compliance against the National Cancer Standards.

I hope our additional information assists the Committee in it's consideration of support to cancer patient in Wales

National Cancer Standards

- **whether there is a shortage of Cancer Nurse Specialists, and if so, how this impacts on your ability to meet cancer standards;**

Cancer Nurse Specialists are part of tumour specific cancer multidisciplinary teams which deliver cancer care from Cancer Centres (and in some places cancer units but as part of a wider multidisciplinary team).

Cancer Centres are designated as such as there is a configuration of services providing diagnosis, investigation and all therapeutic options including surgery, radiotherapy and chemotherapy. They also have importantly, access to intensive care support as is sometimes required during active treatment.

Powys patients are referred for cancer treatment to bordering Cancer Centres in North and South Wales as well as to English Cancer Networks.

From referral, throughout the investigation period to diagnosis the patient will be supported by his/her general practitioner and a specialist nurse from the Cancer Centre. At diagnosis, usually a Clinical Nurse specialist who has expertise in the particular cancer will be assigned to work with the patient to support and assist navigation through complex procedures and transitions between professional teams such as from surgery to chemotherapy.

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Rydym yn croesawu gohebiaeth Gymraeg
Bwrdd Iechyd Addysgu Powys yw enw gweithredd Bwrdd Iechyd Lleol Addysgu Powys

We welcome correspondence in Welsh
Powys Teaching Health Board is the operational name of Powys Teaching Local Health Board

Powys tHB does not have a District General Hospital within its boundaries, our patients are treated in surrounding hospitals based on their geographical location as a result the tHB does not contribute to cancer standards directly but is responsible for ensuring that patients resident in Powys are provided with care which meets the established standards.

Powys tHB does not employ any Cancer Nurse Specialists. Whilst the patient is receiving active treatment he/she will maintain contact with the Cancer team as well as his/her General Practice.

When treatment is less active and remission or cure is achieved the patient will be supported by the General Practice with the assistance of other co –key workers such as physiotherapists, lymphoedema specialists, occupational therapists etc who will be concerned with rehabilitation.

For patients who may not recover from the illness, or who have complex problems, there is a specialist palliative care team of clinical nurse specialists and consultants in palliative medicine who work in partnership with General Practice to support patients who are spending more time at home because they are too unwell to travel.

☐ **Whether you have staff who are able to give advice on benefits to palliative care patients and whether these staff are fully trained and**

Powys t HB has the support of a Welfare Benefits Officer who deploys two Benefits Advisors for Powys to provide an excellent service to palliative patients. The Specialist Palliative Care Team is confident of very timely and prompt support for this vulnerable group of patients.

It is likely their heavy case load may be shared with the introduction of the Hospice at Home Service by St David's Foundation in South and Mid-Powys, as described above in the provision of a spectrum of support provided by a team among whom are benefits advisors.

☐ **Whether you will be in a position to meet the National Standards for Rehabilitation of Adult Cancer Patients, which we understand will come into force in April 2011. If you are not in a position to meet these standards, what are the barriers to full compliance?**

As in the case of the Cancer Nurse Specialists, Powys care delivery both due to rurality and geography is different. In the Cancer Centres and Cancer Units which are established in urban populations the designation of a key worker, whether it is a Nurse Specialist , AHP, Social worker etc is relatively easy and likely to remain with the patient until the identified problem has been resolved. The standards for Rehabilitation require assessment of patients in many domains which are not unique to cancer patients and it is recognized that this holistic assessment is fundamental to the management of all patients with both acute and chronic conditions being supported by the community teams which are developed in Powys. There are no clinicians or therapists dedicated to cancer care, and of necessity most work with all patient groups so the identification of key workers of other than level 1 will not be possible. Patients will identify their General Practitioners as lead for ongoing management and it is the GP who signposts or refers patients to other professionals. Powys tHB is working on an appropriate model which will ensure effective transfer of care to and from key workers associated with the Cancer MDTs.

I hope that the Committee find this additional information helpful in their further consideration of support available to cancer patient sin Wales.

Yours sincerely

Andrew Cottom
Chief Executive Officer

4)

Response from ANEURIN BEVAN LHB

GIG
NHS

Bwrdd Iechyd
Aneurin Bevan
Health Board

Ref: JP/CC/JP/MH/vep   Direct Line: 01495 765072   24 February 2011

Christine Chapman AM
Chair Petitions Committee
Petitions Committee
Cardiff Bay
Cardiff
CF99 1NA

Dear Ms Chapman

RE: P-03-150 National Cancer Standards

Further to your letter dated 26 January 2011 regarding further information relating to support available to cancer patients, I have now had the opportunity to discuss this matter with cancer services colleagues within Aneurin Bevan Health Board (ABHB).

I am encouraged that on an All Wales basis improvements in service delivery to cancer patients have been observed since the introduction of the All Wales Cancer Standards and certainly within ABHB there have been significant service improvements e.g. the establishment of a dedicated Psychological Support Service for cancer patients.

With regards to the further queries that you raise I will address these in turn as follows:

I can confirm that at the core of the All Wales Cancer Standards is the concept of a fully functional Multi Disciplinary Team, and that a core member of this team is the Cancer Nurse Specialist who in the secondary care environment often undertakes the role of key worker for cancer patients in their respective tumour site. All tumour sites within ABHB have a dedicated Cancer Nurse Specialist and further investment in this staff cohort was observed as part of the implementation of the All Wales Cancer Standards Action Plan for the

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NHS
GIG

Bwrdd Iechyd Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Aneurin Bevan
Aneurin Bevan Health Board is the operational name of Aneurin Bevan Local Health Board

Health Board e.g. a Colorectal Cancer Nurse Specialist for Nevill Hall Hospital was appointed on a substantive basis.

As a result of the All Wales Cancer Standards Action Plan the Health Board undertook a review of Palliative Care input into every Multi Disciplinary Team across all tumour sites and as a result of this each tumour site team has an identified dedicated Palliative Care Specialist Nurse resource.

One of the key milestones of implementing the National Standards for the Rehabilitation of Adults with Cancer is the roll out of the Key Worker concept to co-ordinate a cancer patient's treatment in secondary care, and subsequently within primary care by the end of March 2011. Within ABHB a multidisciplinary Local Implementation Group has been established to agree the way forward of implementing the Key Worker concept. This group reports to the South East Wales Cancer Network Group that is co-ordinating the implementation of the Standards within the Region, and subsequently progress is reported to the South Wales Cancer Network Group that is dedicated to the roll out of this initiative. In many instances the Key worker concept is already in place, it just needed to be formalised and the work within ABHB has recognised that the Key Worker is a concept and an important reference point for the patient and therefore handovers between Key Workers is crucial during the duration of a patient's pathway both within secondary and primary care environments.

I trust that this update provides you with the additional information required for the Petitions Committee but please do not hesitate to contact me further should you wish any further information.

Yours sincerely

Judith Paget

Judith Paget
Deputy Chief Executive
For and on behalf of Dr Andrew Goodall, Chief Executive, and signed in his absence

Response from SWANSEA LHB

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

☎Direct line/Rhif llinell union: 01639 683311
🖹Fax/ffacs:

Your ref/Eich Cyf: P-03-150
Our Ref/Ein Cyf: DS/MMT/DG/jw

Dyddiad/Date: 22nd February 2011

Ms. Christine Chapman AM
Chair,
Petitions Committee,
Welsh Assembly Government,
Cardiff Bay,
Cardiff.
CF99 1NA

Dear Ms. Chapman,

P-03-150 National Cancer Standards

Thank you for your letter dated the 26th January 2011 concerning the delivery of the National Cancer Standards within Abertawe Bro Morgannwg University Health Board.

The Health Board recognises the importance of the Cancer Standards and continues to work to deliver and sustaining these targets within the very challenging financial environment that the NHS finds itself in. In your correspondence you have identified a number of areas for further clarification. The Health Board's response to these is set out below:-

- **Whether there is a shortage of Cancer Nurse Specialists, and if so, how this impacts on your ability to meet cancer standards;**

The Health Board has not experienced a shortage of Cancer Nurse Specialists and is able to successfully recruit to these key posts when vacancies arise.

- Chairman/Cadeirydd: **Win Griffiths**
- Chief Executive/ Prif Weithredydd: **David Sissling**

ABM Headquarters/ Pencadlys ABM, One Talbot Gateway, Seaway Parade, Baglan Energy Park, Port Talbot. SA12 7BR.
Telephone: 01639 683300 Ffon 01639 683300 FAX: 01639 687675 and 01639 687676
Bwrdd Iechyd ABM yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg
ABM University Health Board is the operational name of Abertawe Bro Morgannwg University Local Health Board
www. abm.wales.nhs.uk

- **Whether you have staff who are able to give advice on benefits to palliative care patients and whether these staff are fully trained**

Benefits advice is provided by trained workers from within the Maggie's service on site at Singleton Hospital. Additional information is available from within the Health Board's Palliative Care Services.

- **Whether you will be in a position to meet the National Standards for Rehabilitation of Adult Cancer Patients, which we understand will come into force in April 2011. If you are not in a position to meet these standards, what are the barriers to full compliance?**

The Health Board recognises the need to meet these Standards. The service currently has a number of Macmillan funded appointments in place that already delivers a large number of the Standards, but the funding for these is time limited. The Health Board is currently reviewing arrangements as to how it can financially sustain these appointments during 2011 and beyond.

I hope that these comments reassure you that the Health Board is making every endeavour to ensure that these Standards are met within the time limits. Should you require any further clarification, then please do not hesitate to contact me.

Kind regards.

Yours sincerely,

DAVID SISSLING
CHIEF EXECUTIVE.

CWM TAF LHB response

5

GIG
NHS
Bwrdd Iechyd
Cwm Taf
Health Board

Your ref/eich cyf:
Our ref/ein cyf: AW:DE
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Fax/ffacs: 01443 744888
Email/ebost: Allison.Williams4@wales.nhs.uk
Dept/adran:

Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff
CF99 1NA

Dear Mrs ~~Chapman~~ Christine

Re: P-03-150 National Cancer Standards

Further to your letter dated 26th January 2001, regarding the elements of support available to cancer patients, our response is as follows:

Shortage of Clinical Nurse Specialists

Cwm Taf do not have Clinical Nurse Specialists (CNS) for gynaecology, haematology or skin cancer. All other cancer sites have a single CNS. These individuals are a tremendous asset to the service and are very highly valued by the multi-disciplinary team and patients alike. They make a significant contribution to compliance with cancer standards however, given the small numbers, availability and coverage is inevitably limited which can result in challenges with sustained compliance as follows:

- The standards are quite specific around the attendance at cancer multi-disciplinary meetings. A CNS is listed in standards as a core member therefore if not present this standard cannot be met. Core members have to attend at least 50% of meetings and cover has to be in place so that a total of 90% of meetings have that profession represented. Therefore even when there is a single CNS with annual leave, study leave and potentially sick leave with no cover arrangements this standard cannot be met.
- The standards state that certain cancer specialities have to have a CNS present with a patient when they are informed of a diagnosis of cancer. Again more than one cancer patient can be in a clinic at anyone time therefore a CNS may not be available for every patient. Also with no cover arrangements for a single CNS this means that a CNS may not always be in clinic.

As demonstrated above despite having a cohort of CNSs within Cwm Taf the very specific nature of the standards impact on the support offered to cancer patients as CNS time is in our view not always best utilised on direct patient care/support. This also effects our compliance rates against cancer standards. Cwm Taf acknowledge that we have some specific cancer sites without CNS cover, with current financial restraints, we are looking at how we can utilise our existing resources differently. It must also be noted that in certain areas where is no CNS e.g gynaecology there are nurses who have a special interest in cancer who offer support to patients and therefore whilst the functionality might be achieved the strict definitions within the standards means that compliance would not be achieved.

Benefits advice to palliative care patients

Initially Specialist Palliative Nurses can provide advice and can 'signpost' the patient and their families to the relevant agencies. Some patients will also have a social worker who will obviously advise and support the patient in relation to accessing their benefits. In respect of all cancer patients, not just palliative care, advice is also provided by the local Citizens Advice Bureau and we have been made aware that Tenovus have recently appointed 6 Benefits Officers in Wales out of Lottery Funding. Therefore, once more details are available we will be able to signpost all cancer patients to the right person who will be able to help them access the appropriate support.. Signposting for benefits advice will also be one of the responsibilities undertaken by the Key Worker when implemented on 1st April 2011.

Position Report on National Standards for Rehabilitation of Adults Cancer Patients

Cwm Taf has been working in partnership to progress plans to meet the above standards. This will ensure there is equity and consistency in meeting these standards across South East Wales. A joint Action Plan between all Health Boards in South East Wales and Velindre Trust has been developed and submitted to the Welsh Assembly Government (WAG). The implementation of this Plan is being monitored by a Co-Coordinating group with appropriate representation for each of the Health Boards as well as Velindre.

A full resource mapping exercise to meet the new full standards has yet to be completed as the end implementation date is not until 2015. However, the first target to be met is the implementation of the Key Worker by 1st April 2011. A joint implementation plan for the Key Worker has been developed which will ensure a holistic and consistent approach both across primary and secondary care as well as across neighbouring Health Boards and Velindre. It is felt that this is necessary as many patients access services across our organisations.

Cwm Taf is working towards meeting the target for the Key Worker however it must be noted that when a patient is being treated within secondary care in the majority of cases the most appropriate professional to be their Key Worker will be the CNS. As mentioned above this will be difficult where we do not have a CNS for a cancer site. In these instances we will of course identity an alternative member of the multi-disciplinary team.

I can reassure you that Cwm Taf does have a work programme in place so that we will be compliant with the minimum requirement to have a key worker in place for all newly diagnosed cancer patients for each stage of the patient journey.

Yours sincerely

Allison.

Allison Williams
Chief Executive

Betsi Cadwaladr response

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Christine Chapman AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

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Eich cyf / Your ref:
☎: 01248 384910
Gofynnwch am / Ask for: Mary Burrows
Ffacs / Fax: 01248 384937
E-bost / Email: mary.burrows@wales.nhs.uk
Dyddiad / Date: 28th February 2011

Dear Ms Chapman

P-03-150 National Cancer Standards

Please find enclosed a response to the Petitions Committee request for information regarding the following:-

- **Whether there is a shortage of Cancer Nurse Specialists, and if so, how this impacts on your ability to meet cancer standards.**
  A shortage of speciality trained cancer nurses have been identified through our monitoring and reporting of the National Cancer Standards. Where we have identified gaps staff have been recruited and in so doing we have built in cross cover arrangements as we see a risk with having single handed individuals in such roles.

- **Whether you have staff who are able to give advice on benefits to palliative care patients and whether these staff are fully trained.**
  I'm pleased to say we continue to maintain the long and successful history of working with the Welfare Rights Departments and Macmillan Cancer Support. Support and advice is available for palliative and non palliative care patients to access such services. Having said this, it would be worth asking all County Councils about their level of funding as we see variation in how this is approached in local government.

- **Whether you will be in a position to meet the National Standards for Rehabilitation of Adult Cancer Patients, which we understand will come into force in April 2011. If you are not in a position to meet these standards, what are the barriers to full compliance?**
  We believe we will be in a position in 2011/12 to meet these standards, the main area will be to agree with cancer users and carers the definition and role of a cancer key worker. In some cases this role is already fulfilled by primary care staff, cancer and palliative care clinical nurse specialists. We believe it is important to utilize, develop and grow skills in existing roles so we address any inequity in provision. We will however formalize the position with key performance indicators to demonstrate value for patients. A Health Board wide plan for rehabilitation has been submitted with timescales and priorities identified.

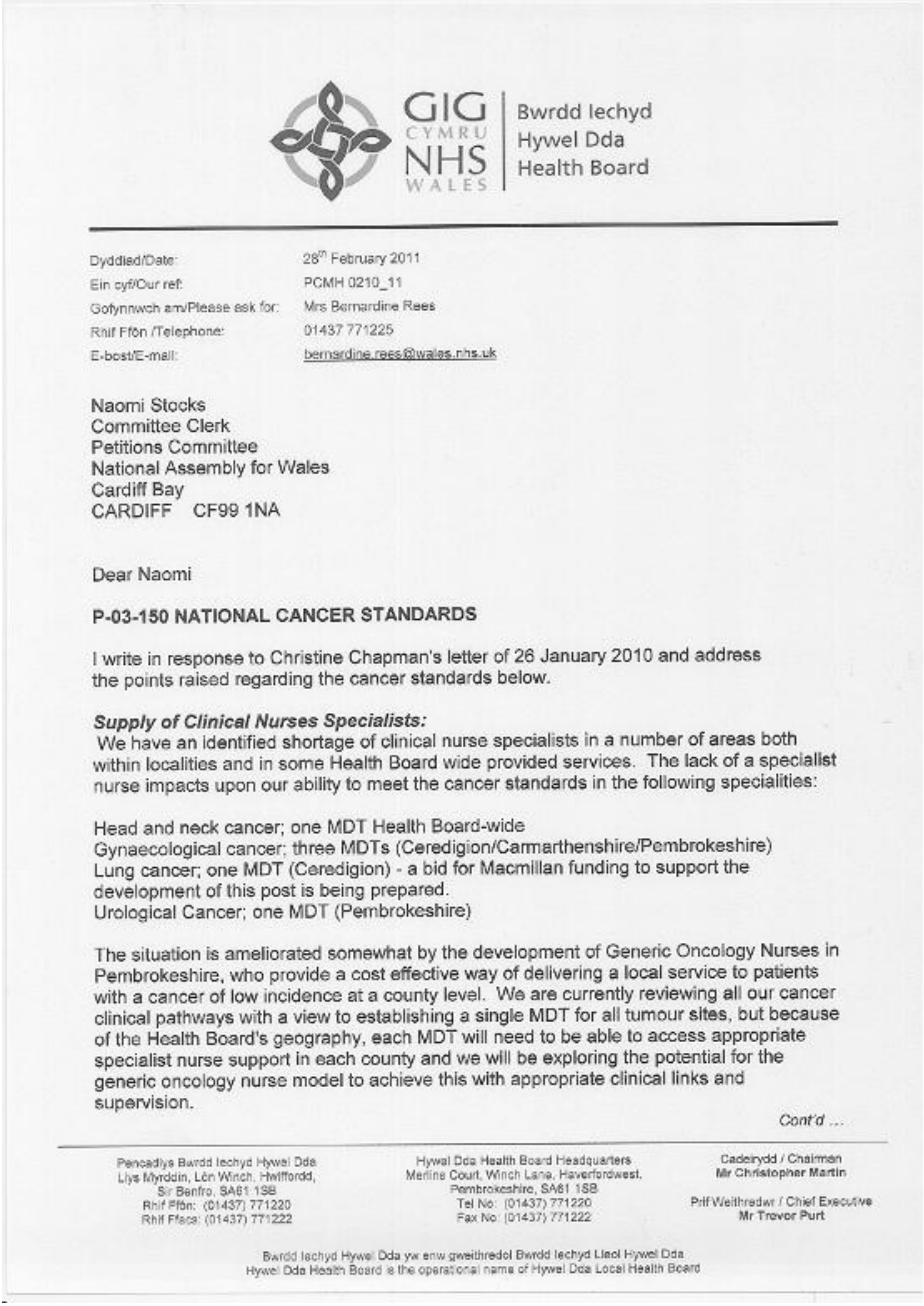
Cyfeiriad Gohebiaeth ar gyfer y Cadeirydd a'r Prif Weithredwr / Correspondence address for Chairman and Chief Executive:
Swyddfa'r Gweithredwyr / Executives' Office
Ysbyty Gwynedd, Penrhosgarnedd
Bangor, Gwynedd LL57 2PW
Gwefan: www.pbc.cymru.nhs.uk / **Web:** www.bcu.wales.nhs.uk

Should you require any further information, please let me know. Equally if any of the members of the Petitions Committee would wish to discuss any elements of my response, I would be more than happy to do so.

Yours sincerely

MARY BURROWS
CHIEF EXECUTIVE

Hywel Dda response



GIG CYMRU NHS WALES
Bwrdd Iechyd
Hywel Dda
Health Board

Dyddiad/Date: 28th February 2011
Ein cyf/Our ref: PCMH 0210_11
Gofynnwch am/Please ask for: Mrs Bernardine Rees
Rhif Ffôn /Telephone: 01437 771225
E-bost/E-mail: bernardine.rees@wales.nhs.uk

Naomi Stocks
Committee Clerk
Petitions Committee
National Assembly for Wales
Cardiff Bay
CARDIFF CF99 1NA

Dear Naomi

P-03-150 NATIONAL CANCER STANDARDS

I write in response to Christine Chapman's letter of 26 January 2010 and address the points raised regarding the cancer standards below.

Supply of Clinical Nurses Specialists:
We have an identified shortage of clinical nurse specialists in a number of areas both within localities and in some Health Board wide provided services. The lack of a specialist nurse impacts upon our ability to meet the cancer standards in the following specialities:

Head and neck cancer; one MDT Health Board-wide
Gynaecological cancer; three MDTs (Ceredigion/Carmarthenshire/Pembrokeshire)
Lung cancer; one MDT (Ceredigion) - a bid for Macmillan funding to support the development of this post is being prepared.
Urological Cancer; one MDT (Pembrokeshire)

The situation is ameliorated somewhat by the development of Generic Oncology Nurses in Pembrokeshire, who provide a cost effective way of delivering a local service to patients with a cancer of low incidence at a county level. We are currently reviewing all our cancer clinical pathways with a view to establishing a single MDT for all tumour sites, but because of the Health Board's geography, each MDT will need to be able to access appropriate specialist nurse support in each county and we will be exploring the potential for the generic oncology nurse model to achieve this with appropriate clinical links and supervision.

Cont'd ...

Palliative Care

We do not specifically employ benefits advisors and because of the complexity of this area and the tendency for the regulations to change, we ensure that staff are trained and are aware of who they need to involve to ensure patients receive both general and specific advice.

Standard for Rehabilitation of Adult Patients

We have developed and adopted a key worker protocol to ensure they are identified by the MDTs. In terms of the acute pathway, we are confident that we will be able to meet this requirement, more easily so when we have a full compliment of specialist nurses and we have also been working closely with the network to explore how use of the evolving Community resource Teams will allow us to provide a sustainable service to patients post acute phase and who are returning to normality.

With regard to the skills and training staff require as set out in the standard, the Health Board is undertaking the Cancer Network audit of staff to identify gaps in this area. Because the remedial action will require training and education to achieve the appropriate level, we intend to develop this part of the standard as a continuous improvement exercise; we will, however, only know the extent of the gap once the audit has been completed and analysed, which the Network intend to do by the end of June.

If you require any further information, please contact Matthew Willis, Head of Cancer Services (matthew.willis@wales.nhs.uk).

Yours sincerely

Bernardie Rees

BERNARDINE REES OBE
Director of Primary, Community and Mental Health Services

Macmillan Cancer Support Report - Welsh (English below)

NI YW MACMILLAN.
CYMORTH CANSER

WE ARE MACMILLAN.
CANCER SUPPORT

NEWID GOFAL CANSER YNG NGHYMRU

Adroddiad
gan Gymorth
Canser
Macmillan

Mawrth 2011

Cynnwys

Tudalen

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Rhagair

Rydym wedi cwblhau rhaglen ymchwil helaeth dros dair blynedd ar draws Cymru er mwyn deall anghenion pobl sy'n byw gydag ac wedi canser – a pha mor dda mae'r system gofal canser yn diwallu'r anghenion hynny. Fel rhan o'r broses hon siaradom ni gyda phobl sydd wedi cael profiad o ganser eu hunain, yn ogystal â gydag academyddion a gweithwyr proffesiynol ym maes gofal iechyd a chymdeithasol yng Nghymru.

Mae ein hymchwil yn dangos yn eglur bod y system bresennol o fynd i'r afael â chanser yn ddrud, ac yn syml, nid yw'n diwallu anghenion pobl. O gofio'r nifer cynyddol o bobl sydd wedi cael diagnosis o ganser neu sy'n byw gyda neu wedi'r afiechyd, y baich mae hyn yn ei osod ar y GIG a darparwyr gwasanaethau eraill, a'r hinsawdd economaidd sydd ohoni, rydym yn credu ei bod yn hanfodol, yn ariannol ac yn foesol, i lywodraeth nesaf y Cynulliad i wneud gofal canser yn flaenoriaeth yng Nghymru.

Rydym yn cydnabod bod yna gyfyngiadau ar gyllidebau ar hyn o bryd. Ond mae tystiolaeth yr adroddiad hwn yn dangos y gallwn ddiwallu anghenion pobl sydd â chanser a defnyddio adnoddau'n fwy effeithiol, o roi'r gwasanaethau cefnogi iawn ar waith nawr, a gwella cydgysylltu a chyfathrebu ar draws asiantaethau a gydol y profiad o ganser.

Mae hefyd yn amlwg bod pobl sy'n byw gydag a'r tu hwnt i ganser, yn ogystal â gweithwyr proffesiynol a rheolwyr, am weld newid yn y ffordd y mae gofal canser yn cael ei ddarparu yng Nghymru. Rydym yn credu bod angen i ni gydweithio gyda'n gilydd er mwyn trawsnewid gofal canser fel y gallwn ddiwallu anghenion newidiol a chynyddol pobl. Ac er mwyn sicrhau'r trawsnewidiad hwn, mae angen datblygu strategaeth ganser cenedlaethol, sy'n rhoi pobl yn ganolog.

Fel gwlad fechan, mae Cymru mewn lle unigryw i ailgynllunio ei gwasanaethau canser. Mae etholiadau'r Cynulliad Cenedlaethol ym mis Mai yn rhoi'r cyfle i ni weithredu'n fwy radical yn ein dull o drin a gofalu am bobl sy'n byw gydag ac wedi canser yng Nghymru. Ac i ddarparu gwasanaethau sy'n fwy cost-effeithiol ac sy'n diwallu anghenion yr unigolyn cyfan.

Rydym yn hyderus y gall Cymru ddatblygu gwasanaethau canser sydd ymhlith y gorau yn Ewrop ac rydym am helpu Llywodraeth nesaf y Cynulliad i wireddu hyn. Ein gobaith ni yw y bydd y llywodraeth yn mabwysiadu'r argymhellion a'r atebion a gynigir yn yr adroddiad hwn. Gyda'n gilydd, ein cred yw y gallwn wella bywydau pobl sydd wedi'u heffeithio gan ganser yng Nghymru.

Cath Lindley
Rheolwr Cyffredinol Cymru,
Cymorth Canser Macmillan

Crynodeb ac argymhellion

Mae canser yn afiechyd cymhleth. Gyda dros 200 o fathau gwahanol, mae ei drin yn dod yn fwy cymhleth ac yn ddrytach nag erioed o'r blaen.

Mae canser yn afiechyd cymhleth. Gyda dros 200 o fathau gwahanol, mae ei drin yn dod yn fwy cymhleth ac yn ddrytach nag erioed o'r blaen.

Mae rhoi diagnosis o ganser ar gam cynnar yn her fawr i Gymru. Rydym yn gwybod o astudiaethau a gwblhawyd mewn mannau eraill o'r DU y gellid arbed miloedd o fywydau pe byddai pobl yn cael diagnosis yn gynharach ac yn cael cynnig triniaeth addas yn gynt.[1] Ond bellach mae ystyriaethau eraill heblaw a yw pobl yn goroesi canser neu beidio. Diolch i ddatblygiadau o ran triniaeth a diagnosis cynharach, mae mwy o bobl yn byw'n hirach gyda chanser neu'r tu hwnt iddo, sy'n golygu bod arnyn nhw angen cymorth parhaus, a thymor hir yn aml. Erbyn 2030, amcangyfrifir y bydd y nifer o bobl sy'n byw gyda neu wedi canser yng Nghymru bron â dyblu, i bron i chwarter miliwn.[2]

Gall canser a'i driniaeth gael effaith ddinistriol ar fywydau pobl. Ar yr un pryd, mae'r system gofal canser presennol yn ddrud ac nid ydyw'n diwallu anghenion pobl. Er mwyn darparu'r cymorth a'r gofal cost-effeithiol sydd ei angen ar bobl Cymru yn ystod a'r tu hwnt i ganser, mae angen i ni drawsnewid gofal canser yn radical.

Yr hyn sydd ei angen arnom yw strategaeth ganser cynhwysfawr i Gymru, sy'n gosod pobl yn ganolog. Strategaeth a chanddi eglurder, gweledigaeth a chyfeiriad; sydd yn defnyddio dull eang, systemau-cyfan o ran atal canser, rhoi diagnosis, triniaeth a gofal, ac sy'n ystyried y nifer cynyddol o bobl sy'n byw gyda chanser, datblygiadau technolegol a'r cyfnod economaidd heriol.

Rydym yn credu y dylai'r strategaeth newydd gynnwys pedair menter allweddol er mwyn gwneud gofal canser yng Nghymru yn fwy personoledig: gwell asesiadau a chynllunio gofal, diwygio ôl-ofal, mwy o gymorth a gwybodaeth bersonoledig, a gweithiwr allweddol i bawb sydd â chanser. Bydd strategaeth o'r fath yn galluogi gwasanaethau canser i symud i ffwrdd oddi wrth y dull un-ateb-i-bawb o weithredu tuag at ofal mwy unigolyddol gydol y profiad o ganser. Bydd hyn yn sicrhau canlyniadau gwell i bobl sy'n byw gydag a'r tu hwnt i ganser, tra bod ymchwil wedi dangos y bydd hefyd yn arbed arian.

Fodd bynnag, nid yw strategaeth yn unig yn ddigonol. Mae penderfynu sut mae clustnodi arian yn benderfyniad anodd i Lywodraeth Cynulliad Cymru, y GIG ac awdurdodau lleol. Mae angen arweinyddiaeth gref er mwyn cefnogi rheolwyr a chlinigwyr i gymryd y penderfyniadau cywir. Mae arweinyddiaeth genedlaethol gref hefyd yn hanfodol er mwyn cadw'r sylw ar weithredu, a sicrhau cysondeb a chydraddoldeb ar draws y wlad fel bod pawb yn derbyn yr un gofal a thriniaeth o ansawdd uchel, waeth ble maen nhw'n byw.

Mae Macmillan wedi bod yn gweithio er mwyn gwella bywydau pobl sy'n byw gydag ac wedi canser ers dros ganrif. Bob blwyddyn rydym yn buddsoddi miliynau o bunnoedd mewn gwella gwasanaethau canser yng Nghymru. Mae ein hymchwil a'n profiad yn dangos i ni'r hyn sydd ar bobl Cymru ei angen a'i eisiau. Nawr rydym yn ymrwymo i weithio gyda Llywodraeth nesaf y Cynulliad er mwyn helpu i sicrhau gofal canser o safon ryngwladol i'r genedl.

Ein hargymhellion

1: Datblygu strategaeth ganser i Gymru sy'n gosod pobl yn ganolog ym mlwyddyn gyntaf tymor nesaf y Cynulliad.

Mae ar Gymru angen strategaeth ganser cenedlaethol sy'n cydnabod natur newidiol yr afiechyd ac sy'n arwain y ffordd i drawsnewid gofal canser. Mae angen iddi ymgorffori'r holl lwybr drwy ganser – o'i atal a goroesedd i ofal lliniarol a diwedd oes – a diwallu anghenion y bobl sy'n byw gyda chanser.

Dylai'r holl driniaeth a gofal roi'r unigolyn yn ganolog - mae angen i hynny fod yn thema ganolog yn rhedeg drwy'r strategaeth ganser newydd i Gymru. Ceir diffiniad o ofal sy'n gosod yr unigolyn yn ganolog ar dudalen 17.

Mae'n allweddol bod y strategaeth yn cael ei datblygu law yn llaw gyda'r bobl yng Nghymru sy'n deall y materion hyn orau: budd-ddeiliaid sy'n cefnogi pobl sy'n byw gydag ac wedi canser, a'r rhai sydd wedi profi canser drostyn nhw eu hunain.

2: Cynnwys pedair menter allweddol o fewn y strategaeth ganser er mwyn sicrhau gofal cost-effeithiol sy'n gosod pobl yn ganolog.

Drwy fabwysiadu'r newidiadau hyn dros dymor nesaf y Cynulliad, gallwn wella gofal canser a sicrhau defnydd mwy cydgysylltiedig ac effeithiol o adnoddau'r GIG.[3]

i. Gwell asesiadau a chynllunio gofal
   - o Dylid cynnig asesiad a chynllun gofal i bob claf canser ar bob cam addas o'u profiad o ganser.

ii. Diwygio ôl-driniaeth canser
   - o Wedi'u triniaeth gychwynnol, dylai pob claf canser yng Nghymru dderbyn cefnogaeth barhaus sydd wedi'i theilwra i ddiwallu ei lefel bersonol o angen a risg.

iii. Cymorth a gwybodaeth sy'n fwy personoledig
   - o Dylai pawb sy'n byw gyda chanser gael cynnig gwybodaeth a chymorth teilwredig gydol eu profiad o ganser.

iv. Mynediad at weithiwr allweddol dynodedig
   - o Dylai pob claf canser gael mynediad at weithiwr allweddol dynodedig sy'n deall ei anghenion ac sy'n gallu cynnig cymorth yn ystod ac wedi triniaeth.

Rhan 1: Yr angen am newid

Ble yr ydym ni nawr

Mae Cymru'n wynebu sawl her enfawr wrth gefnogi pobl i fyw gydag a'r tu hwnt i ganser, yn ogystal â gofalu am y rhai sydd, gwaetha'r modd, yn marw o'r afiechyd.

Mae'r materion heriol hyn wedi'u cydnabod gan Lywodraeth Cynulliad Cymru[4], sydd ag uchelgais i weld Cymru'n cael ei chyfrif ymhlith y gorau yn Ewrop erbyn 2015. Ond, a ninnau'n agosáu at y dyddiad hwnnw, ac wrth i wledydd eraill yn Ewrop barhau i wella, mae angen gwneud llawer cyn gwireddu'r uchelgais hwn.[5]

Mae'n rhaid cyflawni'r gwaith pwysig hwn o fewn cyd-destun newidiol canser. Heddiw, mae'r gallu i roi diagnosis ac i drin yr afiechyd yn dod yn fwyfwy effeithiol diolch i ddatblygiadau mewn technoleg a meddygaeth. O ganlyniad, mae llawer iawn mwy o bobl yn byw trwy ganser, ac mae cyfraddau'r rhai sy'n goroesi 10 mlynedd a mwy wedi dyblu dros y 30 mlynedd diwethaf i 46%.[6] I nifer, mae canser o hyd yn salwch anwelladwy tymor byr, ond yn achos miloedd o bobl eraill, mae eu profiad o ganser yn esblygu i fod yn gyflwr tymor hir gyda nifer o ganlyniadau posib. Wrth i natur canser newid, felly hefyd anghenion pobl sydd wedi'u heffeithio ganddo – a hefyd yr amrediad o wasanaethau a gweithwyr gofal iechyd a chymdeithasol proffesiynol sydd eu hangen er mwyn helpu i ddiwallu'r anghenion hynny.

Mae'r trawsnewidiad hwn hefyd yn digwydd ar adeg heriol iawn yn economaidd i'r GIG a'r sector cyhoeddus. Bydd yn rhaid gwneud penderfyniadau anodd ynghylch clustnodi adnoddau cyfyngedig dros y blynyddoedd nesaf. Mae arweinyddiaeth ac eglurder gan y llywodraeth o ran ei gweledigaeth a'i huchelgais ar gyfer gwella gwasanaethau canser yn hanfodol er mwyn cefnogi'r rhai sy'n gwneud penderfyniadau ar bob lefel o ofal canser, a datblygu gwasanaethau a pholisi.

Mae'n amlwg bod angen i ni drawsnewid ein ffordd o ddarparu gofal canser yng Nghymru os ydym am ddiwallu anghenion y nifer cynyddol o bobl sydd wedi'u heffeithio gan ganser yn yr hinsawdd sydd ohoni. Mae angen i wasanaethau canser yng Nghymru roi pobl yn fwy canolog – barn sydd â chefnogaeth y bobl sy'n byw gyda chanser ac sy'n gweithio yn y maes.[7] Ac yr ydym yn gwybod, o sicrhau bod gwasanaethau canser yn fwy integredig ac wedi'u cydgysylltu'n well, y gallwn sicrhau nid yn unig ganlyniadau gwell i bobl sydd wedi'u heffeithio gan ganser, ond hefyd rhyddhau arbedion sylweddol i'r GIG a phartneriaid statudol eraill.[8] Fodd bynnag, bydd angen newid sylweddol er mwyn darparu gwasanaethau o ansawdd uchel, sy'n gosod pobl yn ganolog ac sy'n gost-effeithiol. Ni fydd hyn yn digwydd dros nos, ac ni all ddigwydd heb arweinyddiaeth ac ymyrraeth gan y llywodraeth a'r rhai sy'n cynllunio gwasanaethau.

Wrth i ni agosáu at bedwerydd tymor y Cynulliad, mae gan Gymru gyfle unigryw i fod ar flaen y gad o ran yr ymdrechion i drawsnewid gofal canser i ddiwallu anghenion y bobl sydd wedi'u heffeithio gan ganser ac wynebu'r heriau ariannol anodd sydd i ddod.

Faint o bobl sydd wedi'u heffeithio?

Ym maes canser, mae Cymru'n wynebu rhai heriau arwyddocaol. Mae nifer y bobl sy'n cael diagnosis o ganser wedi cynyddu dros y ddeng mlynedd diwethaf. Er bod y cyfraddau goroesi wedi gwella, maen nhw'n parhau i lusgo'n sylweddol y tu ôl i rai Ewrop a gwledydd datblygedig eraill.[9] Ac wrth i fwy o bobl oroesi ac wrth i'r boblogaeth heneiddio, mae yna niferoedd cynyddol o bobl yn byw gyda neu'r tu hwnt i ganser.[10]

FFEITHIAU ALLWEDDOL

- Bob diwrnod mae 50 o bobl yn cael diagnosis o ganser yng Nghymru – dros 17,000 bob blwyddyn.[11]
- Ar hyn o bryd, mae dros 120,000 o bobl yn byw gyda neu'r tu hwnt i ganser yng Nghymru – tua 4% o'r boblogaeth.[12]
- Os yw'r tueddiad presennol yn parhau, erbyn 2030 bydd y nifer wedi dyblu bron iawn i dros 7% o'r boblogaeth.[13]
- Gan Gymru mae'r ganran uchaf o bobl sy'n byw gyda chanser yn y DU, sydd ynghlwm â bod â'r boblogaeth hynaf o'r pedair cenedl.[14]
- Mae canran uwch o bobl yn marw o ganser yng Nghymru o gymharu â gweddill y DU. Y gyfradd farwolaethau canser yn ôl oed safonedig yng Nghymru yw 183 o farwolaethau i bob 100,000 o'r boblogaeth, o gymharu â 176 o farwolaethau i bob 100,000 o'r boblogaeth yn y DU.[15]

Datblygiadau mewn diagnosis a thriniaeth

Gyda datblygiadau newydd i dechnoleg a chyffuriau, mae diagnosis a thriniaeth i gleifion canser yn gwella ac mae niferoedd uwch o bobl yn byw trwy ganser a'r tu hwnt iddo. Os ydym am sicrhau cyfraddau goroesi gwell fyth, mae'n hanfodol ein bod yn parhau i fuddsoddi mewn ymchwil a datblygiadau technolegol fydd yn sicrhau gwell gofal clinigol a chanlyniadau i gleifion.

Hefyd mae angen i ni ddatblygu dull o weithredu, strwythur a phroses sy'n galluogi gweithwyr gofal iechyd proffesiynol i weithredu'r datblygiadau diweddaraf mewn triniaethau a diagnosteg - unwaith eu bod wedi'u profi ac yn gost-effeithiol. Os yw Cymru i ddatblygu gwasanaeth rhyngwladol ei safon ni ellir gadael hyn i hap. Mae angen arweinyddiaeth glinigol ar bob lefel er mwyn sicrhau bod y dasg allweddol hon yn cael ei rheoli'n briodol, fel y gall cleifion dderbyn y gofal gorau a diweddaraf, waeth ble maen nhw'n byw yng Nghymru.

Yr her ariannol

Mae canser yn gyfrifol am 7.1% o holl wariant y GIG yng Nghymru.[16] Yn 2008-09 roedd y swm hwn yn £358.8 miliwn – y pedwerydd maes mwyaf o ran gwariant i'r GIG ar ôl iechyd meddyliol, problemau cylchrediad, a thrawma ac anafiadau.

Wrth i nifer y bobl sy'n cael diagnosis ac sy'n byw gyda chanser gynyddu, mae cost gwasanaethau canser yn debygol o fod yn fwrn ariannol cynyddol ar y GIG.

Er bod cost triniaethau a chyffuriau canser yn sicr yn uchel, dengys tystiolaeth y gallwn wneud arbedion effeithlonrwydd eraill mewn gofal canser. Er enghraifft, wrth ddarparu asesiadau a chynllunio gofal, gwybodaeth, cyngor ar fudd-daliadau a chymorth un i un personoledig drwy nyrsys clinigol arbenigol – gallwn ddefnyddio adnoddau lawer yn fwy effeithiol, yn ogystal â lleihau dyddiau gwely diangen a derbyniadau brys am ganser.[17]

Mae ymchwil a wnaed gan Monitor ar ran Macmillan[18] hefyd wedi dangos y gallai gofal canser mwy cydgysylltiedig arwain at arbedion. Mae'r adroddiad yn tynnu sylw at gyfleoedd i arbed arian drwy wneud y canlynol:

- gwella cyfathrebu, cydgysylltu a gwybodaeth
- gwella gofal er mwyn lleihau hyd arhosiad wedi triniaeth, apwyntiadau claf allanol, marwolaethau mewn ysbytai, ac ymgynghoriadau gyda meddygon teulu
- cefnogi cleifion i fynd yn ôl i'r gwaith

Daw'r adroddiad i'r casgliad y gallai gwella cydgysylltu gofal, lleihau nifer y derbyniadau brys y gellid eu hosgoi a hyd arosiadau yn yr ysbyty, a galluogi mwy o bobl i farw gartref, arwain at arbedion i'r GIG o hyd at 10% i'r cleifion canser gafodd eu harchwilio drwy'r astudiaeth. Darganfu hefyd y gellid rhoi hwb o £30 miliwn i economi'r DU bob blwyddyn pe bai 5% yn unig yn fwy o'r rhai sy'n goroesi canser y fron yn cael gwell cefnogaeth i aros yn y gwaith.[19] Byddai hyn yn hwb sylweddol i'r economi yng Nghymru.

Dengys ymchwil ychwanegol[20] mai cyfanswm cost canser i'r DU yn 2008 oedd £18.33bn, o gynnwys costau'r gwasanaeth iechyd a chynhyrchiant coll. Mae disgwyl i'r ffigwr hwn godi i £24.72 biliwn erbyn 2020. Ond pe bai gwasanaethau canser a chyfraddau goroesi yn gwella ddigon i fod ymhlith y gorau yn Ewrop, gellid gostwng y ffigwr hwnnw o £10bn yn Lloegr yn unig, gan arbed 71,500 o fywydau – nifer anhygoel. Gellid sicrhau gwelliannau fel hyn yng Nghymru hefyd.

Mae'r dystiolaeth yn eglur: mae canser yn cael effaith ar y gymuned yn ehangach, ar gymdeithas ac ar yr economi. Mae'n rhaid i lywodraeth nesaf Cymru osod gweledigaeth glir ar gyfer gwasanaethau canser fel y gall cynllunwyr ganolbwyntio ar flaenoriaethau buddsoddi a chanfod meysydd ble y gellid gwneud arbedion drwy arloesi a gwell gofal. Bydd gosod strategaeth genedlaethol ar waith ym maes canser yn hybu mwy o arbedion drwy leihau dyblygu o ran gwasanaethau rheng flaen, drwy annog arloesi, a helpu i wneud yr arfer gorau yn arfer cyffredin.

Mae canser yn wahanol nawr

Ugain mlynedd yn ôl, roedd canser yn cael ei ystyried yn ddedfryd o farwolaeth i lawer o bobl, ac yn aml unig fwriad triniaeth oedd estyn bywyd am rai misoedd. Nawr, mae gwelliannau i ddiagnosis a thriniaeth yn golygu y bydd 60% o bobl sydd â chanser yn byw am bum mlynedd a mwy.[21] Yn achos rhai mathau o ganser, fel canser y fron, mae cyfraddau goroesi wedi pum mlynedd mor uchel â 80%. Oherwydd hyn, mae canser bellach yn fwy na chwestiwn o fyw neu farw. I nifer cynyddol o bobl, mae'n salwch cronig a all ddilyn patrwm o ailwaelu a gwella dros nifer o flynyddoedd.

Yn ddiddorol ddigon, nid yw canfyddiadau o ganser a'r ffordd mae gofal yn cael ei ddarparu wedi dal i fyny gyda'r datblygiadau hyn.[22] Canfu ymchwil diweddar i Macmillan – gyda gweithwyr proffesiynol ym maes gofal canser yng Nghymru - eu bod yn cydnabod nad yw gwasanaethau yn esblygu, er eu bod yn cydnabod bod y darlun o ran canser yn newid.[23]

Mae natur newidiol canser felly yn golygu her sylweddol i'r GIG, i wasanaethau cymdeithasol ac i'r sector wirfoddol, wrth iddyn nhw geisio ffyrdd newydd a gwell i ddiwallu anghenion pobl sydd â chanser a defnyddio'u hadnoddau prin yn well.

Beth sydd ar bobl ei eisiau a'i angen?

Dywed pobl sydd wedi'u heffeithio gan ganser wrthym fod yr afiechyd yn troi eu bywydau wyneb i waered. Mae'n effeithio ar sut y maen nhw'n teimlo amdanyn nhw eu hunain a'u hanwyliaid, ar eu gwaith, eu sefyllfa ariannol, a'u lles emosiynol. Ar lefel ymarferol mae'n cael effaith enfawr ar eu gallu i fyw eu bywydau o ddydd i ddydd. Ac maen nhw'n teimlo'r effeithiau hyn gydol eu profiad o ganser.

Yn ôl gweithwyr proffesiynol ym maes gofal canser yng Nghymru, mae prif ffocws gofal ar yr ochr glinigol o hyd - 'trin y cyflwr yn hytrach na'r unigolyn'.[24] O ganlyniad, mae nifer o'r anghenion eraill sydd gan bobl sydd â chanser heb eu diwallu. Mae gweithwyr proffesiynol wedi mynegi eu rhwystredigaeth na roddir sylw digonol yn aml i'w hanghenion anghlinigol. Maen nhw'n siarad am yr angen i newid diwylliant clinigol 'sydd yn aml yn credu bod gofal yn ddigonol, cyn belled â'i bod yn cael yr ochr feddygol a chorfforol yn iawn.'[25]

Anghenion emosiynol a seicolegol

'Byddai'n braf pe baech chi'n cael gwybod am y gwasanaethau emosiynol sydd ar gael, ar yr un pryd â chlywed bod canser arnoch chi...mae angen i chi ddysgu sut mae ymladd y peth hwn achos mae'n debygol eich bod chi'n meddwl "Rwy'n mynd i farw".'[26]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Mae canser yn gosod pobl o dan straen emosiynol a seicolegol enfawr, a all arwain at amrediad eang o anawsterau ymarferol mewn bywyd dyddiol.[27] Ar adeg diagnosis, mae tua 50% o bobl sydd â chanser yn profi lefelau o bryder ac iselder sy'n ddigon difrifol i effeithio ar eu hansawdd bywyd. I tua 25% mae hyn yn parhau am y chwe mis nesaf. Yn y flwyddyn wedi diagnosis, bydd tua 1 o bob 10 o bobl sy'n byw gyda neu'r tu hwnt i ganser yn profi symptomau mor ddifrifol nes bod angen gwasanaethau seicolegol neu seiciatryddol arbennig arnyn nhw.[28]

Dengys ymchwil mai cleifion sydd â chanser yr ysgyfaint, canser pancreatig, lymffoma Hodgkins, canser yr ymennydd, y pen neu'r gwddf, lewcemia a lymffoma sy'n profi'r lefelau uchaf o ofid.[29] Rydym hefyd yn gwybod bod mwy o gleifion yn ei chael hi'n fwy anodd ymdopi gydag effeithiau emosiynol canser o gymharu â'r effeithiau corfforol neu ymarferol, ac mae hyn yn arbennig o wir yn achos menywod, y rhai sydd â phlant ifanc, a'r rheiny o gefndiroedd economaidd-gymdeithasol is.[30]

Am y rhesymau hyn yn aml mae ar bobl sydd â chanser angen cymorth emosiynol adeg eu diagnosis, yn ogystal ag yn ystod ac wedi eu triniaeth. Er gwaethaf hyn, dywed pobl eu bod nhw'n ei chael hi'n anodd darbwyllo gweithwyr proffesiynol i'w cyfeirio nhw at fwy o help. Er bod ar rai pobl angen cymorth seicolegol proffesiynol i'w helpu i ddelio gydag effeithiau canser, y cwbl sydd ar rai ei angen yw cael siarad gyda rhywun.

Roeddwn i'n unig iawn ac mewn iechyd gwael pan adewais i'r ysbyty. Cefais nifer o gymhlethdodau, fel creithiau heintiedig, a barodd am chwech i saith wythnos. Roedd nyrsys yn trin y briwiau ond roedd ganddyn nhw gymaint o waith papur i'w wneud fel nad oedd ganddyn nhw amser i siarad.'[31]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Mae ein hymchwil diweddar ni ein hunain wedi dangos i 20% o'r bobl â chanser ddweud eu bod nhw am gael cwnsela pan oedd canser arnyn nhw, ond ni chafodd dros hanner ohonyn nhw wybod sut i gael gafael arno.[32]

'Rhoddwyd llyfryn i fi a oedd yn egluro gwahanol fathau o ganser a thriniaethau ond ar adeg y diagnosis yn y clinig, dyna'r cyfan. Roeddwn i mewn gofid a byddwn i wedi hoffi siarad gyda rhywun.'[33]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Mae gweithwyr proffesiynol a holwyd gan Macmillan yn cytuno nad oes digon o sylw yn cael ei roi i effaith emosiynol canser a bod pobl sy'n byw gydag ac wedi canser yn aml yn cael eu gadael i ymdopi ar eu pen eu hunain gyda'r ôl effeithiau dinistriol.

'Mae'n rhaid i gleifion a pherthnasau ddod o hyd i'w cefnogaeth eu hunain ar adeg pan maen nhw'n straffaglu. Nid yw'r rhai sydd angen adferiad a chymorth seicolegol er mwyn byw gyda'u hafiechyd neu eu hafiechyd blaenorol yn ei gael.'[34]

Gweithiwr Proffesiynol Perthynol i Iechyd, Cymru

Anghenion ariannol

Dengys astudiaethau y gall canser effeithio'n sylweddol ar sefyllfa ariannol pobl ac arwain at ddyledion newydd neu gynyddol.[35] Mae tystiolaeth hefyd yn awgrymu y gall beichiau ariannol ychwanegu at bryder a straen, a bod rhai pobl yn teimlo bod anawsterau ariannol yn 'fwy o bryder na'r canser'.[36]

Mae dros 5% o bobl sy'n byw gyda neu'r tu hwnt i ganser - dros 10% os ydyn nhw'n hunangyflogedig - yn colli eu cartref ar ôl cael diagnosis.[37] Mae 91% o aelwydydd gyda phobl sydd wedi'u heffeithio gan ganser yn profi colledion incwm a/neu gostau uwch. Er enghraifft, ar gyfartaledd, mae unigolyn â chanser yn ymweld â'r ysbyty 53 o weithiau yn ystod eu triniaeth.[38] Gall biliau gwresogi a biliau eraill y cartref godi hefyd, efallai y bydd angen dilyn diet arbennig a phrynu dillad newydd.[39 40]

Nid yw nifer o bobl sy'n byw gydag ac wedi canser yn hawlio'r budd-daliadau sy'n ddyledus iddyn nhw. Mae hyn yn arbennig o wir ymysg pobl hŷn a phobl anabl, sydd yn aml angen help er mwyn hawlio arian.

Canfu arolwg diweddar gan Macmillan ynghylch derbyn cyngor wedi triniaeth, mai dim ond 6% o oedolion Cymru gafodd rhywun i siarad â nhw am faterion ariannol fel budd-daliadau a grantiau, a dim ond 3% gafodd rhywun i siarad â nhw am bryderon neu faterion ariannol.[41]

Mae ein hymchwil yn awgrymu mai dim ond poen sy'n achosi mwy o straen i bobl sydd â chanser na phryderu am arian.[42] Mae angen i ni sicrhau bod pobl sydd wedi cael diagnosis o ganser yn derbyn y budd-daliadau ariannol sy'n ddyledus iddyn nhw fel y gallan nhw fod yn rhydd er mwyn canolbwyntio ar eu triniaeth a'u hadferiad.

Anghenion gwybodaeth

Mae ar bobl sy'n byw gyda chanser, a'u gofalwyr, angen cymorth a gwybodaeth ddibynadwy i'w helpu i ddod o hyd i'w ffordd drwy'r driniaeth am ganser a'r tu hwnt. Gyda'r wybodaeth gywir mae ganddyn nhw'r grym i wneud y penderfyniadau gorau iddyn nhw ac i'w teuluoedd.

Dywed y rhan fwyaf o bobl sydd â chanser y bydden nhw'n hoffi cael rhagor o wybodaeth. Dywed rhai nad ydyn nhw'n derbyn unrhyw wybodaeth o gwbl.[43] Canfu arolwg diweddar a wnaed ar ein rhan ni bod 72% o gleifion canser yng Nghymru eisiau gwybodaeth am eu cyflwr, roedd 77% eisiau deall effeithiau tymor hir eu triniaeth, a 71% eisiau gwybod am y dewisiadau gwahanol o ran triniaeth a oedd ar gael. Yn anffodus, o'r bobl â chanser a fu'n rhan o'r arolwg hwn, derbyniodd lai na 33% y wybodaeth hon mewn gwirionedd.[44]

Wrth i ganser a'i ofal newid, mae angen i ni gefnogi pobl sy'n byw gyda neu wedi canser

i gymryd rôl weithredol a blaenllaw yn eu hadferiad. Mae'r wybodaeth gywir yn rhoi'r grym i bobl i wneud penderfyniadau am eu triniaeth eu hunain, ond mae angen ei rhoi mewn ffordd ystyrlon. Rydym yn croesawu ymdrechion diweddar Iechyd Cyhoeddus Cymru i wella llythrennedd iechyd a gwella dealltwriaeth pobl o'u cyflwr a'u triniaeth. Nawr mae angen gwneud mwy o waith er mwyn sicrhau bod pawb sy'n byw gydag ac wedi canser yn cael cynnig cymorth a gwybodaeth bersonol er mwyn rheoli eu cyflwr.

Dywed pobl sy'n byw gydag a'r tu hwnt i ganser nad yw gwybodaeth hawdd ei deall, cymorth na chyfeirio at wasanaethau eraill ar gael ymhobman yng Nghymru. Ble mae gwybodaeth a chymorth ar gael, nid yw llawer o bobl yn sylweddoli eu bod nhw'n bodoli.

'Roedd y staff yn yr ysbyty yn llawn gofal, ac yn rhagorol. (Ond) chefais i ddim gwybodaeth gan y gwasanaethau cymdeithasol ar sut i gael help gyda gofal yn fy nghartref ar fy mhen fy hun, a dim syniad ynglŷn â sut i gael help.'[45]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Er bod gwybodaeth ar gael yn gynyddol, mae arolwg diweddar gan weithwyr proffesiynol[46] yn dadlennu bod pobl yn aml yn ei chael yn llethol, yn enwedig wrth gael diagnosis am y tro cyntaf. Dywed y gweithwyr proffesiynol hefyd bod ar bobl angen mwy o amser i lyncu'r newyddion ac i gael cyfle i holi cwestiynau y tu allan i'r ystafell ymgynghori.

Dywedodd un nyrs a holwyd:

'Er bod gwybodaeth ar gael, nid yw wastad yn cael ei rhoi mewn ffyrdd sy'n goleuo pobl. Fel

arfer mae meddygon yn ceisio egluro dewisiadau triniaeth ac ati yn nhermau canrannau, ffigyrau o brofion, gan ddyfynnu cyfraddau goroesi ar ôl pum mlynedd, sy'n gallu achosi gofid gan mai'r hyn mae cleifion yn ei glywed yw "pum mlynedd". Maen nhw'n canolbwyntio ar hyn, gan gredu iddyn nhw gael prognosis. Yn aml maen nhw'n cael eu hanfon i ffwrdd heb sicrhau eu bod nhw'n deall, ac mae disgwyl iddyn nhw wneud penderfyniad gyda'r wybodaeth hon, a heb gymorth seicolegol er mwyn gwneud hynny. Am wn i yr hyn rwy'n ceisio'i ddweud yw bod gwybodaeth ar gael, yn aml yn helaeth, ond nid yw'n rhoi'r unigolyn yn ganolog.'[47]

Nyrs Canser, Cymru

Anghenion tymor hir pobl wedi triniaeth

Tra bod pobl yn derbyn triniaeth am ganser, maen nhw'n cael cefnogaeth amrywiaeth o weithwyr proffesiynol yn yr ysbyty, yn mynd o apwyntiad i apwyntiad. Ond unwaith y daw triniaeth i ben, mae cryn dipyn o'r gefnogaeth yn diflannu er y gall pobl barhau i fod ag amrediad o anghenion cymdeithasol, seicolegol a chorfforol cymhleth. Gall pobl ddioddef o salwch cronig – megis problemau gyda'r coluddyn, blinder cronig, lymffoedema, analluedd, anffrwythlondeb ac iselder – a gall mathau newydd o ganser neu gyflyrau yn sgil y driniaeth ddod i'r amlwg misoedd neu hyd yn oed flynyddoedd yn ddiweddarach.

Er gwaetha'r problemau niferus sy'n dilyn triniaeth am ganser, dywed pobl sy'n byw gyda neu'r tu hwnt i ganser wrthym fod yna ddiffyg cymorth.[48] Mae'n nhw'n teimlo iddyn nhw gael eu gadael yn y cyfnod wedi triniaeth. Mae nifer yn cymharu'r teimlad i sefyll ar ymyl dibyn.

Canfu arolwg a wnaed ar ein rhan bod ar 60% o bobl oedd yn byw gyda neu'r tu hwnt i ganser eisiau gwybodaeth, cyngor a chymorth ynghylch y camau nesaf a'r dewisiadau yn y profiad o ganser wedi triniaeth. 23% yn unig sy'n eu cael. Canfu hefyd bod 27% o bobl sy'n cwblhau eu triniaeth yn teimlo bod y system iechyd yn cefnu arnyn nhw.[49]

'Y cyfnod wedi triniaeth yw un o'r rhannau anoddaf o'r profiad o ganser, er syndod. Mae ôl effeithiau triniaeth yn golygu bod cymaint o docsinau a gwenwyn yn mynd drwy'ch corff fel bod effaith corfforol a meddyliol arnoch chi. Fe ges i hyn yn anodd iawn, iawn.'[50]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

'Mae yn teimlo eich bod chi ar eich pen eich hunan ar ôl eich sesiwn olaf o gemotherapi. Dyna'r adeg, heb gymaint o gefnogaeth gan y nyrsys, y meddygon ac ati, pan mae'r hyn sydd wedi digwydd yn eich taro chi ac mae'r elfen 'iechyd meddyliol' yn cychwyn. Dyna pryd rwy'n teimlo bod y gefnogaeth yn eisiau.'

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Dengys ymchwil a wnaed ar ein rhan gan Athrofa Iechyd a Gofal Cymdeithasol Cymru[51] mai'r gwasanaethau a gynigir wedi triniaeth oedd leiaf tebygol o roi'r unigolyn yn ganolog. Canfu fod pobl yn aml yn teimlo 'ar gyfeiliorn' unwaith y daw triniaeth i ben, ar yr union adeg pan fo'r angen am gymorth fwyaf taer. Mae gweithwyr proffesiynol yn yr astudiaeth yn cydnabod yr angen i ddarparu asesiadau a chynllunio gofal wedi triniaeth, ond yn dweud mai anaml y mae hyn yn digwydd. Maen nhw'n ymwybodol o'r anawsterau ymarferol ac emosiynol lu sy'n wynebu pobl yn y cyfnod wedi triniaeth, ac yn teimlo y byddai pobl sydd â chanser a'u gofalwyr yn elwa o well cyfeirio tuag at ffynonellau gwybodaeth a chymorth anghlinigol.

Disgrifiodd nifer y 'cysgod hir o ofn' y mae canser yn ei daflu dros fywydau pobl a'r angen i adennill hyder yn eu hiechyd eu hunain.

'Wedi triniaeth mae yna deimlad llethol o hyd bod pobl wedi troi cefn arnyn nhw, ac nid yw hyn wedi gwella. Mae hyrwyddo mentrau byw gyda chanser yn araf iawn i fod ar gael.'[52]

Rheolwr Gweithredol, GIG Cymru

Mae arolwg diweddar a wnaed yng Nghymru a ein rhan gan YouGov yn datgelu hyn[53]:

- Dywed 50% o bobl sy'n byw gyda neu'r tu hwnt i ganser na thrafododd neb eu hanghenion wedi i'w triniaeth glinigol ddod i ben.
- Dywed 61% na dderbynion nhw unrhyw gymorth gan weithwyr proffesiynol iechyd a gofal cymdeithasol allweddol wedi triniaeth.
- Dywed 56% na chawson nhw weithiwr iechyd dynodedig i helpu eu cefnogi nhw yn ystod y flwyddyn gyntaf wedi triniaeth.
- O'r rheiny gafodd rhywun i siarad gyda ynghylch eu hanghenion wedi triniaeth, dywed 76% nad oedd y rhain wedi'u cofnodi mewn cynllun gofal.

Ar drywydd gofal cydgysylltiedig a gwasanaethau o ansawdd uchel

Mae cymhlethdod a difrifoldeb canser yn ei gwneud hi'n heriol ond yn hanfodol bod y gwasanaethau cywir yn cael eu darparu mor effeithiol a chyn gynted â phosib.

Gall diagnosis gael ei oedi am nifer o resymau gan gynnwys cyflwyniad hwyr gan yr unigolyn, systemau cyfeirio sydd wedi'u cydgysylltu'n wael rhwng gwasanaethau a llwybrau diagnostig cymhleth.[54] Mae cynlluniau triniaeth ganser pobl hefyd yn amrywio'n sylweddol, gan ddibynnu ar y math o ganser sydd arnyn nhw a'r broses o gael diagnosis. Gall eu cynllun gynnwys triniaethau cymhleth, sydd o bosib yn niweidiol, fel llawdriniaeth, radiotherapi, cemotherapi, a therapi hormonau. Nid yw effeithiau triniaethau newydd, blaengar, yn hysbys, ond rydym yn gwybod y gall canser a'i driniaeth effeithio ar fywyd rhywun am wythnosau, misoedd a blynyddoedd i ddod. Ar yr un pryd, mae'r gofal maen nhw'n ei dderbyn yn digwydd mewn nifer o leoliadau ac yn aml y tu hwnt i ffiniau byrddau iechyd lleol a rhwydweithiau canser. Mae rhai triniaethau arbenigol yn digwydd ar draws ffiniau'r DU ac mewn gwledydd eraill yn Ewrop.

Mae'r cymhlethdod hwn yn ei gwneud hi'n anodd sicrhau gofal cydgysylltiedig o fewn y system iechyd a'r sectorau sylfaenol, cymunedol, gofal iechyd a gwirfoddol. Gall dilyniant gofal ddioddef ac mae pobl yn adrodd eu bod yn teimlo fel petaent yn syrthio i'r bylchau rhwng darparwyr gwasanaethau. Dyma oedd gan weithwyr proffesiynol yng Nghymru i'w ddweud ar y mater mewn ymchwil diweddar:

'Mae gweithwyr proffesiynol unigol yn garedig, ond mae'r systemau a'r prosesau yn ddigyswllt felly gall eich drysu, a gallwch orfod dibynnu ar un unigolyn i ddarparu gofal cydgysylltiedig a chymryd cyfrifoldeb cyffredinol.'[55]

Unigolyn sydd wedi'i effeithio gan ganser, Cymru

Os nad yw pobl yn cael llwybr gofal sydd wedi'i ddiffinio'n glir - o lawdriniaeth, cemotherapi neu radiotherapi i hunanofal gyda chefnogaeth - sy'n eu helpu i gael gafael ar y cymorth sydd ei angen arnyn nhw ar unrhyw adeg benodol, yna'r peryg yw y byddan nhw'n gorfod ymweld â'r uned achosion brys. Byddan nhw'n cael eu gweld gan weithwyr proffesiynol sydd heb wybodaeth am eu cyflwr na'u hanes, sy'n arwain at gymorth drud, o ansawdd isel.

Dywed pobl sy'n byw gydag ac wedi canser wrthym fod y gwasanaethau yn dameidiog ac yn anghyson ar draws Cymru.[56] Mae'r farn hon yn gyson ag adroddiadau eraill diweddar, y byddwn ni'n eu crybwyll yma.

Methiant i gwrdd â safonau

Yn 2005, lansiwyd y Safonau Canser Cenedlaethol er mwyn darparu arweiniad ar gyfer rheolaeth ganser yng Nghymru. Gofynnwyd i ddarparwyr iechyd i gwrdd â'r safonau hyn erbyn mis Mawrth 2009.

Ym mis Mawrth 2010, cyhoeddodd Llywodraeth Cynulliad Cymru ddadansoddiad cydymffurfio[57], sy'n dangos bod yna fylchau sylweddol o ran pa wasanaethau canser sydd ar gael ar draws Cymru, gyda lefelau sylweddol o ddiffyg cydymffurfio ym mhob ardal bron iawn. Un bwrdd iechyd lleol yn unig lwyddodd i gael dros 50% o gydymffurfiad. Y gwasanaethau gyda'r lefelau isaf o gydymffurfiad oedd asesu cymorth parhaus, a mynediad chwim at gymorth seicolegol.

Mae'r adroddiad nid yn unig yn tynnu sylw at faint mae perfformiad yn amrywio ar draws Cymru, ond mae hefyd yn awgrymu bod gwasanaethau'n amrywio gan ddibynnu ar y math o ganser sydd ar yr unigolyn.

Diagnosis ac atgyfeirio hwyr

Dywed adroddiad diweddar gan Cancer Research UK (CRUK) mai un o'r prif resymau pam bod canlyniadau canser yn y DU y tu ôl i rai gwledydd Ewropeaidd yw bod diagnosis yn aml yn hwyr.[58] Yn ôl yr adroddiad, gellid osgoi hyd at 10,000 o farwolaethau bob blwyddyn yn y DU pe bai canser yn cael diagnosis cynt. Mae yna dystiolaeth gadarn hefyd bod canser yn cael ei ganfod yn hwyrach, a bod diagnosis yn cael ei roi'n hwyrach yng Nghymru a bod hyn yn chwarae rhan bwysig yng nghyfraddau goroesi gwael y wlad.[59]

Mae ymchwil a gomisiynwyd gennym ni gan Athrofa Iechyd a Gofal Cymdeithasol Cymru (WIHSC)[60] yn datgelu bod gweithwyr proffesiynol sy'n gweithio ym maes gofal canser yng Nghymru yn dweud bod rhywfaint o gynnydd wedi'i wneud o ran rhoi diagnosis cynharach i bobl. Ar yr un pryd, fodd bynnag, mae'r adroddiad yn nodi bod pobl a'u meddygon teulu yn aml yn rhy araf i ymateb i symptomau ac y gall systemau atgyfeirio cymhleth oedi diagnosis hyd yn oed ymhellach.[61] Ac er bod y rhan fwyaf o bobl i'w gweld yn gwneud cynnydd gweddol sydyn unwaith iddyn nhw gael eu diagnosis, mae'n stori wahanol os yw'r diagnosis a'r driniaeth yn fwy cymhleth. Gall hyn fod diolch i natur eu hafiechyd – er enghraifft, gall fod yn fath prin o ganser. Ond cafodd ei adrodd bod pobl a atgyfeirwyd i fannau eraill yn aml yn wynebu oedi diangen oherwydd cyfathrebu gwael rhwng gwasanaethau.

Yn Lloegr, mae'r National Awareness and Early Diagnosis Initiative (NAEDI) wedi helpu i godi ymwybyddiaeth o bwysigrwydd diagnosis cynnar. Yn ôl Cancer Research UK, mae'r NAEDI wedi cael effaith gadarnhaol ar y gweithlu canser ac wedi'u helpu nhw i ddeall ac i flaenoriaethu diagnosis cynnar. Mae'n rhaid i Gymru fabwysiadu dull tebyg o weithredu er mwyn gwella diagnosis cynnar, os ydyw am wireddu ei bwriad i fod ymhlith y gorau yn Ewrop ar ddiagnosis cynnar a goroesiad.

Mynediad at driniaeth

Yn 2008, gwnaethom arolwg o'r 22 bwrdd iechyd lleol a fodolai ar y pryd er mwyn cael darlun cliriach o'r broses ariannu ar gyfer pobl sydd am gael triniaeth nad yw'n cael ei chynnig yn rheolaidd gan y GIG.[62] Datgelodd yr arolygon fod yna 'loteri cod post', yn nhermau pa mor hawdd yw hi i bobl lywio'u ffordd drwy'r broses 'cyllido eithriadol' hon, a'r ffactorau sydd yn y pendraw yn effeithio ar benderfyniadau cyllido.

Yn hwyr yn 2008, comisiynodd y llywodraeth adroddiad i wella argaeledd meddyginiaethau yng Nghymru.[63] Argymhelliad yr adroddiad, a gyhoeddwyd ym mis Ionawr 2009, oedd cynhyrchu canllawiau o fewn chwe mis er mwyn cefnogi BILl i weithredu'n fwy cyson mewn dull a gytunwyd yn genedlaethol i geisiadau am gyllid eithriadol. Wrth i'r adroddiad hwn fynd i'r wasg, cyn belled â bod Macmillan yn ymwybodol, nid yw'r canllawiau cenedlaethol wedi'u rhannu gyda BILl o hyd.

Gwasanaethau diwedd oes

Rydym yn gwybod y byddai 67% o bobl Cymru yn dewis marw gartref.[64] Ond dim ond 26.1% sy'n gwneud hynny mewn gwirionedd.[65] Pa na ddiwallir dymuniadau diwedd oes pobl sydd â chanser oherwydd diffyg gwasanaethau, gall arwain at brofiadau trawmatig iawn iddyn nhw, a synnwyr parhaus o euogrwydd ac edifeirwch i'w teulu a'u ffrindiau a adewir ar ôl.

Yn aml, mae pobl sy'n derfynol wael gyda chanser yn cael eu derbyn i'r ysbyty yn ddiangen, sy'n ingol iddyn nhw ac yn gostus i'r GIG. Yn Lloegr, mae'r Swyddfa Archwilio Cenedlaethol yn amcangyfrif y gellid arbed £104 miliwn y flwyddyn drwy leihau derbyniadau brys i'r ysbyty gan bobl sydd â chanser o 10%, a thrwy fyrhau'r arhosiad ar gyfartaledd o dridiau. Gellid rhyddhau'r arian hwnnw er mwyn helpu pobl i ddewis y man gofal maen nhw'n ei ffafrio.[66] Cefnogir y dystiolaeth hon gan Hospital Care at Home – adroddiad diweddar ar y cyd gan Healthcare at Home a Dr Foster – sy'n amcangyfrif y gellid arbed £160 miliwn i'r GIG pe bai gofal diwedd oes yn cael ei ddarparu yn y cartref.[67] [68]

Yr hyn a ddatgelodd ein hymchwil am fynediad at driniaethau sydd heb eu cymeradwyo gan NICE:

- Mae gan holl fyrddau iechyd lleol Cymru (BILl) broses ar gyfer cyllido triniaethau eithriadol, ond gyda 15 enw gwahanol.
- Er bod gwybodaeth ar gael i'r cyhoedd gan y rhan fwyaf o BILl am eu proses cyllido eithriadol, dim ond traean ddywedodd bod y broses yn cael ei hyrwyddo'n weithredol.
- Dim ond 6% o ymatebwyr yng Nghymru ddywedodd bod yna oncolegydd ar y panel penderfynu ar gyfer triniaethau canser.
- Dywedodd 67% eu bod nhw'n ystyried amgylchiadau personol, megis oedran, dibynyddion, a statws priodasol.
- Dywedodd ddau BILl bod cyhoeddusrwydd lleol a gweithgaredd y cyfryngau yn chwarae rhan weithredol yn eu penderfyniadau.
- Mae un BILl yn ystyried ym mha gyfnod yn y flwyddyn ariannol y derbyniwyd y cais.

Rydym yn croesawu'r gwaith diweddar gan yr Athro y Farwnes Ilora Finlay a'r Bwrdd Gweithredu i wella gofal canser lliniarol yng Nghymru. Gwnaed camau breision yn y maes pwysig hwn, ond mae angen gwneud mwy o waith er mwyn gwella gwasanaethau y tu allan i oriau, cymorth i ofalwyr a gofal i bobl mewn cartrefi nyrsio.

Rhan 2: Strategaeth ganser cenedlaethol i Gymru sy'n rhoi pobl yn ganolog

Ble yr ydym ni nawr - polisïau presennol

Mae gofal canser wedi gwella yng Nghymru dros y ddegawd ddiwethaf diolch i gyflwyno'r Safonau Canser Cenedlaethol a'r datganiad polisi, Cynllun i Fynd i'r Afael â Chanser yng Nghymru. Ond rydym yn pryderu na fydd Cymru'n llwyddo i gyflawni'r gofal canser o safon ryngwladol, sy'n gost effeithiol ac yn rhoi pobl yn ganolog, sydd ei angen arnom, heb weledigaeth glir a strategaeth genedlaethol gynhwysfawr i ganser.

Symud ymlaen o'r Safonau Canser Cenedlaethol

Mae pobl yn cydnabod nad yw'r safonau canser presennol, a luniwyd yn 2005, bellach yn ddigon eang, nac uchelgeisiol, ac nad ydynt yn rhoi pobl yn ddigon canolog, er mwyn cyflawni'r newidiadau sydd eu hangen i ofal canser yng Nghymru. Fel y maen nhw, mae'r ffocws ar fesur systemau, prosesau, a thargedau clinigol cyfyngedig, yn hytrach nag ar fonitro ansawdd y gwasanaethau hynny, profiad pobl sy'n derbyn gofal, nag unrhyw welliant yn y canlyniadau i bobl sy'n byw gyda neu'r tu hwnt i ganser.

Datblygwyd y safonau o ganlyniad i adroddiad Calman Hine, a archwiliodd gwasanaethau gofal canser yn y DU dros ddegawd yn ôl.[69] Ar y pryd, y flaenoriaeth oedd gwella safonau gofynnol yng Nghymru, a sefydlu set o anghenion craidd ar gyfer gweithwyr proffesiynol ym maes gofal canser.

Ers hynny, mae natur canser a'n ffordd o'i drin wedi newid. Felly hefyd y tirlun cyfansoddiadol a gwleidyddol, athroniaeth a strwythur y GIG, a disgwyliadau pobl sy'n byw gydag ac wedi canser.

A yw'r polisi Cynllun i Fynd i'r Afael â Chanser yn ddigon?

Wrth i wledydd eraill ddatblygu eu ffordd o feddwl yn seiliedig ar wasanaethau canser sy'n rhoi pobl yn ganolog, mae polisi Cymru yn syrthio ar ei hôl hi gyda dull o weithredu sy'n cael ei arwain o hyd gan agweddau clinigol ac acíwt gofal. Ar y cyfan, nid oes fawr o weithredu yn dilyn datganiadau ac ymrwymiadau: fel yn achos y safonau canser, mae gweithredu wedi bod yn dameidiog.

Comisiynon ni ymchwil[70] i gymharu'r dull o weithredu o ran polisi canser yng Nghymru gyda gwledydd eraill yn y DU, Ewrop ac ymhellach. Ein casgliad oedd nad yw hi'n 'bendant o gwbl' y bydd Cymru'n cyflawni ei thargedau ar gyfer 2015, a osodwyd allan yn y Cynllun i Fynd i'r Afael â Chanser (DTTC).[71] Yn enwedig wrth i wledydd eraill barhau i wella.

Mae ein hymchwil yn tynnu sylw at y ffaith fod DTTC yn canolbwyntio ar bedwar prif faes yn unig: atal, canfod, gwell mynediad a gwasanaethau gwell. Nid yw hyn yn cynnwys y meysydd pwysig newydd – 'byw y tu hwnt i ganser' a 'gofal sy'n rhoi'r claf yn ganolog', sy'n nodweddu strategaethau gwledydd eraill.

Mae'r adroddiad yn disgrifio dull o weithredu sydd 'rhywfaint yn dameidiog' o ran cynllunio canser yng Nghymru, a ellir ei briodoli yn rhannol i 'newid gweinidogion, dau gyfnod o newid trefniadol, blaenoriaethau newidiol, dulliau comisiynu a chynllunio'. Ar ôl edrych ar gynnydd triniaethau a gofal canser mewn mannau eraill, daw'r adroddiad i'r canlyniad mai creu strategaeth ganser un pwrpas yw'r 'garreg sylfaen' wrth sicrhau mai Cymru yw un o'r darparwyr gofal canser gorau yn Ewrop.

Mewn adroddiad gan Cancer Research UK[72], dywed yr elusen, 'Mae cynlluniau canser yn bwysig ac yn ddefnyddiol. Maen nhw'n gosod cyfeiriad ac yn gwneud y defnydd gorau o adnoddau'. Un o'u prif argymhellion yw: 'Dylid datblygu cynllun mwy cynhwysfawr er mwyn sicrhau cysondeb o ran darparu, gweithredu ac integreiddio ar draws Cymru'. Mae'r adroddiad hefyd yn argymell y dylai Cymru ddatblygu 'menter goroesi'; mater sy'n 'faes polisi pwysig sy'n dod i'r amlwg, ac a ddylid ei fewnosod yn llawn yn llwybr gofal y claf'.

Mae ymchwil yn dangos bod gweithwyr iechyd proffesiynol hefyd yn rhwystredig yn wyneb diffyg strategaeth ganser cynhwysfawr i Gymru.[73]

Datblygiadau polisi a strategaeth eraill

Ar hyn o bryd, nid oes gan Gymru un strategaeth gynhwysfawr sy'n cynllunio ar gyfer yr holl lwybr canser. Yn 2010 daeth nifer o bolisïau ychwanegol i'r golwg:

- Ym mis Mawrth, cyhoeddodd y Grŵp Cydgysylltu Gwasanaethau Canser yr adroddiad Living With and After Cancer, sy'n cydnabod pwysigrwydd bod pob gweithiwr clinigol proffesiynol yn gweld goroesiad fel cyfnod arbennig o ofal canser.

- Ym mis Mai, cyhoeddodd Llywodraeth Cynulliad Cymru y Safonau Cenedlaethol ar gyfer Adferiad Cleifion Canser[74], sydd hefyd yn mynd i'r afael â materion yn ymwneud â goroesiad.
- Cyhoeddodd y Gweinidog Iechyd, Edwina Hart, bolisi newydd sy'n bwriadu darparu gweithiwr allweddol i bawb yng Nghymru sy'n byw gydag ac wedi canser erbyn mis Mawrth 2011.

Bellach mae gan Gymru tua 20 strategaeth, polisi a fframwaith gwahanol sy'n ymwneud â gofal canser, fel a welir yn y tabl isod. Mae'r gorlwyth polisi hwn wedi mynd mor gymhleth a thameidiog nes ei bod bron yn amhosibl bod â gweledigaeth glir ynglŷn â'r ffordd orau o ddiwallu anghenion pobl sy'n byw gydag ac wedi canser.

Rhestr o rai o'r strategaethau, polisïau a fframweithiau presennol yn ymwneud â gofal canser yng Nghymru:

- Creu'r Cysylltiadau: Cyflawni Ar Draws Ffiniau: Gweddnewid Gwasanaethau Cyhoeddus yng Nghymru
- Delivering a Five-Year Service, Workforce and Financial Strategic Framework for NHS Wales
- Fframwaith Gweithredu Blynyddol
- Cynllun i Fynd i'r Afael â Chanser yng Nghymru (2006) a'r cynllun gwaith dilynol (2008-2011)
- Y Safonau Canser Cenedlaethol
- Y Cynllun Iechyd Gwledig
- Gosod y Cyfeiriad: Gwasanaethau Cychwynnol a Chymuned - Rhaglen Strategol
- Gwasanaethau Cymdeithasol Cynaliadwy i Gymru: Fframwaith Gweithredu
- Strategaethau i'r gweithlu e.e. Strategaeth Nyrsio Cymunedol, Y Cynllun Gwaith
- Strategaeth Cynhwysiant Ariannol
- Fframwaith Pobl Hŷn
- Mesur Strategaethau ar gyfer Gofalwyr (Cymru) 2010
- Argymhellion 'Sugar' 2008 a gwaith y Bwrdd Gweithredu Gofal Lliniarol
- Rhaglenni sgrinio canser, megis y coluddyn, ceg y groth, y fron
- Rhaglenni ymwybyddiaeth o symptomau
- Strategaeth Rheoli Cyflyrau Cronig
- Strategaeth Lymffoedema
- Adroddiad y Grŵp Cydgysylltu Gwasanaethau Canser ar fyw gyda/wedi canser
- Gwaith y Bwrdd Hunan Ofal
- Lles drwy Waith
- Canllawiau NICE ar Ofal Cefnogol a Lliniarol
- Y Fframwaith o Safonau Aur
- Llwybr Gofal Integredig

Datblygu strategaeth ganser effeithiol i Gymru

Rydym yn gwybod bod strategaethau canser un pwrpas yn cynyddu ymrwymiad gan y llywodraeth ac yn codi proffil canser yn y gweithlu. Mae hyn yn ei dro yn helpu i leihau anghyfartaledd mewn gofal canser.[75]

Rydym yn cydnabod bod llawer o bolisïau a strategaethau cyffredinol Llywodraeth Cynulliad Cymru yn gweithio tuag at ofal cost-effeithiol sy'n rhoi pobl yn ganolog. Nawr mae arnom angen strategaeth benodol er mwyn sicrhau'r newidiadau hyn ar gyfer canser hefyd.

Bydd strategaeth o'r fath yn:

1. Darparu eglurder a gweledigaeth i bawb sy'n ymwneud â chynllunio a darparu gofal canser yng Nghymru.
2. Darparu fframwaith i fewnosod arweinyddiaeth glinigol ar lefel genedlaethol, rhwydwaith a lleol.
3. Newid y ffordd y mae canser yn cael ei ystyried a'i gynllunio.
4. Gosod allan disgwyliad eglur bod angen i ddarparwyr iechyd, gofal cymdeithasol a'r sector gwirfoddol gydweithio er mwyn darparu llwybr di-dor o ran triniaeth a gofal.
5. Gwella darparu gofal canser cydgysylltiedig, sy'n rhoi'r unigolyn yn ganolog ar bob cam, o atal, diagnosis a thriniaeth i ôl-ofal neu ddiwedd oes.
6. Helpu i ddatblygu ffyrdd mwy arloesol, cost-effeithiol ac o ansawdd uchel o ddarparu gofal.
7. Annog partneriaid i fabwysiadu'r arfer gorau.

Sut beth fyddai strategaeth ganser effeithiol?

Comisiynon ni ymchwil er mwyn adolygu strategaethau canser ar draws nifer o wledydd.[76] Defnyddion ni ganlyniadau'r ymchwil hwn er mwyn creu'r templed a welwch chi yn y blwch isod. Ein bwriad yw bod Llywodraeth nesaf Cynulliad Cymru yn gallu defnyddio'r templed hwn i ddatblygu strategaeth ganser sy'n cynnwys yr arfer gorau o wahanol rannau o'r byd.

Rydym yn gwybod o'n hymchwil na ellir ysgrifennu na chynnal strategaeth ar ei phen ei hunan. Er mwyn iddi fod yn effeithiol, mae'n rhaid iddi ystyried pob agwedd o'r system reoli canser, o ariannu i werthuso.

Pwysigrwydd arweinyddiaeth a chydweithio

Mae angen arweinyddiaeth gref er mwyn datblygu a gweithredu pob elfen o strategaeth gynhwysfawr sy'n cyffwrdd ag amrediad eang a gwasgaredig o fudd-ddeiliaid. Mae arweinyddiaeth o'r fath yn hanfodol os ydym am drawsnewid y system gofal canser a darparu gwasanaethau - a chyflawni'r symudiad diwylliannol angenrheidiol sydd ei angen o ran dealltwriaeth canser ymhlith gweithwyr proffesiynol iechyd a gofal cymdeithasol.

Mae pobl sy'n byw gydag ac wedi canser yn arbenigwyr trwy brofiad a dylent chwarae rhan wrth ddatblygu'r strategaeth newydd hon. Mae angen arweinyddiaeth gref yma hefyd, er mwyn ysbrydoli, cynnig cyfeiriad a meithrin cydweithio ymhlith budd-ddeiliaid.

Mae arweinyddiaeth wleidyddol, reolaethol a chlinigol effeithiol a phenderfynol yn hanfodol os yw Cymru am sicrhau gofal canser sy'n diwallu anghenion pobl sy'n byw gyda chanser ac sy'n defnyddio'r GIG, gofal cymdeithasol ac adnoddau eraill yn effeithiol.

Ein templed ar gyfer strategaeth ganser sy'n rhoi pobl yn ganolog, yn seiliedig ar arfer gorau rhyngwladol.

Gweledigaeth ac amcanion

- Mynegi gweledigaeth sydd â'r bwriad o gwtogi ar ganser, cynyddu cyfraddau goroesi ac sy'n helpu pobl i fyw bywydau iach, cynhyrchiol wedi diagnosis.
- Mynd i'r afael ag anghyfartaledd: hyd yn oed mewn gwledydd lle cafwyd gwelliannau sylweddol mewn gofal, nid ydyn nhw wastad yn cael eu cynnig yn deg.

Proffil Cenedlaethol

- Cynnwys proffil cenedlaethol gyda dadansoddiad trwyadl o'r ystadegau a'r materion yn ymwneud â phatrymau'r afiechyd. Mae cymariaethau hefyd yn ddefnyddiol.
- Archwilio patrymau darparu gwasanaethau a dyraniadau adnoddau ar gyfer canser, er mwyn helpu i ganfod bylchau ac i flaenoriaethu datblygiadau yn y dyfodol.

Taith yr unigolyn

Creu'r strategaeth o safbwynt taith bersonol, gan gynnwys:

- Atal a hyrwyddo
- Sgrinio a diagnosis cynnar
- Darparu gwasanaeth
- Gofal lliniarol
- Gwella ansawdd profiad yr unigolyn.

  Mae mwy o bwyslais wedi'i roi ar ofal personol. Mae hwn yn faes sy'n dod i'r amlwg, sydd angen rhagor o ddatblygu ac ymwneud gyda phobl sy'n byw gydag a'r tu hwnt i ganser, gofalwyr, teuluoedd a chymdeithas yn gyffredinol.
- Byw y tu hwnt i ganser.

  Mae'r datblygiad newydd hwn yn cydnabod bod llawer o bobl bellach yn byw y tu hwnt i ganser - neu gyda'r afiechyd gan ei fod yn gronig yn hytrach nag yn bennod acíwt, farwol - ac sy'n canolbwyntio ar ddatblygu gwasanaethau y tu hwnt i ofal iechyd. Ystyried cynnwys cynlluniau dilynol gydol oes personol, cymorth seicolegol a mynediad at gymorth ariannol.

Isadeiledd

Ystyried yr isadeiledd cenedlaethol sydd ei angen er mwyn cefnogi gweithredu'r strategaeth.

Ymchwil

- Caniatáu ariannu ychwanegol ar gyfer ymchwil, sy'n chwarae rôl ganolog wrth ddatblygu strategaeth.
- Pwysleisio'r angen i drosglwyddo canfyddiadau ymchwil i arfer clinigol yn gyflym er mwyn gwella mynediad i dreialon clinigol.

Gwybodaeth a TG

Mae angen ystyried dwy elfen graidd:

- Darparu gwybodaeth hygyrch i'r cyhoedd, i gleifion ac i weithwyr proffesiynol.
- Datblygu casglu a dadansoddi data drwy isafswm setiau data.

Datblygu'r gweithlu

Mae'n bwysig bod â digon o staff, sydd wedi'u hyfforddi'n dda. Galluogi recriwtio, cadw, hyfforddi a datblygiad proffesiynol parhaus.

Cyfalaf a thechnoleg

Ystyried a chynllunio ar gyfer y dechnoleg fydd ei hangen, er enghraifft sganwyr PET a meddyginiaethau, yn ogystal â datblygu canolfannau rhagoriaeth ar gyfer triniaeth ganser.

Cyllido

Canfod faint o gyllid sydd ar gael ar gyfer gwasanaethau canser, a chynllunio ar ei gyfer. Gall hyn amrywio yn ôl faint o gyfrifoldeb sydd ar gyfer hyn yn genedlaethol, dyraniad cyffredinol ac arian newydd sy'n cael ei dargedu ar gyfer datblygiadau penodol.

Rhan 3: Sut allwn ni ddarparu gwasanaethau canser sy'n gost-effeithiol ac sy'n rhoi pobl yn ganolog?

Yn gyntaf: beth yw ystyr 'gofal sy'n rhoi pobl yn ganolog'?

Mae angen thema allweddol yn rhedeg drwy'r strategaeth ganser newydd i Gymru, sef bod yr holl ofal yn rhoi pobl yn ganolog. Cam cyntaf da byddai egluro'r hyn a olygwn o ddweud hyn.

Diffiniad o ofal sy'n rhoi pobl yn ganolog

Ystyr gofal sy'n rhoi pobl yn ganolog yw bod anghenion yr unigolyn sy'n byw gyda chanser wastad wrth galon y ffordd mae'r gwasanaethau'n cael eu cynllunio, ac nid anghenion y darparwyr gwasanaeth.

Mae'n golygu trin pobl gyda sensitifrwydd a thosturi a sicrhau bod eu gofal wedi'i gynllunio a'i ddarparu'n holistig.

Mae'r gofal hwn yn mynd y tu hwnt i'r clinigol ac yn mynd i'r afael â phryderon cymdeithasol, ariannol, emosiynol, ymarferol, seicolegol ac ysbrydol ehangach.

Ystyr rhoi pobl yn ganolog wrth gynllunio gofal yw eu bod[77]:

- yn cael cyfle i fynegi eu barn, a bod gwrandawiad a pharch i'r farn honno
- yn derbyn y gofal sydd ei angen arnyn nhw, ar yr adeg iawn, waeth beth yw'r ffiniau trefniadol - ac os na ellir darparu gwasanaeth maen nhw'n cael gwybod pam
- yn gwybod sut ac o ble i gael gafael ar wybodaeth a chymorth parhaus.

Mae dull newydd o weithredu ym maes gwasanaethau canser yng Nghymru, sy'n rhoi pobl yn ganolog, yn golygu symud i ffwrdd oddi wrth ganolbwyntio ar brosesau, ar systemau ac ar dargedau clinigol, i ddatblygu gwasanaethau sy'n diwallu anghenion pobl – clinigol ac anghlinigol – gydol eu profiad o ganser.

Yr alwad am newid diwylliannol

Mae cefnogaeth enfawr ar gyfer newid yn y ffordd y darparir gofal canser. Mae hefyd yn glir y bydd y trawsnewidiad o ofal traddodiadol, clinigol yn bennaf, i fodel sy'n rhoi pobl yn fwy canolog, yn golygu newid dramatig o ran agwedd a diwylliant.[78] Bydd angen i'r gweithlu iechyd a gofal cymdeithasol ddeall goblygiadau canser fel cyflwr tymor hir yn ogystal ag fel cyflwr acíwt.

Hefyd mae angen newidiadau pwysig yn y dull o gefnogi a gofalu am bobl sy'n byw gydag ac wedi canser, er mwyn rhoi mwy o bwyslais ar adferiad, iechyd a lles.

Yn gyntaf, bydd angen newid yn y ffordd o ddelio â chydweithredu a chyfathrebu o fewn y gwasanaeth iechyd a'r sectorau gofal cymdeithasol a gwirfoddol.

Yn ail, mae angen rhoi mwy o bwyslais ar sicrhau bod pobl yn fwy gwybodus ac wedi'u grymuso i reoli eu cyflwr eu hunain. Er mwyn gwneud hyn yn realiti, mae angen trawsnewid y berthynas rhwng y gweithiwr iechyd proffesiynol a'r unigolyn sy'n byw gydag neu'r tu hwnt i ganser, o roi a derbyn gofal yn unig, i greu partneriaeth sy'n canolbwyntio ar gyflawni canlyniadau iechyd a gofal cytûn. Bydd ar nifer o weithwyr proffesiynol angen help er mwyn cyflawni'r trawsnewidiad hwn. Mae arnyn nhw angen hyfforddiant fydd yn eu galluogi i asesu anghenion gofal pobl, i ddarparu gwybodaeth ystyrlon, i ddatrys problemau a chanfod gwasanaethau y tu fewn a'r tu allan i'r gwasanaeth iechyd.

Mesur ansawdd gwasanaethau, profiadau pobl o'u gofal a'r canlyniadau

Mae nifer o strategaethau iechyd newydd y llywodraeth, a'r GIG newidiol yng Nghymru, yn cydnabod bod angen newid yn y ffordd yr ydym yn darparu gofal iechyd a chymdeithasol. Mewn rhai achosion mae angen darparu gwasanaethau arbenigol mewn canolfannau rhagoriaeth, ond mewn nifer o achosion eraill, mae angen darparu cymorth yn agosach at gartrefi pobl. Waeth ble mae'r gofal yn cael ei ddarparu, mae'r strategaethau hyn yn cydnabod bod angen ei deilwra i anghenion tymor hir yr unigolyn, a bod angen iddo fod yn fwy integredig ac wedi'i gydgysylltu'n well.

Rydym yn credu bod y datblygiadau newydd cyffredinol hyn ym maes gofal iechyd a chymdeithasol yn cynnig cyfle unigryw i ddiweddaru polisi canser yng Nghymru. Wrth adlewyrchu amcanion gofal fframwaith bum-mlynedd newydd y GIG[79], bydd Cymru mewn sefyllfa gref i wneud gofal canser yn fwy effeithiol, yn fwy cost-effeithiol, a rhoi pobl yn ganolog.

Er mwyn cyflawni hyn, pan fyddd targedau neu safonau newydd yn cael eu gosod ar gyfer gofal canser yng Nghymru, mae angen i ni roi mwy o bwyslais ar fonitro ansawdd y gwasanaeth, profiad yr unigolyn o'i ofal a'r canlyniadau.

Mae gwaith diweddar gan Macmillan gyda phobl sy'n byw gydag ac wedi canser, eu gofalwyr, y rhai sy'n gweithio mewn gofal canser a budd-ddeiliaid eraill, wedi sefydlu sut y dylid profi gofal a thriniaeth o safbwynt yr unigolyn sy'n byw gyda chanser.[80] Mae'r gwaith hwn wedi'n harwain ni at naw canlyniad allweddol yr ydym ni'n credu ddylai fod yn nod i bob gofal canser:

Rydym yn annog y llywodraeth yn frwd i ystyried y naw canlyniad allweddol hyn mewn unrhyw dargedau neu safonau newydd a ddatblygir fel rhan o strategaeth ganser cenedlaethol i Gymru sy'n rhoi pobl yn ganolog.

Cefais ddiagnosis cynnar	**Rwy'n deall, ac felly'n gwneud penderfyniadau da**	**Rwy'n cael y driniaeth a'r gofal sydd orau ar gyfer fy nghanser i a'm bywyd i**
Mae yna gefnogaeth dda i'r bobl o'm cwmpas i	**Rwy'n cael fy nhrin gydag urddas a pharch**	**Rwy'n gwybod beth allaf ei wneud er mwyn helpu fy hunan, a phwy arall all fy helpu**
Rwy'n gallu mwynhau bywyd	**Rwy'n teimlo'n rhan o gymuned ac rwyf wedi fy ysbrydoli i roi rhywbeth yn ôl**	**Rwyf am farw'n dda**

Tuag at ofal personol, holistig

Pan fo gofal wedi'i gydgysylltu'n dda, a chyfeirio yn effeithiol, mae pobl sy'n byw gydag a'r tu hwnt i ganser yn cael yr hyn sydd ei angen arnyn nhw, ar yr adeg iawn ac yn y ffordd iawn. Mae'n osgoi dyblygu, ymweliadau gwastraffus neu aneffeithiol - ac yn bwysicach fyth - mae'n sicrhau nad yw pobl yn mynd ar goll wrth bontio rhwng mudiadau a phroffesiynau.[81] Mae ein hymchwil ni - a chefnogir hyn gan ddatganiadau o strategaethau'r llywodraeth ei hun[82] - yn cadarnhau bod gwasanaethau sy'n gost-effeithiol ac sy'n rhoi pobl yn ganolog yn mynd law yn llaw â'i gilydd.

Rydyn yn cydnabod na fydd y newidiadau yn y canfyddiad o ganser fel salwch sydd yn un acíwt ac yn hir dymor, na'r symudiad tuag at ofal sy'n rhoi pobl yn ganolog, yn digwydd dros nos. Mae angen cynllunio, gweithredu a monitro newidiadau i ofal canser yn ofalus. Ni allan nhw ddigwydd heb ymyrraeth y llywodraeth a'r rhai sy'n cynllunio gwasanaethau.

Mae'r adran hon o'r adroddiad yn edrych ar yr hyn y gellir ei wneud er mwyn rhoi pobl yn fwy canolog i wasanaethau, a sut y gellid ymgorffori'r mentrau hyn i strategaeth ganser cenedlaethol i Gymru.

Pedair menter genedlaethol allweddol

Rydym yn credu bod y pedair menter isod yn hanfodol er mwyn gwneud gwasanaethau canser yn fwy cost-effeithiol a rhoi pobl yn fwy canolog.

1. Gwell asesiadau a chynllunio gofal
2. Diwygio ôl-driniaeth canser
3. Gwybodaeth a chymorth sy'n fwy personoledig
4. Mynediad at weithiwr allweddol dynodedig

Mae'r mentrau hyn wedi'u seilio ar ein hymgynghoriadau gyda phobl sy'n byw gydag ac wedi canser, a'r rhai sy'n gweithio ym maes gofal canser yng Nghymru. Edrychon ni hefyd ar wersi gan gyflyrau cronig eraill ac ar yr hyn sy'n digwydd ym maes gofal canser y tu allan i

Gymru.

1. Gwell asesiadau a chynllunio gofal

Dylai pobl sy'n byw gydag ac wedi canser fod a'u cynllun gofal a thriniaeth eu hunain, yn ogystal ag asesiadau cyson a'u hanghenion clinigol ac anghlinigol.

Mae asesiadau cyson yn hanfodol er mwyn sicrhau bod cynlluniau gofal a thriniaethau wedi'u teilwra at anghenion pob unigolyn. Maen nhw hefyd yn hanfodol er mwyn sefydlu lefelau risg ar gyfer cymhlethdodau posib neu ailymddangosiad y canser. Os nad oes modd gwella eu cyflwr, mae cynllunio gofal ac asesiadau parhaus yn hanfodol er mwyn monitro datblygiad yr afiechyd. Felly, gall yr unigolyn fyw orau posib gyhyd ag sy'n bosib.

Mae gofal sydd wedi'i deilwra ac sy'n bersonol yn helpu gweithwyr proffesiynol i ddarparu cymorth i'r rhai sydd yn yr angen mwyaf, a chyfyngu ar gymorth i'r rhai sy'n fodlon ac sy'n gallu gofalu amdanyn nhw eu hunain. Mae hyn yn ffordd mwy cost-effeithiol o ddyrannu adnoddau cyfyngedig.

Dylai'r drafodaeth ar gyfer yr asesiad a'r cynllun gofal ddigwydd gyda gweithiwr iechyd proffesiynol sy'n helpu i gydlynu gofal yr unigolyn (gweler pwynt pedwar isod: Mynediad at weithiwr allweddol): yn aml, nyrs glinigol arbenigol. Mae angen iddyn nhw fod â'r sgiliau a'r profiad i helpu i ganfod a delio gyda phryderon yr unigolyn, gwybodaeth ddiweddar am wasanaethau lleol a chenedlaethol, ac mae'n rhaid eu bod nhw'n gwybod sut i gyfeirio pobl at wasanaethau arbenigol addas a gwasanaethau y tu allan i'r GIG os oes eu hangen. Dylid rhoi copi o'r cynllun gofal i'r unigolyn sydd â chanser fel bod ganddyn nhw gofnod i gyfeirio ato.

Rydym am i bawb sy'n byw gyda chanser gael cynnig asesiad a chynllun gofal ar gamau allweddol o'u profiad o ganser erbyn diwedd tymor nesaf y cynulliad.

2. Diwygio ôl-driniaeth canser

Mae angen gwella'r trefniadau ôl-ofal wedi'r driniaeth gychwynnol fel bod pob unigolyn sy'n byw gyda neu'r tu hwnt i ganser yng Nghymru yn cael cymorth parhaus sydd wedi'i deilwra i'w lefel eu hunain o angen a risg.

Dengys astudiaethau bod yna botensial sylweddol i wella trefniadau ôl-ofal wedi i driniaeth ddod i ben.[83] Ac mae'r asesu a'r cynllunio gofal hwnnw yn hanfodol er mwyn cyflawni'r newid hwn.

Sut beth yw asesiadau a chynlluniau gofal?

Mae **asesiad** yn broses o hel a thrafod gwybodaeth gyda'r claf a'i ofalwr neu gefnogwr er mwyn deall yr hyn y mae'r unigolyn sy'n byw gydag a'r tu hwnt i ganser yn ei wybod, ei ddeall a'i angen. Mae'r asesiad holistig yma yn canolbwyntio ar y person cyfan. Trafodir eu lles fel cyfanwaith: corfforol, emosiynol, ysbrydol, meddyliol, cymdeithasol, ac amgylcheddol. Yna defnyddir y canlyniadau er mwyn goleuo eu cynllun gofal.[1]

Dylai asesiad o anghenion unigolyn drafod y canlynol:

The assessment of an individual's needs should include discussion of:

- Effeithiau corfforol (e.e. colli pwysau, problemau gydag archwaeth bwyd, blinder)
- Materion yn ymwneud â ffordd o fyw (e.e. diet, ymarfer corff, peidio ag ysmygu)
- Pryderon emosiynol (e.e. pryderon am y dyfodol, am berthynas ag eraill)
- Materion teuluol (e.e. siarad gyda'ch teulu a'ch ffrindiau am ganser, pryderon am risg genetig)
- Pryderon am waith a/neu arian (e.e. cael cydbwysedd rhwng gwaith a thriniaeth, cyngor ar fudd-daliadau neu arian, ac am fynd yn ôl i'r gwaith)
- Materion yn ymwneud â'r driniaeth (e.e. pryderon am sgil effeithiau, ffrwythlondeb, peryglon a manteision triniaeth)
- Materion ymarferol (e.e. sortio gwaith tŷ neu arddio, bwyta'n iach, o ble i gael offer i'r tŷ er mwyn hwyluso tasgau dyddiol)
- Ysbrydolrwydd (e.e. ffydd, crefydd neu ysbrydolrwydd ac unrhyw effaith y rhain ar driniaeth).

Mae **cynllun gofal** wedi'i seilio ar ddiagnosis ac asesiad holistig o'r unigolion sy'n byw gyda neu'r tu hwnt i ganser. Mae'n blaenoriaethu eu materion nhw ac yn gosod allan gamau i fynd i'r afael â nhw. Mae'r broses asesu a chynllun gofal yn sicrhau bod gofal yn gyson ag anghenion yr unigolyn. Yn achos nifer bydd hyn yn helpu i bontio tuag at hunan reolaeth gyda chefnogaeth.[1]

Mae'r system bresennol o gyfarfodydd dilynol wyneb yn wyneb gydag ymgynghorwyr yn ddrud ac yn aml mae'n methu â chanfod os yw'r canser yn dod yn ei ôl. Mae hefyd gan fwyaf yn aneffeithiol wrth gefnogi pobl sy'n profi effeithiau hwyr yn sgil canser a'i driniaeth. Canfu astudiaeth ddiweddar o dros 1,000 o bobl mewn 66 o ganolfannau yn y DU bod ganddyn nhw bum angen cymedrol neu ddifrifol oedd heb eu diwallu ar ddiwedd triniaeth. Yn achos 60% o'r bobl hyn, nid oedd yr anghenion hyn wedi gwella chwe mis wedi triniaeth.[84]

Diwygio ôl-driniaeth canser yng Nghymru – Prosiect Llwybrau Herceptin Felindre/Macmillan

Mae Gill Donovan, sy'n nyrs arbenigol anfeddygol sy'n rhagnodi ym maes oncoleg y fron yng Nghanolfan Ganser Felindre, wedi bod yn arwain prosiect ers 2009 i ddiwygio trefniadau ôl-driniaeth i fenywod sydd â chanser y fron sydd yn cael triniaeth Adjuvant Herceptin. Mae'r menywod hyn yn wynebu llwybr hir o driniaeth, er bod y rhan fwyaf eisoes wedi cael llawdriniaeth, cemotherapi, ac mewn rhai achosion, radiotherapi. Mae sgil effeithiau i'r holl driniaethau hyn, ond mae menywod sy'n cael herceptin fel arfer yn teimlo'n iach ac maen nhw am ailafael yn eu bywydau. Mae'r Prosiect Llwybrau Herceptin yn darparu ôl-ofal dros y ffôn gyda mynediad sydyn at gymorth arbenigol pe bai angen amdano. Mae'r dull hwn o weithredu yn hyrwyddo hyblygrwydd gan fod gofal yn cael ei ddarparu yn agosach i'r cartref ac nid oes angen cymaint o ymweliadau â'r ysbyty.

Manteision i'r GIG:

- Llai o apwyntiadau drud gydag ymgynghorwyr.
- Gall clinigwyr ganolbwyntio eu hamser ar achosion mwy cymhleth.
- Arbedion cost o 17% i bob claf, cyfanswm o £143,836 pe bai'n cael ei weithredu yn achos yr holl gleifion cymwys yn Ne Ddwyrain Cymru.

Manteision i bobl sy'n byw gyda neu'r tu hwnt i ganser:

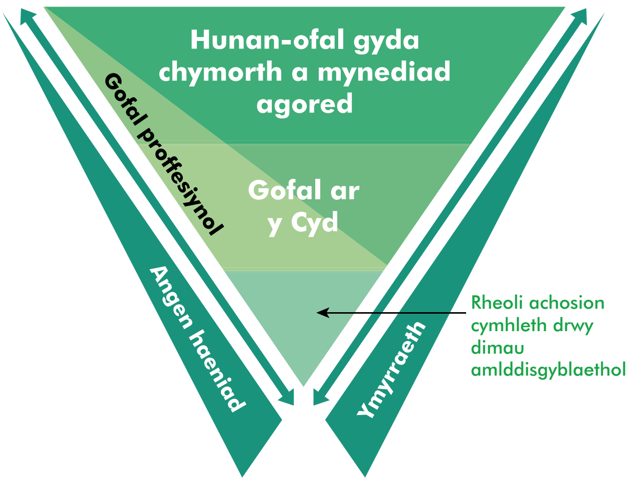
- Llai o ymweliadau â'r ysbyty, gan arbed amser ac arian. Gall hyn olygu 5 ymweliad yn hytrach na 30.
- Gall pobl barhau â'u bywydau wedi triniaeth a radiotherapi heb orfod poeni am apwyntiadau yn yr ysbyty.
- Cefnogaeth gan nyrs arbenigol drwy wasanaeth llinell ffôn 24 awr a system galw yn ôl.
- Dywed 92% o bobl sy'n byw gyda neu'r tu hwnt i ganser eu bod nhw'n hynod fodlon â'r gwasanaeth newydd.

Gall effeithiau hwyr triniaeth effeithio ar ansawdd bywyd yn hir wedi i driniaeth ddod i ben, ac yn aml mae hyn yn arwain at dderbyniadau diangen brys i'r ysbyty. Gyda dros 200 o fathau gwahanol o ganser a rhwng 30% a 50% o bob math o ganser yn cael eu cyfrif yn rhai 'prinnach'[85], gwybodaeth gyfyngedig yn unig sydd gan feddygon teulu am effeithiau hwyr yr afiechyd a'i driniaeth, ac ni allan nhw gefnogi pobl yn llawn bob tro yn y ffordd sydd ei hangen.

Ar y cyfan, mae gan Gymru agwedd un ateb i bawb i ôl-driniaeth. Waeth beth yw'r peryg y daw'r canser yn ei ôl neu o gymhlethdodau eraill, mae'r rhan fwyaf o bobl yn dilyn yr un broses ôl-ofal yn y misoedd a'r blynyddoedd wedi triniaeth.

Mae asesiad trylwyr ar ddiwedd triniaeth unigolyn yn ei gwneud hi'n bosib datblygu cynllun ôl-ofal sydd wedi'i deilwra i'w lefel o angen a risg. Er bod yn rhaid i rai profion rheolaidd barhau, fel profion gwaed neu ddelweddu, mae yna dystiolaeth gynyddol y gallai teilwra ôl-ofal i anghenion yr unigolyn olygu arbedion sylweddol i'r GIG, gan wella profiad a chanlyniadau pobl, a darparu gwasanaeth o ansawdd well.

Mae'r 'model gofal haenau o risg' canser[86] a ddangosir isod yn debyg i'r dull o weithredu a gynigir yn Strategaeth Rheoli Cyflyrau Cronig Llywodraeth Cynulliad Cymru:[87]



Model Gofal Haenau o Risg

Llwybrau Gofal Wedi'u Trawsnewid, NCSI, Yr Adran Iechyd

Mae profiad o'r Fenter Cenedlaethol Goroesi Canser (NCSI) yn awgrymu bod ar 15-25% o bobl sy'n goroesi canser angen monitro wyneb yn wyneb neu ofal o dan arolygaeth o hyd. A dim ond 5-10% ohonyn nhw sydd ag anghenion sydd heb eu diwallu – fel canlyniadau difrifol a chymhleth i driniaeth ganser – sydd yn golygu bod angen gwasanaethau arbenigol. Bydd canrannau'n amrywio yn ôl math y tiwmor.[88]

Yn achos pobl sydd ag anghenion cymhleth, bydd diwygio ôl-ofal canser yn rhoi mwy o gysylltiad iddyn nhw gyda gweithwyr iechyd proffesiynol nag sydd ganddyn nhw ar hyn o bryd. I'r mwyafrif o bobl sydd ag anghenion llai cymhleth ac sy'n gallu hunan-reoli gyda chymorth a gwyliadwriaeth addas, bydd diwygio ôl-ofal yn golygu eu bod yn cael llai o gyswllt gyda gweithwyr iechyd proffesiynol yn y cyfnod wedi triniaeth. Yn hytrach, bydd angen rhoi gwybodaeth iddyn nhw am arwyddion a symptomau ac ynglŷn â phwy i gysylltu â nhw.

Beth yw cyfarwyddebau a llwybrau gwybodaeth?

Mae **llwybrau gwybodaeth** yn gosod allan y mathau o wybodaeth y gall pobl sy'n byw gyda chanser eu heisiau ar wahanol adegau yn eu gofal. Ar hyn o bryd, mae mynediad at wybodaeth yn amrywio ar draws Cymru ac ar gyfer mathau gwahanol o ganser. Mae mapio'r holl opsiynau gwybodaeth mewn un man yn golygu ei bod hi'n hawdd cynnig i bobl yr holl wybodaeth berthnasol y gall fod arnyn nhw ei hangen ar y pryd. Dylai'r llwybrau gynnig cyfoeth o wybodaeth o ffynonellau uchel eu parch ar wahanol fathau o ganser, am y gwahanol ddewisiadau o ran triniaeth, y symptomau a'r sgil effeithiau, a'r effeithiau y gall canser a'i driniaeth eu cael ar eu bywydau – er enghraifft, ar berthynas, rhyw, arian neu waith. Hefyd dylid cynnig gwybodaeth am wasanaethau a grwpiau cymorth lleol, ac i ble i fynd am gymorth a gwybodaeth pellach. Dylai gwybodaeth ar y llwybr fod yn rhad ac am ddim, yn seiliedig ar dystiolaeth, yn gyfoes, yn sensitif yn ddiwylliannol, ac ar gael mewn nifer o ffurfiau, gan gynnwys yn Gymraeg, a thrwy nifer o sianeli.

Cyfarwyddebau gwybodaeth yw copi ysgrifenedig o'r sgwrs rhwng y gweithiwr canser proffesiynol a'r person sy'n byw gyda neu'r tu hwnt i ganser am anghenion gwybodaeth y claf. Mae'r gweithiwr proffesiynol yn defnyddio'r llwybr i fframio'r sgwrs ac yn cynnig gwybodaeth sy'n berthnasol ar yr adeg honno. Gall yr unigolion hynny wedyn ddarllen yr hyn a ddywedwyd, a chael eu cyfeirio at ragor o ffynonellau o gymorth.

Byddai angen arweinyddiaeth glinigol gref er mwyn rhoi cychwyn ar unrhyw waith i newid ôl-ofal y tu hwnt i driniaeth gychwynnol.

Mae Macmillan am i bob unigolyn sy'n byw gyda neu'r tu hwnt i ganser yng Nghymru i dderbyn ôl-ofal sydd wedi'i deilwra i'w anghenion erbyn diwedd tymor nesaf y Cynulliad.

3. Gwybodaeth a chymorth mwy personoledig

Dylid cynnig cymorth a gwybodaeth wedi'u teilwra i bob claf canser yng Nghymru gydol eu profiad o ganser.

Er mwyn cael gwasanaethau sydd yn rhoi pobl yn ganolog go iawn, mae angen i bobl sy'n byw gydag ac wedi canser fod wrth galon y penderfyniadau a wneir am eu triniaeth a'u gofal. Mae darparu gwybodaeth a chymorth bersonoledig yn hanfodol. Mae hyn yn golygu mwy na dim ond rhoi taflen i rywun am eu canser. Mae'n golygu dewis detholiadau byrion o wybodaeth sy'n ateb eu gofynion a'u cyfnod nhw yn eu profiad o ganser. Rydym yn credu y dylid datblygu cyfarwyddebau a llwybrau gwybodaeth er mwyn gwneud cymorth a gwybodaeth bersonoledig yn realiti yng Nghymru.

Wrth gynnwys cyfarwyddebau a llwybrau gwybodaeth fel rhan o ofal canser gallwn sicrhau bod gwybodaeth o ansawdd uchel yn cael ei chynnig i bobl ar adegau allweddol yn ystod eu profiad o ganser, yn ogystal â'r cymorth sydd ei angen arnyn nhw er mwyn deall a gweithredu ar sail yr hyn a ddysgwyd.

Rydym yn gwybod bod rhoi cymorth a gwybodaeth bersonoledig i bobl, a'u helpu nhw i hunan-reoli, yn arwain at well canlyniadau ar gyfer cyflyrau cronig hir dymor[89], gan gynnwys canser. Pan fo pobl yn meddu ar wybodaeth dda, maen nhw'n gwybod am beth i chwilio a beth i'w wneud er mwyn rheoli eu harwyddion a'u symptomau. Os ydyn nhw'n gwybod beth i'w ddisgwyl, maen nhw'n pryderu llai, yn llai tebygol o geisio cyngor gan y gwasanaethau brys a gallan nhw ddatrys problemau heb ymyrraeth broffesiynol.[90]

Mae nifer o'r gwasanaethau cymorth sydd ar bobl sy'n byw gydag ac wedi canser eu hangen eisoes yn bodoli, ac yn aml maen nhw'n cael eu darparu gan y sector gwirfoddol. Nawr mae ar Gymru angen adeiladu'r ddarpariaeth o

Ein gwybodaeth a chymorth

Sut yr ydym yn helpu gyda datblygu gwybodaeth a chymorth i bobl sy’n byw gydag ac wedi canser yng Nghymru:

1. Prosiect Gwybodaeth Canser Cymru Gyfan Macmillan

Cyfnod 1: Prosiect Llwybrau Gwybodaeth Canser Cymru Gyfan

Gwnaeth y prosiect adolygiad trylwyr er mwyn canfod pa wybodaeth sy’n cael ei chynnig i gleifion canser, i’w gofalwyr a’u teuluoedd ar draws Cymru. Roedd yr adolygiad yn cynnwys mapio beth oedd ffynonellau, fformat ac ieithoedd y wybodaeth a gynigir. Gan ddefnyddio’r canlyniadau hyn, datblygwyd llwybrau gwybodaeth drafft ar gyfer mathau allweddol o ganser gan gynnwys canser y fron, wroleg, gynaecoleg, y colon a’r rhefr, a gastroberfeddol uchaf. Bydd y llwybrau hyn yn cael eu cwblhau wedi ymgynghoriad. Yn y cyfamser, mae trafodaethau’n parhau er mwyn cael hyd i gyfleuster storio ar-lein fel y gall gweithwyr iechyd proffesiynol ar draws Cymru gael mynediad at y llwybrau.

Cyfnod 2: Arweinydd Strategaeth Wybodaeth Canser Macmillan (Cymru)

Mae Macmillan Cymru yn buddsoddi mewn swydd strategaeth wybodaeth, fydd wedi’i lleoli gydag Iechyd Cyhoeddus Cymru. Bydd y swydd yn helpu i wella cydgysylltu a darparu gwybodaeth i bobl sy’n byw gydag ac wedi canser ar draws Cymru. Bydd hefyd yn asesu a ellid trosglwyddo’r model gwybodaeth ganser i gyflyrau cronig eraill.

2. Cydlynwyr a chanolfannau gwybodaeth a chymorth canser Macmillan

Yn 2008, dechreuon ni raglen o fuddsoddi er mwyn gwella mynediad at wybodaeth a chymorth. Gweithion ni mewn partneriaeth gyda’r GIG a mudiadau eraill yn y sector gwirfoddol er mwyn agor canolfannau gwybodaeth a chymorth Macmillan yn Wrecsam a Llandrindod. Rydym hefyd yn gweithio gydag awdurdodau lleol yng Nghymru er mwyn datblygu gwybodaeth a chymorth canser mewn llyfrgelloedd lleol, ac rydym yn cyllido cydgysylltwyr gwybodaeth a chymorth i reoli ein canolfannau a’n presenoldeb mewn llyfrgelloedd. Mae’n cydgysylltwyr yn gweithio ochr yn ochr â gwirfoddolwyr er mwyn darparu gwasanaeth cynhwysfawr i drigolion lleol.

3. Mynediad at wybodaeth a chymorth canser gartref

Ers i ni uno â’r elusen gwybodaeth ganser, Cancerbackup, yn 2008, rydym wedi gallu cynnig amrediad eang o adnoddau cymorth a gwybodaeth o ansawdd uchel i bobl sy’n byw gydag ac wedi canser. Bellach mae rhai o’r teitlau a ddefnyddir amlaf ar gael yn Gymraeg. Rydym yn darparu gwybodaeth a chymorth canser cynhwysfawr yn rhad ac am ddim, yn ogystal â mynediad at wybodaeth ar ein gwefan, a gwasanaeth ffôn yn rhad ac am ddim ar 0808 808 00 00.

wybodaeth a chymorth i’w strategaeth newydd fel y daw’n rhan annatod o’r llwybr gofal.

Rydym am i bob claf canser yng Nghymru gael cynnig gwybodaeth a chymorth gydol eu profiad o ganser erbyn diwedd tymor nesaf y Cynulliad.

4. Mynediad at weithiwr allweddol dynodedig

Dylai’r holl gleifion canser fod â mynediad at weithiwr allweddol dynodedig sy’n deall eu hanghenion ac sy’n gallu’u cefnogi nhw yn ystod ac wedi triniaeth.

Ym mis Mai 2010 cyhoeddodd y llywodraeth y byddai pawb oedd â diagnosis o ganser yng Nghymru yn cael gweithiwr allweddol i gydlynu eu gofal.[91] Roedd gofyn i’r Byrddau Iechyd Lleol weithredu’r polisi hwn erbyn mis Mawrth 2011. Rhoesom groeso cynnes i’r cyhoeddiad hwn. Yn ôl a ddeallwn, mae’r gwaith wedi cychwyn, ond hyd yma nid oes unrhyw ddiffiniad clir, wedi’i gytuno’n genedlaethol, o rôl y gweithiwr allweddol, ac mae’r rhan fwyaf o’r cynllunio ar gyfer cwmpas a swyddogaeth rôl y gweithiwr allweddol yng Nghymru yn digwydd yn lleol. Gallai hyn arwain at anghysondeb ac anghyfartaledd daearyddol yn lefel ac ansawdd y gwasanaeth a ddarparir.

Rydym yn credu ei bod hi’n bwysig bod y fenter gweithiwr allweddol yn cael ei gweithredu’n gyson yng Nghymru. Er y gall gweithwyr allweddol fod yn weithwyr proffesiynol gwahanol ar gyfnodau gwahanol o brofiad rhywun o ganser, dylid cael cysondeb o ran eu swyddogaethau a’u dyletswyddau ledled

Cymru. Gyda'r dull presennol o weithredu, mae yna beryg y bydd y math o weithiwr allweddol sydd gan unigolion i'w cefnogi yn dibynnu ar ble maen nhw'n byw yn hytrach nag ar eu hanghenion a'u hamgylchiadau.

Wrth ddatblygu rôl y gweithiwr allweddol, mae'n hanfodol bwysig ystyried parhad y gofal. Mae materion fel mynediad at weithwyr allweddol y tu allan i oriau, pontio o ofal eilaidd i sylfaenol a'r defnydd o gofnodion electronig i gyd yn hanfodol i lwyddiant y fenter hon.

Er mwyn sicrhau cysondeb ar draws Cymru, mae'n rhaid cytuno ar rôl a chylch gwaith y gweithiwr allweddol ar lefel genedlaethol erbyn diwedd blwyddyn gyntaf tymor nesaf y Cynulliad. Erbyn diwedd ail flwyddyn tymor nesaf y Cynulliad, rydym am i bawb sy'n byw gyda neu'r tu hwnt i ganser yng Nghymru fod â mynediad at weithiwr allweddol perthnasol dynodedig.

Beth yw gweithiwr allweddol?

Beth ddylai gweithiwr allweddol ei wneud?

Yn seiliedig ar ein hymchwil ni , a gwaith a wnaed gan lywodraethau mewn mannau eraill yn y DU , dyma yw rôl y gweithiwr allweddol:

- Bod yn brif fan cyswllt.
- Gwneud asesiadau, cytuno ar gynlluniau gofal a sicrhau bod manylion y cynllun gofal wedi'u cyfathrebu i'r unigolyn sy'n byw gyda chanser ac eraill sy'n ymwneud â'i ofal.
- Bod yn bennaf gyfrifol am gydgysylltu gofal a rheoli pontio gofal.
- Darparu gwybodaeth am driniaeth ganser a'i heffeithiau. Helpu'r unigolyn sy'n byw gydag ac wedi canser i ddeall y wybodaeth honno er mwyn gallu gwneud penderfyniadau deallus.
- Darganfod pa gymorth a chefnogaeth ychwanegol sydd eu hangen ar yr unigolion a'u sicrhau. Gall hyn olygu eu cyfeirio at wasanaethau cymorth eraill, fel cyngor ariannol, help ymarferol a chymorth emosiynol. Sicrhau bod pobl yn gwybod gyda phwy i gysylltu gydag unrhyw gwestiynau neu am help.
- Rhoi cyngor i unigolion a'u gofalwyr.

Dylid cydnabod y gall gofal unigolyn gael ei weithredu a'i gydgysylltu gan nifer o weithwyr proffesiynol clinigol ac anghlinigol.

Pwy fyddan nhw?

Yn ystod cyfnod y driniaeth, mae'n debygol mae'r gweithiwr allweddol fydd y nyrs glinigol arbenigol. Wedi triniaeth, bydd y gweithiwr allweddol mwyaf addas yn dibynnu ar y math o ganser, ei ddifrifoldeb a'i gyfnod, ac anghenion yr unigolyn. I bobl sy'n byw gydag ac wedi canser ac sydd ag anghenion cymhleth, mae'n debygol y bydd y gweithiwr allweddol yn chwarae cryn dipyn o ran. Yn achos y rheiny sydd ag anghenion cymedrol, mae'n debygol y bydd llai o gyswllt gyda'r gweithiwr allweddol, er y dylai'r gweithiwr allweddol fod ar gael pe bai unrhyw faterion yn codi. Y peth pwysig yw bod yr unigolion sy'n byw gydag a'r tu hwnt i ganser yn gwybod pwy yw eu gweithwyr allweddol, a bod y gweithwyr allweddol yn gwybod beth yw eu cyfrifoldeb tuag at yr unigolion hynny.

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CHANGING CANCER CARE IN WALES

A report by
Macmillan
Cancer
Support

March 2011

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Foreword

We have carried out an extensive three-year research programme across Wales to understand what people living with and after cancer need – and how well the cancer care system meets those needs. As part of this process we spoke to people who have experienced cancer themselves, as well as to academics and professionals working in Welsh health and social care.

Our research clearly shows that the current system of tackling cancer is costly and simply doesn't meet people's needs. Given the growing number of people diagnosed or living with and after cancer, the burden this is placing on the NHS and other service providers, and the current economic climate, we believe it is financially and morally vital for the next Welsh Assembly Government to prioritise cancer care in Wales.

We recognise that right now budgets are limited. But the evidence in this report shows that if we put the right support services in place now – and improve coordination and communication across agencies and throughout the cancer journey – we can meet the needs of people with cancer and use resources more effectively.

It is also clear that people living with and beyond cancer, as well as professionals and managers, want to see a change in the way cancer care is delivered in Wales. We believe we all have to work together to transform cancer care so that we can meet people's changing and increasing needs. And that we must develop a national, person-centred cancer strategy to make this transformation happen.

As a small country, Wales is in a unique position to redesign its cancer services. The National Assembly for Wales election in May gives us the chance to take a more radical approach to the way we treat and care for people living with and after cancer in Wales. And to provide services that are more cost-effective and meet the needs of the whole person.

We are confident that Wales can develop cancer services that are among the best in Europe and we want to help the next Welsh Assembly Government make this a reality. It is our hope that the government will take up the recommendations and solutions offered in this report. We believe that together we can improve the lives of people affected by cancer in Wales.

Cath Lindley
General Manager for Wales,
Macmillan Cancer Support

Summary and recommendations

Cancer is a complex disease. With over 200 different types, treating it is becoming more complicated and expensive than ever before.

Diagnosing cancer at an early stage is a major challenge for Wales. We know from studies carried out elsewhere in the UK that if people were diagnosed earlier and offered appropriate treatment more quickly thousands of lives could be saved.[1] But it is no longer simply a matter of whether people survive cancer or not. Thanks to advances in early diagnosis and treatment, more people are living longer with cancer or beyond it, which means they need ongoing and often long-term support. By 2030, it's estimated that the number of people living with or after cancer in Wales will nearly double to almost a quarter of a million.[2]

Cancer and its treatment can have a devastating impact on people's lives. At the same time, the current cancer care system is expensive and doesn't meet people's needs. To provide people in Wales with the cost-effective care and support they need during and beyond cancer, we must radically transform care.

What we need is a comprehensive, person-centred cancer strategy for Wales. One with clarity, vision and direction. A strategy that has a wide-ranging, whole-systems approach to preventing, diagnosing, treating and caring for people with cancer, that takes into account the growing number of people living with cancer, advances in technology and the challenging economic times.

We believe the new strategy should include four key initiatives to make cancer care in Wales more person-centred: improved assessment and care planning, reforms to follow-up care, more personalised information and support and a key worker for everyone with cancer. Such a strategy will enable cancer services to move away from a one-size-fits-all approach to more individual care throughout the entire cancer pathway. This will ensure better outcomes for people living with and after cancer, while research has shown it will save money too.

However, a strategy alone is not enough. Deciding where to allocate funding is a difficult decision for the Welsh Assembly Government, the NHS and local authorities. Strong leadership is needed to support managers and clinicians to take the right decisions. Strong national leadership is also essential to maintain a focus on implementation and ensure consistency and equality across the country so that no matter where they live, everybody receives the same high quality treatment and care.

At Macmillan, we have been working to improve the lives of people living with and after cancer for 100 years. Every year we invest millions of pounds in improving cancer services in Wales. Our research and experience show us what people in Wales want and need. Now our commitment is to work with the next Welsh Assembly Government to help deliver world-class cancer care for our nation.

What we recommend

1: Develop a person-centred cancer strategy for Wales in the first year of the next Assembly term.

Wales needs a national cancer strategy that recognises the changing nature of the disease and leads the way to transforming cancer care. It must incorporate the entire cancer pathway – from prevention and survivorship to palliative care and end of life – and meet the needs of people living with cancer.

The key theme running throughout the new cancer strategy for Wales should be that all treatment and care is person-centred. A definition of person-centred care can be found on page 17.

It is critical that the development of the strategy involves the people in Wales who understand the issues best: stakeholders who support people living with and after cancer, and those who have experienced cancer firsthand.

2: Include four key initiatives within the cancer strategy to achieve person-centred, cost-effective cancer care.

By adopting these changes over the next Assembly term, we can improve care and achieve a more coordinated and efficient use of NHS resources.[3]

i. Improved assessment and care planning
    - o Every cancer patient should be offered an assessment and care plan at each appropriate stage of their cancer journey.

ii. Reforms to cancer follow-up care
    - o After their initial treatment, every cancer patient in Wales should receive ongoing support that is tailored to meet their own level of need and risk.

iii. More personalised information and support
    - o Everyone living with cancer should be offered tailored information and support throughout their cancer journey.

iv. Access to an identified key worker
    - o All cancer patients should have access to an identified key worker who understands their needs and is able to support them during and after treatment.

Part 1: The need for change

Where we are now

Wales faces many enormous challenges in supporting people to live with and beyond cancer, as well as caring for those who sadly die of the disease.

These challenges have been recognised by the Welsh Assembly Government[4], whose ambition is to see Wales take its place among the best in Europe by 2015. But as other European countries continue to improve and the deadline approaches, much needs to be done before this ambition can become a reality.[5]

This important work must be accomplished within the changing context of cancer. Today, the diagnosis and treatment of the disease is becoming evermore effective as advances in technology and medicine are made. As a result, many more people are living through cancer, with ten year survival rates doubling over the past 30 years to 46%.[6] For many, cancer is still a short-term incurable illness, but for thousands of others, their experience of cancer is evolving to a long-term condition with many possible outcomes. As the nature of cancer changes, so do the needs of people who are affected by it – and the range of health and social care professionals and services required to help meet those needs.

This transformation is also taking place during very challenging economic times for the NHS and the public sector. Difficult decisions about the allocation of limited resources must be made over the next few years. Leadership and clarity from the government on its vision and ambition for improving cancer services are essential to support decision makers at every level of cancer care, and service and policy development.

It is clear that we must transform the way we deliver cancer care in Wales if we are to meet the needs of the growing number of people affected by cancer in the current climate. Cancer services in Wales need to be more person-centred – a view that people living with and working with cancer support.[7] And we know that if services are more integrated and better coordinated, we can not only achieve better outcomes for people affected by cancer, but also release considerable savings for the NHS and other statutory partners.[8] However, delivering high quality services that are person-centred and cost-effective requires a step change that will not happen overnight and cannot happen without leadership and intervention from the government and service planners.

As we approach the Assembly's fourth term, Wales has a unique opportunity to be at the forefront of efforts to transform cancer care to meet the needs of people affected by cancer and meet the tough financial challenges that lie ahead.

How many people are affected?

When it comes to cancer, Wales faces some significant challenges. The number of people diagnosed with cancer has increased over the last ten years. While survival rates are improving, they still lag significantly behind those in Europe and other developed countries[9]. And as survival improves and our population ages, there are growing numbers of people living with and beyond cancer[10].

KEY FACTS

- 50 people are diagnosed with cancer every day in Wales – more than 17,000 every year.[11]
- Right now, more than 120,000 people are living with or after cancer in Wales – around 4% of the population.[12]
- If current trends continue, by 2030 this will have almost doubled to more than 7% of the population.[13]
- Wales has the highest proportion of people living with cancer in the UK, this is related to having the oldest population of the four nations.[14]
- A higher proportion of people die from cancer in Wales as compared to the rest of the UK. The age standardised cancer mortality rate in Wales is 183 deaths per 100,000 population compared to 176 deaths per 100,000 population in the UK.[15]

Advances in diagnosis and treatment

As breakthroughs in technology and drug therapies are made, diagnosis and treatment for cancer patients improves and greater numbers of people live through and beyond cancer. If we are to achieve even better survival rates, it is critical that we continue to invest in research and technological advances that will deliver improved clinical care and patient outcomes.

We also need to develop an approach, structure and process that enables healthcare professionals to implement the latest advances in treatment and diagnostics – once they are proven and cost effective. For Wales to achieve a world-class service this can't be left to chance. Clinical leadership at all levels are needed to ensure this vital task is properly managed, so that patients receive the best and latest care, wherever they live in Wales.

The financial challenge

Cancer accounts for 7.1% of all NHS expenditure in Wales[16]. In 2008-09 this amounted to £358.8 million – the fourth highest area of expenditure for the NHS after mental health, circulation problems and trauma and injury.

As the number of people diagnosed and living with cancer increases, the cost of cancer services is set to become an increasing financial burden on the NHS.

While the cost of cancer drugs and treatments is undeniably high, evidence shows that we can make other efficiency savings in cancer care. For example, by providing assessment and care planning, information provision, benefits advice and personalised one-to-one support through clinical nurse specialists – we can use resources much more efficiently. As well as reduce unnecessary bed days and emergency admissions for cancer.[17]

Research carried out by Monitor on behalf of Macmillan[18] has also shown that more coordinated cancer care can lead to savings. The report highlights opportunities to save money by:

- improving communication, coordination and information
- improving care in order to reduce length of stay after treatment, outpatient follow up, hospital deaths, and GP consultations
- supporting patients to return to work

The report concludes that improving care coordination, reducing avoidable emergency admissions and the length of stay in hospital, and enabling more people to die at home, could generate NHS savings of up to 10% for the cancer patients it examined through the study. It also found that the UK economy could be boosted by £30 million every year if just five per cent more breast cancer survivors were better supported to stay in work.[19] This would represent a substantial boost to the economy in Wales.

Additional research[20] shows that when you take health service costs and lost productivity into account, the total cost of cancer to the UK in 2008 was £18.33bn. This is set to rise to £24.72 billion by 2020. But if cancer services and survival rates improve enough to be among the best in Europe, that figure could be reduced by £10bn in England alone, saving a staggering 71,500 lives. Improvements like these could also be achieved in Wales.

The evidence is clear: cancer impacts the wider community, society and the economy. The next Welsh government must set a clear vision for cancer services so that planners can focus on investment priorities and identify areas where savings can be made through innovation and improved care. A national strategic approach to cancer will encourage greater savings by minimising duplication in front line services, encouraging innovation and helping to make best practise common practise.

Cancer is different now

Twenty years ago, cancer was considered to be a death sentence for many people and the aim of treatment was often just to extend life for a few months. Now, improvements in diagnosis and treatment mean that 60% of people with cancer will live for five or more years[21]. For some cancers, such as breast, five-year survival rates are as high as 80%. Because of this, cancer is no longer simply kill or cure. For an increasing number of people, it is a chronic illness that may follow a relapse and remission pattern over several years.

Interestingly, perceptions of cancer and the way care is provided haven't kept pace with these developments[22]. Recent research for Macmillan – with professionals working in cancer care in Wales – found that while they acknowledge that the cancer landscape is changing, they also recognise that services are not evolving with it[23].

This changing nature of cancer poses a significant challenge for the NHS, social services and the voluntary sector as they seek new and better ways to meet the needs of people with cancer and use their limited resources effectively.

What do people want and need?

People affected by cancer tell us that the disease turns their lives upside down. It affects how they feel about themselves and those they care about, their work, finances and emotional wellbeing. On a practical level it has a huge effect on their ability to live their day-to-day lives. And they feel these impacts throughout their cancer journey.

According to professionals working in cancer care in Wales, the dominant focus of care is still a clinical one – 'of treating the condition rather than the individual'.[24] As a result, many of the other needs that people with cancer have are left unmet. Professionals have expressed their frustration that non-clinical needs are often poorly addressed. They speak of the need to challenge a clinical culture 'that often believes that as long as you get the medical and physical side of care right, that is adequate care'.[25]

Emotional and psychological needs

'It would be nice if, when being told you have cancer, you are also informed of emotional services to access…you need to learn how to fight this thing because you are likely to be thinking I'm going to die.'[26] *Person affected by cancer, Wales*

Cancer places people under extreme emotional and psychological strain, which can lead to a huge range of practical difficulties in daily life.[27] At the time of diagnosis, around 50% of people with cancer experience levels of anxiety and depression severe enough to affect their quality of life. For 25% this continues for the following six months. In the year after diagnosis, around 1 in 10 people living with or beyond cancer will experience symptoms so severe they need specialist psychological or psychiatric services.[28]

Research shows that lung, pancreatic, Hodgkin's lymphoma, brain, head and neck, leukaemia and lymphoma patients experience the highest levels of distress.[29] We also know that more patients find the emotional effects of cancer most difficult to deal with compared to the physical or practical effects, and that this is particularly the case for women, those with young children, and those from lower socio-economic backgrounds.[30]

For these reasons people with cancer often need emotional support when they are diagnosed, as well as during and after treatment. In spite of this, people say they find it difficult to persuade professionals to refer them to more help. Although some people need professional psychological support to help them deal with the effects of cancer, many simply need someone to talk to.

'I was very lonely and poorly in health when I left hospital. I had lots of complications like infected scars, which lasted six to seven weeks. Nurses treated the sores but had so much paperwork to see to they had no time to talk.'[31]

Person affected by cancer, Wales

Our own recent research has shown that 20% of the people with cancer said they wanted counselling while they had cancer but less than half were told where they could get it.[32]

'I was given a booklet which explained various cancers and treatments but at the time of diagnosis in the clinic that was all. I was upset and would have liked someone to talk to.'[33]

Person affected by cancer, Wales

Professionals surveyed by Macmillan agree that the emotional impact of cancer is not being addressed and that people living with and after cancer are often left to deal with the devastating after effects alone.

'Patients and relatives have to source their own support at a time when they are floundering. Those who need rehabilitation and psychological support to live with their disease or former disease do not get it.'[34] *Allied Health Professional, Wales*

Financial needs

Studies show that cancer can have a significant impact on people's finances and lead to new or increasing debts.[35] Evidence also suggests that financial burdens can increase anxiety and stress, with some people feeling that financial difficulties are 'more of a worry than the cancer'.[36]

Over 5% of people living with or beyond cancer – over 10% if they are self-employed – lose their home after being diagnosed.[37] 91% of households with people affected by cancer experience loss of income and/or increased costs. For instance, a person with cancer makes, on average, 53 trips to hospital during the course of their treatment.[38] Heating and other household bills can also go up, special diets may need to be catered for and new clothes may have to be bought.[39] [40]

Many people living with and after cancer never claim the benefits they are eligible for. This is particularly the case among elderly and disabled people, who often need help to make a claim.

A recent Macmillan survey found that in terms of patients receiving advice following treatment, just 6% of Welsh adults had someone talk to them about money issues such as benefits and grants, and just 3% had someone talk to them about work worries or issues.[41]

Our research suggests that worrying about money is second only to pain as a cause of stress to people with cancer.[42] We need to make sure that people with a cancer diagnosis receive the financial benefits they are entitled to so they can be free to focus on their treatment and recovery.

Information needs

People living with cancer, and their carers, need sound information and support to help them negotiate their way through cancer treatment and beyond. With the right information they have the power to make the best choices for themselves and their family.

Most people with cancer say they would like more information. Some say they don't receive any information at all.[43] A recent survey done on our behalf found that 72% of cancer patients in Wales wanted information about their condition, 77% wanted to understand the long-term effects of treatment, and 71% wanted to know about the different treatment options available. Unfortunately, less than 33% of people with cancer who took part in the survey actually received this information.[44]

As cancer and its care changes, we need to

support people living with or after cancer to take an active and leading role in their recovery. The right information empowers people to make decisions about their own treatment, but it needs to be given in a way that is meaningful. We welcome the recent efforts of Public Health Wales to improve health literacy and increase people's understanding of their condition and treatment. Now more work needs to be done to make sure everyone living with and after cancer is offered personalised information and support to manage their condition.

People living with and beyond cancer tell us that easy-to-understand information, support and signposting to other services aren't in place everywhere in Wales. Where information and support are available, many people don't realise they exist.

'The staff in the hospital were very caring and excellent. (But) I had no information from the social services on how to get help with care at home on my own and no idea about how to get help.'[45]
Person affected by cancer, Wales

A recent survey of professionals[46] reveals that although information is increasingly available, people often find it overwhelming, especially when first diagnosed. The professionals also say that people need more time to absorb what they are told and to have the opportunity to ask questions outside the consulting room.

One nurse surveyed said:

'Whilst information is available it is not always given in ways that inform. Medics usually try to explain treatment options etc in terms of percentages, figures from trials, quoting five-year survival rates, which can cause distress as patients only hear "five years". They focus on this, feeling that they have been given a prognosis. Often they are sent away with no checking of understanding and are expected to make a decision with this information and no psychological support to do so. I guess what I am trying to say is that information is there, often in copious amounts, but it is not person-centred.'[47]
Cancer Nurse, Wales

People's long term needs following treatment

While people are receiving treatment for cancer, they are supported by a variety of professionals in the hospital, going from appointment to appointment. But once treatment has finished, much of the support disappears even though people can continue to have a range of complex physical, psychological and social needs. People can experience chronic illness – such as bowel problems, chronic fatigue, lymphoedema, impotence, infertility and depression – while new cancers or treatment-related conditions can emerge months or even years later.

In spite of the many problems that follow cancer treatment, people living with or beyond cancer tell us there is a lack of support.[48] They talk about the period after treatment as one of abandonment. Many compare it to feeling like they are on the edge of a cliff.

A survey conducted on our behalf found that 60% of people living with or beyond cancer want information, advice and support about next steps and choices in the cancer journey after treatment. Only 23% get it. It also found that 27% of people who complete their treatment feel abandoned by the health system.[49]

'After treatment is the part of the cancer journey that's surprisingly one of the hardest. The after effects of treatment mean there's so much toxins and poison going through your body you're affected both physically and mentally. I found it very, very hard.'[50] *Person affected by cancer, Wales*

'It does feel like after your last chemo session you are on your own. It's then when you are not so much supported by the nurses, doctors etc that it hits home what has happened and the 'mental health' element kicks in. That is where I feel support is lacking.' *Person affected by cancer, Wales*

Research carried out for us by the Welsh Institute of Health and Social Care[51] shows that services offered after treatment were the least likely to be person-centred. It found that people are often 'left adrift' once treatment finishes, just when the need for support is most pressing. Professionals in the study recognise the need to provide post-treatment assessment and care planning but say this rarely happens. They are aware of the many practical and emotional difficulties faced by people in the post-treatment stage and feel that people with cancer and their carers would benefit from better signposting towards sources of information and non-clinical support.

Several described the 'long shadow of fear' that cancer casts over people's lives and the need to regain confidence in their own health.

'There is still an overwhelming response of abandonment following treatment which has not improved. The promotion of living with cancer initiatives is extremely slow in availability.'[52]
Operational Manager, NHS Wales

A recent survey carried out in Wales on our behalf by YouGov reveals that[53]:

- 50% of people living with or beyond cancer say no one talked through their needs after their clinical treatment finished.
- 61% say they didn't receive any support from key health and social care professionals after treatment
- 56% say they were not given a named health professional to help support them in their first year after treatment.
- Of those who did have someone to talk to about their post treatment needs, 76% said these were not written into a care plan.

The quest for coordinated care and high quality services

The complexity and severity of cancer makes it challenging but vital to deliver the right services, as quickly and efficiently as possible.

Diagnosis can be delayed for a number of reasons including late presentation by the individual, poorly coordinated referral systems between services and complex diagnostic pathways.[54] People's cancer treatment plans also vary significantly, depending on the type of cancer they have and the process of diagnosing it. Their plan can include complicated and potentially harmful treatments such as surgery, radiotherapy, chemotherapy and hormone therapy. The effects of new, advanced treatments are unknown but we know that cancer and its treatment can impact someone's life for weeks, months and years to come. At the same time, the care they receive takes place in many locations and often goes beyond local health board and cancer network boundaries. Some specialised treatments happen across UK borders and in other European countries.

This complexity makes it difficult to achieve joined-up care within the healthcare system and the primary, community, social care and voluntary sectors. Continuity of care can suffer and people report feeling as though they are falling into the gaps between service providers. This is what healthcare professionals in Wales say about it in recent research:

> *'Individual professionals are kind, but the systems and processes are disjointed so it can be very confusing and reliant on a sole person to provide coordinated care and take overall responsibility'*[55]
>
> *Person affected by cancer, Wales*

If people aren't given a clearly defined pathway of care – from surgery, chemotherapy or radiotherapy to supported self-care – that helps them access the support they need at any given moment, there is a danger they will turn up at accident and emergency. Then they will be seen by professionals with no knowledge of their condition or history, which leads to expensive, poor quality support.

People living with and after cancer tell us that services are patchy and inconsistent across Wales.[56] This view is echoed in other recent reports, which we will touch on here.

Failing to meet standards

In 2005, the National Cancer Standards were launched to provide guidance for cancer management in Wales. Healthcare providers were asked to meet these standards by March 2009.

In May 2010, the Welsh Assembly Government released a compliance analysis[57], which shows there are substantial gaps in the availability of cancer services across Wales, with significant non-compliance in almost all areas. All but one local health board achieved less than 50% compliance. The services with least compliance were for the assessment of ongoing support, and prompt access to specialist psychological support.

Not only does the report highlight how much performance varies across Wales, it also suggests that services vary depending on the type of cancer a person has.

Late diagnosis and referral

A recent Cancer Research UK (CRUK) report, says that one of the main reasons that cancer outcomes in the UK lag behind some European countries is that it is often diagnosed late.[58] According to the report, up to 10,000 deaths could be avoided each year in the UK if cancer was diagnosed earlier. There is also hard evidence that cancer is being detected and diagnosed later in Wales and that this plays an important part in the country's poor survival rates.[59]

Research we commissioned from the Wales Institute for Health and Social Care (WIHSC)[60] reveals that professionals working in cancer care in Wales say that some improvement has been made in diagnosing people earlier. At the same time, however, the report notes that people and their GPs are often too slow to act on symptoms and that poorly coordinated referral systems can delay diagnosis even more.[61] And that while most people appear to progress relatively swiftly once a diagnosis is made, it's a different story if the diagnosis and treatment are more complicated. This may be related to the nature of their disease – for instance, it may be a rare cancer. But it was reported that people who had to be referred to other areas often experienced unnecessary delays because of poor communication between services.

In England, the National Awareness and Early Diagnosis Initiative (NAEDI) has helped raise awareness of the importance of early diagnosis. According to Cancer Research UK, the NAEDI has had a positive impact on the cancer workforce and helped them understand and prioritise early diagnosis. Wales must have a similar national approach to improve early diagnosis if it is to achieve its aim of ranking among the best in Europe on early diagnosis and survival.

Access to treatment

In 2008, we surveyed the then 22 local health boards in Wales to get a clearer picture of the funding process for people who want treatment that isn't routinely offered on the NHS.[62] The surveys revealed a 'postcode lottery', both in terms of how easy it is for people to navigate this 'exceptional funding' process, and the factors that ultimately affect funding decisions.

In late 2008, the government commissioned a report to improve the availability of medicines in Wales.[63] The report, published in January 2009, recommended national guidelines were produced within six months to support LHBs to apply a more consistent and nationally agreed approach to exceptional funding requests. At the time of going to print, as far as Macmillan is aware, national guidelines have still not been shared with LHBs.

End of life services

We know that 67% of people in Wales would choose to die at home.[64] But only 26.1% actually do.[65] When the end-of-life wishes of people with cancer are not met because of a lack of services, it can lead to very traumatic experiences for them, and a lasting sense of guilt and remorse for friends and family left behind.

Often, terminally ill people with cancer are admitted to hospital unnecessarily, which is distressing for them and costly for the NHS. In England, the National Audit Office estimates that by reducing emergency hospital admissions for people with cancer by 10%, and the average length of stay by three days, £104 million a year could be released to help people choose the place of care they prefer.[66] This evidence is supported by Hospital Care at Home – a recent joint report by Healthcare at Home and Dr Foster – which estimates that NHS savings of £160 million could be made if end of life care was delivered in the home.[67] [68]

We welcome the recent work of Professor the Baroness Ilora Finlay and the Implementation Board to improve palliative cancer care in Wales. Huge strides have been made in this important area, but more work is needed to improve out-of-hours services, support for carers and care for people in nursing homes.

What our research revealed about access to treatments not approved by NICE:

- All Welsh local health boards (LHBs) have a process for the exceptional funding of treatments, but with 15 different names.
- While most LHBs make information on their exceptional funding process available to the public, only around one-third said the process is actively promoted.
- Only 6% of respondents in Wales said that there was an oncologist on the decision making panel for cancer treatments.
- 67% said they take personal circumstances into account, such as age, dependents and marital status.
- Two LHBs said that local publicity and media activity plays an active part in their decision making.
- One LHB considers the stage of the financial year at which the application is received.

Part 2: A national, person-centred cancer strategy for Wales

Where we are now – existing policies

Cancer care has improved in Wales over the last decade thanks to the introduction of the All-Wales Cancer Standards and the Designed to Tackle Cancer policy statement. But we are concerned that without clear vision and a comprehensive national strategy for cancer, Wales will not achieve the world-class, cost-effective and person-centred cancer care it needs.

Moving on from the All-Wales Cancer Standards

People recognise that the existing cancer standards, drafted in 2005, are no longer wide-ranging, ambitious or person-centred enough to achieve the changes needed to cancer care in Wales. As they stand, the focus is on measuring systems, processes and limited clinical targets. Not on monitoring the quality of those services, the experience of people receiving care, or any improvement in the outcome for people living with or beyond cancer.

The standards were developed as a result of the Calman Hine report, which examined cancer care services in the UK more than a decade ago.[69] At the time, the priority was to improve minimum standards in Wales, and establish a set of core requirements for professionals working in cancer care.

Since then, the nature of cancer and how we treat it has changed. So have the constitutional and political landscape, the philosophy and structure of the NHS, and the expectations of people living with and after cancer.

Is the Designed to Tackle Cancer policy enough?

While other countries develop their thinking around person-centred cancer services, Welsh policy lags behind with an approach that is still dominated by the clinical and acute aspects of care. Overall, statements and commitments are followed by little action: as with the cancer standards, implementation has been patchy.

We commissioned research[70] to compare the approach to cancer policy in Wales with other countries in the UK, Europe and beyond. We found that it is 'not at all certain' that Wales will achieve its 2015 targets, set out in Designed to Tackle Cancer (DTTC).[71] Especially as other countries continue to improve.

Our research highlights that DTTC focuses on only four general areas: prevention, early detection, improved access and better services. This leaves out the important new areas of 'living beyond cancer' and 'patient-centred care', which feature in the strategies of other countries.

The report describes a 'somewhat piecemeal approach' to cancer planning in Wales, which can be attributed in part to 'changing ministers, two periods of organisational change, changing priorities, methods of commissioning and planning'. After looking at the progress of cancer treatment and care elsewhere, the report concludes that a dedicated cancer strategy is the 'fundamental building block' to Wales becoming one of the best cancer care providers in Europe.

In a report by Cancer Research UK[72], the charity says, 'Cancer plans are important and useful. They set direction and make the best use of resources'. One of their chief recommendations is that, 'A more comprehensive plan should be developed to ensure consistent delivery, implementation and integration across Wales'. The report also recommends that Wales should develop a 'survivorship initiative'; an issue that 'is an important and emerging policy area, which should be fully embedded in the patient care pathway'.

Research shows that health professionals are also frustrated by the lack of a comprehensive cancer strategy for Wales.[73]

Other policy and strategy developments

Right now, Wales doesn't have a single, comprehensive strategy that plans for the entire cancer pathway. In 2010 a number of additional policies emerged:

- In March, the Cancer Services Coordinating Group published the Living With and After Cancer report, which recognises the importance of clinical professionals seeing survivorship as a distinct phase of cancer care.
- In May, the Welsh Assembly Government published The National Standards for Rehabilitation of Cancer Patients[74], which also addresses issues relating to survivorship.
- The Minister for Health, Edwina Hart, announced a new policy that aims to provide every person in Wales living with and after cancer with a key worker by March 2011.

Wales now has around 20 different strategies, frameworks and policies that relate to cancer care, which you can see in the table below. This policy overload has become so complex and fragmented it's virtually impossible to have a clear vision of how best to meet the needs of people living with and after cancer.

A list of some of the current strategies, policies and frameworks relating to cancer care in Wales:

- Delivering Beyond Boundaries: Transforming Public Services in Wales
- Delivering a Five-Year Service, Workforce and Financial Strategic Framework for NHS Wales
- Annual Operating Framework
- Designed to Tackle Cancer in Wales (2006) and subsequent work plan (2008-2011)
- The National Cancer Standards
- The Rural Health Plan
- Setting the Direction: Primary and Community Care Strategic Framework
- Sustainable Social Services for Wales: A Framework for Action
- Workforce strategies e.g Community Nursing Strategy, Designed to Work
- Financial Inclusion Strategy
- Older People's Framework
- Carers Strategies (Wales) Measure 2010
- 2008 'Sugar' recommendations and the work of the Palliative Care Implementation Board
- Cancer screening programmes, such as bowel, cervical, breast
- Symptom awareness programmes
- Chronic Conditions Management Strategy
- Lymphoedema Strategy
- The CSCG Living With/After Cancer report
- The work of the Self Care Board
- Wellbeing Through Work
- NICE Supportive and Palliative Care Guidance
- The Gold Standards Framework
- Integrated Care Pathway

Developing an effective cancer strategy for Wales

We know that dedicated cancer strategies increase commitment from the government and raise the profile of cancer in the workforce. This in turn helps to reduce inequalities in cancer care.[75]

We recognise that many of the Welsh Assembly Government's general health policies and strategies are working towards person-centred, cost-effective care. Now we need a specific strategy to achieve these changes for cancer too.

Such a strategy will:

1. Provide clarity and vision for everyone involved in planning and delivering cancer care in Wales.
2. Provide a framework to embed clinical leadership at national, network and local level.
3. Change the way cancer is considered and planned.
4. Set out a clear expectation that health, social care and voluntary sector providers must work together to provide a seamless treatment and care pathway.
5. Improve the delivery of coordinated, person-centred cancer care at every stage, from prevention, diagnosis and treatment to after care or end of life.

6. Help to develop more innovative, high quality, cost-effective ways to deliver care.
7. Encourage partners to adopt best practice.

What would an effective cancer strategy look like?

We commissioned research to review cancer strategies across a number of countries.[76] We used the results of this research to create a template that you can see in the box on page 16. Our aim is for the next Welsh Assembly Government to be able to use this template to develop a cancer strategy that builds in best practice from around the world.

We know from our research that a strategy cannot be written or exist in isolation. To be effective, it must take into account every aspect of the cancer control system, from funding to evaluation.

The importance of leadership and collaboration

It takes strong leadership to develop and implement every element of a comprehensive strategy that involves a wide and dispersed range of stakeholders. Such leadership is critical if we are to transform the cancer care system and the delivery of services – and achieve the necessary cultural shift in the understanding of cancer amongst health and social care professionals this requires.

People living with and after cancer are experts by experience and should also be involved in the development of the new strategy. Strong leadership is needed here too, to inspire, provide direction and foster collaboration amongst stakeholders.

Effective and determined political, managerial and clinical leadership are essential if Wales is to achieve cancer care that meets the needs of people living with cancer and uses NHS, social care and other resources efficiently.

Our person-centred cancer strategy template, based on international best practice.

Vision and objectives

- Express a vision that aims to reduce cancer, increase survival rates and helps people live healthy, productive lives after diagnosis.
- Address inequality: even in countries where there have been significant improvements in care, these are not always offered fairly.

Country profiles

- Include a country profile with an in-depth analysis of the statistics and issues relating to patterns of disease. Comparisons are also useful.
- Explore resource allocations and service delivery patterns for cancer, to help identify gaps and prioritise future developments.

The individual's journey

Create the strategy from a personal journey perspective, including:

- Prevention and promotion
- Early diagnosis and screening
- Service delivery
- Palliative care
- Improving the quality of the individual's experience.

  Personalised care has become more emphasised. This is an emerging field, which requires further development and engagement with people living with and beyond cancer, carers, families and society in general.
- Living beyond cancer.

  This new development recognises that many people will now live beyond cancer – or with it as a chronic illness rather than an acute and terminal episode – and focuses on developing services beyond healthcare. Consider including personalised lifetime follow-up plans, psychosocial support and access to financial support.

Infrastructure

Consider the national infrastructure needed to support the implementation of the strategy.

Research

- Allow extra funding for research, which plays a pivotal role in strategy development.
- Emphasise the need to transfer research findings into clinical practice quickly and to improve access to clinical trials.

Information and IT

There are two core elements to consider:

- The provision of accessible information to the public, patients and professionals.
- The development of data collection and analysis through minimum datasets.

Workforce development

It is important to have sufficient and well-trained staff. Allow for recruitment, retention, training and continuing professional development.

Capital and technology

Consider and plan for what access to technology will be needed, such as PET scanners and medicines, as well as the development of centres of excellence for cancer treatment.

Funding

Identify and plan the funding available for cancer services. This may vary according to how far there is responsibility for this nationally, overall allocation and the new monies being targeted at specific developments.

Part 3: How do we deliver person-centred cost-effective cancer services?

Firstly: what does 'person-centred care' mean?

The key theme running throughout the new cancer strategy for Wales should be that all care is person-centred. A good first step is to define exactly what we mean by this.

A definition of person-centred care

Person-centred care means that the needs of the person living with cancer are always at the heart of how services are planned, not the needs of the service providers.

It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery.

This care goes beyond the clinical to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Putting people at the centre of care planning means they[77]:

- are given the opportunity to express their views, which are listened to and respected
- receive the care they need, when it is needed, regardless of organisational boundaries – and if a service can't be provided they are told why
- know where and how to access ongoing support and information.

A new person-centred approach for cancer services in Wales means moving away from focusing on processes, systems and clinical targets to developing services that meet people's needs – both clinical and non-clinical – throughout their cancer journey.

The call for cultural change

Support for a change in the way cancer care is provided is overwhelming. It is also clear that the transformation from traditional, clinically led care to a more person-centred model will involve a dramatic change in attitude and culture.[78] The health and social care workforce will need to understand the implications of cancer as a long-term condition as well as an acute one.

There must also be some important shifts in the approach to care and support for people living with and after cancer, to bring greater focus on recovery, health and wellbeing.

Firstly, a shift will need to take place in the way coordination and communication are handled within the health service and the social care and voluntary sectors.

Secondly, greater emphasis is needed on making sure people are well informed and empowered to manage their own condition. To make this a reality, the relationship between healthcare professional and the person living with or beyond cancer has to be transformed from simply care-giving and receiving to creating a partnership that focuses on achieving agreed health and care outcomes. Many professionals will need help to make this transition. They need training that will enable them to assess people's needs, provide meaningful information, solve problems and identify services within and outside the health system.

Measuring the quality of services, people's experience of their care and the outcome

Many of the government's emerging health strategies, and the changing NHS in Wales, recognise that the way we deliver health and social care needs to change. In some cases specialised services need to be delivered in centres of excellence, while in many other cases, support needs to be offered closer to people's homes. These strategies recognise that wherever care is delivered, it should be tailored to the individual's long-term needs, more integrated and better coordinated.

We believe these new generic health and social care developments offer a unique opportunity to update cancer policy in Wales. By reflecting the care aims of the new five-year strategic framework for the NHS[79], Wales will be in a strong position to make cancer care more effective, person-centred and cost efficient.

To achieve this, when new targets or standards are set for cancer care in Wales, we need to put more emphasis on monitoring quality of service, the person's experience of their care and the outcome.

Recent work by Macmillan involving people living with and after cancer, their carers, those working in cancer care and other stakeholders has established how care and treatment should be experienced from the perspective of the person living with cancer.[80] This work has led us to arrive at nine key outcomes we believe all cancer care should aspire to:

We strongly urge the government to consider these nine outcomes in any new targets and standards that are developed as part of a national, person-centred cancer strategy for Wales.

I was diagnosed early	**I understand, so I make good decisions**	**I get the treatment and care which are best for my cancer, and my life**
Those around me are well supported	**I am treated with dignity and respect**	**I know what I can do to help myself and who else can help me**
I can enjoy life	**I feel part of a community and I'm inspired to give something back**	**I want to die well**

Towards personalised and holistic care

When care is well coordinated, and referals and signposting are effective, people living with and beyond cancer get what they need, when they need it and in the way they want it. It avoids duplication, wasted or ineffective visits and – more importantly – it ensures that people don't get lost in transtion between organisations and professions.[81] Our research – backed by statements from the government's own strategies[82] – confirms that person-centred and cost-effective services go hand in hand.

We recognise that changes in the perception of cancer as an illness that is both acute and long-term, and the move towards person-centred care, won't happen overnight. Changes to cancer care need to be carefully planned, implemented and monitored. They cannot happen without the intervention of government and service planners.

This section of the report looks at what can be done to make services more person-centred, and how these initiatives could be incorporated into a national cancer strategy for Wales.

Four key national initiatives

We believe the following four initiatives are essential to making cancer services more person-centred and cost effective.

1. Improved assessment and care planning
2. Reforms to cancer-follow up
3. More personalised information and support
4. Access to an identified key worker

These initiatives are based on our consultations with people living with and after cancer and those working in cancer care in Wales. We also looked at learnings from other chronic conditions and at what is happening in cancer care outside Wales.

1. Improved assessment and care planning

People living with and after cancer should have their own treatment and care plan, as well as regular assessments of their clinical and non-clinical needs.

Regular assessments are essential to ensure that treatment and care plans are tailored to each person's needs. They are also vital for establishing risk levels for possible complications or reoccurrence of the cancer. If their condition is incurable, ongoing assessment and care planning are essential to monitor the progression of the disease. That way, the person can live as well as possible for as long as possible.

Tailored and personalised care helps professionals provide support for those most in need, and limit support to those who are willing and able to self-care. This is a more cost-effective way of allocating limited resources.

The assessment and care plan discussion should take place with a health professional who helps to coordinate the person's care (see point four below: Access to a key worker). This will often be a clinical nurse specialist (CNS). They must have the skills and experience to help identify and deal with the person's concerns, up-to-date knowledge of local and national services, and they must know how to refer people to appropriate specialist and non-NHS services if they are needed. The person with cancer should be given a copy of their care plan so they have a record they can refer to.

We want everyone living with cancer to be offered an assessment and care plan at key stages of their cancer journey by the end of the next assembly term.

2. Reforms to cancer follow-up

Follow-up arrangements after initial treatment need to be improved so that every person living with or beyond cancer in Wales gets ongoing support that is tailored to their own level of need and risk.

Studies show there is considerable potential to improve cancer follow-up arrangements after treatment has finished.[83] And that assessment and care planning are vital to achieve this change.

The current system of face-to-face follow-up with consultants is expensive and often fails to detect reoccurrence. It is also largely ineffective at supporting people who experience the late effects of cancer and its treatment. A recent

What do assessments and care plans look like?

An **assessment** is a process of gathering and discussing information with the patient and their carer or supporter to understand what the person living with and beyond cancer knows, understands and needs. This holistic assessment is focused on the whole person. Their entire well-being is discussed: physical, emotional, spiritual, mental, social, and environmental. The results are then used to inform their care plan.[1]

The assessment of an individual's needs should include discussion of:

- Physical effects (eg weight loss, problems with appetite, tiredness)
- Lifestyle issues (eg diet, exercise, not smoking)
- Emotional concerns (eg worries about the future, relationships)
- Family matters (eg talking to your family and friends about cancer, worries about genetic risk)
- Job and/or money worries (eg balancing work and treatment, benefits or financial advice, return to work advice)
- Treatment issues (eg concerns about side effects, fertility, risks and benefits of treatment)
- Practical issues (eg sorting out housework or gardening, healthy eating, where to get equipment for the home to make day-to-day tasks easier)
- Spirituality (eg faith, religion or spirituality and any impact this may have on treatment).

A **care plan** is based on the diagnosis and holistic assessment of the person living with or beyond cancer. It prioritises their issues and sets out actions to address them.

The assessment and care plan process ensures that care is consistent with the person's needs. For many this will help facilitate a move toward supported self management.[1]

study of over 1,000 people at 66 UK centres found that 30% reported five moderate or severe unmet needs at the end of treatment. For 60% of these people, these needs had not improved six months after treatment.[84]

Reforming cancer-follow up in Wales: The Velindre/Macmillan Herceptin Pathways Project

Gill Donovan, a specialist non-medical prescribing breast oncology nurse at Velindre Cancer Centre, has been leading a project since 2009 to reform follow-up arrangements for women with breast cancer who are undergoing Adjuvant Herceptin treatment.

These women face a long treatment pathway, even though most have already had surgery, chemotherapy and, in some cases, radiotherapy. All of these treatments carry side effects, but women receiving herceptin typically feel well and want to regain ownership of their lives. The Herceptin Pathways Project provides telephone follow-up with rapid access to specialist support if needed. This.approach promotes flexibility as care is provided closer to home and fewer visits to hospital are needed.

Benefits for the NHS:

- Fewer expensive consultant appointments.
- Clinicians are able to focus their time on more complex cases.
- Cost savings of 17% per patient, amounting to £143,836 if applied to all eligible patients in South East Wales.

Benefits for people living with or beyond cancer:

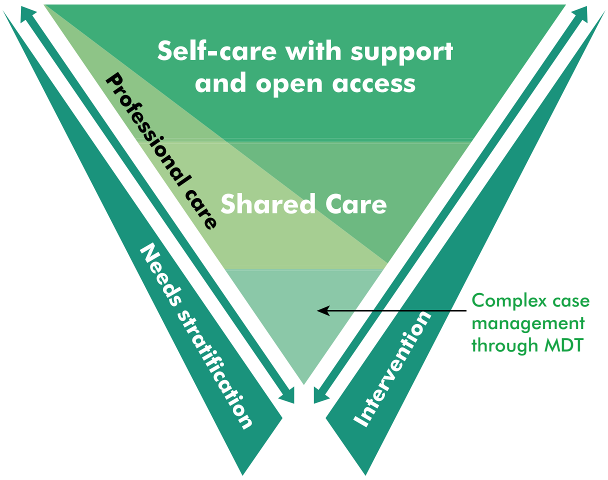
- Fewer visits to hospital, saving time and money. This can mean five visits instead of 30.
- People are able to get on with their lives following surgery and radiotherapy without having to worry about hospital appointments.
- Support from a specialist nurse via a 24 hour phone line and call-back service.
- 92% of people living with or beyond cancer report that they are extremely satisfied with the new service.

The late effects of cancer can affect quality of life long after treatment has ended and often leads to unnecessary admittance to hospital as an emergency. With more than 200 different types of cancers and between 30% and 50% of all cancers classed as 'rarer'[85], many GPs have limited knowledge of the late effects of the disease and its treatment and can't always fully support people in the way they need.

By and large, Wales has a one-size-fits-all approach to follow-up. Regardless of a person's risk of recurring cancer or other complications, most people go through the same follow-up process in the months and years following treatment.

A thorough assessment at the end of a person's treatment makes it possible to develop a follow-up care plan that is tailored to their level of need and risk. Although some routine tests – such as blood tests or imaging – must continue, there is growing evidence that tailoring follow-up care to the individual's needs could make significant savings for the NHS, improve people's experience and outcomes and deliver a better quality of service.

This cancer 'risk stratified model of care'[86] shown below is similar to the approach proposed in the Welsh assembly government's Chronic Conditions Management Strategy[87]:



Risk Stratified Model of Care

Transformed Care Pathways, NCSI, Department of Health

Experience from the National Cancer Survivorship Initiative (NCSI) suggests that 15-25% of people who survive cancer still require regular face-to-face monitoring or guided care. And that only 5-10% of them have unmet needs – such as severe and complex consequences of cancer treatment – that require specialist services. Proportions will vary according to tumour type.[88]

For people with complex needs, a reform of follow-up cancer care will give them more contact with health professionals than they have now. For the majority of people with less complex needs who are able to self-manage with support and appropriate surveillance, follow-up reform means they will have less contact with health professionals in the after-treatment phase. Instead, they will need to be given information about signs and symptoms and who to contact.

Any work to change follow-up beyond initial treatment would need strong clinical leadership to take forward.

Macmillan wants every person living with or beyond cancer in Wales to receive follow-up care that is tailored to their needs by the end of the next assembly term.

What are information pathways and prescriptions?

Information pathways map out the types of information that people living with cancer may want at different stages of their care. Right now, access to information varies across Wales and for different cancer types. Mapping all the information options in one place means it's easy to offer people all the relevant information they might need at that time. The pathways should contain a wealth of information from respected sources on different types of cancer, various treatment options, symptoms and side effects, and the effects cancer or its treatment can have on their life – for example, relationships, sex, finances or work. They should also have information on local support groups and services, and where they can go for further information and support. Information on the pathway should be free of charge, evidence-based, current, culturally sensitive, available in a variety of formats, including the Welsh language, and through a variety of channels.

Information prescriptions are a written copy of the conversation between a cancer professional and the person living with or beyond cancer about the patient's information needs. The professional uses the pathway to frame the conversation and offers information that's relevant at that time. The person can then read what they have been told, and be referred to more sources of support.

3. More personalised information and support

Every cancer patient in Wales should be offered tailored information and support throughout their cancer journey.

To make services truly person-centred, people living with and after cancer need to be at the heart of decisions made about their treatment and care. Providing personalised information and support is essential. This means more than handing someone a leaflet about their cancer. It involves selecting short sections of information that answer their needs and the stage of their cancer journey. We believe that information pathways and prescriptions should be developed to make personalised information and support a reality in Wales.

By building information pathways and prescriptions into cancer care we can ensure that high quality information is offered to people at key points in their cancer journey, as well as the support they need to understand and act on what they've learned.

We know that giving people personalised information and support, and helping them to self-manage, leads to better outcomes for long-term chronic conditions[89], including cancer. When people are well informed they know what to look out for and what to do to manage their signs and symptoms. If they know what to expect, they worry less, are less likely to seek advice from emergency services and can resolve problems without professional intervention.[90]

Many of the support services that people living with and after cancer need already exist, and are often provided by the voluntary sector. Now Wales needs the provision of information and support built into its new strategy so that it becomes an integral part of the care pathway.

Our information and support

How we are helping with the development of information and support for people living with and after cancer in Wales:

1. Macmillan all-Wales Cancer Information Project

Phase 1: All-Wales Cancer Information Pathway Project

The project carried out an in-depth review to see what information is being offered to cancer patients, their carers and families across Wales. The review included mapping the source, format and languages in which information is provided. Using these findings draft information pathways were developed for key cancer sites including breast, urology, gynaecology, colorectal, lung and upper GI. These pathways will be finalised after consultation. In the meantime, discussions are ongoing to source an online storage facility so the pathways can be accessed by health professionals across Wales.

Phase 2: Macmillan Cancer Information Strategy Lead (Wales)

Macmillan Wales is investing in a cancer information strategy post, which will be hosted by Public Health Wales. The post will help improve the coordination and delivery of information to people living with and after cancer across Wales. It will also assess whether the cancer information model can be transferred to other chronic conditions.

2. Macmillan cancer information and support centres and coordinators

In 2008, we began a programme of investment to improve access to information and support. We worked in partnership with the NHS and other voluntary sector organisations to open Macmillan cancer information and support centres in Wrexham and Llandrindod Wells. We are also working with Welsh local authorities to develop cancer information and support in local libraries, and we fund Macmillan information and support coordinators to manage our centres and library presence. Our coordinators work alongside volunteers to deliver a comprehensive service for local people.

3. Access to cancer information and support at home

Since we merged with the cancer information charity, Cancerbackup, in 2008 we have been able to offer a wider range of high quality information and support resources for people living with and after cancer. Some of our most requested titles are now also available in Welsh. We produce free and comprehensive cancer information and support, as well as access to information on our website, and a free phone service on 0808 808 00 00.

We want every cancer patient in Wales to be offered information and support throughout their cancer journey by the end of the next assembly term.

4. 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.[91] 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.

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Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial help and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

Questions about living with cancer?
Call the Macmillan Support Line free
On 0808 808 00 00
(Monday-Friday 9am-9pm).

Alternatively, visit macmillan.org.uk
Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker?
Interpreters available.

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CANCER SUPPORT

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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).

Rhondda
breast friends

Response from the petitioner

Christine Chapman AM
Chair, Petitions Committee
Welsh Assembly
Cardiff, CF99 1NA

25/3/11

Petition no: P-03-150 National Cancer Standards

Thank you for the opportunity to comment on the responses from the LHBs to the January meeting and I look forward to the 14th reading of the petition on 29th March.

Comments:

1. **Cancer Nurse Specialist (CNS) provision**
   I would personally like to support the view offered by Cwm Taf on the value of CNSs from the patient's perspective. A knowledgeable, supportive, friendly face in an extremely hostile environment is a life saver for many a patient and their families. If you are unfortunate not to have a CNS your experience is so much more isolated and frightening as access to consultant's time is limited and you don't like to bother them or worry they will think you stupid or that perhaps you will not understand their answers. I always felt my questions never seemed to be answered but circumvented by my consultant whereas I believed I had straight answers from the CNS (or at least ones I could understand).

   The presence of the CNS at the Multidisciplinary Team (MDT) although mandatory, in my opinion could also provide the patient perspective to the team.

   Thank you for referring this issue together with the issue of cover to the Minister.

2. **Benefits advice**
   It appears many are relying on Tenovus' lottery success to recruit 6 benefits officers in Wales but I am informed these are area specific (not Cwm Taff) and inequality of service may be an issue. Cwm Taff have benefitted from two Macmillan welfare rights officers for three years but funding has ended for one and extended funding for the other one ends this year. This may leave a Cwm Taff with a shortage of advisers.

3. **Rehabilitation Standards and Key workers**
   I am pleased to see the co-ordination of joint action plans being processed and I await action plans for their delivery. I believe that lessons have been learned with regard to implementing existing standards and monitoring systems and that whereas I foresee problems ahead with their implementation I believe that management structures are in place and joint working in evidence to support the task ahead.

   You have identified that the role of the CNSs have been indicated to be major players in identifying key workers along with Allied Health Professionals, so any shortfall will impact

directly on patients. Also the move from secondary care to primary or social care may impact on identification of the appropriate key worker.
The Key workers are to be in place by 1st April, *next week*, for all newly diagnosed patients but I would also like to see the timescale for rolling out the key worker to those already undergoing treatment , in palliative care and rehabilitation as this can be a driver for implementation which may otherwise slip.

4. **Psychological support.**
   Cardiff and the Vale identified progress towards access to psychology services whereas Aneurin Bevan has a dedicated psychological support service. Others made no comment but this question was not asked.

   I believe that this is again an area for concern as I am taking calls from our Mental Health Service looking for help with patients who are in dire straights and cannot cope with their secondary diagnosis. These patients have been referred by cancer services that have identified their psychological need for support but the service cannot support them. It would thus be interesting to see the results of compliance with this standard across Wales.

5. **Thank you**
   On behalf of all those people who have been diagnosed with cancer and undertaken treatments since 2008, I would like to thank the Petitions Committee for your contribution and perseverance to pursuing progress towards implementation of the Standards and improving cancer services in Wales. I strongly recommend the Petitions system as a brilliant example of the way individuals and groups can influence and hold to account public bodies and I hope it continues after the elections.

Best wishes

Diane

Diane Raybould

(Chair)

Response from the Minister for HSS

Edwina Hart MBE OStJ AM
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/01015/11
Your ref: P-03-150

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4 April 2011

Dear Christine,

Thank you for your letter dated 18 March about Petition P-03-150 National Cancer Standards.

The Cancer Standards require all core Multi Disciplinary Team (MDT) members, including the Cancer Nurse Specialists (CNS) to have a deputy. This is a generic requirement that applies across all cancer sites.

Local Health Boards (LHBs) need to ensure that all cancer teams are fully resourced as required by the cancer standards. If an LHB has considered all options and still finds that it is unable to staff and support a specific MDT, patients should be referred to the nearest fully functioning MDT with agreement on what level of care can be provided locally.

The MDT will need to decide who is best placed to be the key worker and it is likely to be the CNS whilst the patient is having active treatment however post treatment and particularly for long term survivors, the key worker may often be the patients own GP.

I have noted your request for the response to be sent directly to the Clerking Team. This has been passed to the relevant officials.

Holding response from Edwina Hart

Edwina Hart MBE OStJ
Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/01196/11
Your ref: P-03-150

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28 April 2011

Dear Naomi

P-03-150 National Cancer Standards

Thank you for your letter of 5 April about National Cancer Standards and the recent Macmillan Cancer Support publication *Changing Cancer Care in Wales*.

This is a matter on which the incoming Government will wish to respond.