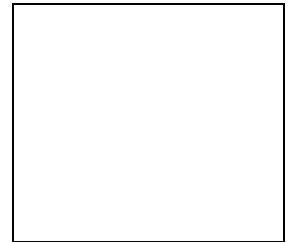


Welsh Government

## **Consultation Document**



Together Against Cancer

Tackling Cancer and Delivering Fast Effective Person Centred  
Cancer Care across Wales

A National Delivery Plan for Wales up to 2016

Date of issue: **19 December 2011**

Responses by: **5 March 2012**

**Overview** The consultation invites views and comments on the Welsh Government's draft Plan for tackling cancer over the next five years.

**How to respond** Response forms should be sent to the following address:-

Adult and Children's Health  
Medical Directorate  
Welsh Government  
Cathays Park  
Cardiff  
CF10 3NQ

Or completed electronically and sent to :-

[adultsandchildrenshealth@wales.gsi.gov.uk](mailto:adultsandchildrenshealth@wales.gsi.gov.uk)

**Further information and related documents** Large print, Braille and alternative language versions of this document are available on request.

**Contact details** For further information:

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**Data protection** How the views and information you give us will be used

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about. It may also be seen by other Welsh

Government staff to help them plan future consultations.

The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tell us this in writing when you send your response. We will then blank them out.

Names or addresses we blank out might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

## **What are the main issues?**

The draft Cancer Delivery Plan sets out Welsh Government's expectations for the NHS in Wales for the prevention of cancer and treatment and care of people with cancer, up to 2016. It is not a detailed directive for every action as our NHS bodies, the Health Boards and Trusts, have their own clearly understood responsibilities for securing, planning and delivering high quality services. The Welsh Government sets out its leadership responsibility to empower the NHS by setting out:-

- A vision for tackling cancer and its consequences
- Ambitions for what NHS services will look like by 2016
- The themes for action up to 2016 through local cancer services delivery plans
- How success will be measured

This Delivery Plan is supported by a shorter publication for the people of Wales which sets out for everyone what we can expect of cancer care in NHS Wales by 2016. There is also a more detailed technical document developed by our clinical advisory Groups for our partners and those working within our cancer services.

[www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=58557](http://www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=58557)

## **Where are we now?**

Informal consultation, with a wide range of stakeholders, including members of the Wales Cancer Alliance took place at the beginning of the process. An informal consultation on an early draft of the Plan took place over the summer with NHS Chief Executive Officers, Macmillan and Cancer Research UK.

The development of the final draft has been an inclusive one with further discussions taking place with Macmillan Cancer Support. The draft now being issued for consultation places a strong focus on patient centred care.

## **The need for change**

In 2006 Wales published its policy, *Designed to Tackle Cancer in Wales*. This set out long term aims of achieving incidence and survival rates for cancer comparable with the best in Europe and set actions for the period up to 2011. This document builds on those aims and responds to important advances in treatment and changes in the nature of the disease, updates our approach within the Government's overall policy on health and health services, as set out in our Programme for Government and Together for Health.

## **Proposals**

The draft cancer plan identifies the following themes for action by Local Health Boards, with their partners, up to 2016:-

- Preventing cancer
- Detecting cancer quickly
- Delivering fast, effective care
- Supporting living with cancer
- Improving information
- Targeting research

Consultation questions (please insert your responses in the box below each question)

<b>1. Are the areas covered within the draft Cancer Plan comprehensive and relevant?</b>
<p>The issues covered in the plan are both comprehensive and relevant as they take in the whole pathway from prevention to palliative care and include information and research needs.</p> <p>There is little emphasis on the evidence base for some of the recommendations, in particular around prevention and early diagnosis, and more emphasis on this would be welcome. Where evidence for the effectiveness of particular interventions is poor, then Wales should be well placed to carry out high quality research.</p>
<b>2. Is the vision for cancer services right?</b>
<p>The vision for cancer services is appropriate, although it would be strengthened if expanded to include mental health, ie to enjoy good physical and mental health.</p> <p>It is noted in the document that although services should be delivered as close to peoples' homes as possible, in the case of some cancers high quality outcomes are more reliably obtained in high volume centres. The tension between the demand for local services and the need for centralisation is alluded to in the document but has not been fully addressed. In many cases, Health Boards will need to work collaboratively to provide seamless high quality care for their population- this should be emphasised in the document</p> <p>Palliative care and end of life care are not mentioned in the bullet points of section 3 although they are covered in the text in sections 4.3 and 5.4.</p> <p>Perhaps owing to the importance of this topic, 1 in 4 of all persons will die of cancer it should be an explicit part of the Vision</p>
<b>3. Are the challenges for cancer services appropriate?</b>
<p>Yes. However many other services, including non-NHS services will contribute to achieving the vision. In many instances their challenges may be as great as or greater than those of the cancer services themselves. For example, open access to ultrasound and CT will have big implications for diagnostics and may lead to a worsening of outcomes elsewhere. Health Boards will need to expand capacity and prioritise workload. Unless there is a coordinated approach this may lead to inequity across Wales, with a real potential for widening the health inequalities that this strategy aims to reduce.</p> <p>There should be an acknowledgement that the current financial climate in NHS Wales will mean additional challenges for the Health Boards in delivering the plan.</p>
<b>4. Are the indicators and performance measures for the NHS right?</b>
<p>The indicators are broadly correct given the limitations of available data and the requirement to provide concise performance measures using Results Bases Accountability methodology.</p> <p>It is useful to have separate measures for incidence, survival and mortality. Whilst mortality data &lt;75yrs in some sense measures the "bottom line" it reflects both incidence and survival.</p>

Incidence data reflects both prevalence of risk factors e.g. smoking as well as ascertainment e.g. PSA testing. Owing to latency the former will operate over a longer timescale, maybe decades.

Survival reflects both early diagnosis as well as the effectiveness of treatment. It is also impacted by comorbidity which may be more prevalent in Wales. In this context screening programmes for breast and colorectal cancer will introduce lead time bias. The global indicators will therefore suffer a number of serious limitations and should be supplemented by more in depth analyses. The indicators are for all cancers. combined and changes in incidence of specific cancer types may be masked. The indicator is correctly based upon EASR rates which reflect risk rather than workload and can be compared from year to year, however this is cross-sectional data and in depth analysis by Age Period and Cohort (APC) may required for interpretation.

Similarly for interpretation of survival. The text notes that there are variations between cancer sites. With changing incidence casemix will vary for year to year so ideally the overall survival should be based on standardising for casemix. Probably the key data item for interpretation of survival is the stage at time of diagnosis or when the treatment decisions are made e.g. at the MDT. The stage distribution will give an indication of whether cancers are being diagnosed early or late. The stage specific survival will give an indication of treatment effectiveness. To some extent it can correct for lead time bias. However if the necessary data is not captured by LHB and transmitted to WCISU proper interpretation of these indicators will be impossible . The CaNISC oncology information system has the potential to capture these data but there are still inconsistencies between MDTs and LHBs. On the whole the data quality is improving and for some cancer sites e.g. lung very good data is obtained but without more rigorous enforcement of standards by LHBs and clinical teams progress is too slow.

To summarise, the indicators are sound but would require supplementation by other data for proper interpretation.

In terms of the performance measures these attempt to encompass the key aspects given the constraint of using available data. There is evidence that delay in diagnosis can adversely affect survival and have a psychological impact on patients. Patient satisfaction with care plan seems to be a key measure but the methodology is being developed as is the link to key worker. Poor communication has been an area where servicers have failed in the past. There is evidence that participation in clinical trials and other studies improves outcome for participants as well as advancing knowledge.

Experience from the ICBMP project has revealed that estimating the percentage of curative treatments can be problematic. Clinicians will have to agree on a list of OPSC codes. Moreover a treatment may start as curative and turn out to be palliative in the light of findings.

In addition, the scope of the thinking could be wider. For example, re: preventing, detecting, delivering, supporting – either using the Dahlgren and Whitehead model or better, the CIFAR model would make it clearer that these areas need action at the levels of all the environments i.e.

- Physical environment – places where we live, work, learn, leisure, et alia

- Biological environment – genetics, lifestyles, self esteem, et alia
- Healthcare environment – supply, quality, access, et alia
- Social and economic environment – community, culture, social status, productivity, legislation, state services including welfare benefits.

Canadian Institute for Advanced Research. Evans, R. G., Barer, M. L., Marmor, T. R. eds. (1994). *Why Are Some People Healthy and Others Not? The Determinants of Health of Populations*. New York: Walter de Gruyter.

*Tackling Health Inequalities: 10 Years On*. (2009). London: Department of Health.

2) Many of the action points would benefit from being explicit about the need to assess the methods and the strengths of the evidence e.g. screening developments, the use of the 1000 Lives (Plus) approach where there are many questions about the validity, peer support (page 10) and the roles of the LHBs compared to the Cancer Networks, acute oncology teams (page 12).

3) The outcome indicators given: important but very broad and really do not assess effective cancer care. More detail is required such as the outcome indicators detailed in the Department of Health's *Improving Outcomes: a Strategy for Cancer* document. More detail would make it easier for LHBs to measure and analyse their performance.

Similarly for the Performance Measures – the measures given are important, but they are too narrow to provide an accurate assessment of the quality of cancer care and need to be supplemented with other measures.

**5. a) Are the Outcome Indicators in Annex 1 going to show how tackling cancer will contribute to the outcome of people of all ages in Wales to enjoy good physical health?**

See comments above.

One aspect which does not seem to be covered is the actual individual health status, including both physical and mental health. For example a patient may have a good outcome in terms of survival but a poor health related quality of life (HRQoL). For example some head and neck cancer patients suffer high levels of pain and disability. More effort should be made to capture such data on a sample basis. It is available for example in clinical trials. Possibly primary care could be a source of these data in the future?

Production of a cancer information strategy will be challenging, and require extensive ongoing work. There are many questions about the use of the 1000 Lives (Plus) approach where there are doubts about the validity of the methods and outcomes.

**b) Are the performance measures in Annex 2 for the NHS to report on to the Welsh Government each year going to capture the effectiveness**



**of NHS cancer care across Wales?**

See comments above. The performance measures need input from the clinical teams about their relevance. Any limited set of measures will have gaps, but these measures seem to encompass most aspects, from patient related measures, to access and research.

**6. Are there any critical issues not covered in the draft Plan?**

The issue of awareness of possible cancer symptoms is not well covered. If diagnosis is to be made earlier, then people with symptoms must be aware of them and decide to contact health services as a result. The outcome of NEADI in England may be helpful in setting a benchmark for the effectiveness of similar initiatives in Wales.

Page 13, 5.5 refers to a “new Public Health Wales NHS Trust post, funded by Macmillan Cancer Support”: this is a mammoth task for one person and therefore there are doubts about the feasibility.

Equality and equity issues in general: it is important to appreciate that what is seen by one patient as essential information to inform rational, evidence based decisions, can be an added burden to another, who would prefer the professionals to make treatment decisions. Information to patients should provide equity of choice and the individual’s right not to know should be respected.

There is only brief reference to childhood cancer in the plan: noted but reference should also be made to the children and young people’s and teenage cancer standards that were issued in 2010/2011 and how they link with the plan.

**7. How might the draft Plan be improved?**

See above sections 4 and 5.

2) Page 10, 4th paragraph, cancer drug provision: Wales should set up an equivalent to the English Cancer Drugs Fund and thence reduce adverse publicity over geographical idiosyncrasies and postcode prescribing.

**8. We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them.**

Although cancer information is covered in sections 4.5 and 5.5 the emphasis seems to be on clinical operational requirements rather than the public health value of the data. One of the problems with the data at present is that MDTs appear to be using the data for diagnosis and treatment but neglecting to record even key data items such as stage and treatment intent.. LGBs and clinicians must take greater responsibility for the recording of accurate data. The secondary use of data is very important not only for public health but for clinical audit.

Although the document mentions in passing the role played by individuals and

other Public Sector bodies in preventing cancer, there is little emphasis on this. Partnership working to promote healthy lifestyles should be promoted further in the document.

More emphasis should be placed on the right of the individual to make informed choices about their care, whether this be the choice as to whether to attend for cancer screening, or the choice of the treatment that they feel best meets their needs.

The text on pg 7 refers to Screening Services Wales- this is actually the Screening Division of Public Health Wales.

In the text box on pg 8, actions for screening state that Health Boards should work with Public Health Wales NHS Trust. Since the primary responsibility for the provision of the cancer screening programmes lies with public health Wales, this might be better if it read 'Public Health Wales NHS Trust, working with Local Health Boards.'

**Consultation  
Response Form**

Your name: Dr Rosemary Fox

Organisation (if applicable): Public Health Wales NHS Trust

email / telephone number: rosemary.fox@wales.nhs.uk

Your address: 18 Cathedral Rd Cardiff

Responses to consultations may be made public – on the internet or in a report. If you would prefer your response to be kept confidential, please tick here: