



Cynulliad National  
Cenedlaethol Assembly for  
Cymru Wales

## Health and Social Services Committee



Review of Cancer Services for the People of Wales

February 2007



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## **Foreword by Chair**

1. When we embarked on this review twelve months ago, the Committee realised that it would not be possible to examine every aspect of cancer service provision in the time available. Therefore, we felt that it was important to home in on issues where the Committee could make recommendations that would be realistic and achievable within the resources available to the NHS in Wales.

2. It was potentially a very wide subject area involving many disciplines and high expertise, which we as Assembly Members do not have. It would not have been possible for us to appoint a single expert adviser to cover all interests and so we appointed an expert reference group.

3. The Committee is indebted to those who have given us their time and shared their knowledge and experience with us. On behalf of the Committee I should like to thank Professor the Baroness Iora Finlay, Professor Tim Maughan and Professor Malcolm Mason for their initial advice and steering, and also to Professor Finlay for arranging our informative visit to the cancer centre in Caen and accompanying us.

3. Professor Jean-François Heron and his colleagues at the Centre François Baclesse in Caen gave generously of their time in talking to us and showing us the way in which they provide cancer services. Our visit was very worthwhile in demonstrating different ways of delivery and the value of comprehensive information technology.

4. I also thank Dr Andrew Fowell for chairing the Expert Reference Group and the members of the group for their diligence in attending meetings and openness in advising us.

5. Finally I should like to express appreciation of the support the Committee has received from the staff of the Members' Research and Committee Service.

6. Although the review has focused on cancer services, some of our conclusions and recommendations will be relevant to health services provided to people with other conditions. I hope that we have succeeded in making recommendations that the Welsh Assembly Government can take forward with the NHS and its partners during the Third Assembly.

**Rhodri Glyn Thomas AM**  
**Chair**



## Members

# The Health and Social Services Committee



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# **1. Recommendations**

## **Recommendation 1**

The Welsh Assembly Government should, with the Cancer Services Co-ordinating Group, formulate an urgent implementation plan to address the issues raised by the previous CSCG reports which it has accepted. This should include:

- i. securing the funding of new and replacement radiotherapy equipment in order to ensure timely radiotherapy; and
- ii. ensuring a stable workforce.

## **Recommendation 2**

The Welsh Assembly Government should consider using incentives such as training bursaries for specialist staff who agree to work in Wales for a period following qualification.

## **Recommendation 3**

The Welsh Assembly Government should ensure that the school nursing service is expanded and strengthened as necessary to enable school nurses to play a greater role in promoting healthy lifestyles.

## **Recommendation 4**

In taking forward its review of the commissioning of cancer services the Welsh Assembly Government should:

- i. take account of the fact that cancer services should be commissioned on a local, regional (network) or national basis, and there are aspects of the service for which each of these levels might be appropriate;
- ii. ensure that there is clarity and transparency about how services are commissioned. In accordance with the conclusions above, this should include the level at which different, specified services are commissioned and the information should be accessible to the public. There should be more clarity regarding the role of Health Commission Wales in this process.
- iii. Ensure that commissioners at all levels have the resources to work towards meeting the National Cancer Standards by 2009.
- iv. Ensure that NHS trusts follow the strategic decisions of the Cancer networks, rather than vice-versa.
- v. Recognise that for the fundamental aspects of cancer treatment (surgery, radiotherapy, chemotherapy and other drug treatment),

commissioning on anything less than a regional level further undermines the ability of the cancer networks to function effectively.

vi. Agree that commissioning for radiotherapy equipment, high cost drugs and specialist surgery needs to be carried out at a national level, possibly by a regional local health board consortium with clear decision making processes and guided by cancer network plans.

vii. Accept that commissioning at regional level should build on the expertise of the three cancer networks, supported by the Cancer Services Co-ordinating Group. The three networks should have more autonomy from the local health boards and NHS trusts from which their membership is derived and a mandate to enable them to make decisions, monitor contracts and to be accountable to the region as a whole.

viii. Ensure that at each level, there is a requirement for the commissioners to consult with appropriate service providers in the statutory, voluntary and private sectors, patient representatives, local authorities and social care providers. At local level there should be a requirement for joint local commissioning.

### **Recommendation 5**

The Welsh Assembly Government should fund and promote the development of the Cancer Network Information System (CaNISC). This should include:

- i. a clear and urgent timetable for incorporating primary, out-of-hours and palliative care;
- ii. measures to secure patient confidentiality; and
- iii. raising the profile of CaNISC within local health boards (LHBs) and NHS trusts by designating a CaNISC “champion” on the board and requiring each LHB and NHS trust to charge a senior manager with responsibility for promoting CaNISC to specialist staff by ensuring support and training to meet individual needs.

### **Recommendation 6**

The Welsh Assembly Government, in consultation with the UK Government, the Scottish Executive and other interested parties, should seek to establish a protocol for the appraisal of new drugs and therapies that will speed up the process and prevent unreasonable and uninformed public expectation. If necessary it could explore the feasibility of co-operating with the Scottish Medicines Consortium to share expertise.

### **Recommendation 7**

The Welsh Assembly Government should review the way in which information about new drugs and therapies is communicated to clinicians and to the media and general public. Clinicians should be given guidance on how best to discuss and explain prescribing options and decisions with their patients.

### **Recommendation 8**

The Welsh Assembly Government should review with the local health boards the arrangements within the NHS in Wales for managing unexpected demands.

### **Recommendation 9**

The Welsh Assembly Government should ensure joint planning between cancer charities and partner organisations ensuring best use of all available resources within the cancer patient pathway.

### **Recommendation 10**

In line with the National Institute for Health and Clinical Excellence's guidance on supportive and palliative care all patients should be:

- i. offered a comprehensive care and rehabilitation package as outlined above at the time of diagnosis. This should include information on prognosis and treatment; rehabilitation and nutrition. The provision of psychological / spiritual / emotional support should also be covered. The package should be reviewed at regular intervals, but especially at the completion of treatment.
- ii. Given clear information on financial support and benefits, employment and other rights.
- iii. Allocated a named key worker as a point of contact for them and their carer(s).

### **Recommendation 11.**

Carers should be identified when patients commence treatment, and their need for support should be assessed and planned.

### **Recommendation 12**

The Welsh Assembly Government should review the Hospital Travel Costs Scheme.

### **Recommendation 13**

The role of the allied health professions (AHPs) in cancer care and rehabilitation should be developed so that expertise is available in primary and secondary care and there is a defined career path to encourage AHPs to specialise in cancer care.

### **Recommendation 14**

The Cancer Co-ordinating Group should identify good practice in cancer care and rehabilitation and disseminate it to practitioners across Wales.

### **Recommendation 15**

Local health boards and NHS trusts should work with a range of voluntary sector organisations with a view to their being engaged in providing information and support for patients and carers.

### **Recommendation 16**

The Welsh Assembly Government should work with the NHS and the voluntary sector:

- i. to ensure that service models and partnerships, including the concept of the “hospice at home”, reflect best practice in other areas;
- ii. to put funding on a more stable footing that reflects more equitably the extent to which the sector provides services which would otherwise fall to the NHS, and that is founded on the Local Health Board’s strategic appraisal of need and evidence of the hospice movement’s ability to deliver services. Given the recent announcement of £2 million for hospices there needs to be robust formulae for its effective and fair distribution that ultimately will improve the care of patients in Wales.
- iii. To explore ways of simplifying the commissioning of palliative care services.
- iv. To ensure that the Welsh Cancer Standards are met by 2009 and that the recommendations of the 2003 strategy document are met.
- v. Funding should be on a three year basis with a formal service level agreement between the NHS and the provider.

## 2. Introduction

2.1 Following preliminary consultation early in 2006, on 5 April the Committee agreed to undertake a policy review of cancer services for the people of Wales with the following terms of reference:

- i. to review equality of provision and equity of access to the full range of high quality cancer services that meet the National Cancer Standards;
- ii. to identify the barriers to good service and recommend measures to overcome them;
- iii. to report the Committee's findings to the Assembly by 2 March 2007.

2.2 The Committee also agreed to appoint an expert reference group (ERG) under the chair-ship of Dr Andrew Fowell, MacMillan Consultant in Palliative Medicine at North West Wales NHS Trust, to advise on the complexities of cancer services. The group covered a wide range of disciplines and the voluntary sector. Details of membership are at Appendix 1. The group met four times, including a final meeting with the Committee on 13 December to advise the Committee on the evidence it received during the review.

2.3 On 25 April 2006 the Committee issued a consultation letter (Appendix 2) seeking views on a number of issues that had been highlighted in the preliminary consultation process. These included:

- ◆ information technology;
- ◆ the integration of research and good practice;
- ◆ commissioning services;
- ◆ the value of screening and immunisation;
- ◆ barriers to the NHS in Wales keeping abreast of new technologies and developments;
- ◆ collaboration between the NHS and voluntary sector;
- ◆ the use of data to inform service planning for the terminally ill;
- ◆ access to drugs; and
- ◆ patient-centred services.

2.4 Thirty seven responses were received. Further written evidence was received in December on the findings from Breast Cancer Care's survey of patients' experience which was carried out between May and October 2006. Responses are listed at Appendix 3<sup>1</sup>.

2.5 In July, the Chair, Rhodri Glyn Thomas AM, and two other members of the Committee, Jonathan Morgan AM and Jenny Randerson AM, visited the Centre François Baclesse, a cancer centre in Caen, Normandy, accompanied by Professor the Baroness Finlay of Llandaff, who had facilitated the visit through her working contacts with the Centre, and Dr Andrew Fowell. A report

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<sup>1</sup> A selection of these responses are cited throughout the report and referenced to Appendix 3

of their visit was submitted to the Committee on 28 September (*paper HSS(2)-13-05(p5)*).

2.6 At that meeting on 28 September the Committee considered all the evidence it had received so far and decided to narrow its focus and concentrate on those areas which were not already being developed actively and where there was felt to be scope to influence change. In the remaining meetings when the Committee took oral evidence, it concentrated on the five areas set out in section 3.

2.7 The Committee took oral evidence at meetings between July and December 2006. Details are at Appendix 4, together with links to the transcripts of those meetings and to committee papers.

## **3. Findings, Conclusions and Recommendations**

### **3.1 Overview**

3.1.1 Although this report makes a number of recommendations for improving services, there is much of which the NHS, the voluntary sector and other partners, including the University of Wales, can be proud and this needs to be recognised. The Committee acknowledges the personal commitment and contribution of those who work in the statutory and voluntary sectors in providing services to cancer patients.

3.1.2 The planning and provision of cancer services is complex, ranging from public health issues of prevention and screening, through diagnosis to highly specialised treatment, and patient support, rehabilitation and palliative care. Modern drugs and therapies are improving prognoses, but for optimum benefit, well planned cancer services with a sound infrastructure to support them are essential so that patients are diagnosed early and treated promptly. This requires a stable and adequate workforce and it may be necessary to offer incentives to encourage staff to work in Wales and to reduce turnover.

3.1.3 The Committee commends the commitment that the Welsh Assembly Government, and the Welsh Office before it, has shown to improving cancer services since the publication in 1996 of the report on Cancer Services in Wales (The Cameron Report), and recognises the enormous strides that have been made. Wales has a superb workforce in the areas of cancer research, screening, and therapy – the latter spanning surgery, radiotherapy, chemotherapy and the allied health professions including nursing, physiotherapy, occupational therapy, radiography, physics and dietetics. However, there remain key shortfalls in the provision of basic cancer treatment (radiotherapy, chemotherapy, surgery) in Wales, as first highlighted by the Cancer Services Co-ordinating Group's (CSCG) Cancer Services Strategic Development Plan and more recently in the CSCG's radiotherapy report<sup>2</sup>.

3.1.4 The need for radiotherapy is increasing as the population ages and cancer incidence increases. Significant investment is needed to ensure that there is sufficient capacity to provide world class chemotherapy and radiotherapy treatment, now and in the future.

3.1.5 A review of service capacity, current workforce and current activity was undertaken in 2005-2006 by the South East Wales Cancer Network which, amongst its recommendations, highlighted the need for a network workforce and capacity plan for the next five to ten years. CSCG is currently undertaking a similar review on an all-Wales basis and preliminary indicators support the need for a workforce and capacity development plan to meet current and

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<sup>2</sup> The Cancer Services Co-ordinating Group website is currently being updated, therefore it has not been possible to include a link to the documents.

future demand. Patient management is more complex than previously and patients have greater care needs as a result of intensity of treatment, so the workforce plans need to include critical care staff as well as chemotherapy nurses and pharmacists. Much good work has been carried out to date on modernisation and service redesign. However, the Committee was advised by the Expert Reference Group that the workforce is currently overstretched which will lead to breaches in 31 and 62 day targets, affect patient safety and will result in patients not having optimum treatment protocol management.

3.1.6 Without addressing these issues, the other recommendations in this report are in danger of floundering, and there is a real danger that Wales will be unable to retain and build on the high quality workforce that it currently has.

3.1.7 The Committee also commends the work being done to inform the public about preventative measures, such as smoking cessation, diet and lifestyle. As a result of these programmes there is a far greater public awareness of how a healthy lifestyle can reduce the risk of cancer. More should be done to bring these messages to children and young people in schools. The Committee takes the view that school nurses are best placed to do this but is aware that the school nursing service is under-resourced. Similarly, health visitors are crucial in providing information to parents of pre-school children and others in the community.

### **Recommendation 1**

The Welsh Assembly Government should, with the Cancer Services Co-ordinating Group, formulate an urgent implementation plan to address the issues raised by the previous CSCG reports which it has accepted. This should include:

- i. securing the funding of new and replacement radiotherapy equipment in order to ensure timely radiotherapy; and
- ii. ensuring a stable workforce.

### **Recommendation 2**

The Welsh Assembly Government should consider using incentives such as training bursaries for specialist staff who agree to work in Wales for a period following qualification.

### **Recommendation 3**

The Welsh Assembly Government should ensure that the school nursing service is expanded and strengthened as necessary to enable school nurses to play a greater role in promoting healthy lifestyles.

## 3.2. Commissioning

### Findings

3.2.1 Many respondents (*Appendix 3: (4) (6) (10) (15) (16) (23) (27) (32) (33)*) reported that there are too many commissioners and that commissioning is overly complicated. There is a need to make it more streamlined and standardised, with clarity on the roles of commissioning bodies (*Appendix 3 (11)*).

3.2.2 The cancer networks are well positioned to take a more active role in commissioning, but fail due to the lack of statutory function or budget (*Appendix 3: (8) (32) (33)*).

3.2.3 Simon Dean, Chief Executive of Health Commission Wales (HCW) submitted that the cancer networks derive their authority from the bodies that constitute them, and it is therefore important that those bodies hold the networks to account (*para 84 transcript of HSS(2)-14-06*). He went on to say that pooled budgets might be the answer in theory, but not necessarily in practice. It would be easier to take the clinical decisions that are affordable within the pooled budget, but the difficulty comes when the pooled or conjoined budgets are insufficient to address all the demands (*para 85 transcript of HSS(2)-14-06*).

3.2.4 Dr Jane Hanson, Director of the CSCG, said that the group's work needed to be completed and supported (*para 148 transcript of HSS(2)-14-06*). When asked what specific things need to be done to support the work, she responded that the most important element would be to improve the commissioning framework (*para 150 transcript of HSS (2)-14-06*).

3.2.5 The Welsh Assembly Government is undertaking work to develop and improve the commissioning framework, but there is little detail in its Assembly Policy Statement *Designed to Tackle Cancer in Wales*, or in its response to *Beyond Boundaries – Citizen-centred Local Services for the People of Wales* (the Beecham Report).

### Conclusions

3.2.6 The Committee noted that the CSCG has done much to raise the profile of cancer services within the NHS and that the three regional cancer networks are working effectively in pooling expertise and good practice. Cancer networks are key to formulating the strategic decisions that are vital if the National Cancer Standards are to be met. However, they are unable to take on this key role, principally because they are subservient to the sometimes conflicting priorities of the individual NHS trusts. This could be solved by obliging the trusts to follow the strategic direction of the networks.

3.2.7 Furthermore, there is confusion and lack of understanding within the NHS about the respective roles of LHBs, HCW, the three regional cancer networks and the three regional NHS offices. As yet there is no indication of whether the role of the regional offices or the LHBs will change in response to the recommendations of the Beecham report. Unlike adult services, cancer services for children are commissioned by HCW at an all-Wales level.

3.2.8 The Committee accepts that the issues around the commissioning of services are complex. It considered the arguments in favour of all commissioning being undertaken at an all-Wales level, at regional level or at LHB level. Members take the view that the level at which commissioning would be undertaken most effectively depends on the nature of the service. There needs to be clarity about who commissions which services.

3.2.9 The Policy Statement, *Designed to Tackle Cancer in Wales*, states that commissioning is key to meeting the challenges of the National Cancer Standards. The document acknowledges that the regional cancer networks are critical to achieving success and that their role should be strengthened further as improved commissioning arrangements are introduced. The document does not say how these new arrangements will fit with the recommendations of the Beecham report.

3.2.10 Commissioning of services should not be undertaken unilaterally. It is important that there is a participative partnership between commissioners, those for whom they provide the services, i.e. the patients, and the providers in both the voluntary and statutory sectors.

3.2.11 Individual LHBs are generally too small to commission specialised services, such as those provided at the cancer centres (as opposed to those provided by every NHS trust). This would be better done at regional level. A consortium representing LHBs, such as the cancer network, would have better negotiating power than an LHB on its own. The three regional cancer networks are well established and well regarded. However, their remit does not give them power to commission and spend with associated accountability.

3.2.12 Within networks there are currently no mechanisms for determining an equitable contribution of funding. This can result in members being defensive and makes decision taking difficult. There needs to be a shift in the remit and culture within the networks. Ideally LHBs should pool their funding and delegate spending to the networks. This would help change the culture and unify the members. As suggested in the Beecham report, the starting point for commissioning should be negotiation, with contracts based on outcomes. This too would engender a more collegiate approach. The increased authority would give the networks negotiating power, and in particular strengthen the position of those LHBs seeking services from English trusts.

3.2.13 At local level, services in primary care and community settings need to be commissioned in partnership with those organisations meeting other health or social care needs. Care at this level is best commissioned by the LHB where there is local knowledge, conterminous boundaries and established

statutory partnership with local authorities. The statutory Health, Social Care and Well-being Strategies should provide the basis for commissioning community and primary care services.

3.2.14 Expensive items of equipment and highly specialised services for treating rare cancers would best be commissioned at an all-Wales level, guided by cancer network plans, where decisions can be made on appropriate equipment in the light of the size and needs of the population, and better value for money can be achieved through economies of scale. The process needs to take account of the fact that many tertiary services are provided by hospitals in England for people living in Wales.

#### **Recommendation 4**

In taking forward its review of the commissioning of cancer services the Welsh Assembly Government should:

- i. take account of the fact that cancer services should be commissioned on a local, regional (network) or national basis, and there are aspects of the service for which each of these levels might be appropriate;
- ii. ensure that there is clarity and transparency about how services are commissioned. In accordance with the conclusions above, this should include the level at which different, specified services are commissioned and the information should be accessible to the public. There should be more clarity regarding the role of Health Commission Wales in this process.
- iii. Ensure that commissioners at all levels have the resources to work towards meeting the National Cancer Standards by 2009.
- iv. Ensure that NHS trusts follow the strategic decisions of the Cancer networks, rather than vice-versa.
- v. Recognise that for the fundamental aspects of cancer treatment (surgery, radiotherapy, chemotherapy and other drug treatment), commissioning on anything less than a regional level further undermines the ability of the cancer networks to function effectively.
- vi. Agree that commissioning for radiotherapy equipment, high cost drugs and specialist surgery needs to be carried out at a national level, possibly by a regional local health board consortium with clear decision making processes and guided by cancer network plans.
- vii. Accept that commissioning at regional level should build on the expertise of the three cancer networks, supported by the Cancer Services Co-ordinating Group. The three networks should have more autonomy from the local health boards and NHS trusts from which their membership is derived and a mandate to enable them to make decisions, monitor contracts and to be accountable to the region as a whole.

viii. Ensure that at each level, there is a requirement for the commissioners to consult with appropriate service providers in the statutory, voluntary and private sectors, patient representatives, local authorities and social care providers. At local level there should be a requirement for joint local commissioning.

### **3.3. Information Technology**

#### **Findings**

3.3.1 There is no single, fully developed all-Wales clinical database (*Appendix 3: (31) (33)*). Many respondents to consultation said that a single, effective and accurate database of cancer patients is crucial (*Appendix 3: (4) (6) (7) (9) (15) (17) (20) (28) (34)*). There is a need to ensure that all voluntary and statutory providers are linked to one uniform patient administration system (*Appendix 3: (31) (33)*). There is a need to link different hospitals and laboratories electronically by making systems compatible (*Appendix 3: (1) (5) (9) (33)*).

3.3.2 The Committee took oral evidence from Jeff Stamatakis, Chair of The Cancer Network Information System (CaNISC), and Dr Gwyn Thomas, Director of Informing Healthcare.

3.3.3 Mr Stamatakis submitted that CaNISC should be the mandatory central cancer database to ensure the availability of accurate outcome data and standards and should be available to clinicians at every stage of patient care (*paper HSS(2)-15-06(p6)*).

3.3.4 CaNISC is an IT system that looks at a single disease. The reason that cancer should be at the forefront of IT is because patients are treated on two or three different sites, and there are potential problems with paper records travelling with patients (*para 7 transcript of HSS (2)-14-06*). CaNISC needs to be compatible with other relevant managerial data systems and should be adopted by Informing Healthcare (*Appendix 3 (4) (9) (20)*). All healthcare professionals need access (*Appendix 3: (27)*).

3.3.5 Persuading doctors and nurses to use the system and to collect information is a big hurdle, but one which is not insurmountable (*para 36 transcript of HSS (2)-14-06*). Two trusts have not have not been using the system and the CaNISC Board endorses the Assembly Government's intention to mandate the use of CaNISC from 1 April 2007 (*paper HSS(2)-15-06(p6)*).

3.3.6 Access from primary care has to be a long-term objective and is being dealt with incrementally at present. In the long term, it is hoped that all primary care providers could access it and there is no reason why patients should not access their own records, given the appropriate security (*para 26 transcript of HSS (2)-14-06*).

3.3.7 CaNISC received limited funding for its first three years from the New Opportunities Fund (*para 42 transcript of HSS(2)-14-06*). The question was raised as to whether funding for the future of CaNISC is now secure and whether the project would continue to go forward in a stable way. Dr Thomas said that the cancer project is strategically very important to Informing Healthcare and that 'we are not going to let the CaNISC system stop for want of decisions about switching investment within the Informing Healthcare programme' (*para 57 transcript of HSS(2)-14-06*).

3.3.8 Palliative care is not included in CaNISC. The current system is used only to log patients and patient contacts. There is nothing about quality, type of care or outcomes. Patients are being disadvantaged, particularly in the community, where access to hospital notes and records is so difficult. However, if money were available, work would start immediately (*para 42 transcript of HSS(2)-14-06*).

## **Conclusions**

3.3.9 The benefits of a comprehensive information technology (IT) system were clearly demonstrated to the Committee Members who visited the cancer centre François Baclesse in Caen, Normandy.

3.3.10 An effective IT system is an important tool for underpinning efficient commissioning and provision of services and also in informing the valuable research work of the Wales Cancer Bank. The NHS needs a fully developed all-Wales clinical database for cancer.

3.3.11 The Committee notes that CaNISC does not cover primary care, including the out-of-hours service, or palliative care. Not all trusts currently use it and it is not compatible with other systems, resulting in duplication of work. Although its potential is recognised, some clinicians and other professionals who do not have computing expertise find it difficult to use. There is also a view that its value as a clinical tool is diminished since it has been adopted by trusts primarily to capture performance information on Service and Financial Frameworks targets.

3.3.12 Despite these drawbacks the Committee accepts that CaNISC is a sound foundation on which a first class IT system can be developed, providing it is properly resourced. Making the system mandatory will be of little benefit if the system is not user friendly, easily accessible and compatible with other systems to avoid duplicating the input of data. The level of commitment and support given to staff by trusts varies considerably. The importance of the system needs to be recognised with leadership by LHBs, NHS trust boards and senior management encouraged by the Welsh Assembly Government.

3.3.13 The successful development of CaNISC will depend also on those designing the system understanding the environment and concerns of the professionals who use it. It is important that they appreciate the perspective of

those who are not at ease with IT and work with trusts to ensure that adequate training and support is provided.

3.3.14 In the medium to long term CaNISC should be developed further to include primary care, out-of-hours service and palliative care. As the system is expanded safeguards should be put in place to ensure patient confidentiality is not breached.

### **Recommendation 5**

The Welsh Assembly Government should fund and promote the development of the Cancer Network Information System (CaNISC). This should include:

- i. a clear and urgent timetable for incorporating primary, out-of-hours and palliative care;
- ii. measures to secure patient confidentiality; and
- iii. raising the profile of CaNISC within local health boards (LHBs) and NHS trusts by designating a CaNISC “champion” on the board and requiring each LHB and NHS trust to charge a senior manager with responsibility for promoting CaNISC to specialist staff by ensuring support and training to meet individual needs.

## **3.4 New Treatments and Drugs**

### **Findings**

3.4.1 Recent advances in the diagnosis and treatment of cancer have often been costly in terms of acquisition and the resources needed to deliver the service (*Appendix 3: (19)*). New drugs or therapies have service consequences which may require additional resources. There has to be a balance between expenditure on cancer drugs and on care (*Appendix 3: (18)*).

3.4.2 Consideration must be given to engagement with the public and professionals in managing expectations for new treatments and technologies (*Appendix 3 (16)*).

3.4.3 The Assembly Government needs to ensure that the National Institute for Health and Clinical Excellence (NICE) delivers on the more rapid evaluation of new technologies and therapies (*Appendix 3: (6) (8) (9) (16) (26)*) and a faster all-Wales response on the guidance for the use of new drugs to avoid postcode prescribing (*Appendix 3: (6)*).

3.4.4 Early warning of new technologies and rapid evaluation is vital (*Appendix 3 (6)*). Further development of horizon scanning may help planning (*Appendix 3: (8) (33)*).

3.4.5 Dr Jane Hanson said that she was working with colleagues and the cancer networks to finalise a proposal for submission to the Assembly Government that will try to create an environment in which clinical advice on cancer drugs and implementing new cancer drugs would be available at an all-Wales level. It would support the All Wales Medicines Strategy Group's (AWMSG) processes (*para 156 transcript of HSS(2)-14-06*).

3.4.6 The AWMSG's evidence referred to its engagement with the Association of British Pharmaceutical Industries in Wales and the commitment to the Therapeutic Development Appraisal (*paper HSS(2)-18-06(p15)*).

## **Conclusions**

3.4.7 It is a fundamental principle that a patient's access to drugs and treatment should be based on their clinician's assessment of the potential benefit to them. Although governments and their agencies scan the horizon for developments, new therapies and drugs are sometimes announced and promoted aggressively to the public by the pharmaceutical company before a proper cost benefit appraisal has been undertaken. This can result in unrealistic public expectations that can be fuelled by the media and cause frustration and distress to patients and their families.

3.4.8 This needs to be countered by a process for better communication with the media and the public and by arrangements for assessing new drugs and therapies more quickly. Members accept that politicians could be more circumspect in responding to queries and complaints from constituents. Clinicians should explain prescribing decisions to their patients in terms that a lay person can understand. They have the expertise to explain the benefits and effectiveness of treatments to meet the individual patient's clinical needs and circumstances.

3.4.9 The Committee noted that AWMSG has established a New Medicines Group that will meet six times a year to appraise evidence on the clinical and cost effectiveness of newly licensed medicines and present recommendations to the main AWMSG.

3.4.10 The Committee agrees that the expertise of NICE cannot be replicated within a country as small as Wales. However, the NICE process often takes longer than that of the Scottish Medicines Consortium and has come to contradictory conclusions on occasions. Evidence from the AWMSG referred to that group liaising with NICE and the Scottish Medicines Consortium. Active liaison within Great Britain is essential to avoid overlap and duplication and to give quick guidance.

3.4.11 It is difficult for the NHS to budget for the cost of new drugs and therapies. Generally the cost has to be borne from any annual uplift to budgets or from savings elsewhere which may not always be possible. Whilst it is possible to assess likely demands through horizon scanning, there need to be mechanisms for managing unforeseen developments.

3.4.12 The Committee considered whether patients should be able to pay for drugs and therapies that are not available through the NHS, while remaining under the care of the NHS. It noted the view that it would not be reasonable for the NHS to have to treat any side effects or other consequences of such treatment. This is an issue that applies to other illnesses and conditions and the Committee concluded that a wider debate is needed across the United Kingdom.

#### **Recommendation 6**

The Welsh Assembly Government, in consultation with the UK Government, the Scottish Executive and other interested parties, should seek to establish a protocol for the appraisal of new drugs and therapies that will speed up the process and prevent unreasonable and uninformed public expectation. If necessary it could explore the feasibility of co-operating with the Scottish Medicines Consortium to share expertise.

#### **Recommendation 7**

The Welsh Assembly Government should review the way in which information about new drugs and therapies is communicated to clinicians and to the media and general public. Clinicians should be given guidance on how best to discuss and explain prescribing options and decisions with their patients.

#### **Recommendation 8**

The Welsh Assembly Government should review with the local health boards the arrangements within the NHS in Wales for managing unexpected demands.

### **3.5 Living Well with Cancer**

#### **Findings**

3.5.1 The need for closer working between agencies is widely recognised, but collaboration needs to be within a strategic framework.

3.5.2 Anne Mills submitted that supportive care needed to be integrated into cancer management, with new ways of working to take patients through the spectrum of care. The patient's quality of life during interventions needs to be addressed and research identified that would inform the development of rehabilitation and survival (*para 54 transcript of HSS(2)-12-06*).

3.5.3 Examples of good practice in the voluntary sector exist and need to be disseminated (*para 188 transcript of HSS(2)-12-06*) (*See also Appendix 3: (4) (6) (7)*).

3.5.4 Dr Fowell referred to NICE guidance on supportive and palliative care which is evidence based. He made specific reference to psychological support; the many recommendations about allied health professions (AHPs),

and every patient having a named health professional as a first point of contact (*para 16 transcript of HSS(2)-15-06*).

3.5.5 Macmillan Cancer Support's research on Cancer Costs found that 91 per cent of cancer patients' households suffer a reduction in income and / or increased costs as a result of the illness. Fifty five per cent of Welsh cancer patients said in response to a survey that they had not received any advice about welfare benefits and 64 per cent of UK patients were not informed about the Hospital Travel Costs Scheme. Macmillan's research indicates that cancer patients are spending on average £229 on travel costs and parking while undergoing treatment. In evidence they proposed that cancer patients should have their travel costs re-imbursed through the Hospital Travel Costs Scheme without a means test and that cancer patients should be exempt from paying parking charges (*Appendix 3: (18)*).

3.5.6 Sue Acreman, from the Nursing and Allied Professions Cancer Advisory Group, said that AHP expertise is concentrated in cancer centres. She flagged up a number of ways in which use of AHPs could be developed (*para 6 transcript of HSS(2)-15-06*). Cardiac rehabilitation is a good model (*para 13 transcript of HSS(2)-15-06*).

3.5.7 Ms Acreman's paper (*paper HSS(2)-15-06(p2)*) contained five recommendations:

- i. Supportive care needs to be recognised as an integral component of cancer care and requires a defined programme.
- ii. Supportive care needs to be accessible in all communities.
- iii. Education and training initiatives need to be developed to ensure an adequately trained and competent workforce can deliver the care.
- iv. Standards of practice and practice guidelines need to be developed for all professional groups providing supportive care.
- v. Community based care needs to be developed to provide supportive care programmes to enable the patient with cancer to live well at home.

## **Conclusions**

3.5.8 The diagnosis of cancer and subsequent treatment and care can have a devastating impact on the patient, their partner and family. More people are living longer following cancer treatment and it is increasingly important that they have the support they need to respond well to their treatment and maintain the quality of their life and that of their family. This requires an holistic approach to a care package to start at the time of the initial diagnosis. This is in line with recommendation 19 of the Committee's report on the Interface between Health and Social Care, published in March 2005.

3.5.9 The care package needs to include psychological / spiritual / emotional support; clear information on prognosis and treatment; rehabilitation; nutrition; information on financial support and benefits, employment and other rights, such as those contained in the Disability Discrimination Acts 1995 and 2005; and support for carers. The patient and their carer should have a named key worker to whom they can turn for advice and information on whom they should contact in any “out-of-hours” crisis.

3.5.10 The Committee notes the evidence from Macmillan Cancer Support about the additional costs cancer patients incur, especially for travelling. Many patients have to travel a considerable distance and the Committee takes the view that there needs to be a review of the Hospital Travel Costs Scheme and the way in which patients are informed about it.

3.5.11 The Committee notes that there is good practice that can be drawn on and disseminated. The ERG advised that the South West Wales Cancer network is hosting the All-Wales Cancer Patient Information project, supported by Macmillan Cancer Support. The project is developing a patient information strategy for Wales and is looking at good practice in northern England.

3.5.12 Rehabilitation is key to helping people return to work and the Committee accepts the importance of both rehabilitation and working with employers to provide the right environment. The Committee notes that Macmillan Cancer Support’s Living with Cancer programme is delivering aspects of the Expert Patient programme. It also notes that work is underway to include rehabilitation in the Cancer Standards.

3.5.13 The appropriate AHPs should be involved in the care planning at an early stage to facilitate rehabilitation.

3.5.14 At present there is no career pathway for occupational therapists and physiotherapists to specialise in the rehabilitation of cancer patients, but there are plans to develop a cancer school at Velindre.

3.5.15 The voluntary and charitable sectors provide many valuable support services, including information points in cancer units. They also fund specialist posts within cancer units. The cancer charities’ expertise can be used most effectively within a strategically planned framework based on the development of clinical pathways, and there may be scope for charities not usually associated with cancer care to become involved in providing information and support.

3.5.16 Not all tumour groups have specialist oncology nurses in post e.g. head and neck cancers, whereas other cancers, e.g. breast, are better provided. Joint planning with cancer charities will ensure that all patient groups can access the specialist nurse/AHP support that they require.

### **Recommendation 9**

The Welsh Assembly Government should ensure joint planning between cancer charities and partner organisations ensuring best use of all available resources within the cancer patient pathway.

### **Recommendation 10**

In line with the National Institute for Health and Clinical Excellence's guidance on supportive and palliative care all patients should be:

- i. offered a comprehensive care and rehabilitation package as outlined above at the time of diagnosis. This should include information on prognosis and treatment; rehabilitation and nutrition. The provision of psychological / spiritual / emotional support should also be covered. The package should be reviewed at regular intervals, but especially at the completion of treatment.
- ii. Given clear information on; financial support and benefits, employment and other rights.
- iii. Allocated a named key worker as a point of contact for them and their carer(s).

### **Recommendation 11**

Carers should be identified when patients commence treatment, and their need for support should be assessed and planned.

### **Recommendation 12**

The Welsh Assembly Government should review the Hospital Travel Costs Scheme.

### **Recommendation 13**

The role of the allied health professions (AHPs) in cancer care and rehabilitation should be developed so that expertise is available in primary and secondary care and there is a defined career path to encourage AHPs to specialise in cancer care.

### **Recommendation 14**

The Cancer Co-ordinating Group should identify good practice in cancer care and rehabilitation and disseminate it to practitioners across Wales.

## **Recommendation 15**

Local Health Boards and NHS trusts should work with a range of voluntary sector organisations with a view to their being engaged in providing information and support for patients and carers.

### **3.6. Palliative Care**

#### **Findings**

3.6.1 The written evidence indicates that there are issues and tensions between the NHS and the voluntary sector about commissioning and funding services.

3.6.2 Dr Fowell said that the Palliative Care Strategy of 2003 was disjointed from other plans. The needs assessment of 2005 (the Tebbit report) identifies gaps in services (*para 164 transcript of HSS(2)-12-06*).

3.6.3 Provision is patchy across Wales (*Appendix 3: (33)*). The evidence base for palliative care and practice is said to be weak and more information is needed to develop services in line with patients' needs and wishes (*Appendix 3: (4) (7) (9) (10) (12)*). Simon Dean emphasised the need for collaboration in commissioning palliative care services (*para 74 transcript of HSS(2)-14-06*).

3.6.4 Hospice services save the NHS considerable money, but are not adequately recompensed. All three hospices that gave evidence referred to the need for security of funding. Most receive a block grant rather than having a service level agreement. (*para 127 transcript of HSS(2)-11-06*) (*paras 203 and 207 transcript of HSS(2)-16-06*).

3.6.5 Mrs Viv Cooper, Clinical Director, George Thomas Hospice Care, said that LHBs had not provided support to complement and continue the Welsh Assembly Government's £10m grant (*para 193 transcript of HSS(2)-16-06*). She endorsed the need for LHBs, trusts and the voluntary sector to collaborate on strategic and operational service planning as well as funding (*para 203 transcript of HSS(2)-16-06*).

3.6.6 Mrs Cooper referred to the National Hospice Council's work in developing a formula for costing core services such as a bed day, or visit by a specialist nurse (*para 214 transcript of HSS(2)-16-06*).

3.6.7 As stated above, palliative care is not covered by CaNISC. This disadvantages patients in the community because of the difficulty in accessing hospital records.

#### **Conclusions**

3.6.8 The voluntary sector makes a valuable and significant contribution to palliative care. It has considerable expertise and provides specialised health

care through doctors and nurses, many of whom are funded by charitable organisations. This relieves pressures on and costs to the NHS.

3.6.9 However, there are tensions between the hospice movement and the NHS. Many hospices have been developed in response to local demand and through local fund raising. Consequently they are constituted individually. This means that each negotiates separately with the LHB(s), which is a complex and time consuming process for both parties.

3.6.10 The Committee noted with some concern that the LHBs have not sustained the funding initiated through the £10 million grant from the Welsh Assembly Government between 2003 and 2006, and that the recommendations of the 2003 strategy document on funding and integration of services to ensure equitable access for all patients have not been met.

3.6.11 The hospice movement accepts that a substantial proportion of its funding should be provided through charitable donations, but the level of funding from the NHS needs to be reviewed to reflect more equitably the extent to which it is providing services that would otherwise fall to the NHS.

3.6.12 The funding stream is unstable as most hospices receive funding as a block grant without a service level agreement (SLA). They would prefer more stability with three year core funding based on more strategic commissioning through SLAs. In response hospices should accept that they should provide the services that the LHB requires, even though it may not accord with their own objectives.

3.6.13 The Committee agrees with the advice of the ERG that the Palliative Care Strategy should be integrated with the National Service Frameworks and the Health, Social Care and Well-being Strategies.

3.6.14 NICE provides comprehensive guidance on the provision of palliative care that is based on evidence.

3.6.15 The ERG advised that clinical management for children and young people with cancer is well organised with 85 per cent accrual into clinical trials, with around a 75 per cent survival rate overall. However, children with brain tumours have much less chance of survival (40-60 per cent). Most children with cancer die at home (around 25-30 children per year in Wales) and they require very intensive management and family support during this period.

3.6.16 Many adults would prefer to die at home. The Committee concludes that the partnership model between paediatric oncology specialist nurses, social workers, AHPs and primary care is crucial for minimising the traumatic experience for all concerned, including the child, family and primary care professionals. The children and young people's service model is an excellent example that could be applied elsewhere.

3.6.17 While this review is concerned with cancer services, the Committee takes the view that the provision of palliative care needs to be considered for people with other conditions.

### **Recommendation 16**

The Welsh Assembly Government should work with the NHS and the voluntary sector:

i. to ensure that service models and partnerships, including the concept of the “hospice at home”, reflect best practice in other areas;

ii. to put funding on a more stable footing that reflects more equitably the extent to which the sector provides services which would otherwise fall to the NHS, and that is founded on the Local Health Board’s strategic appraisal of need and evidence of the hospice movement’s ability to deliver services. Given the recent announcement of £2 million for hospices there needs to be robust formulae for its effective and fair distribution that ultimately will improve the care of patients in Wales.

iii. To explore ways of simplifying the commissioning of palliative care services.

iv. To ensure that the Welsh Cancer Standards are met by 2009 and that the recommendations of the 2003 strategy document are met.

v. Funding should be on a three year basis with a formal service level agreement between the NHS and the provider.

## Appendix 1

### Expert Reference Group

The Committee established a multi disciplinary reference group to ensure Members received a range of professional and voluntary expertise, with a geographical and urban / rural balance. The group's role was to steer the Committee in considering and weighing the evidence submitted in response to the written consultation and subsequent oral evidence and to advise the Committee on its conclusions and recommendations.

The establishment of the group allowed the Committee to consult the group as a whole at key stages of the review, and also consult individual members on an ad hoc basis where their specialist knowledge would be valuable.

Members of the group met four times during the review process to advise the Committee on the issues that emerged from the written consultation, on organisations and individuals to give oral evidence to the Committee, and on the conclusions and recommendations of the review.

The membership of the expert reference group consisted of:

<b>Name</b>	<b>Representing</b>
Dr Andrew Fowell (Chair)	MacMillan Consultant in palliative medicine. North West Wales NHS Trust
Dr Malcolm Adams	Medical Director, Velindre Cancer Centre
Sian Evans	Royal Pharmaceutical Society
Beverlea Frowen	Welsh Local Government Association
Dr Bridget Gwynne	Royal College of General Practitioners
Dr Rachel Hargest	Royal College of Surgeons
Professor Malcolm Mason	Cancer Research UK
Anne Mills	Royal College of Nursing
Cath Lindley	MacMillan Cancer Support
Maureen Noonan	Society and College of Radiographers

## Appendix 2

### Text of Consultation Letter and Terms of Reference

25 April 2006

#### CANCER SERVICES FOR THE PEOPLE OF WALES

The Health and Social Services Committee is undertaking a review of cancer services for people in Wales.

The terms of reference for the review are:

- i. to review equality of provision and equity of access to the full range of high quality cancer services that meet the National Cancer Standards;
- ii. to identify the barriers to good service and recommend measures to overcome them;
- iii. to report the Committee's findings to the Assembly by 2 March 2007.

The Committee has identified a number of issues as a result of preliminary consultation undertaken earlier this year. These are set out in the Annex to this letter. I am writing to invite you to provide written evidence to the Committee on some or all of them. It would be helpful if you could respond electronically using the annex as a template. A copy of the template can be obtained on the committee's website at <http://www.wales.gov.uk/keypubassemhealsocsvs/content/policy-e.htm>. Please contact me if that causes you a problem.

You may find it helpful to read the transcript of the Committee's meeting on 23 March as background. This can be obtained on the internet at <http://assembly/rop/ROP/Committees/HSS/hss060323fv7.pdf>. Let me know if you would prefer a hard copy.

It is normal practice for the National Assembly to publish evidence either within a report, or as supplementary evidence to a report. We will not publish information which we consider to be personal data, such as name and contact details, unless consent has been provided or these are details relating to an organisation.

The National Assembly operates within the Data Protection Act 1998 and the Freedom of Information Act 2000.

If any information, other than personal data, is being submitted that is regarded by the provider not to be suitable for public disclosure, it is up to the

provider to stipulate what part(s) of the information should not be published and provide a reasoned argument to support this. The National Assembly will take this into account when publishing evidence in accordance with the Freedom of Information Act 2000.

In the event of a request for information, it may be necessary for information which has been provided either as evidence, communication or any other written information, to be disclosed. This may include information which has previously been removed by the National Assembly for publication purposes.

The Committee will start to take oral evidence in June. This will continue in the Autumn, when the Committee will have considered the evidence received through this written consultation. At this stage the Committee may decide to limit the number of issues it takes forward.

Please send your evidence by e-mail to me at [jane.westlake@wales.gsi.gov.uk](mailto:jane.westlake@wales.gsi.gov.uk) please head you e-mail: Canc Serv. The closing date for responses is Monday 24 July 2006.

Mrs Jane Westlake  
Committee Clerk

## Appendix 3

### List of respondents

Ref	Respondent
01	Children's Hospital for Wales - Dr Heidi Traunecker,
02	South Wales Gynaecological Oncology Service
03	Ceredigion and Mid Wales NHS Trust
04	Velindre NHS Trust
05	Neath & Port Talbot CHC
06	Tenovus
07	South West Wales Cancer Network
08	Rhondda Cynon Taff Local Health Board
09	Dr Malcolm Adams
10	Cardiff Community Health Council
11	Conwy & Denbighshire NHS Trust
12	Meirionnydd Community Health Council
13	Brecknock & Radnor Community Health Council
14	Community Pharmacy Wales
15	Wales Centre for Health - Jonathon Gray
16	Royal Pharmaceutical Society of Great Britain
17	Cardiff and Vale NHS Trust
18	Macmillan Cancer Support
19	The Royal Pharmaceutical Society of Great Britain
20	Royal College of Nursing
21	Wales Centre for Health
22	College of Occupational Therapists
23	The Chartered Society of Physiotherapy
24	Sanofi Pasteur MSD
25	Breast Cancer Care Cymru
26	Association of the British Pharmaceutical Industry
27	Pfizer Oncology
28	Society and College of Radiographers
29	Roche Products Limited
30	Welsh Consumer Council
31	Marie Curie Cancer Care Penarth Hospice
32	North East Wales Cancer Partnership Board
33	Cancer Services Co-ordinating Group
34	Cancer Research UK Cymru
35	Jo's Trust
36	Claire House Children's hospice
37	All Wales Cancer and Palliative Care Nurse Education Forum

## Appendix 4

### Committee Papers and Oral Evidence

#### Oral evidence sessions

##### 28 June 2006

Dr Malcolm Adams, Medical Director, Velindre Cancer Centre;  
St David's Hospice, Llandudno  
Paper ref HSS(2)-11-06(p2c)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200606>

##### 5 July 2006

Dr Andrew Fowell, Consultant in Palliative Medicine, Ysbyty Gwynedd

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200607>

##### 11 October 2006

Dr Gwyn Thomas, Informing Healthcare Implementation Strategy

Paper ref HSS(2)-14-06(p1a)

Jeff Stamatakis, CaNISC

Paper ref HSS(2)-14-06 (p1b)

Simon Dean, Health Commission Wales

Paper ref HSS(2)-14-06(p1c)

Dr Jane Hanson, Cancer Services Co-ordinating Group

Paper ref HSS(2)-14-06(p1d)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200610>

##### 26 October 2006

Sue Acreman, Nursing and Allied Health Professions Cancer Advisory Group

Paper ref HSS(2)-15-06(p2)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200610>

##### 15 November 2006

Viv Cooper, George Thomas Hospice Care

Paper ref HSS(2)-16-06(p6)

Karen Wright & Muriel Barber, Claire House Children's hospice

Paper ref HSS(2)-16-06(p7)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200611>

##### 13 December 2006

Mike Ponton & Jonathan Davies, Welsh NHS Confederation

Paper ref HSS(2)-18-06(p6)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

## **Committee papers**

### **23 March 2006**

Consideration on terms of reference for the review – discussion with Professors from the Department of Oncology and Palliative Care, Cardiff University

Paper ref HSS(2)-06-06(p1) & HSS(2)-06-06(p2)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200603>

### **5 April 2006**

#### **Approval of terms of reference**

Paper ref HSS(2)-07-06(p4)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200604>

### **28 June 2006**

Approval of terms of reference for the Expert Reference Group

HSS(2)-11-06(p2b)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200606>

### **28 September 2006**

Consideration of the written evidence received / Report of the Committee's visit to the Centre François Baclesse, Caen, Normandy

HSS(2)-13-06(p5)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200609>

## **Papers to note**

Correction to Paper HSS(2)-06-06(p2) Cancer Services

HSS(2)-08-06(p10)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200605>

Review of Cancer Services – Availability of new drugs therapies and treatment

HSS(2)-14-06(p4)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200610>

Additional Information on CaNISC

HSS(2)-15-06(p6)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200610>

Additional Information from Cancer Services Co-ordinating Group.

HSS(2)-16-06(p.10)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200611>

Palliative Care – Baseline Service Review - 10m Assembly Government  
Funding for Palliative Care

HSS(2)-18-06(p11)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

Review of Cancer Services – Minutes of South Wales East Regional  
Committee meeting 16 June 2006

HSS(2)-18-06(p12)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

Findings from a survey conducted by Breast Cancer Care on breast cancer  
patients' experiences in Wales

HSS(2)-18-06(p13)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

Review of Cancer Services – Report of Dr Andrew Fowell's attendance at the  
international conference - Saving Lives in Cancer: policies and practices that  
make a difference

HSS(2)-18-06(p14)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

Review of Cancer Services - Evidence from All-Wales Medicines Strategy  
Group HSS(2)-18-06(p15)

<http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000/8ca125790c8f970177610d0ede03fc59.htm>

## Appendix 5

### Bibliography

#### Information technology

Allam O, et al, 2004, Benefits from Accessing the Cancer Patient Pathway in Wales. 2004. <a href="http://www.health-informatics.org/hc2004/P12_Allam.pdf">http://www.health-informatics.org/hc2004/P12_Allam.pdf</a>
NHS Confederation 2005
NHS Wales. <i>Informing Healthcare: The National Case</i> , 2 <sup>nd</sup> Ed. January 2006.  <a href="http://www.wales.nhs.uk/ihc/documents/Nat%20Case%202nd%20Edition.pdf">http://www.wales.nhs.uk/ihc/documents/Nat%20Case%202nd%20Edition.pdf</a>
NHS Wales. <i>Informing Healthcare Implementation Strategy</i> (Summary of the 3rd Edition of the IHC National Case), October 2006 HSS(2)-14-06(1a)  <a href="http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000">http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000</a>
Informing Healthcare Achievements – published May 2006  <a href="http://www.wales.nhs.uk/ihc/documents/IHCAchievements2006.pdf">http://www.wales.nhs.uk/ihc/documents/IHCAchievements2006.pdf</a>
Evidence paper for the Health and Social Services Committee: Cancer Network Information System Cymru (CaNISC), HSS(2)-14-06(p1b) Jeff Stamatakis, BSc MS FRCS  <a href="http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000">http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000</a>
Department of Health/Welsh Office. <i>A Policy Framework for Commissioning Cancer Services</i> , April, 1995 (Also referred to as the Calman/Hine Report.)  <a href="http://www.dh.gov.uk/assetRoot/04/01/43/66/04014366.pdf">http://www.dh.gov.uk/assetRoot/04/01/43/66/04014366.pdf</a>
NHS Wales. <i>Cancer Services in Wales</i> . Vol.1. A Report by the Cancer Services Expert Group (Cameron Report). Cardiff: Welsh Office, 1996.
NHS Wales. Welsh Health Circular. WHC (2005) 027. <i>Monthly data collection of cancer waiting times to start of definitive treatment</i> . 21 March 2005.  <a href="http://www.wales.nhs.uk/documents/WHC_2005_0271.pdf">http://www.wales.nhs.uk/documents/WHC_2005_0271.pdf</a>

#### General

Department of Health. <i>The NHS Cancer Plan</i> . September 2000.  <a href="http://image.guardian.co.uk/sys-files/Society/documents/2003/08/26/cancerplan.pdf">http://image.guardian.co.uk/sys-files/Society/documents/2003/08/26/cancerplan.pdf</a>  The first comprehensive strategy from any government to tackle cancer setting out the actions needed to improve cancer prevention and screening services, cut cancer patient waiting times, enhance treatment and palliative care services, and boost UK cancer research.  Strategic Development Plan developed by the Cancer Services Coordinating Group for WAG.  Welsh Assembly Government. <i>Standards for Children and Young People's Oncology and Palliative Care Services</i> . Committee Paper HSS(2)-06-06(p2), March 2006.
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<p><a href="http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200603">http://www.wales.gov.uk/cms/2/HealthAndSocialServicesCommittee/37D6A89F00087B550000121400000000?month=200603</a></p>
<p>Welsh Assembly Government. <i>The Review of Health and Social Care in Wales</i>. 9 July 2003. (The Wanless Report)</p> <p><a href="http://www.wales.nhs.uk/documents/wanless-review-e.pdf">http://www.wales.nhs.uk/documents/wanless-review-e.pdf</a></p>
<p>Welsh Assembly Government. <i>The Review of Health and Social Care in Wales</i> (Summary). 9 July 2003. (The Wanless Report)</p> <p><a href="http://www.wales.nhs.uk/documents/wanless-summary-e.pdf">http://www.wales.nhs.uk/documents/wanless-summary-e.pdf</a></p>
<p>Welsh Assembly Government. Welsh Health Circular WHC (2005) 76, <i>Clinical Networks</i>. 25 August 2005.</p> <p><a href="http://www.wales.nhs.uk/documents/WHC_2005_076.pdf">http://www.wales.nhs.uk/documents/WHC_2005_076.pdf</a></p>
<p>Welsh Assembly Government. <i>Designed for Life</i>. May 2005.</p> <p><a href="http://www.wales.nhs.uk/documents/Designed-for-life-e.pdf">http://www.wales.nhs.uk/documents/Designed-for-life-e.pdf</a></p>
<p>Welsh Assembly Government. Welsh Health Circular WHC (2005) 051. 16 June 2005. <i>Cancer Services in Wales – Publication of National Cancer Standards and the implication for Commissioners and Providers, through the Cancer Networks</i>.</p> <p><a href="http://www.wales.nhs.uk/documents/WHC_2005_051_ENGLISH.pdf">http://www.wales.nhs.uk/documents/WHC_2005_051_ENGLISH.pdf</a></p>
<p>RCN Paper <i>Safe Staffing Levels</i> - <a href="http://www.rcn.org.uk/members/downloads/research/setting-safe-staffing-levels-summary.pdf">http://www.rcn.org.uk/members/downloads/research/setting-safe-staffing-levels-summary.pdf</a></p> <p><i>Modernising Nursing Careers</i> <a href="http://www.dhsspsni.gov.uk/modernising_nursing_careers-2.pdf">http://www.dhsspsni.gov.uk/modernising_nursing_careers-2.pdf</a></p> <p>Scottish Executive <i>Advanced Nursing Practice Framework – Cancer Nurse Specialist Example</i> – <a href="http://www.eventsforce.net/advancednursing">www.eventsforce.net/advancednursing</a></p>

## Palliative Care

<p>National Cancer Research Institute. <i>Strategic analysis 2002: An overview of Cancer Research in the UK</i>. October 2002.</p> <p><a href="http://www.ncri.org.uk/includes/Publications/reports/ncri_strategic_analysis_2002.pdf">http://www.ncri.org.uk/includes/Publications/reports/ncri_strategic_analysis_2002.pdf</a></p>
<p>NHS Wales Cancer Services Co-ordinating Group. <i>All Wales Population Based Palliative Care Needs Assessment Report</i>. October 2005.</p>
<p>Welsh Health Circular WHC (2006) 030. <i>End of Life Care – All Wales Care Pathway for the Last Days of Life</i>. June 2006.</p> <p><a href="http://www.wales.nhs.uk/sites3/Documents/362/WHC%5F2006%5F030%2DEnglish%2Epdf">http://www.wales.nhs.uk/sites3/Documents/362/WHC%5F2006%5F030%2DEnglish%2Epdf</a></p>
<p>Website of the Gold Standards Framework for Community Palliative Care programme.</p> <p><a href="http://www.goldstandardsframework.nhs.uk/">http://www.goldstandardsframework.nhs.uk/</a></p>
<p>Website of the Liverpool Care Pathway developed by Marie Curie and the NHS Modernisation Agency. The website contains links to publications, evaluations and on-going research. (See also Welsh Health Circular WHC (2006) 030.)</p> <p><a href="http://www.lcp-mariecurie.org.uk/about/">http://www.lcp-mariecurie.org.uk/about/</a></p>
<p>Website for the Preferred Place of Care.</p> <p><a href="http://www.cancerlancashire.org.uk/ppc.html">http://www.cancerlancashire.org.uk/ppc.html</a></p>
<p>National Institute of Health and Clinical Excellence. <i>Improving supportive and palliative care for adults with cancer</i>. March 2004.</p>

<a href="http://www.nice.org.uk/page.aspx?o=csqsp">http://www.nice.org.uk/page.aspx?o=csqsp</a>
Picker Institute report <i>Engaging Patient in their Healthcare??</i>
<a href="http://www.pickereurope.org/page.php?id=48">http://www.pickereurope.org/page.php?id=48</a>
Tebbit, P. <i>Findings from a Population-based Palliative Care Needs Assessment in Wales</i> . National Council for Palliative Care.
<a href="http://www.ncpc.org.uk/download/events/Wales_080506/PeterTebbit_080506.pdf">http://www.ncpc.org.uk/download/events/Wales_080506/PeterTebbit_080506.pdf</a>
Carers Strategy for Wales
<a href="http://new.wales.gov.uk/docrepos/40382/dhss/403821211/40382121/carers_e.pdf?lang=en">http://new.wales.gov.uk/docrepos/40382/dhss/403821211/40382121/carers_e.pdf?lang=en</a>
Welsh Assembly Government. <i>A Strategic Direction for Palliative Care Services in Wales</i> . February 2003.
<a href="http://howis.wales.nhs.uk/doclib/pall-care-final-e.pdf">http://howis.wales.nhs.uk/doclib/pall-care-final-e.pdf</a>
Kings College, London. Gomes, B and Higginson, IJ. <i>Factors influencing death at home in terminally ill patients with cancer: systematic review</i> (BMJ 2006; 332;515-521)
Morris, J. <i>Independent Hospices in Wales: a consumer perspective</i> . July 2005. Welsh Consumer Council.
<a href="http://www.wales-consumer.org.uk/Research%20and%20policy/pdfs/Independent%20Hospices%20in%20Wales%20-%20Welsh%20Consumer%20Council.pdf">http://www.wales-consumer.org.uk/Research%20and%20policy/pdfs/Independent%20Hospices%20in%20Wales%20-%20Welsh%20Consumer%20Council.pdf</a>
National Assembly for Wales. (HSSSSC(2)-02-05) <i>Palliative Care</i> . 17 November 2005. Scrutiny sub-Committee of the Health and Social Services Committee.
<a href="http://www.wales.gov.uk/keypubassemhealsocsvsscruity/content/0205-paper1-e.htm">http://www.wales.gov.uk/keypubassemhealsocsvsscruity/content/0205-paper1-e.htm</a>

### Commissioning and cancer networks

CSCG Audit of Ovarian Cancer
Healthcare Inspectorate Wales. <i>Inspection Report of the Three Cancer Networks in Wales</i> . March 2006.
<a href="http://www.wales.nhs.uk/sites3/Documents/477/Cancer%5FNetworks%2Epdf">http://www.wales.nhs.uk/sites3/Documents/477/Cancer%5FNetworks%2Epdf</a>
<i>Examples of good care in GP OOH in palliative care</i>
<a href="http://www.goldstandardsframework.nhs.uk/content/guides_and_presentations/ExofGoodPracticeResourceGuide_JustinCaseBoxes.pdf">http://www.goldstandardsframework.nhs.uk/content/guides_and_presentations/ExofGoodPracticeResourceGuide_JustinCaseBoxes.pdf</a>
Preferred place of care project in Lancashire
<a href="http://www.cancerlancashire.org.uk/ppc.html">http://www.cancerlancashire.org.uk/ppc.html</a>

### Developing technologies and therapies (including drugs)

SW Wales Cancer Network clinical trials portfolio June 2006
Radiotherapy and Chemotherapy Advisory Group of the Cancer Services Coordinating Group, <i>Radiotherapy Equipment Needs and Workforce Implications 2006 to 2016</i> , May 2006.
<a href="http://newydd.cymru.gov.uk/docrepos/40382/dhss/reportsenglish/Radiotherapy_equipment_nee_d1.pdf?lang=cy">http://newydd.cymru.gov.uk/docrepos/40382/dhss/reportsenglish/Radiotherapy_equipment_nee_d1.pdf?lang=cy</a>
Medicines Use Review - Community Pharmacy contract
National Assembly for Wales. Welsh Health Circular WHC (2002) 86. <i>Palliative Care and Out of</i>

Hours Access to Essential Drugs. 23 July 2002.

Welsh Health Circular, WHC (2005) 051, *Cancer Services in Wales – Publication of National Cancer Standards and the implication for Commissioners and Providers, through the Cancer Networks*, 16 June 2005.

[http://www.wales.nhs.uk/sites3/documents/362/WHC\\_2005\\_051\\_ENGLISH.pdf](http://www.wales.nhs.uk/sites3/documents/362/WHC_2005_051_ENGLISH.pdf)

Lerman, C et al (1990) *Effects of coping style and relaxation on cancer chemotherapy side effects and emotional responses*. *Cancer Nursing* 13(5) pp308-315.

Department of Health. *Radiography Skills Mix: A Report on the four-tier service delivery model*, 2003.

[www.doh.gov.uk/radiography](http://www.doh.gov.uk/radiography)

The Society and College of Radiographers. *Radiographic Staffing: Short term Guidance 2005 Benchmark for Standard Core functions within Radiotherapy*, SCoR, November 2005.

[www.sor.org/public/pdf/rad\\_staffing.pdf](http://www.sor.org/public/pdf/rad_staffing.pdf)

The Society and College of Radiographers. *Positioning Therapeutic Radiographers within Cancer Services: Delivering Patient-Centred Care*, SCoR, March 2006.

[www.sor.org/public/pdf/pos\\_therapeutic\\_rad.pdf](http://www.sor.org/public/pdf/pos_therapeutic_rad.pdf)

## NHS and Voluntary Sector

Association of the British Pharmaceutical Industry in association with Cancerbackup and Ask About Medicines. *The Cancer Information Maze: Report investigating information access for people with cancer*. October 2005.

[http://www.cancerbackup.org.uk/News/Mediacentre/Pressreleasesstatements/2005/24034101/Cancer\\_information\\_maze\\_report.pdf](http://www.cancerbackup.org.uk/News/Mediacentre/Pressreleasesstatements/2005/24034101/Cancer_information_maze_report.pdf)

## Living Well with Cancer/Patient centred services

Macmillan Survey on Welfare Rights advice and costs *Worried Sick – the emotional cost of living with cancer*. April 2006.

[http://www.macmillan.org.uk/About\\_Us/Newsroom/Impact\\_of\\_cancer\\_in\\_Wales.aspx](http://www.macmillan.org.uk/About_Us/Newsroom/Impact_of_cancer_in_Wales.aspx)

Reynolds, F & Prior S (2006) *Creative Adventures and Flow in Art-Making: a Qualitative Study of Women Living with Cancer*. *British Journal of Occupational Therapy* 69(6) pp255-262.

College of Occupational Therapists *Occupational Therapy Intervention in Cancer*. April 2004, Crompton, S. College of Occupational Therapists Ltd.

National Audit Office, England and Department of Health. *Tackling Cancer: improving the patient journey*. 25 February 2005.

<http://www.nao.org.uk/pn/04-05/0405288.htm>

National Council for Palliative Care. *Fulfilling Lives: Rehabilitation in Palliative Care*, Crompton S/Working Party on Rehabilitation, Updated August 2006 (A4, 22 pages) ISBN 1 898915 24 5.

National Council for Palliative Care. *Priorities and Preferences for End of Life Care in England, Wales and Scotland*, ISBN: 1 898 915 31 8.

Fundamentals of Care - <http://www.wales.nhs.uk/documents/booklet-e.pdf>

RCN Paper Safe Staffing Levels - <http://www.rcn.org.uk/members/downloads/research/setting-safe-staffing-levels-summary.pdf>

Modernising Nursing Careers [http://www.dhsspsni.gov.uk/modernising\\_nursing\\_careers-2.pdf](http://www.dhsspsni.gov.uk/modernising_nursing_careers-2.pdf)

Scottish Executive Advanced Nursing Practice Framework – Cancer Nurse Specialist Example – [www.eventsforce.net/advancednursing](http://www.eventsforce.net/advancednursing)

### **Other documents not mentioned in the written evidence submitted to the Committee**

House of Commons, Committee of Public Accounts. *NHS Cancer Plan: a progress report*. Twentieth Report of Session 2005-06. 19 December 2005.

<http://www.publications.parliament.uk/pa/cm200506/cmselect/cmpublicacc/791/791.pdf>

The three tools, *Gold Standard Framework*, *Care Pathway* and *Preferred Place of Care*, (see *Palliative Care section*) come under the umbrella of the Department of Health's End of Life Care Initiative announced in December 2003 by the then Secretary of State for Health. Links to all three and the DH's End of Life Care programme are available at:

[http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EndOfLifeCare/EndOfLifeCareArticle/fs/en?CONTENT\\_ID=4106262&chk=lpWBHL](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EndOfLifeCare/EndOfLifeCareArticle/fs/en?CONTENT_ID=4106262&chk=lpWBHL)

Henry, C. *End of Life Care Programme*. NHS England. 13 May 2005. (Presentation)

[http://www.ncpc.org.uk/download/events/SE\\_130505/Claire\\_Henry.pdf](http://www.ncpc.org.uk/download/events/SE_130505/Claire_Henry.pdf)

National Statistics. *Review of the Registrar General on deaths in England and Wales*. 2003.

[http://www.statistics.gov.uk/downloads/theme\\_health/Dh1\\_36\\_2003/DH1\\_2003.pdf](http://www.statistics.gov.uk/downloads/theme_health/Dh1_36_2003/DH1_2003.pdf)

Department of Health. *Information for the palliative care sector: Healthcare Resource Groups; Payment by Results; HM Treasury's Cross Cutting Review (full cost recovery)*. November 2005.

<http://www.ncpc.org.uk/download/policy/pbr/Briefing%20on%20HRGs%20and%20PbR%20for%20Vol%20Sector.pdf>

MacMillan, *Cancer costs, the hidden price of getting treatment*, June 2006.

[http://www.macmillan.org.uk/Get\\_Involved/Campaigns/Better\\_Deal/Latest\\_research.aspx](http://www.macmillan.org.uk/Get_Involved/Campaigns/Better_Deal/Latest_research.aspx)

South East Wales Cancer Network review on current workforce and current activity, 2005-06.