

## Health and Social Services Committee

### HSS(2)-13-06(p.5)

**Date: Thursday 28 September 2006**

**Venue: Committee Room 1, National Assembly for Wales**

**Title: Review of Cancer Services for the People of Wales  
Responses to Written Consultation**

#### **Purpose**

1. The Committee is invited
  - i. to consider the responses to the written consultation undertaken during the summer;
  - ii. in the light of these responses and also the oral evidence given to the Committee on [28 June \(linked here\)](#) and [5 July \(linked here\)](#) and of the report visit by three Members to the Centre François Baclesse (the cancer centre in Caen, France), to agree the focus for the remainder of the review;
  - iii. to confirm the organisations to be invited to give oral evidence to the Committee at its meetings on 11 October and 15 November; and
  - iv. to agree the timetable for completion of the review.
  - v. to consider a resolution under Standing Order 8.24(vi) to exclude the public from its meeting on 13 December and 25 January when the Committee will be discussing the content of its report, its conclusions and recommendations.
2. The responses to the written consultation are available on the [Committee's website](#). A summary of the responses is at Annex 1 and analysis at Annex 2. The report of the visit to Caen is at Annex 3.

#### **Written Consultation**

3. The Expert Reference Group considered the 36 written responses at its meeting on 11 September and agreed that a number of themes had emerged from the consultation. These include:
  - i. the development of IT systems and the roll-out of the CaNISC system to statutory and non-statutory agencies would be beneficial. This should include GP surgeries and out-of-hours services.
  - ii. The Commissioning of Services, including good practice in other countries.
  - iii. Horizon scanning the development of new therapies and drugs and their availability for prescription.
  - iv. Palliative and supportive care.
  - v. The interface between the NHS and the voluntary / private sector.

- vi. The service users' perspective.
- vii. The role of the Cancer Services Co-ordinating Group.

### **Focus for the Remainder of the Review**

4. It is recommended that the Committee focuses on issues i. to v. above, taking the service users' perspective into account in discussions with the voluntary sector. Members have also suggested that the Committee looks at the principles of screening.

### **Organisations to be invited to give oral evidence**

5. The Committee has allocated one hour and forty five meetings for taking oral evidence at each of its meetings on 11 October and 15 November. It is recommended that the Committee uses this time to take evidence from the following:

**11 October:** the development of IT systems, CaNISC and arrangements for commissioning, with input from Jeff Stamatakis, (the Chair of CaNISC); Informing Healthcare; Health Commission Wales; and the NHS Confederation.

**15 November:** palliative and supportive care; new therapies and drugs; and the principles of screening. Marie Curie Cancer Care and Claire House Children's Hospice in the Wirral should be invited to give evidence on palliative and supportive care. Dr Cerilan Rogers, Director of the National Public Health Service, could be invited to give oral evidence on cancer screening. The Committee might find it helpful to have background papers on drugs and therapies and cancer screening. A paper on drugs and therapies would be helpful before deciding whether anyone other than NICE might be invited to give evidence.

### **Timetable for the completion of the review**

6. It has been suggested that the report be launched at the Wales Against Cancer conference in February. The following timetable should achieve this.

13 December 2006 Committee discusses evidence, reaches conclusions and decides recommendations.

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25 January 2007 Committee agrees report

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5 February 2007 Report is launched at Wales Against Cancer Conference.

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March 2007 Report debated in plenary session of National Assembly for Wales.

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## **Consideration of Evidence, Conclusions and Recommendations**

7. We recommend that the Committee resolves to exclude the public from its deliberations on 13 December and 25 January.

**Committee Service  
September 2006**

## Annex 1

### Health and Social Services Committee Review of Cancer Services in Wales Consultation Responses Summary

#### Question 1

How can information technology be used more effectively to track and facilitate the patient's journey?

#### 01. Children's Hospital for Wales

- Linking electronically different hospitals / labs etc by making systems compatible

#### 02. South Wales Gynaecological Oncology Service

- Referral into the gynaecology oncology service via the internet using the CSCG review would ensure more efficient referrals. Users need to be aware that it is a secure facility.

#### 03. Ceredigion and Mid Wales NHS Trust

- Improved and increased use of tele-health – E referral televised MDT meetings, availability of PACS imaging of telepath systems.

#### 04. Velindre NHS Trust

- The entry of clinical data into a single fully developed data base such as CANISC should be mandatory.
- The databases should be accessible to clinicians at all stages of the patient pathway.
- Funding is needed to facilitate entry of quality validated data.
- The database needs to be compatible with other relevant data systems.
- Cancer screening Services use a similar database (ISCO) for colposcopy assessments in cervical screening. It is used to audit patient management and is vital for failsafe processes in the care pathway.

#### 05. Neath & Port Talbot CHC

- I.T would be more effective if every hospital and GP practice was on the same system, therefore patients' information would pass instantly to any hospital the patient attends.

#### 06. Tenovus

- CANISC should be used extensively within the cancer service by all users within Wales in order to provide an all agency access to the key facts.

#### 07. South West Wales Cancer Network

By raising awareness of the benefits of fully implementing the e-health/telemedicine agenda to strengthen the site specific cancers multidisciplinary teams clinical networks by ensuring adequate resources are available to support. This can be done by

- continuous training & education programme for clinicians;
- Improving videoconferencing facilities;
- Better access to videoconferencing equipment;
- Telepathology systems to improve access to specialist diagnostic teams;
- Developing telemammography and teledermatology systems;
- Establishing electronic referral systems from primary to secondary care;
- Full implementation of the Cancer Network Information System Cymru (CaNISC);
- Electronic prescribing systems for chemotherapy (Clinisys Chemocare);
- Electronic patient records;
- Providing consistent information for patients.

**08. Rhondda Cynon Taff Local Health Board**

- A single electronic record for both health and social care would be the ideal
- ISCO is very helpful though cannot yet be accessed by everyone.

**09. Dr Malcolm Adams**

- Entry of clinical data into a single, fully developed, All –Wales clinical data base for example Cancer Network Information System Cymru (CANISC) must be made mandatory, to ensure the availability of accurate outcome data and ensure that standards such as waiting time are accurately monitored.

**10. Cardiff Community Health Council**

- Need to make Primary, Secondary and Teritary Care more compatible to improve speed and communications.

**11. Conwy & Denbighshire NHS Trust**

- Process mapping to analyse the gaps.

**12. Meirionnydd Community Health Council**

N/R

**13. Brecknock & Radnor Community Health Council**

- Record of the patient's treatment should be accessible centrally. For example, if the patient receives treatment in Velindre and then goes to North Wales, a record of the treatment should be available to both.

**14. Community Pharmacy Wales (CPW)**

- Strong supporters of the introduction of an 'Individual Health Record' (IHR) and would ask that it remains a priority to connect all health providers via e-mail as soon as is practicable.
- A combination of electronic communication and access to electronic patient information will increase the speed and ease of decision making and improve the patient experience.
- One of the most frequently encountered problems for community pharmacy is obtaining authorisation for controlled drugs dose adjustments (especially for medication administered via a syringe driver) out of hours and on Saturdays. Having electronic access to NHS systems would allow an audit system to be put in place where Macmillan/district nurses, pharmacists and on-call doctors can reach a consensus on appropriate action and record the decision making process electronically. This would enable the LHB to audit the process and reduce the likelihood of a 'Shipman' like decision being taken alone while also creating flexibility in controlling pain.

**15. Wales Centre for Health, Jonathon Gray**

- We need a common data set for all cancer patients and families across Wales. Too often episodes of care are recorded in separate databases. This should include cancer genetic information.

**16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- We strongly support the development of a single patient record with appropriate read and write access to all professionals involved in the care of patients.
- The inclusion of a full electronic medication record is vital for health professionals to support a patient's holistic health needs, as patients suffering from cancer often have complex medication regimes and need support for self care for medication related or unrelated minor ailments.
- Community and hospital pharmacists should be included when planning for integration of information technology for healthcare as they can often provide useful information on a patient's medication history, and by receiving information on medication changes they are able to plan and thus help elevate any potential supply problem when switching care settings.

**17. Cardiff And Vale NHS Trust**

- Full availability of the CaNISC system including a module for MDT meetings.
- Availability of CaNISC to clinical areas as soon as possible.

**18. Macmillan Cancer Support**

- An electronic patient record system which enables health professionals to track patients in the system could potentially aid co-ordination of care.
- Patients want a single point of contact throughout their treatment.
- Macmillan recommends that the existing models and tools, including IT tools, with a view to developing a standardised IT enabled co-ordination of care model in cancer services.
- Would like to see cancer included as a specific target within the Informing Healthcare initiative.
- Better co-ordination between NHS and social care departments would reduce in-patient bed days, and improve earlier detection of cancer and the quality of the patient experience.
- Wales has great potential to benefit from advances in telemedicine – Bronglais hospital an example of good practice. Would support the piloting of this resource in rural areas.

**19. The Royal Pharmaceutical Society of Great Britain**

- A single patient record would allow all professionals involved in the care of a patient to access and contribute to the patient's medical record.
- It would be beneficial to patients if community pharmacists could receive information on medication changes.
- Electronic prescribing ensures that prescribing complies with agreed protocols and can provide good information for patient management, clinicak audit and service planning. An all-Wales system would provide these benefits.

**20. Royal College of Nursing**

- RCN suggests that the Cancer Network Information System Cymru should be the mandatory central cancer database in Wales, and should be made available to clinicians at every stage of patient care. Informing Healthcare should fully incorporate this system to ensure compatibility with other NHS data systems.

- Confidentiality must be assured.

**21. Wales Centre for Health**

- Need a common data set for all cancer patients and across Wales. This should include cancer genetic information.

**22. College of Occupational Therapists**

- An electronic patient record would facilitate better support for service users as they move across services and agencies.
- The Information System for Clinical Organisations is a valuable resource which enables staff to access clinical and therapy notes of cancer patients. Access to this system is not fully utilised due to the lack of access to IT.

**23. The Chartered Society of Physiotherapy in Wales**

- The Electronic patient record will assist in the clinicians having far better access to information on the patient throughout their journey. All clinicians need access. Many physiotherapists have limited access to IT.
- Effective IT will decrease duplication and data collection can be used effectively to improve performance and thus the patient experience.
- Many patients move between NHS Trusts and therefore accurate information must be easily available.

**24. Sanofi Pasteur MSD**

No response.

**25. Breast Cancer Care**

- The introduction of electronic patient records would mean that records could be accessed within different hospital departments and services, which would reduce the need for patients to have to repeat information to different hospital staff.
- Macmillan nurses often do not have access to patients' notes.
- It is important that primary care officials are kept informed about the cancer treatment their patients received as people may approach them for information and advice.

**26. Association of the British Pharmaceutical Industry**

- Improved use of information technology has the potential to help deliver significant improvements by expanding the range of information available to support patients; Enabling greater and appropriate access to the patient records by all healthcare professionals throughout the patient journey; Facilitating more convenient levels of care closer to a patient's home; Increasing service efficiency and freeing up resources to be used to improve other aspects of patient care; Improving the tracking and monitoring of care, ensuring that all patients gain access to the most appropriate and effective treatments, and Measuring and analysing patient outcome data.

**27. Pfizer Oncology**

- Improved use of information technology has the potential to help deliver significant improvements by enabling greater access to the patient records by all healthcare professionals throughout the patient journey.

**28. Society and College of Radiographers**

- It would enable the length of the pathway to be clearly seen.
- It would provide a baseline template to review the patient's journey.

- It would provide an information resource so all the team is aware of the stage of the patients journey.
- Waiting times from referral could easily be tracked and monitored.

#### **29. Roche Products Limited (Jacqui Goom)**

- Improved use of information technology has the potential to help deliver significant improvements:
  - Enabling greater expert involvement at all stages of a patient's care
  - Facilitating greater levels of care closer to a patient's home
  - Increasing service efficiency and freeing up resources to be used to improve other aspects of patient care
  - Improving the tracking and monitoring of care, ensuring that all patients gain access to the most appropriate and effective treatment for them
  - Expanding the range of information available to support patients, including making available more telephone and written support materials.

#### **30. Welsh Consumer Council**

No response

#### **31. Marie Curie Cancer Care Penarth Hospice**

- All statutory and voluntary providers should be linked to one uniform patient administration system, which isn't costly for voluntary organisations.

#### **32. North East Wales Cancer Partnership Board**

- Development of a single electronic record and systems that are able to 'talk' to each other across hospitals and national boundaries are key to support the appropriate function of the treatment pathway.
- Patient tracking systems as implemented within English Trusts alongside prospective tracking is pivotal if predictive waiting times are to be monitored and reported.

#### **33. Cancer Services Co-ordinating Group**

- Use of a single electronic cancer health record accessible to all healthcare professionals providing care for the patient.
- A system that allows patient records and information to be electronically transferred between primary and secondary care is an imperative.
- Software needs to be developed to register all patients with suspected or diagnosed cancer. Weekly reports need to be produced, flagging up patients likely to breach targets.

#### **34. Cancer Research UK Cymru**

- A single, effective and accurate database of cancer patients is crucial to the improvement of cancer services in Wales. The Cancer Network Information System Cymru (CaNISC) is an essential tool for tracking patients throughout their treatment and follow up care. This system should become the mandatory central cancer patient database in Wales.
- CaNISC should be made available to clinicians at every stage of patient care.
- *Informing Healthcare* should also fully incorporate this system to make sure that it is compatible with other NHS data systems.
- The cross-disciplinary nature of cancer services means that the co-ordination of information systems is important in providing effective cancer services across many areas of the NHS, as well as services provided by the voluntary, private and independent sector.



### **35. Jo's Trust**

- The Cervical Cancer Screening Programme relies entirely on an effective population database and highly effective tracking software and procedures. Jo's Trust is concerned that the Cervical Cancer Screening Programme may not always be as effective as it could be.

### **36. Claire House Children's hospice**

- The NW Cancer Network Group is setting up a data base to track patients and to share information with a view to informing the group working on the Care for the dying Pathway.
- A type of 'passport' could be developed, containing all relevant information for patients to hold.

## **Question 2**

How effectively is research and good practice being integrated with service delivery? What can be done and by whom to improve this?

### **01. Children's Hospital for Wales**

- Poor cross linking between adult and paediatric services from diagnosis; and
- raising awareness to discuss children and young adult cancer sufferers prior to commencing therapy or investigations.

### **02. South Wales Gynaecological Oncology Service**

- Clinical trials unit support is required to get through the paperwork required by the Trust R&D, MREC, MHRA etc.
- Support is required to empower and facilitate clinical staff to partake in clinical trials.
- Access NCRN nurses needs to be improved to support Gynaecological studies.

### **03. Ceredigion and Mid Wales NHS Trust**

- The Welsh Cancer Trials Network has done much to change the culture of R&D in Wales and needs to be built on with more financial support.

### **04. Velindre NHS Trust**

- Maximising involvement in clinical trials is key to keeping practice up to date, improving care and integrating new treatment developments appropriately into service delivery.
- Clinicians need to be further encouraged to enter patients into clinical trials.
- The All Wales tumour groups under the aegis of the Cancer Services Coordinating Group are key to defining best practice and standards and should be able to regularly perform All Wales audits of treatment outcomes, morbidity of treatment and compliance with good practice standards.
- Such audits demand that clinical data be readily available and that all relevant clinicians are participating across all aspects of the treatment across trusts and all cancer networks.
- These All Wales tumour groups should also be more proactive in supporting research.
- Currently the Welsh Cancer Intelligence and Surveillance Unit (WCISU) is under utilised for monitoring changing cancer incidence and outcome of treatment.
- In palliative care, research is particularly hard to undertake as patients are often too ill to consent and the patient population is far from homogeneous. However much that is undertaken clinically to relieve symptoms is based only on accumulated practice experience. There are important opportunities to develop new research methodologies

for this patient group so that new and more effective interventions can be developed for the intractable problems such as weakness and fatigue.

**05. Neath & Port Talbot CHC**

- In the main effective, but communication to patients is still poor in some areas.

**06. Tenovus**

- Support currently being provided by the Assembly should continue.
- Audit outcomes should be undertaken by widespread availability of the CANISC system.

**07. South West Wales Cancer Network**

- Responding to recommendations in the National Institute for Health & Clinical Excellence commissioning guidance and clinical guidelines;
- Utilising the South West Wales Cancer Network Cancer Services Directory for each of the site specific cancers multidisciplinary teams;
- Through the South West Wales Cancer Network clinical Governance framework;
- Developing the Patient Pathway;
- Organising workshops and learning events;
- Promoting the Welsh Cancer Trials Network to support clinical trials;
- Working in collaboration with the South West Wales Cancer Institute;
- Raising awareness of the patient experience through the Network Patient satisfaction Survey;
- Implementation of the National Cancer Standards and Targets;
- Promoting the work undertaken by the Welsh Cancer Trials Network and the South West Wales Cancer Institute: list of cancer trials underway within the Mid & West Wales Region can be found in Appendix 1;
- Sharing best practice through workshops.
- By establishing an Audit Support group;
- The Cancer Services Co-ordinating Group should establish a system and infrastructure to support horizon scanning on an all-Wales basis to identify the potential impact of cancer research trials and treatment guidelines;
- By improving the assessment process for licensing new drugs;
- The Welsh Assembly Government should accept and endorse National Institute for Health & Clinical Excellence guidance.

**08. Rhondda Cynon Taff Local Health Board**

- There are limited resources for research and we need to improve links with Universities.
- The Last Days of Life Care Pathway is a good example of good practice being integrated with service delivery.

**09. Dr Malcolm Adams**

- See Velindre.

**10. Cardiff Community Health Council**

- More resources are needed for research to be carried out.

**11. Conwy & Denbighshire NHS Trust**

- Through modernisation & redesign – research & good practice is being integrated. But the allowance of time & availability can hamper more further integrated service delivery projects

## **12. Meirionnydd Community Health Council**

N/R

## **13. Brecknock & Radnor Community Health Council**

- Research is vital.
- One regulatory body would be more beneficial as it can cut down on all the administration that a hospital such as Velindre would have to do to obtain a service agreement. It will have the result of allowing them more time with their patient's.

## **14. Community Pharmacy Wales (CPW)**

- It is essential that pharmacists are recognised as an integral member of the primary care team and as such need to enjoy the same access to training, research and briefing on good practice that is available to other members of the primary care team.
- Pharmacists are the only group of health professionals that are not provided with protected learning time or part of the co-ordinated approach to NHS skills development. NLIAH should extend their role to include community pharmacists and community pharmacy technicians.
- In terms of good practice integration LHBs in the old Gwent HA area have recently updated an Out of Hours Palliative Care Service using local community pharmacies that provides access to palliative care medication within two hours. Despite being hailed as a 'Gold Standard Scheme' by oncology consultants commissioning of the service has not moved outside of the initial trial area.
- CPW feel that there is the potential for pain management in palliative care to be addressed by community pharmacists who are supplementary or independent prescribers and should be looked at as a future working model.
- It is also worth noting that chemotherapy is now being offered from a community pharmacy consultation room in Clerkenwell in a bid to improve access to cancer care. The Greenlight Pharmacy has teamed up with Whittington hospital and Macmillan Cancer Support as part of a study into cancer services in North London. In addition community pharmacists have been involved in schemes to raise the awareness of oral cancer and in referring patients to cancer services.

## **15. Wales Centre for Health, Jonathon Gray**

- Moderately well. There is a clear need to increase the recognition of Cancer Genetics (provided through all Wales Medical Genetics Service) as a conduit for research in the critical area of genetics to the patient/family.

## **16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- There is a need for effective support for dissemination of information on good practice through clinical networks, supported by audit to measure improvement in practice.
- Within pharmacy there are opportunities for research and service development projects but often the heavy workload faced by most healthcare practitioners provides a barrier.

## **17. Cardiff And Vale NHS Trust**

- Need sessions in clinicians work programmes for educational and academic meetings. Need funding for research staff (medical and nursing). Research and educational standards need to be built into commissioning.

## **18. Macmillan Cancer Support**

- The evidence base for current and future palliative care policy and practice is weak. The NCRI published in 2002 that only 4% of the total expenditure on cancer research

in the UK is on palliative care. The NICE supportive and palliative care guidance recommends extending the evidence base for palliative care.

- Macmillan would urge the Committee to consider the wider issue of best practice in cancer care / support, in addition to the focus on drugs and treatment.

#### **19. The Royal Pharmaceutical Society of Great Britain**

- Opportunities for research are available, but healthcare practitioners' heavy workloads discourage many from undertaking practice research.
- Resources are problematic – short term costs and the lack of flexibility between budgets can delay the introduction of new technologies into practice e.g. the use of erythropoietin.
- The setting up and running of non – sponsored clinical trials is difficult due to the associated service costs. Current levels of support for service costs associated with clinical trials often do not provide enough support for departments such as Pharmacy and Radiology.

#### **20. Royal College of Nursing**

- The work of the Wales Cancer Trials Networks needs to be built on, and fully linked with other cancer clinical networks and the Cancer Co-ordinating Group.
- Scientific research deserves a higher political profile.

#### **21. Wales Centre for Health**

- Need to increase the recognition of Cancer Genetics as a conduit for research in the critical area of genetics to the patient / family.

#### **22. College of Occupational Therapists**

- Research activity outside the medical profession needs to be enhanced and greater finance needs to be made available for therapists and other research.
- Occupational therapy research is limited, partly because of the lack of finance / research funding, partly because of the lack of specialists in post, expertise and time.
- The Cancer Networks are not receiving adequate involvement from therapists to inform their work.
- There needs to be more multi professional engagement across Wales with communication and ideas flowing between Networks and services.

#### **23. The Chartered Society of Physiotherapy in Wales**

- There is a need for involvement of all professions involved in cancer service provision and research, and good practice should be multi disciplinary and multi agency.

#### **24. Sanofi Pasteur MSD**

No response

#### **25. Breast Cancer Care**

- The creation of an All Wales Cancer charity coalition would be an invaluable vehicle to benchmark with and ensure that patients' views and external research is factored into service delivery.

#### **26. Association of the British Pharmaceutical Industry**

- The cancer networks do not have any statutory powers, making co-ordination and implementation a challenge.
- National standards for R&D should be established to ensure that all patients can benefit from research breakthroughs as soon as possible.
- The trials infrastructure in Wales e.g. Cancer Trials Network and Wales

Cancer Institute should continue to be supported and further encouraged by WORD and the Welsh Assembly.

**27. Pfizer Oncology**

- Pharmaceutical companies can help by sharing knowledge on their oncology pipeline to the NHS.
- Should identify research areas important within Wales based on epidemiology and consultants experience.

**28. Society and College of Radiographers**

- Implementing research into routine radiotherapy practice is slow.
- Lack of spare treatment capacity to develop and implement new technologies to their fullest extent.

**29. Roche Products Limited (Jacqui Goom)**

- Translating research findings into standard practice remains a challenge, with many important discoveries being implemented at varying speeds.
- There is a clear case for the early setting of national standards to ensure that all patients can benefit from research breakthroughs as soon as possible.

**30. Welsh Consumer Council**

No response

**31. Marie Curie Cancer Care Penarth Hospice**

- Better co-ordination and funding are required to improve research and evidence based practice in palliative care.

**32. North East Wales Cancer Partnership Board**

- Medical research is being integrated and introduced rapidly, sufficient financial resources is the only real issue that would speed this up.
- Qualitative, non medical research is limited, in part due to poor quality of research.

**33. Cancer Services Co-ordinating Group**

- There has been some progress in this area, where WCTN have supported Trials nurses. This possibly requires higher priority by steering groups and cancer networks.
- There have been good developments both in WCTN and disseminating knowledge via the NHS network and web links for clinicians. The development of multi-disciplinary site specific teams are key.
- Translating research evidence into clinical practice is difficult due to the constraints of the commissioning processes. More clinical auditing of cancer services is necessary to ensure quality assurance of identified good practices using a cancer information system of high validity, completeness and timeliness linked to a population-based cancer registration system.
- Integration is limited by the lack of resources and recognition by managers and clinicians of the need for change.
- There is a need for everyone to accept the need for sharing the results of research and good practice and implementing a fast track process between trusts and the pharmaceutical industry and research.

**34. Cancer Research UK Cymru**

- Scientific research in Wales deserves a higher political profile and call for a named Minister for Science to be introduced, in line with practice in Scotland and England.
- More work is needed to ensure that research and good practice are integrated with

service delivery.

- There is evidence to show that patients do better when treated in a research active environment, even when not themselves research participants, and we therefore believe that more should be done to actively encourage patients and healthcare professionals to become involved in research.
- Despite a number of initiatives that have put Wales at the forefront of service development, including the establishment of the Welsh Cancer Trials Network, there is a need to further strengthen the links between cancer research and service delivery

### **35. Jo's Trust**

- We welcome the introduction of the new cancer bank as this will provide an opportunity to monitor adequately the effects of vaccination on HPV type prevalence in cervical cancers.

### **36. Claire House Children's hospice**

- Alderhay Children's hospital and the Children's Palliative Care Team share information on Palliative Care for Children and Care of the Dying Pathway with the North West Palliative Care forum, which is a good model.

## **Question 3**

What are your views on the complexity of commissioning services? Is the process hampered by the involvement of the local health boards, cancer networks and Health Commission Wales? How could it be simplified?

### **01. Children's Hospital for Wales**

- Little has been achieved on practical level; interface between funding for tertiary and secondary cancer care in paediatrics is blurred and causes difficulties trying to set up shared care services locally.
- Networks have the knowledge but little power and money.

### **02. South Wales Gynaecological Oncology Service**

- In England there is a clear line for commissioning cancer services. In Wales there is no organisation responsible for Cancer Services answerable to the public for the poor quality of cancer care throughout Wales.
- Women in Wales with gynaecological cancer are subject to the vagaries of referral, indifferent expertise in diagnosis and care and there is no-one auditing or accepting responsibility for poor outcome, (please see our own report: Audit of Ovarian Cancer 1999).
- The funding should be top sliced, management should be by sub-specialty groups and there should be responsibility and audit of outcomes.

### **03. Ceredigion and Mid Wales NHS Trust**

Significantly hampered by LHB's – would favour regional commissioning by cancer networks.

### **04. Velindre NHS Trust**

- There is inconsistency in cancer commissioning across Wales.
- Commissioners do not have adequate information on case mix and activity.
- Effective commissioning requires quality measurements of activity and complexity defined by tools such as HRGs which are defined by indicators.
- Commissioners frequently lack expertise as well as information.
- The quality of commissioning seems to have deteriorated since the introduction of

LHBs as specialist commissioning expertise has been distributed thinly across a large number of commissioning organisations.

- Commissioning for cancer services needs to be organised on at least a regional basis and capital funding issues for expensive equipment need to be planned on an All Wales basis.
- The cancer networks have not been enabled to enact their advice as trusts hold all the authority with respect to Consultant appointments. Mechanisms need to be developed to ensure that advice on service configuration is implemented.
- Commissioners are often confused between specialist palliative care services and those in the charitable sector that offer nursing and social care at a generalist level. The needs assessment undertaken by the National Council for Palliative Care should be a starting base for more effective commissioning.
- To date, commissioners have appeared reluctant to be firm about what they will and will not support. Block grants rather than full service level agreements have been awarded to some organisations and political pressures have been brought to bear by Trustees of some organisations to the detriment of others.
- The LHBs act at too local a level to have an overview and are not able to exert the difficult pressure on the charitable sector partners to alter practice to fit with the needs of an area.

**05. Neath & Port Talbot CHC**

- Commission should be done on a regional basis.

**06. Tenovus**

- The Cancer Networks provide a potentially useful source of professional advice to commissioning.
- They have been hampered by their lack of ability to implement decisions.
- Funding is an issue.
- It would be more effective to have a single commissioner for specialist cancer services across the whole of Wales.
- If we were to have an integrated high quality equitable service then a Pan-Wales commissioning process would be the best way to achieve this.

**07. South West Wales Cancer Network**

- The Cancer Network would advise the commissioning organisations about the priorities for improving cancer services.

**08. Rhondda Cynon Taff Local Health Board**

- Networks are the way forward, but with limited powers their abilities and subsequent outcomes are limited.
- We need to develop strong working agreements with the proposed Regional Commissioning processes and the cancer networks.

**09. Dr Malcolm Adams**

- The relative role of local health boards, cancer networks and Health Commission Wales is ill defined and there is inconsistency in cancer commissioning across Wales.
- Commissioners need adequate information to commission properly .
- Effective commissioning requires quality measurements of activity and complexity defined by indicators.
- Commissioners frequently lack expertise as well as information.
- Commissioning for cancer services needs to be organised on at least a regional basis and capital funding issues for expensive equipment for example linear accelerators which needs to be planned on an All Wales basis.

- Mechanisms need to be developed to ensure that advice on service configuration is implemented.

**10. Cardiff Community Health Council**

- Too complex, needs simplifying and there are too many commissioning bodies involved.

**11. Conwy & Denbighshire NHS Trust**

- A more standardised process, rather than several similar ones.
- Clarification of the roles of such bodies

**12. Meirionnydd Community Health Council**

- There are too many commissioners currently.
- If the numbers are reduced and become population based we may lose out in the rural areas.
- Palliative care in rural areas is poor and there is no equity of access. There is not sufficient attention given to rural areas since the change in GP hours under the new contract.

**13. Brecknock & Radnor Community Health Council**

- Breast screening has saved the lives of many women, and it would be advantageous to screen women for ovarian cancer and men for prostate cancer.
- One of the barriers to developing technologies is cost and funding.

**14. Community Pharmacy Wales (CPW)**

- Concerned by the high degree of variance in the quality of commissioning at LHB level and feels that part of the answer lies in the extension of the remit of the regional/health economy commissioning groups, proposed in the Designed to Deliver strategies, to cover the commissioning of primary care services.
- There is evidence that community pharmacy enhanced services are continually being bumped to the back of the commissioning queue.
- CPW are also disappointed with the willingness of WAG to actively support the introduction of National Enhanced Services and Directed Enhanced Services for community pharmacy.

**15. Wales Centre for Health, Jonathon Gray**

- Currently too complex. We should use the networks to commission on a regional level.

**16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- It's too complex.
- By the nature of the commissioning process Trusts that provide cancer services have to negotiate with all 22 Local Health Boards and Health Commission Wales, this process is bureaucratic and time consuming for all parties concerned. Additionally LHBs have a responsibility to ensure that services provided by Trusts are clinically and cost effective but within individual 22 LHBs there is often a lack of expertise to evaluate specialist services.
- To maximise the use of available expertise regional consortia or an all Wales commissioning service should be considered with responsibility to ensure a clinically and cost effectiveness service delivered.

**17. Cardiff And Vale NHS Trust**



- Current lack of clarity in commissioning hampers patient management.
- The network boards should insist on commissioners meeting standards through service reconfiguration. Suggest a Regional Commissioning for Cancer Services in SEW/SWW and NW.

### **18. Macmillan Cancer Support**

- Macmillan strongly believes that patients and carers should have a voice in the commissioning process.
- Cancer commissioning in Wales is unclear at the moment, including the role of cancer networks. Macmillan believe that the cancer networks could be in an ideal position to co-ordinate the commissioning process in their areas.
- Concern over the degree of expertise at LHB level in relation to commissioning cancer services.
- Commissioning of large pieces of equipment appears to be lengthy and complicated e.g. linear accelerators, which have to be approved by the WAG.
- Macmillan suggests implementing a plan for expensive equipment, which had a budget allocated to it, and with cancer networks signing off request for new equipment and replacements within the agreed plan and budget.

### **19. The Royal Pharmaceutical Society of Great Britain**

- Commissioning of cancer services in Wales appears overly complex. Trusts negotiate with all 22 LHBs and HCW, which is time consuming and wasteful for both sides. LHB's often do not have the expertise to evaluate specialist services.
- Regional consortia or for highly specialised services, all Wales commissioning would appear a better solution.

### **20. Royal College of Nursing**

- Cancer services should continue to be commissioned on a regional basis. Regional Cancer Networks and WAG regional offices should take a stronger role in overseeing regional commissioning.
- WAG should ensure that commissioning services should take account of local need and secure parity across Wales.
- Specialised services should be commissioned on a national basis by HCW in consultation with the Cancer Services Co-ordinating Group.

### **21. Wales Centre for Health**

- Currently too complex.
- Networks should be used to commission on a regional level.
- A national framework is needed to guide and inform the commissioning process.

### **22. College of Occupational Therapists**

- Lack of coherence in commissioning services.
- 'Living well with cancer' and the recognition of cancer as a chronic condition are not yet reflected in the service commissioning.
- Commissioners need better advice on how therapy can be provided.

### **23. The Chartered Society of Physiotherapy in Wales**

- All stakeholders have important roles in the commissioning of cancer services, however the process is hampered by the complexity of the range of organisations and their own agendas.
- LHBs and HCW could devolve the decision making to the networks. It would be essential for the networks to be fully inclusive of all the stakeholders and receive appropriate advice from professions such as therapists. If this model is not possible,

then the networks and HCW must be purely advisory to the LHB who will commission with the providers.

#### **24. Sanofi Pasteur MSD**

No response.

#### **25. Breast Cancer Care**

- Concern that devolving commissioning to PCT level will put the commissioning of specialised services at risk. Few commissioners at PCT level have experience of commissioning from the voluntary sector.

#### **26. Association of the British Pharmaceutical Industry**

- Further clarity is needed as to the commissioning of services, and the important role of Health Commission Wales requires greater transparency.
- Although clinicians may wish to prescribe clinically effective medicines, shown to improve the quality and/or duration of life, there is confusion over whether these should be funded if NICE/AWMSG guidance is not available
- Funding mechanisms should be in place at a local level which allows the prescribing of a medicine in advance of a NICE/AWMSG decision and greater clarity in this respect would help patients and clinicians.
- A regular audit of the uptake of NICE-approved medicines by Healthcare Inspectorate Wales would be beneficial, ensuring that areas of continuing weakness can be identified and addressed by local health boards and cancer networks.
- All local health boards should appoint a cancer lead to champion the needs of oncology services and cancer patients, as well as co-ordinating commissioning activity.
- Health boards and cancer networks therefore need to work more closely together to accurately assess and forecast future capacity requirements. Such assessments should be based on predicted demand rather than current requirements.
- As well as potentially improving patient quality of life, oral therapies can free up capacity to be used to deliver treatments which cannot be administered orally, we would welcome a recommendation from the Committee that clinicians actively engage patients in the medicine option process and encourage patient choice.

#### **27. Pfizer Oncology**

- The commissioning service is too complex with no accountability for cancer services.
- There is a requirement for more clarity with regards to NICE / AWMSG process.

#### **28. Society and College of Radiographers**

- Cancer Networks have an important role in the prioritising of developments across each network and should advise the commissioning process and LHB's.
- The process could be considerably easier by identifying a lead LHB commissioner for Cancer services.

#### **29. Roche Products Limited (Jacqui Goom)**

- The roles of HCW and LHBs need to be clearly defined.
- An audit of the uptake of NICE approved medicines would be beneficial.
- LHBs should appoint a cancer lead to champion cancer and oncology services and co-ordinate commissioning.
- LHBs and cancer networks need to work together to assess future capacity requirements.

#### **30. Welsh Consumer Council**

No response.

### **31. Marie Curie Cancer Care Penarth Hospice**

- Commissioning process hampered by current situation. LHBs have limited funds and commissioning is not activity based.
- Central commissioning would be preferable.

### **32. North East Wales Cancer Partnership Board**

- Commissioning of cancer services in Wales is complex and the lack of capacity and limited cancer specific expertise within LHBs and HCW further confuse the issue.
- Networks are well positioned to take a more active role in commissioning but fail due to having no statutory function or budget.

### **33. Cancer Services Co-ordinating Group**

- LHBs have too small a population to commission cancer services effectively. These should be commissioned at network level for common cancers and HCW (or equivalent) for rare cancers. The list of cancer services commissioned by HCW requires review.
- LHBs and HCW seem to be failing to manage the cancer commissioning process. The 22 separate LHBs do not have the necessary expertise or experience and HCW only cover certain specialised cancers. Commissioning should be undertaken at network/ regional level or at an all Wales level for specialised cancer. High level cancer intelligence support from WCISU is required.
- There is continuing confusion between the commissioning roles of the Local Health Boards and Health Commission Wales for cancer services. The three cancer networks do not appear clear about their roles in facilitating the commissioning of cancer services.
- There is insufficient clinical and managerial information to inform the commissioning process.
- This process must be simplified by making the networks responsible for commissioning the more costly elements of cancer treatment.

### **34. Cancer Research UK Cymru**

- The Multi-Disciplinary Team (MDT), comprising all of the professionals involved in patient care, provides co-ordination along the patient pathway. This model has been shown to be effective by ensuring a holistic approach to individual care planning with the patient at the centre of the process.
- Cancer services should continue to be planned on a network basis to reflect this complexity. Network Plans for cancer services should be reflected in Local Health Board Commissioning Plans.
- Currently the strategic planning and oversight that is the strength of the Cancer Networks is undermined by their lack of authority over local health boards. This needs to be urgently addressed.
- The number of LHBs in Wales works against the commissioning and delivery of co-ordinated cancer services across the country; they should be reduced in number.
- The Regional Cancer Networks and WAG regional offices should take a far stronger role in overseeing the commissioning process.
- Specialised cancer services need to be planned for geographical areas that span more than one cancer network. These should be planned by consortia of Networks and commissioned on a national basis by HCW in consultation with the Cancer Services Co-ordinating Group. To maintain standards it is important that these services continue to be commissioned on a multi-service provider/cancer network basis.
- The Strategic Development Plan developed by the Cancer Services Co-ordinating Group is an excellent document, addressing the key issues affecting cancer in Wales

and making recommendations not only for funding, but also for workforce planning across the region up to 2008. We believe that this document makes a strong argument for the need for a co-ordinated cancer strategy in Wales and should be used as a template on which future planning can be based.

**35. Jo's Trust**

- Commissioning is complex with too many LHB's involved. We welcome the all Wales approach to commissioning for Cervical Screening Wales and we hope this will continue.

**36. Claire House Children's hospice**

- The process could be simplified by setting up services for children which cross all agencies, and meet all of children's needs, i.e. health, care, education, protection etc. This would prevent any discrepancies over which agency's budget should fund services.

**Question 4**

What evidence is there of the value of screening and immunisation?

**01. Children's Hospital for Wales**

- Post chemotherapy immunisation is following RCPCH guidelines.

**02. South Wales Gynaecological Oncology Service**

- Cervical Screening of Wales – please refer to annual reports. There are ongoing studies of ovarian cancer screening (UKCTOCS UKCFOCS). Prophylactic HPV vaccination will be an issue from 2007 when the vaccines are expected to receive a European licence.

**03. Ceredigion and Mid Wales NHS Trust**

- Screening for cervical and breast cancer has a reasonable evidence base, but screening for prostate and colo-rectal CA remains uncertain.

**04. Velindre NHS Trust**

a) Cervical Cancer

- Organised cervical screening programmes have been estimated to have reduced the mortality of cervical cancer by 80%.
- Two highly effective prophylactic vaccines against the strains of human papilloma virus responsible for 70% of cervical cancer have completed late stage clinical trials and are likely to be licensed very shortly.
- Cervical screening will need to continue unchanged but as the incidence of HPV disease is reduced by vaccination the screening programme will need to be modified.
- An HPV vaccination programme needs to be planned to ensure effective prevention with high acceptability for the vaccine without undermining the current cervical screening programme.

(b) Breast Cancer

- Breast Test Wales (BTW) always meets or exceeds the programme standards for uptake and cancer detection. The National Health Service Breast Screening Programme (NHSBSP) Annual Review 2005 shows that Wales has the highest cancer detection rates and standardised ration in the UK for the year 2003/2004.

(c) Colo/rectal Cancer

- It has been proven that population based faecal occult blood screening with follow up colonoscopy for confirmed positives reduces deaths from colo/rectal cancer by earlier

detection.

- The faecal occult blood screening should be instituted as soon as possible, but ensuring the colonoscopy service is adequately staffed or resourced to deliver increased demand and ensuring a quality assured, adequately funded screening programme is established.

#### **05. Neath & Port Talbot CHC**

- There is evidence that cervical screening and regular mammograms is valuable.

#### **06. Tenovus**

- Screening is vital for early detection of cancer in Wales.
- Cervical and breast screening are functioning effectively in Wales and are extremely high quality.
- The development of colorectal cancer screening is the next step.
- There is evidence that lives can be saved and mortality reduced from colorectal cancer by faecal occult blood testing.
- Only problem is the service provision for colonoscopies to evaluate those confirmed positive FOBs and this process needs to be available in such a way that it does not undermine the routine service delivery.

#### **07. South West Wales Cancer Network**

- Evidence is available confirming that screening programmes are effective at reducing breast cancer mortality.
- It is the recommendation of the UK Breast Screening Programme and the World Health Organisation that screening should be offered to eligible women.

#### **08. Rhondda Cynon Taff Local Health Board**

- For many infectious diseases vaccination is once in a lifetime event which means vaccination is often very cost effective.
- Screening uses much more resource per individual screened.
- Screening throws up both false positive and false negative test results which complicate quality assurance and public confidence issues. This is why screening programmes should conform with National Screening Committee criteria.
- The public need to be kept informed.

#### **09. Dr Malcolm Adams**

See Velindre's response.

#### **10. Cardiff Community Health Council**

- Cervical screening has reduced incidence of cervical cancer.
- Early diagnosis has improved outcomes.
- Colo-rectal should be screened.
- Immunisation against cervical cancer is proven and a programme must be introduced to cover pre-pubescent boys and girls.

#### **11. Conwy & Denbighshire NHS Trust**

- The value of screening and immunisation is in the earlier detection, diagnosis and treatment of cancers thus decreasing the potential of complications and increased costs for treatments in later stages – leading to a better quality of life for the patient and their family and an improved chance of cure.

#### **12. Meirionnydd Community Health Council**

- Screening would reduce costs by early diagnosis

### **13. Brecknock & Radnor Community Health Council**

NR

### **14. Community Pharmacy Wales (CPW)**

- The potential of the community pharmacy network to become involved in population screening is regularly overlooked.
- In a recent review of bowel cancer services we recommended that the distribution of testing kits should be carried out through the community pharmacy network.
- Community pharmacies are the most accessible of all of the health outlets and are ideally placed to support population screening and the provision of public health advice.

### **15. Wales Centre for Health, Jonathon Gray**

- Screening is critical. Cancer genetics can identify many at risk – and we can build on the successful breast cancer screening collaboration to effectively detect other cancers in at-risk people.

### **16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- Further investment in screening for a broader range of cancers should be considered.
- Immunisation against viruses associated with certain cancers, such as Human papilloma virus and cervical cancer will become a potential significant step in the coming years. Careful consideration of the managed application of these new vaccines must be undertaken and coordinated.

### **17. Cardiff And Vale NHS Trust**

- Well established data for breast and cervix. Awaiting evidence for prostate, colon and lung.

### **18. Macmillan Cancer Support**

- Macmillan's expertise lies in cancer care and support.
- Patients are not allocated a clinical nurse specialist until a cancer diagnosis has been made, no-one is responsible for co-ordinating patient care.

### **19. The Royal Pharmaceutical Society of Great Britain**

NR

### **20. Royal College of Nursing**

- RCN endorses the strengthening of National Screening programmes in Wales. The all Wales programme of breast cancer has been a tremendous success, and the RCN are supportive of the introduction of a National Screening Programme for bowel cancer.
- Informing Healthcare must prioritise the fulfilment of the necessary information services associated with screening.
- RCN sees immunisation as a vital weapon in the battle to improve cancer services, although recognises that a number of questions need to be answered before going ahead with such a programme.
- Education is crucial in the prevention or reduction in cancer. School nurses are in an ideal position to educate children about the risks of diet, smoking and environmental factors.
- The review could encourage steps towards the development of a preventative health service for Wales by focusing on methods such as screening, immunisation and

education.

**21. Wales Centre for Health**

- Screening is critical.
- Cancer genetics can identify many at risk.
- Can build on success of breast cancer screening.
- Have piloted work on addressing family history of cancer so that screening can be put in place for the surviving family. Would suggest that more work be done on this.

**22. College of Occupational Therapists**

No view

**23. The Chartered Society of Physiotherapy in Wales**

No view

**24. Sanofi Pasteur MSD**

- Trials of the vaccine Gardasil show that it is likely to be highly effective in reducing the incidence of cervical cancer and other clinical diseases related to Human Papillomavirus. Universal vaccination of girls and young women, prior to significant exposure to Human Papillomavirus, could be achieved through a schools based programme. A health economic evaluation has demonstrated that Gardasil, if given through a schools based programme, in addition to current UK screening programmes, is cost effective.

**25. Breast Cancer Care**

- Evidence that the NHS Breast Screening Programme does save lives. Also international evidence of the value of breast cancer screening, which shows that there is a 35 per cent reduction in mortality from breast cancer among screened women aged 50 – 69 years old.
- Concern that women are not always aware of the screening programme and their access to screening opportunities.
- Crucial that information about screening be readily available to women leaving the screening programme. Also a need for better education campaigns around breast awareness and the availability of the screening programme.

**26. Association of the British Pharmaceutical Industry**

- There is a significant amount of evidence to support that immunisation and screening are effective in preventing and offering early detection of disease. Programmes for breast and cervical cancer screening have been shown to result in substantial health benefits.

**27. Pfizer Oncology**

- More extensive screening for biomarkers would allow better identification of suitable patients for targeted therapies.
- There is evidence to suggest that early intervention is critical, perhaps focus attention on groups who don't present early.

**28. Society and College of Radiographers**

No response

**29. Roche Products Limited (Jacqui Goom)**

- Evidence to show that screening is effective in preventing and offering early detection of cancer.
- A national bowel cancer screening programme for Wales should be implemented

without delay.

### **30. Welsh Consumer Council**

No response.

### **31. Marie Curie Cancer Care Penarth Hospice**

- Feedback from colleagues in other provider organisations would suggest that screening is positive.

### **32. North East Wales Cancer Partnership Board**

- The value of screening may be challenged in that the infrastructure could be more efficient in terms of sharing resources and expertise, however this does not challenge the value of the service in terms of detecting early cancers.

### **33. Cancer Services Co-ordinating Group**

- Trials looking at the effectiveness of low dose screening CT Thorax are still on-going.
- In lung cancer there is no national screening programme because there is insufficient knowledge about the natural histories and there is no test that meets the relevant criteria.
- A national screening programme for colorectal cancers has been proposed to the Welsh Assembly Government because there is sufficient knowledge of the natural history of the diseases, the testing processes meets the relevant criteria, and the facilities for diagnosis, treatment, care etc. could be organised if the resources are made available.
- There is no national screening programme for prostate cancers because their long natural histories mean that many cancers will not cause symptoms.
- The most likely cancer that could be prevented by immunisation is cancer of the cervix of the uterus. The scientific evidence for effectiveness exists but there are important issues to be resolved concerning acceptability to the population, age for offering the vaccine, etc.
- Screening has particularly provided a process of earlier detection for some cancers and if proved to be effective money should be provided i.e. bowel, prostate cancers.

### **34. Cancer Research UK Cymru**

- Screening provides the ability to detect abnormalities early in disease. Cancer Research UK Cymru strongly endorses the strengthening of National Screening Programmes in Wales.
- The two screening programmes currently operating across Wales - the national breast cancer screening programme, and the cervical cancer screening programme, have been very successful. Cancer Research UK Cymru notes that a National Screening Programme for bowel cancer is being introduced in England and Scotland. It is essential to the saving of lives that this programme is introduced in Wales as soon as possible.
- *Informing Healthcare* must also prioritise the provision of the necessary information services associated with screening.
- In addition to screening, prevention is a vital weapon in the battle to improve cancer services. Given that it is estimated that a third of all cancers could be prevented by lifestyle changes, we are disappointed that this review does not address issues of prevention.
- Education is crucial in the prevention or reduction of cancer in the population. A far greater emphasis on this is needed in the school curriculum and clear joint planning is required between health and education policy at a national level. School Health nurses for example are in an ideal position to educate children about the risks of diet,



smoking and environmental factors.

### **35. Jo's Trust**

- Cervical screening has been highly effective in the UK and research has proven that it has prevented a cervical cancer epidemic. However cervical screening without doubt causes significant stress and anxiety and sometimes morbidity for the thousands of women who have to be investigated for an abnormal smear.
- New medical intervention, in the form of immunisation against types of the HPV virus which can lead to cervical cancer may ultimately mean that HPV malignancy and pre-malignancy becomes uncommon reducing the costs and morbidity associated with screening.
- Jo's Trust also believes that care must be taken to ensure that settled refugee and immigrant women in Wales are brought into the screening database system: and that appropriate communications programmes are used to overcome cultural and other resistance to participation.
- Two vaccines against HPV are currently awaiting licences. Data from completed trials to date have shown both vaccines to be 100% effective against the two Human Papillomavirus types 16 & 18, which research has proven cause 70% of all cervical cancers. One of the vaccines offers additional protection against types 6 & 11, which cause genital warts.
- HPV is highly infectious and starts to infect young people, when they become sexually active. Therefore, an effective vaccination programme should include universal vaccination of teenage girls before first sexual contact, probably at around 11 or 12 years old. Older girls and young women should also benefit from receiving the vaccine.
- The public will expect the NHS to provide access to these vaccines as soon as they are launched in the UK. To meet this expectation in time would require urgent steps to be taken soon to agree the method of delivery and resources needed for immunisation and the accompanying communications with health professionals and the public.

### **36. Claire House Children's hospice**

No response.

### **Question 5**

What are the barriers to the NHS in Wales keeping abreast of, and responding to, developing technologies and therapies? How might these barriers be overcome?

#### **01. Children's Hospital for Wales**

- Linking electronically different hospitals / labs etc by making systems compatible.

#### **02. South Wales Gynaecological Oncology Service**

- We accept that there is a limited budget for health, but we do not accept the tensions brought about by having large bureaucracies starving other areas of funding.

#### **03. Ceredigion and Mid Wales NHS Trust**

- Lack of investment in new technologies – e.g. chart is not available in some networks.

#### **04. Velindre NHS Trust**

- Implementing new technologies into good practice requires planned resources otherwise there is inevitable delay in implementation.

- Adequate review of new technologies and practice requires a large pool of expertise.
- Wales needs to be part of the NICE review process and avoid unnecessary duplication of expert review.
- Wales is too small to develop its own process and horizon planning is required to identify new developments in adequate time to enable resources and capacity planning requirements to be defined in a timely fashion.
- WAG needs to ensure that Wales does not repeatedly lag behind new technological developments by moving to more rapidly commissioning new technologies (eg PET-CT).

#### **05. Neath & Port Talbot CHC**

- Lack of human and monetary resources.

#### **06. Tenovus**

- It is essential that Wales remain remains with the NICE process.
- NICE process needs to be speeded up.
- WAG needs to ensure that NICE delivers on this more rapid evaluation of new technologies and therapies.
- Funding is needed to match the service need.
- High quality IT needed.
- Restriction of usage to certain sub-specialists with oncology will be able to control the flow of the specialist drug usage.

#### **07. South West Wales Cancer Network**

- There is a lack of co-ordination at an all-Wales level to agree the process for assessing the impact of new treatments/technologies.
- WAG should confirm arrangements for decision-making about the evidence base for improving services in Wales for example, endorsement of National Institute for Health & Clinical Excellence appraisals/Scottish Intercollegiate Guidelines Network.

#### **08. Rhondda Cynon Taff Local Health Board**

- We need improved horizon scanning for new drugs and a faster All Wales response on the guidance for their use to avoid postcode prescribing.
- Improved handling of the media and ring fenced funding would also be helpful.
- Cancer Networks are ideal for disseminating best practice.

#### **09. Dr Malcolm Adams**

- If we are to implement new technologies into good practice in a timely fashion we need to carefully plan resources.
- As new developments occur it is important that Wales is part of the National Institute for Health and Clinical Excellence review process to
- Wales is too small to develop its own process and we need to maximise the pool of expertise available for review.

#### **10. Cardiff Community Health Council**

- Funding.
- Prioritisation based on evidence to maximise outcomes.

#### **11. Conwy & Denbighshire NHS Trust**

- More staffing.
- Integration of different systems across the North Wales network.

- Lack of understanding of service needs i.e. Lymphoedema Service.
- Improve communication skills/avenues for an improved integration and ensuring support for service maintenance.

**12. Meirionnydd Community Health Council**

NR

**13. Brecknock & Radnor Community Health Council**

NR

**14. Community Pharmacy Wales (CPW)**

NR

**15. Wales Centre for Health, Jonathon Gray**

- Fragmented commissioning – resolve by using the networks.

**16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- Recent advances in diagnostics and cancer treatments have placed additional burdens on the cancer services in terms of acquisition costs and manpower needs.
- A published timetable of appraisals and process to fast track appraisals will help minimise the anguish caused to patients and allow the NHS in Wales to deliver the World Class Health Service promised to its patients.
- Additionally positive appraisals should be supported by inclusion of workforce and capacity issues of service deliver to avoid any delays in patient's receiving the new service or treatment.
- Whilst we recognise and accept the climate of conflicting priorities within the NHS, we feel that due consideration must be given to engagement with the public and professionals in managing expectations for new treatments and technologies, through communication of decisions in an open and understandable format.

**17. Cardiff And Vale NHS Trust**

- There is little scope for investment in new therapies other than NICE appraisals which lag behind published evidence. Lack of general availability of modern techniques which require LHB approval.

**18. Macmillan Cancer Support**

- The NHS in Wales needs to strike a balance between expenditure on cancer drugs and expenditure on care. It's vital that LHB budgets are not swallowed up by drugs expenditure and that adequate resources are directed towards improving the quality of cancer care and support.
- Concern over the in-adequate provision of major cancer equipment in Wales, specifically PET Scanners and Linear Accelerators.

**19. The Royal Pharmaceutical Society of Great Britain**

- Faster appraisals of new technologies with a clear timetable are needed.

**20. Royal College of Nursing**

- Adequate, consistent and sustainable funding alongside investment in the education, training and research interests of health professionals is the foundation of successful technological and therapeutic development.
- Capital investment required in technological hardware.

**21. Wales Centre for Health**

- Fragmented commissioning could be resolved by using the networks.
- Joined up approaches essential and should be informed by Community Health Profiles.
- Constraints in service capacity impacts on variation in practice and treatment.
- Increase in the use of chemotherapy results in lack of appropriate facilities to prepare and administer cytotoxic drugs.
- Shortages in health care professionals and specialist pharmacists add to the problem.

## **22. College of Occupational Therapists**

- Better access to therapy advice by the Cancer Networks is needed. There needs to be recognition of the complexity of the needs of cancer patients and of the contribution that therapy services can make.
- A culture of valuing CPD and professional activity for staff groups needs to be developed to enhance knowledge and skills.
- Collaboration across specialist services and the generic services that patients rely on in their own locality is needed.

## **23. The Chartered Society of Physiotherapy in Wales**

- Staffing levels are too low, and work with patients must be prioritised.
- Staff do not have enough time to spend away from patients researching and accessing information or training on new technologies and techniques.
- Training budgets are too low and treating patients will be top priority for over-stretched budgets.
- Physiotherapy services have limited resources for IT development and access to IT will therefore be restricted.

## **24. Sanofi Pasteur MSD**

No response

## **25. Breast Cancer Care**

- Delays over the appraisal of new treatments by the NICE are commonly reported.
- The introduction of the new NICE Single Technology Appraisal process aims to speed up the approval of new treatments for use in the NHS in England and Wales, and ensure they are reviewed closer to receiving a licence. This will require NHS providers to plan in advance and monitor new treatments on the horizon to ensure funding for new treatments is available.

## **26. Association of the British Pharmaceutical Industry**

- Barriers to the adoption of new technologies include shortages in funding, clinical conservatism, delays in assessing the cost effectiveness of new technologies, capacity limitations, uncertainty regarding whether to fund treatments which have yet to go through the NICE / AWMSC process and lack of awareness.
- If new technologies are to be adopted swiftly, it is vital that the NHS in Wales plans appropriately for their introduction and we suggest closer collaboration with the National Horizon Scanning Centre.
- The level of complexity regarding the introduction of new technologies within the Welsh health service is counter productive. The system as it currently operates is poorly understood by many health care professionals within the service leading to significant amounts of confusion and process fatigue.
- A centralised and streamlined system for funding requests would have the multiple benefits of making the introduction of new technologies more straightforward and rapid, increasing the transparency of decision making and most importantly ensuring parity of access for all patients across the

Principality.

- Greater clarity still needs to be given in relation to whether treatments should be funded pre-NICE/AWMSG guidance.

### **27. Pfizer Oncology**

The main barriers are the continuous and rapidly changing landscape within the NHS, negative perception of the industry and delays in trial coordination leading to low recruitment and less experience of new therapies. The barriers could be overcome by a number of initiatives;

- Open invites for industry representatives to discuss horizon scanning or R&D pipeline
- Overcome by simplifying the R&D appraisal process
- WIG groups should be able to have open discussions with leading / all companies and NHS groups
- Negative perceptions of industry overcome by building ethical scientific partnership.

### **28. Society and College of Radiographers**

- There's no coherent development plan / strategy for radiotherapy services development in Wales, a strategy is required to model service needs for future years. The lack of a plan has resulted in difficulty in securing resources for new equipment and replacement equipment e.g. linear accelerators, and in inadequate workforce planning to meet service needs.
- The lack of long term investment in staff training results in less optimal use of their potential skills. If radiographers were trained to work at advanced and consultant levels, bottlenecks could be reduced.
- Lack of partnership arrangements with English education providers which is important due to the geography of Wales.
- Lack of investment in funding and implementing alternative learning methods.

### **29. Roche Products Limited (Jacqui Goom)**

- Better horizon scanning would be key to addressing the barriers.
- NHS needs to do more to ensure that capacity planning mechanisms are in place to enable it to plan effectively for the introduction of new technologies.

### **30. Welsh Consumer Council**

No response.

### **31. Marie Curie Cancer Care Penarth Hospice**

- General poor co-ordination and a lack of funding.

### **32. North East Wales Cancer Partnership Board**

- Wales needs to look forward and be better prepared for the future, by adopting the best technologies and training staff for future need.
- Where ideas and developments are adopted elsewhere in the UK, there should be a system of automatic adoption where appropriate e.g. NICE.
- Wales needs a long term strategy for cancer care, and prepare for the future.
- The main risk is inability to recruit, and a national training programme should be considered.

### **33. Cancer Services Co-ordinating Group**

- Further development of horizon scanning may help planning. Rapid assessment of new therapies by the All Wales Medicines Group / NICE is required.

- Barriers include competition between NHS Trusts, confusion between the commissioning roles of the Local Health Boards and Health Commission Wales, and the roles of the cancer networks. There is a need for greater clarity over the roles of the National Public Health Service for Wales in advising providers and commissioners.

#### **34. Cancer Research UK Cymru**

- It is vital that the Welsh Assembly Government promotes the development of its healthcare professionals and actively plans to respond to the advancement of technology.
- Central management and funding is needed to evaluate equipment needs to address shortages in linear accelerators and ensure appropriate access to CT/PET scanning for Welsh patients. Support is also needed for countrywide clinical specialist training programmes to be introduced alongside a review of current training numbers to meet increased needs.
- Whilst adequate funding plays an important part, it is also imperative that an environment exists where qualified personnel choose to remain in Wales and Welsh institutions can compete on an international scale to attract high quality clinicians from elsewhere in the UK, and the World.
- We would also like to see a focus from the Welsh Assembly on establishing a central point for policy making on public health and screening initiatives, and a mechanism to cost and plan for the introduction of new cancer drugs.

#### **35. Jo's Trust**

- Forthcoming changes in technology will allow for more effective screening, treatment and even prevention of many cancers, and NHS Wales needs to take a strategic, rather than an ad hoc approach to these developments.
- There are several examples available when Wales follows what happens in England after considerable but inexplicable delay.

#### **36. Claire House Children's hospice**

No response.

#### **Question 6**

How can the NHS and the voluntary sector work together more effectively to deliver services?

##### **01. Children's Hospital for Wales**

NR

##### **02. South Wales Gynaecological Oncology Service**

- We are unable to provide basic facilities to allow the voluntary sector to function and support patients.
- There is huge potential role for WAG to utilise voluntary, sector input, e.g. there could be an equivalent organisation to the Prince's Trust.

##### **03. Ceredigion and Mid Wales NHS Trust**

- Hospital at Home is a good example of the need for more linkage between NHS & voluntary sector – voluntary bodies should be allowed better engagement.

##### **04. Velindre NHS Trust**

- There is already major input from the voluntary and charity sector to support cancer services and palliative care in South East Wales.
- There are a large number of joint specialist cancer and palliative medicine nursing posts already being funded by charity.
- Funding of such posts is not made within a strategic framework and might benefit from an umbrella organisation e.g. WCVO in conjunction with the cancer networks to coordinate.
- If voluntary organisation and charities disappeared they would leave a deficit of at least £ 2 m + for funding key professional support staff for Velindre Cancer Services alone.
- Charitable sector should work more closely with the statutory sector.
- Clear strategic planning is needed to define what the NHS will fund and what is to be left to outside agencies.

#### **05. Neath & Port Talbot CHC**

- A better understanding from the NHS as to the role of voluntary agencies.
- Regular meetings with commissioners and all voluntary services in their area would avoid duplication.

#### **06. Tenovus**

- There are already a number of good models of the voluntary sector cooperating with the NHS.
- More pro-active collaboration could achieve even more and WAG should actively collaborate with the charitable sector especially in seeking partnerships for equality services it cannot fully fund. (E.g. Provision of level 2 & 3 psychological care for patients with psychological morbidity related to cancer.

#### **07. South West Wales Cancer Network**

- As a result of the needs assessment of Palliative Care services undertaken in south west Wales much progress has been achieved to improve partnership working by agreeing priorities for funding developments to improve services and avoid duplication of effort.
- Within the South West Wales Cancer Network, Macmillan Cancer Support provided funding to support the following areas of work:
  1. Network development programme;
  2. User Carer Involvement Project;
  3. GP early referral project;
  4. Patient Pathway Project.
- WAG should continue to provide funding to ensure these important areas of work are sustained.

#### **08. Rhondda Cynon Taff Local Health Board**

- There needs to be a clear commissioning strategy, service specifications.
- A transparent tendering process along with pooled budgets would help.
- Direct commissioning of the voluntary sector to deliver appropriate elements of the service would be a potential way forward.

#### **09. Dr Malcolm Adams**

- Tenovus provides a vital role in providing patient information.
- Patients with cancer are inevitably frightened and it is very important that they are able to phone up and talk through their worries with expert specialist nurses who can provide immediate information.
- Funding must be made within a strategic framework and need coordination.

**10. Cardiff Community Health Council**

- Work more collaboratively and communicate availability of funding to NHS.

**11. Conwy & Denbighshire NHS Trust**

- More openness and willingness to listen.
- Encouraging more involvement through forums to shape local services.

**12. Meirionnydd Community Health Council**

- Use of voluntary sector as members of the PLG at the North Wales Cancer Centre is an excellent example where patients have a voice to improve services.

**13. Brecknock & Radnor Community Health Council**

- The voluntary sector and the NHS should work closer together.
- The voluntary sector should work alongside the NHS and not be expected to be a “cheap option” of care.

**14. Community Pharmacy Wales (CPW)**

NR

**15. Wales Centre for Health, Jonathon Gray**

NR

**16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- The voluntary sector provides a valuable service to patients and healthcare professionals looking after people with cancer. Further encouragement and support to joint working and their engagement should be given.

**17. Cardiff And Vale NHS Trust**

- Care of cancer patients should be an adequately funded service, with plans drawn up on the basis of required investment, and not dependant on charitable donations. Voluntary Services could then deal with providing additional quality to the patient experience.

**18. Macmillan Cancer Support**

- Macmillan provide funding for specialist posts, typically for 3 years, on the condition that the NHS would provide the funding thereafter. Concern that Macmillan’s investment is being jeopardised and that Health Trust may be renegeing on funding commitments.
- Would like assurance that the guidelines set out in the WAG’s Voluntary Sector Scheme, particularly around consultation with the sector, are being implemented.

**19. The Royal Pharmaceutical Society of Great Britain**

- The voluntary sector provides a valuable service to patients and healthcare professionals looking after people with cancer.

**20. Royal College of Nursing**

- Organisations such as Macmillan Cancer Support or Tenovus provide crucial support services to patients and carers. It may be helpful for the NHS to support voluntary organisations who are involved in the provision of cancer services to promote the sustainable provision of integrated services.

**21. Wales Centre for Health**



- Important to involve voluntary sector to engage effectively with the public and inform public opinion.

## **22. College of Occupational Therapists**

- In South Wales, the occupational health therapy service in Velindre is working to set up a collaborative OT team across Velindre and the Marie Curie Hospice to help provide continuity of care. It is hoped that this will reduce duplication, enhance good access to notes enabling information to be shared.
- Clear funding agreements, which recognise the specific difficulties that voluntary agencies have with use of money raised by voluntary contribution need to be established.

## **23. The Chartered Society of Physiotherapy in Wales**

- There is a need for the NHS in Wales to recognise the reliance on cancer charities, and look to strengthen the relationship between the two sectors.
- Concordats and clear funding protocols are essential. The NHS should be clear about what it will deliver and the voluntary sector must be clear about what it can provide. There is a need to ensure enhancement and not duplication.

## **24. Sanofi Pasteur MSD**

No response

## **25. Breast Cancer Care**

- Would suggest that a Taskforce set up in Wales with representatives from the NHS and voluntary sector to look at the development of partnerships.
- Suggests that the NHS examines how to more effectively use and disseminate resources that have been developed by the voluntary sector, such as patient information. Also would be useful to examine strategies for referral of patients to support services provided by the voluntary sector.
- Patient organisations from the voluntary sector could help the NHS to consult with users, which could help support the development of NHS services in the future.

## **26. Association of the British Pharmaceutical Industry**

The voluntary sector can offer a great deal of value to the NHS by:

Helping raise awareness of cancer messages, including prevention, early identification and treatment

Providing additional support to patients and ensuring access to other patients who may have shared similar experiences

Contributing expertise and intelligence on the development of cancer services

Ensuring service users are involved in the development of policy

Working as a partner to the NHS in developing research programmes and piloting new approaches to care

For these potential benefits to become a reality, it is essential that voluntary organisations have a voice in the policy-making process.

## **27. Pfizer Oncology**

- There should be a single source of funding for more joint accountability and responsibility by getting patient representatives fully involved in this process.

## **28. Society and College of Radiographers**

No response.

**29. Roche Products Limited (Jacqui Goom)**

See answer 26 above.

**30. Welsh Consumer Council**

- Independent hospices and support organisations have a great deal of expertise in delivering patient centred services for the terminally ill, and can provide an invaluable contribution to the debate as well as serving as a source of data and information.

**31. Marie Curie Cancer Care Penarth Hospice**

- Better understanding of voluntary sector provision, less duplication, facilitation by networks.

**32. North East Wales Cancer Partnership Board**

- The sectors work well together in terms of cancer, however the voluntary sector could work better by being less competitive between themselves and by supporting the NHS not just through investment, but also shaping policy.

**33. Cancer Services Co-ordinating Group**

- A common agenda and goals should be agreed. Are voluntary bodies represented at Network level?
- Better communications between the NHS and patients and carers / relatives is required. More data on the various burdens of cancer, fears and practical issues such as travelling and parking costs would be beneficial.
- Collaborations would be helped by a Government framework that established the policy and strategy and improved the commissioning processes.
- Joint access to better patient information and electronic information sharing would be beneficial.
- The co-ordination of involving voluntary and statutory organisations in cancer services could be improved.

**34. Cancer Research UK Cymru**

No response.

**35. Jo's Trust**

- Jo's Trust has experienced some difficulty in establishing as effective a relationship with Cervical Screening Wales (CSW) as has been established with comparable services in England and Scotland and indeed Europe. For instance, a request to reciprocate website links between Jo's Trust and the CSW was refused due Jo's Trust not having dedicated offices in Wales.

**36. Claire House Children's hospice**

- An example of good practice in England are the models developed by the NW Palliative Care group, working with Children's Hospices. This prevents beds in Hospitals and especially ITU being taken up by children with very complex Health needs who need care not necessarily treatment. The hospices can provide care from qualified and competent people in a home from home environment, at less cost than a Hospital or ITU bed.

**Question 7**

How can the collection and use of data on where the terminally ill spend their last weeks of

months be improved better to inform service provision for those people?

#### **01. Children's Hospital for Wales**

- Paediatric Services are not available to deliver 24 hour, 7 day care in paediatric hospices.
- Paediatric oncology patients have no choice but to die at home with expert nurse support if a hospital death is not wanted.
- 

#### **02. South Wales Gynaecological Oncology Service**

- "You do not get a pig fatter by weighing it". We do not feel we should be spending limited resource on collecting data about the terminally ill, but rather using it to provide clinical services for the terminally ill.

#### **03. Ceredigion and Mid Wales NHS Trust**

- It should be possible to enhance CANISC to capture this data.

#### **04. Velindre NHS Trust**

- It is important that data for the last weeks of life is collected and not only the last few days. Research suggests that most patients wish to die at home but in practice most patients die in hospital.
- Statistics suggest that most people who die in hospital do so in the first week after admission (NHS Confederation 2005). This suggests that an acute event, exacerbation of symptoms or inability to cope with present situation necessitated admission to hospital.
- Pre-emptive care plans should be made.
- Some patients who would have wanted to die at home, die in hospitals. It is important to collect data to help us identify where services could be introduced or refined to prevent hospital admission.
- It is important to identify :-
  1. Where patients state they would wish to die.
  2. Whether this changes as illness progresses.
  3. When patients are dying are the patient and family happy about where they are being cared for.
- In order to develop services to meet patient's needs the following questions should be asked:
  1. If a patient is admitted to hospital (or other inpatient/hospice unit) what prompted the admission?
  2. Was the decision to admit taken by a professional or requested by the patient or family.
  3. If patient/family request, why did they feel the need for admission?
  4. How long had the patient been ill, what level of professional and social support had been required in the previous weeks and what had changed?
  5. Was the patient/family happy with the care and support at home?
  6. Was the patient/family happy with the decision to admit to hospital?
  7. What, if anything could have been provided at home to prevent hospital admission?

A centrally accessible database is required for this data, e.g. Integrated Care Pathway (ICP) which was used for the last days of life, it's managed successfully and data collection is ongoing.

Most healthcare professional are familiar with the use of the ICP, it could therefore be used for this if agreed by the Wales collaborative Care Pathway group.

ISCO could be used, but not everyone can access it.

**05. Neath & Port Talbot CHC**

Analysis of data in the past has not been objective.

**06. Tenovus**

Important to have data on where the terminally ill themselves wish to die.  
More data collection is necessary.

**07. South West Wales Cancer Network**

- There is much evidence to support the need for choice in place of care and place of death, however, the Palliative Care needs assessment identified that in south west Wales there is limited choice about the care setting.
- The Network would welcome investment in further studies to identify local needs.

**08. Rhondda Cynon Taff Local Health Board**

- IT systems / programmes should be available in primary and secondary care to monitor this data. This should inform commissioning.
- Work needs to be done around patients choice and indeed whether they feel they have had it.
- We need to understand the barriers – improve intermediate care services and incorporate data collection and audit into nGMS contract / OOHs contractor information.

**09. Dr Malcolm Adams**

- We need information as to the precise circumstances which determine why a patient dies in hospital.
- Patient's wishes may change.
- No adequate information currently available.
- It is important to determine whether the circumstances leading to where a patient dies are related to the illness or home support.

**10. Cardiff Community Health Council**

- Database needs to be set up with more discussion of patient choice.

**11. Conwy & Denbighshire NHS Trust**

- Having the palliative care department utilising the CANISC database system – integrated with the PAS Database system.
- Identify where people die in order to be able to plot trends to redesign the service to ensure the gaps are covered

**12. Meirionnydd Community Health Council**

- Collection of data necessary – but method of funding needs changing to provide a service for those people in rural areas. Consideration must be given to the geographical and rural situation.
- Funding per head of the population for Palliative Care in rural areas will never give an equal service.

**13. Brecknock & Radnor Community Health Council**

- Often patients have to go into hospital because it is impossible to provide a 24hr nursing care at home.
- A date base on terminally ill patient and their needs could be kept to see how services

could be better delivered.

**14. Community Pharmacy Wales (CPW)**

NR

**15. Wales Centre for Health, Jonathon Gray**

- We have piloted, but would ask for more work on addressing family history of cancer in terminally ill so that screening can be put in place for surviving family.

**16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- Information sharing across the care setting is paramount. At present community pharmacy is excluded from information sharing via care pathways, but receives information via the patient or family.
- The contractual requirement for GP's to hold a palliative care register and discuss this register with a multidisciplinary team is encouraging. However the information pertinent to medication should be shared with a patient designated pharmacy and the practice should be encouraged to liaise and include the patients designated pharmacy within the multidisciplinary team.
- Patients, carers and all health professionals should be consulted on palliative care service provision and best practice shared across Wales.

**17. Cardiff And Vale NHS Trust**

- Need data on delayed discharge to determine requirement of social services.

**18. Macmillan Cancer Support**

- Data collection on where people die or receive end of life care needs to be mapped against other data in order to better understand what factors influence end of life care.
- It would be valuable to map where patients die against the availability of 24 hours specialist palliative care provision and Out of Hours arrangements, as these services are fundamental pre-requisites of good quality end of life care.

**19. The Royal Pharmaceutical Society of Great Britain**

- Important to ascertain from terminally ill patients where they wish to die, and to be able to provide the support necessary for patients who wish to die at home.
- Access to controlled drugs and other palliative care medicines is often difficult, especially out of hours.
- Patients and carers should be asked of their experiences and their answers used to inform future service provision.

**20. Royal College of Nursing**

NR

**21. Wales Centre for Health**

NR

**22. College of Occupational Therapists**

- The Integrated Care Pathway is being used to gather data on last days, but services could be better informed by data gathered across health and social care.
- Specific data for people with cancer could show whether referrals are made to therapists, waiting times for social care provision, allocation to social workers and meeting times for panels to approve care package finance, to better inform service provision for people.

**23. The Chartered Society of Physiotherapy in Wales**

- There should be one 'key worker' for the person and their family. Any information about wishes should go to that person and planning put in place to try and achieve those wishes.
- The patient's wishes must be central and an emphasis on rehabilitation and 'Living well with cancer' must be the philosophy. This requires investment.

**24. Sanofi Pasteur MSD**

No response

**25. Breast Cancer Care**

- A recent study carried out by King's College London that examined terminally ill cancer patients' wishes to die at home recommends a five pronged approach to make it easier for people to choose to die at home if they wish:
  - families should have more say and support in what happens
  - there should be public education about the issue
  - continued effort to improve home care facilities
  - early risk assessment
  - palliative care training for nurses and home help as well as experts
- The lack of data on the number of people living with secondary breast cancer greatly impedes the planning of services for people living with the condition. Without such data it is extremely difficult to ensure the right services are being provided for this group of patients.

**26. Association of the British Pharmaceutical Industry**

- Electronic patient records present an opportunity to improve the quantity and quality of data recorded on the location of end of life care. Cancer networks should also be required to demonstrate that they have offered all patients a realistic choice about where they wish to be cared for.
- Once robust data on the choices and preferences of patients is available, it should be used to inform commissioning, ensuring that sufficient capacity is available to enable all patients access to suitable palliative care.

**27. Pfizer Oncology**

- This requires good IT links to essential services, and the ability to audit at local level.
- Services could be redesigned to take account of relatives, patients and carers.

**28. Society and College of Radiographers**

- Improved tracking of palliative patients will highlight areas of low service provision.
- Inequality of services available in rural areas, patients often referred to acute services due to unavailability of 24hr support and guidance at home.
- Improve co-ordination of support for patients and help for professionals and GP's to look after patients in the community.

**29. Roche Products Limited (Jacqui Goom)**

See answer 26 above.

**30. Welsh Consumer Council**

- More research should be commissioned on public attitudes to dying prior to further engagement with people on the planning and provision of services.

**31. Marie Curie Cancer Care Penarth Hospice**

- This is vital if patients are going to be cared for appropriately in a place of their choice. The All Wales pathway is one way to begin to address the collection of vital data but more needs to be done.

### **32. North East Wales Cancer Partnership Board**

- The recent Tebbitt report on Palliative Care in Wales highlighted the fact that too many people were dying in hospital, as well as major resource deficits in community services. There should be adequate support for patients who want to die at home.
- Palliative care should be a major priority for Wales as the ageing population and levels of chronic disease put pressure on the service.

### **33. Cancer Services Co-ordinating Group**

- Many people wish to die at home, but lack of palliative care support makes this impossible. Past experience suggests that provision is likely to be patchy.
- Data collection for those who are dying should be provided if most professionals are implementing the pathway for life.
- Subject to gaining informed consent from patients, clinical auditing of care would help to ensure quality assurance of identified good practices using a cancer information system of high validity, completeness and timeliness linked to a population-based cancer registration system.

### **34. Cancer Research UK Cymru**

No response.

### **35. Jo's Trust**

- More information needs to be collected to ensure terminally ill patient wishes are adequately respected.

### **36. Claire House Children's hospice**

- A database being developed at Alderhey Children's hospital is a good model, leading to Care of the Dying Pathways being agreed with individual patients, allowing the necessary resources to be planned for and used more effectively.
- Individual Agreements re Ventilation and Resuscitation should be shared with all partners.

### **Question 8**

There are a number of issues around prescribing and the cost of drugs:

**8(i)** What should be done and by whom to reduce continued prescribing of inappropriate drugs?

**8(ii)** Should people who are prepared to pay privately for drugs not available to them on the NHS, be able to do so without having to become private patients and having to pay for all their treatment?

**8(iii)** Do doctors, pharmacists and other health professionals have adequate access to *independent* advice and guidance on the prescribing of drugs?

### **01. Children's Hospital for Wales**

(i) Paediatric oncology has a problem with GPs refusing to prescribe drugs rather than prescribing inappropriately.

(ii) Yes, continuity of care through same service providers is important assuming health professionals happy to supervise therapy.

(iii) Yes

## **02. South Wales Gynaecological Oncology Service**

- (i) Ensure that the patient is managed by the correct pathway by the correct professionals!
- (ii) This is patient choice and they should not have to pay for all their treatment. Useful drugs should be available to them.
- (iii) Yes

## **03. Ceredigion and Mid Wales NHS Trust**

- (i) Within each network there should be a patient pathway with explicit guidance on chemotherapy regimes. Regular audit by cancer network required.
- (ii) This sets a dangerous precedent and puts clinicians in an invidious position.
- (iii) Yes

## **04. Velindre NHS Trust**

- (i)
- There needs to be appropriate audits of drug usage to verify compliance with good practice, standards and guidelines.
  - Pharmacists are in the ideal position to perform these if the relevant information and professional time is available.
  - The current system may prevent people from taking reasonable steps to improve their care when the NHS cannot afford to do so.
  - Patients are often the most powerful group at initiating a review of drugs, by simply asking their doctor if they really still need to take all they are taking. A campaign to raise public awareness may help, such as *'ask your doctor' – "Do I really need to take this?"*
- (ii)
- However the service is funded in the future it is essential that there is consistency of care irrespective of patient means.
  - The NHS Act (1948) clearly sets out health service provision as free at the point of delivery and service users can chose to 'opt out' of this system to access treatment in it's entirety. Any reforms to this Act must ensure that NHS Wales has national policies over what is not funded. This cannot be left to be decided at a local level.
- (iii)
- It is essential that Wales be part of the NICE process to ensure that an adequate pool of independent expert advice is available for guidance on appropriate prescribing of drugs.
  - Perhaps WAG could take a more pro-active role in negotiating with Pharmaceutical companies for Wales-wide contracts. This occurs in other European countries and helps to keep costs down.
  - The Drugs and Therapeutics Bulletin was perhaps a little long winded at times, but independent advice is essential, otherwise it is only the pharmaceutical industry that will have the role of disseminating information.

## **05. Neath & Port Talbot CHC**

- (i) More training on interaction of drugs for hospital doctor & GPs. A pharmacist should always be a member of the multi-disciplinary team.
- (ii) Yes, as long as the drugs are licensed in this country.



(iii) Not sure.

**06. Tenovus**

(i) Inappropriate drug prescribing needs to be monitored by an audit process and this would best lead by pharmacy staff.

(ii) This raises a very major issue about the balance between equality of care and an individual's right to supplement therapy with evidence based improvements. A thorough debate needs to be undertaken and patient's views considered.

(iii) Yes.

**07. South West Wales Cancer Network**

(i) Improved data collection and audit through the introduction of electronic prescribing systems for example, Clinisys Chemocare.

(ii) It would be more appropriate if the need for such practice is eliminated by ensuring that all licensed treatments are available in a more equitable manner with cost effective treatments available through the NHS.

(iii) This information is available through:

- Results of clinical trials;
- Evaluation by the National Institute for Health & Clinical Excellence, the All-Wales Medicines Partnership;
- Collaborative working with the New London Cancer Group.

**See appendix 1 for list of cancer trials across the South West Wales Cancer Network area**

**08. Rhondda Cynon Taff Local Health Board**

(i)

- Education and communication with clinical staff is required. It should be part of the core clinical curriculum.
- LHBs and Trusts need to work collaboratively.

(ii)

- We should not single out cancer drugs in this debate. This is an ethical issue and needs a national debate e.g. who pays for the side effects of the drug?
- There should be an element of choice for parts of treatment.

(iii)

- Depends what is meant by independent.
- NICE / Bro Taf Formulary advice is available, which is independent from drug companies.
- The Drugs and Therapeutics Bulletin is an excellent source of independent advice which has now been lost. This is a very real concern.

**09. Dr Malcolm Adams**

(i)

- We need appropriate audits of drug usage and compliance with NICE guidelines.
- Audits across the UK have shown variable usage of drugs recommended by NIC guidelines. We need audits of drug usage in Wales to verify compliance with good practice, standards and guidelines. Pharmacists are in the ideal position to perform

these if the relevant information and professional time is available.

(ii) N/R

(iii) N/R

#### **10. Cardiff Community Health Council**

(i) NICE guidance must be adhered to. Re-introduce prescription charges.

(ii) Yes – re- introduce prescription charges.

(iii) All have adequate access but only Pharmacists are the experts in drug prescribing.

#### **11. Conwy & Denbighshire NHS Trust**

(i)

- More standardisation of available drugs – thus reducing the chance of prescribing inappropriately. Seeking clarification or 2<sup>nd</sup> opinion for exceptional cases
- To have network protocols for the provision of uniformity in the prescribing of drugs

(ii)

- Patients should be able to have the drugs if they are willing to pay but in the present financial climate, this should be carried out across the whole of that patients' treatment process, from the first consultation through to the final discharge consultation and investigations performed.

(iii)

- Not via the internet/intranet – as not all health professionals have access to the internet let alone a computer.
- Some information is not readily disseminated to front line staff.

#### **12. Meirionnydd Community Health Council**

NR.

#### **13. Brecknock & Radnor Community Health Council**

(i)

- A better use of the care pathway for the last days of life would prevent unnecessary drugs being given.

(ii)

- Patients should not have to pay for their drugs at all. Patients with cancer can often end up in debt to pay for these drugs.

(iii)

- Yes, better than it was.

#### **14. Community Pharmacy Wales (CPW)**

(i)

- A 'Medicines Use Review' service has been introduced as part of the New Community Pharmacy Contract and a clinical medication review service is available for commissioning as an enhanced service. If supported by specialist training this Enhanced Service could be used to review patient's cancer medication on a domiciliary visit by a community pharmacist. This would reduce the incidents of inappropriate prescribing and improve patient concordance.
- Independent Prescribing rights have recently been extended to community pharmacists and over time this will provide community pharmacists with the

opportunity to become more involved in the management of patients suffering from chronic conditions. This will facilitate community pharmacists in becoming an integral part of a multidisciplinary response to the management of cancer patients.

(ii)

- CPW feels that the act of prescribing by a GP should be an act of confirmation that the medicines being planned for the patient are in their opinion both necessary and appropriate. CPW believes that all medication that will be of benefit to cancer patients, or will improve their quality of life, should be available to the patient. If the NHS in Wales is unable to make this medication available to patients as part of the NHS service then it should facilitate access to these medicines by patients who are able or willing to cover the cost of the medicines themselves with the minimum of additional barriers and bureaucracy.

(iii)

- Community pharmacists have access to independent advice through many sources including an in-house journal, NICE Guidelines, the Wales Medicines Partnership and access to the Medicines Information Service provided by the trusts.
- Recent moves to provide community pharmacists with access to the Electronic Library for Health have further improved their access to independent information although we have recently been made aware that planned funding for this element has been withdrawn.

#### **15. Wales Centre for Health, Jonathon Gray**

NR

#### **16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

(i)

- Better use could be made of pharmacists expertise in medicines. All Cancer Networks should have access to dedicated pharmaceutical advice.
- A specialist network pharmacist would be available to offer medicine management advice, be aware of new treatment appraisals and support the development, audit and dissemination of clinical guidelines.
- The utilisation of independent and supplementary prescribing by pharmacists is another development which can support improved use of medicines.
- Pharmacist in both secondary care and community settings are successfully carrying out patient centred medication reviews, highlighting compliance problems and inappropriate prescribing. There is scope to develop these services.
- Pharmaceutical advisors based in LHB's now providing GPs with evidence based advice on prescribing and cost effectiveness of drugs. The compliance to this advice can be audited via prescribing data and reduce the knock on effect in other care settings.

(ii)

- Cancer drugs cannot be taken in isolation when considering this question and any debate on resources and the potential rationing of access to some therapies should be had in an open forum with the people of Wales and not taking in isolation depending on the diagnosed condition , the debate should consider:

1. Can patients mix and match NHS and private care, or should they have to choose

- between entirely NHS or entirely private care
2. Patients have already paid for their NHS care through their taxes, and if they want something extra why shouldn't they pay for it privately or through health insurance?
  3. Other UK health services are successfully provided through mixing private and NHS care, notably dentistry and optical services, pharmacy. It would be unfair to penalize cancer patients by denying them access to NHS care if they purchase some care privately, particularly as cancer care is very expensive.
  4. Experience of other European countries.

(iii)

- Continued support for these initiatives must be forthcoming with the availability of online evidence based prescribing through a user friendly portal being of paramount importance to meet the demands of the profession. This must be available to professionals in all care settings.

### **17. Cardiff And Vale NHS Trust**

(i)

- All cancer care should be protocol driven, following agreement with Primary and Secondary sectors.

(ii)

- The NHS should provide the best possible NHS care for all patients within existing resource. Any patient should be able to purchase additional elements that are important to them. Care should be equitable across LHB boundaries.

(iii)

- Health Professionals must analyse evidence from as many sources as possible and prescribe for individual patients in line with their needs.

### **18. Macmillan Cancer Support**

- (i) It is estimated that half of prescribed medicines in Wales are not taken. Effective prescribing requires good communication between clinicians and patients about treatment options and possible side effects.
- (ii) No view on this question.
- (iii) No view on this question – Stresses that patients need information and support about prescribed drugs and their side effects in order to make informed decisions.

### **19. The Royal Pharmaceutical Society of Great Britain**

- (i) The CSCG Cancer Standards and All Wales guidelines ensure that appropriate treatments are prescribed. Medication reviews by pharmacists in primary and secondary care can highlight problems with medication including compliance issues and the prescribing of unnecessary drugs. Pharmaceutical advisers in primary care are now providing advice to GPs on prescribing.
- (ii) Providing a drug treatment to a patient involves prescribing, dispensing and usually administration. If a patient were to pay for a drug which was not available on the NHS who would provide to associated costs? The administration of a system of charging patients for drugs would also incur costs. Equity of care is important – if NHS Wales were to allow patients to pay for expensive new drugs whilst remaining NHS patients, it would not be long before the patient who couldn't afford treatment

became headline news. The view of pharmacists in Wales is that the disadvantages to NHS Wales in allowing patients to pay for drugs whilst remaining NHS patients outweigh any advantages.

- (iii) The expansion of health evidence sites on HOWIS and the Access to Knowledge initiative has improved information available to health professionals. Availability of HOWIS within and beyond secondary care may need improvement.

## **20. Royal College of Nursing**

NR

## **21. Wales Centre for Health**

- (i) More effort should be made to engage and communicate with the public. A structured and robust strategy needed to effectively harness the power of the media, community leaders, voluntary groups and stakeholders.
- (ii) Cautious approach needed. Generally the policy is probably unwise, and could be inequitable. Clinicians should have a pivotal role in deciding the merits of the case.
- (iii) Current mechanisms for issuing independent and authoritative guidance in this area needs to be strengthened.

## **22. College of Occupational Therapists**

- (i) Growing evidence that the use of therapy, relaxation and creative techniques can help people with cancer to develop psychological strength, confidence and control, helps in pain management and reduces anxiety and depression. Greater provision of therapy services may impact on the drug provision in such areas.
- (ii) No view.
- (iii) No view as occupational therapists are not able to prescribe.

## **23. The Chartered Society of Physiotherapy in Wales**

- (i) The CSP supports key involvement of the pharmacy profession working in partnership with those who can prescribe. This is a work area for the clinical networks.
- (ii) No definitive view – members are divided.
- (iii) No view at present – once physiotherapists are supplementary prescribers, there will be advantages for those who work in the field of cancer care to be able to develop the role and it will be essential for them to have appropriate training, advice and guidance.

## **24. Sanofi Pasteur MSD**

No response

## **25. Breast Cancer Care**

- (i) Clear guidance on new treatments from NICE along with clinical guidance on treatment should help to ensure appropriate prescribing. However, to ensure this happens implementation of guidance needs to be supported and adequate scrutiny of implementation carried out.
- (ii) Breast Cancer Care believes all effective breast cancer treatments should be available on the NHS. However, if there is a situation in which a breast cancer drug is not available on the NHS, patients should *not* have to become private patients and have to pay for all their treatment in order to access this one treatment. It is important that patients can continue to access the support services available through the NHS.
- (iii) NICE should provide independent advice and guidance on the prescribing of drugs.

## **26. Association of the British Pharmaceutical Industry**

- (i) Local Medicines and Therapeutics Committees can play an important role in ensuring that patients are not prescribed inappropriate or ineffective medicines and that, equally, they are given access to treatments which could be beneficial in terms of either survival or quality of life. For those cancer patients on long term medication, medicines utilisation reviews can play an important role in ensuring that they receive appropriate medication.
- (ii) The primary objective should remain that all cancer patients would have access to all medications which are proven to be clinically and cost effective for their condition. All eligible patients should be given access to the best medicines, irrespective of their ability to pay. It is only right that patients should be able to utilise whatever resource is available to them to secure treatment including private funds.
- (iii) There should be more collaboration across trusts and networks to ensure consistency and equity for all patients. NICE/AWMSG guidance should be promoted more proactively to health professionals, ensuring that they are aware of both positive and negative appraisals so as to inform prescribing decisions. There is also the need for the comprehensive monitoring of the adoption and implementation of NICE/AWMSG guidance.

#### **27. Pfizer Oncology**

- (i) The inappropriate prescribing of drugs could be reduced by allowing LHBs to flag up patients that are on certain medications that are suitable to change, prescribing advisers, the industry working with NHS to meet the goals of both sides, MTS / Peer reviews, pathways / protocols and peer review of the networks, audits and accountability.
- (ii) Patients should be allowed to pay for treatment to relieve pressure for the NHS current financial environment. However, patients should not be forced to pay for part or all treatment if all their financial ability does not allow them to do so.
- (iii) No, for truly independent advice and guidance.

#### **28. Society and College of Radiographers**

- (i) Electronic prescribing of all drugs is essential to enable meaningful audit and monitoring changes to practice; agreed protocols for chemotherapy across Wales, and improved early forecasting of new drugs, their use and implementation consequence on service provision.
- (ii) There may be a case if cost is the only reason it is not available on the NHS, However new treatments and drugs may have other service consequences – mode of delivery which may require additional manpower resources to deliver. Ethically difficult to support
- (iii) No response.

#### **29. Roche Products Limited (Jacqui Goom)**

See answer 26 above.

#### **30. Welsh Consumer Council**

No response.

#### **31. Marie Curie Cancer Care Penarth Hospice**

- (i) Agreed formularies should be adhered to, variances collected and then challenged. Pharmacists have a key role in such matters.
- (ii) No response.
- (iii) This is variable, for example the Marie Curie hospice in Penarth provides symptom control advice for most of Wales out of hours, this information should be available more locally. Nurse prescribing has not developed in Wales as it has in

England, this is a missed opportunity.

### **32. North East Wales Cancer Partnership Board**

- (i) Organisations that employ the 'prescribers' should be more prescriptive of what can and what cannot be prescribed. This control can then be used to an advantage by excluding post code prescribing and introducing earlier new cancer drugs in a controlled but accessible way.
- (ii) The reality is that if you are a private patient that is what you should be until they decide/or otherwise to revert to NHS.
- (iii) Yes

### **33. Cancer Services Co-ordinating Group**

- (i) In terms of hospital care, this is a matter for clinical audit and MDT as well as hospital drugs and therapeutics. For GPs it is possible to monitor prescribing. Formularies can be more effective when all these stakeholders are involved in decision making. All- Wales national guidance is needed for statutory bodies with high percentages of clinicians, specialist nurses and senior NHS staff.
- (ii) This raises ethical questions. A Government policy is needed to determine the issue as decisions taken at a local level could lead to inequalities.
- (iii) Generally, there is adequate guidance. The National Public Health Service could be well placed to provide independent advice and guidance.

### **34. Cancer Research UK Cymru**

No response.

### **35. Jo's Trust**

- (i) No response.
- (ii) it is essential that however the health service is funded that all patients irrespective of economic circumstances have access to the most up to date therapies, screening and immunisation methods.
- (iii) Jo's Trust would like to see Wales continue to heed the recommendations of NICE and related bodies regarding the timely introduction of new technologies and treatments.

### **36. Claire House Children's hospice**

- (i) Many children have such complex needs that their treatment is very individual, and innovative care and drug regimes are needed to keep them comfortable. Consultants should be empowered to prescribe whatever they think appropriate.
- (ii) Any drugs deemed appropriate by the partners in care should be made available on the NHS. Any other method would lead to a 2 tier system, which would be particularly unfair when applied to children.
- (iii) Doctors and pharmacists would be best placed to answer this question. Claire's hospice run training courses for GPs, consultants and the Palliative Care Team so that they can meet regularly to discuss issues.

### **Question 9**

Are services centred on the patient, with service users consulted? If not what are the reasons for this and how can patient involvement be improved?

### **01. Children's Hospital for Wales**

- Paediatric services is centred on service users but doesn't consult them often.

### **02. South Wales Gynaecological Oncology Service**

- Services throughout Wales are skewed to political and medical interests with the patient coming low down on the list of priorities.

### **03. Ceredigion and Mid Wales NHS Trust**

- To some extent yes, but room for increased patient and carer involvement.

### **04. Velindre NHS Trust**

- Major steps have been taken to integrate the patient perspective into cancer services and palliative medicine with patient representatives now being an integral part of clinical governance, ethics and R&D committees.
- CHCs play a vital role in supporting the interest of the patient with trusts, commissioners and government and identifying deficiencies and gaps in the service.
- The vital role of patient involvement is now totally accepted, supported and encouraged by health professionals.

### **05. Neath & Port Talbot CHC**

- Professionals feel the services are centred around the patient, but in the main it is not.
- Patients with cancer move around hospitals and teams because they cannot always be dealt with by the consultant. The whole situation is complex and confusing.
- The setting up of cancer centres within the grounds of acute hospitals would at least mean that patients could visit their surgeon and oncologist at the same time.
- Patient groups are useful.

### **06. Tenovus**

- There has been improvement but there is still some way to go.
- Service users are now routinely involved this needs to be continually increased.

### **07. South West Wales Cancer Network**

- The South West Wales Cancer Network led this initiative on behalf of the 3 cancer networks in Wales and as a result of this work, a User Carer Involvement Strategy for cancer patients was published in January 2006. Macmillan Cancer Support undertook an evaluation of the project and the final report has been presented to the Cancer Services Co-ordinating Group Core Group. This was the first project of its kind in Wales with a particular focus on the needs of cancer patient and their carers.
- The Health Inspectorate Wales review undertaken during 2005 highlighted the need to ensure this work continued and the final report included a recommendation to the Welsh Assembly Government indicating that this work should be fully resourced.
- It is not clear whether the Welsh Assembly Government will allocate funding to support implementation of the strategy.

### **08. Rhondda Cynon Taff Local Health Board**

- Service users are included in the Cancer Network Framework.
- The LHB has established Valley Fora.

### **09. Dr Malcolm Adams**

NR

### **10. Cardiff Community Health Council**

- No – patients in cancer centres are consulted but in general hospitals services are



patchy.

- Anonymous patient satisfaction survey.
- Patients should be consulted on the questionnaire to ensure that the right questions are asked.

#### **11. Conwy & Denbighshire NHS Trust**

- Service
- More involvement
- Culture to become more open

#### **12. Meirionnydd Community Health Council**

NR

#### **13. Brecknock & Radnor Community Health Council**

- Velindre is excellent at involving patients in treatment options and care.

#### **14. Community Pharmacy Wales (CPW)**

- CPW is not able to comment on this section from the patient involvement perspective. From the perspective of a stakeholder and member of the primary care team CPW are regularly disappointed with the level of engagement with the profession.

#### **15. Wales Centre for Health, Jonathon Gray**

- There have been good attempts through the networks but I would suggest more coordinated approach with charities in developing agendas for services.

#### **16. Welsh Executive of the Royal Pharmaceutical Society of Great Britain**

- There has been some improvement in patient- centred services and this improvement should be encouraged through constructive feed back from service users.
- A mechanism to allow patients to share their experiences and evaluate the service they have received would be useful. Additionally the sharing of good practice across Wales should be the norm.

#### **17. Cardiff And Vale NHS Trust**

- Services are centred on patients and their families.

#### **18. Macmillan Cancer Support**

- Services are still not sufficiently patient centred. Patients need information and support throughout the cancer journey and people affected by cancer need a stronger voice in the design and delivery of cancer services.
- No WAG funding for cancer specific patient involvement. Macmillan is currently providing short term funding for patient involvement projects in the 3 cancer networks until 2006/2007. The long term sustainability of user involvement in cancer services is in jeopardy unless the WAG commits long term funding to these projects. Would like to see a clear strategy developed, including funding, for supporting patient involvement in cancer services.
- Patients should be given a greater say in everyday decisions about their treatment.
- Macmillan would like to see a baseline cancer patient survey, repeated on a regular basis, which would measure all aspects of the patient experience in Wales.
- Provision of information and referral to specialist sources of advice needs to be built into care pathways.

- Research published in June 2006 suggests that 91% of cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer. There is also evidence to show that patients are not receiving advice about existing welfare benefits. Macmillan wants all cancer patients to be offered specialist benefit advice at diagnosis and at key points thereafter in the patient journey. Macmillan want cancer patients to have their travel costs reimbursed through the Hospital Travel Costs Scheme without a means test, for hospitals to exempt cancer patients from parking charges and for the HTCS to be properly publicised.
- Macmillan would like to see an implementation strategy for the NICE supportive and palliative care guidance as a core component of a cancer plan for Wales.
- Not aware of the actions taken as a result of the Tebbit Review of Palliative Care Services in Wales.
- Concerned that palliative care is not a feature of Designed for Life, and would like WAG to produce a strategy for palliative care in Wales as part of an overarching cancer strategy or plan.
- Would like to see each cancer network appoint a carer's lead and develop a strategy for identifying carers and advising about their carers' rights and services.
- Absence of any strategic direction for cancer services. Macmillan would like to see the WAG develop a long term strategy or cancer plan for Wales in order to drive forward the modernisation of cancer services, with ringfenced funding and performance targets against which to measure progress.

#### **19. The Royal Pharmaceutical Society of Great Britain**

- Patient centred services have improved, but we must continue to listen to patients' views. However, it's often difficult as patients often provide over enthusiastic praise or have suffered an unfortunate experience.

#### **20. Royal College of Nursing**

- Nursing care must be patient centred care.

#### **21. Wales Centre for Health**

- A co-ordinated approach with charities in developing agendas for services is essential.

#### **22. College of Occupational Therapists**

- The way in which services are commissioned and the financial constraints will impact on the provision of equitable services and thus on the achievement of a truly patient centred service.

#### **23. The Chartered Society of Physiotherapy in Wales**

- Structures and processes that are clearly evident in the NHS make it difficult to achieve the goal of putting the patient at the centre of service provision and future service planning.
- It would be for patient groups and advocates to say how far they feel they have been consulted in the provision and development of services.
- Perhaps a solution would be to have a patient reference group as a sub-group of the cancer network and a patient or their advocate on the network group.

#### **24. Sanofi Pasteur MSD**

No response

#### **25. Breast Cancer Care**

- User involvement in Wales could be improved.
- Focus groups, patient involvement groups, forums on the internet are all ways to

capture user involvement.

- User involvement is about making sure that patients' and families' views are represented.
- It is important that the NHS in Wales undertakes a comprehensive consultation on user involvement. Voluntary organisations such as Breast Cancer Care could support the further development of user involvement in Wales and help the NHS access patients for their views.
- Breast Cancer Care is currently conducting a survey which aims to gather patients' views and experiences of breast cancer treatment, support services and information in Wales. The findings of the survey will be shared with the Committee in due course.

#### **26. Association of the British Pharmaceutical Industry**

- We recommend that NHS Wales undertakes regular surveys of the cancer patient experience so as to achieve patient centred services.

#### **27. Pfizer Oncology**

- Patient involvement could be improved by the development of jointly written and signed treatment management plans by patient and MDT. Inviting patient experience to be inputted on services and potential changes may assist the future patient led NHS.

#### **28. Society and College of Radiographers**

- Useful to review radiotherapy service arrangements and to consider what will be the requirements for 2011 and 2015. Important to involve service users to ascertain their expectations and to build a patient focused service.

#### **29. Roche Products Limited (Jacqui Goom)**

- Patients and voluntary sector groups should be involved at a much earlier stage of policy development.
- 

#### **30. Welsh Consumer Council**

- The general principles of services centred on the patient and patient involvement in the development of services are vital.
- It is important that palliative care services available are flexible, and that patients and their carers have a direct input into their design.
- Hospice services require an more pro-active commitment to meet the diverse needs present in a bilingual, multilingual, multi cultural and multi faith society.

#### **31. Marie Curie Cancer Care Penarth Hospice**

- Many services do not appear to be patient centred but process driven. Patient 'experts' and representatives should be better utilised.

#### **32. North East Wales Cancer Partnership Board**

- Many Boards and Committees have patient reps integral to their membership which provides an extremely helpful viewpoint.
- User involvement needs to be more focused and assessed in terms of its impact to the service development.

#### **33. Cancer Services Co-ordinating Group**

- Things are moving in the right direction, but come more patient friendly.
- Most NHS Trusts appear to discuss issues with patient/service user groups. However the extent that these discussions are influenced by decisions taken by the Trusts needs to be researched.

- A single, electronic patient-centric cancer record which is used by primary, secondary, tertiary and palliative care services would be a major improvement.
- Improvements have been made in this area, however there is a need to bring all of the separate strands together in a more cohesive way.
- To ensure less duplication and effective communication, there is a need to cost cancer services and to ensure effective manpower and equipment provision and ensure effective involvement of users and carers in the decision making process and make the system sustainable.

#### **34. Cancer Research UK Cymru**

- Patient involvement in their care and treatment will be improved by the provision of information at all points along the patient pathway, whether this involves treatment options, choice of hospital or health outcomes.
- Patient involvement should be embedded into the work of cancer networks as a matter of principle. The Cancer Services Collaborative projects have demonstrated that significant improvements can be made by re-designing services with the patient at the centre of the process, and by involving them throughout the process.

#### **35. Jo's Trust**

- It is essential for Wales to continue to maximise representative patient involvement in NHS management committees, ethical and research committees to ensure the patient's perspective is adequately presented.

#### **36. Claire House Children's hospice**

- Claire House employ a social worker and a family support worker and hold regular meetings for parents and siblings. The difficulty lies in providing suitable services for patients within the 16 – 25 age range, who often die in inappropriate places.

## Annex 2

### Health and Social Services Committee

#### Policy Review: Cancer Services for the People of Wales

##### Analysis of consultation responses September 2006

The written consultation exercise was carried out between April and July 2006. There were 36 organisational responses, with a good mix between statutory and voluntary bodies. Some responses comprised a number of individual contributions and there is some repetition because individuals have responded to the consultation via a number of routes. Two of the responses are from the same organisation but with different authors (16) and (19); (15) and (21).

A number of responses referred to paediatric services, but there were no responses from organisations representing ethnic minority groups.

The main issues raised by respondents and the key themes identified are set out under each of the three overarching *Terms of Reference* headings. There are sub headings which, for sections 2 and 3, correspond to the questions asked in the consultation questionnaire. Numbers in brackets refer the reader to the appropriate consultation response.

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## **1. To review equality of provision and equity of access to the full range of high quality cancer services that meet the National Cancer Standards**

### **i) KEY MESSAGES**

- ◆ Several respondents argued that many of the issues highlighted in their responses are indicative of the broader absence of any strategic direction for cancer services. In Wales there is no organisation responsible for cancer services answerable to the public for the quality of cancer care throughout Wales.
- ◆ There needs to be a baseline audit against the Cancer Standards in order to inform the question about whether there is equality of provision and equity of access to the full range of cancer services in Wales.
- ◆ Services for certain cancers are better organised and resourced than others. There is a tension with having large bureaucracies which starve other clinical areas of cash (2). There is a 'grave lack of therapy services in cancer care' (23).
- ◆ Commissioning is overly complicated. Suggestions are made for how best to tackle this but a key message is that patients do not, and should not, have to consider which organisation is responsible for which part of their care. Patients want a seamless provision of health and social care. 'Living well with cancer' and the recognition of cancer as a chronic condition are not yet reflected in the service commissioning.
- ◆ The cancer pathway is a complex clinical journey, involving departments within hospitals and often different hospitals and organisations. The need for a single electronic record so that systems are able to talk to each other across hospitals, services and boundaries is emphasised repeatedly.
- ◆ An environment needs to exist where qualified personnel stay in Wales. There is a skills shortage, especially, in radiographic (for radiotherapy) medical physics, pharmacy. This is not unique to Wales but is said to be exaggerated by the developments in Cancer Services in England. (11)
- ◆ Central management and funding is needed to evaluate equipment needs to address shortages in linear accelerators and ensure appropriate access to CT/PET scanning for Welsh patients. Support is also needed for countrywide clinical specialist training programmes to be introduced alongside a review of current training numbers to meet increased need (34).
- ◆ Robust data is needed on the choices and preferences of terminally ill patients in order to better inform commissioning and to ensure sufficient capacity.
- ◆ The answers to the question of patient involvement were variable but can be summarised as 'significant improvements but still some way to go'. Patients in cancer centres are consulted, but general hospital service is patchy (10). Patient involvement can be process rather than patient driven (31). Paediatric services are centred on service users but don't consult them often (1).

- ◆ The question of whether individuals should have the right to pay privately for treatment not accessible to them on the NHS raises major issues. Some respondents were strongly for, others equally against, but the majority were split, i.e. expressing the view that the primary objective should remain that all cancer patients should have access to all medications which are proven to be clinically and cost effective. It was suggested that a thorough debate is needed and that cancer drugs cannot be taken in isolation. Any such debate on resources and access to some therapies should be held openly.
- ◆ The importance of the voluntary sector is repeatedly emphasised. If voluntary organisations and charities were to disappear, they would leave a deficit of £2m for funding key professional staff for Velindre Cancer Services alone. Many examples were given of good working relationships see (4) (7) and in (6) e.g. Cancer Research UK and the Assembly Government in the Wales Cancer Trials Network; Tenovus with helpline and specialist support nurses; Macmillan and Palliative Care nurse provision; Marie Curie and the Palliative Care Service. However, some reported problems, particularly in relation to funding (2) (35) and the need for voluntary bodies to be allowed better engagement (3).

## **ii) Developments that have been welcomed**

- ◆ The establishment of the Wales Cancer Trials Network which has done much to change the culture of research and development (34) (3) and increased recruitment into trials (4) (9) (11); Welsh Cancer Institute (34 p3); Wales Cancer Bank (34) (35); All Wales Cancer Expert Advisory groups (34 p3); Wales Cancer Centre Intelligence and Surveillance Unit (33); the Cancer Services Expert Group, which plays a vital role in defining and monitoring cancer standards (9).
- ◆ Minimum standards and clinical management guidelines (34).
- ◆ There are long established strengths in basic and clinical cancer research (34) Wales has great potential to be a world leader in cancer research.
- ◆ Some respondents argued that medical research and good practice is being integrated with service delivery, whilst others felt that more needs to be done (34) (33). There were many examples of good practice given (7) (36), but others outside the medical profession lack the specialists in expertise and time to engage in research (14) (22) (23) (28).
- ◆ Cancer networks have undertaken invaluable work in developing best practice and integrating research findings into mainstream patient care (29).
- ◆ Cancer services should continue to be planned on a network basis to reflect the complexity of cancer services (34).
- ◆ The MDT model has been shown to be effective in ensuring an holistic approach to individual care planning. (34) Some multi disciplinary teams are under resourced (34).
- ◆ Many respondents referred to the success of cervical and breast screening in Wales which were described as 'extremely high quality services'. (6) The all Wales approach to commissioning for Cervical Screening Wales is welcomed (35) and has been successful in reducing rates. (4) (10) Breast Test Wales always meets or exceeds the programme standards for uptake and cancer

detection. The 'excellent' overall performance was recently independently reviewed by Cancer Research UK. (4) The development of colorectal cancer screening is the next step (6) (9) (10).

- ◆ There were many examples of good practice in various settings e.g. the 'Last Days of Life Care Pathway' is a good example of good practice being integrated with service delivery (8).

### **iii) Specific issues about equality of provision/equity of access**

#### **GEOGRAPHY**

- ◆ Solutions for services in south Wales (with the M4 link and concentration of population) does not necessarily work for patients in mid and north Wales. Services there have to work with North West England providers and training establishments e.g. there will be no direct impact on north Wales with the planned provision of PET scanning and the increase in radiotherapy students in Cardiff (11).

#### **CERVICAL SCREENING**

- ◆ Care must be taken to ensure that settled refugee and immigrant women in Wales are brought into the screening database system and that appropriate communications programmes are used to overcome cultural and other resistance to participation (35).

#### **PAEDIATRIC SERVICES**

- ◆ Poor cross linking between adult and paediatric services from diagnosis (1).
- ◆ The interface between funding for tertiary and secondary cancer in paediatrics is blurred and causes difficulties trying to set up shared services locally (1).
- ◆ Difficulties with the 16-25 age group. The transition to adult services is often difficult with adult services not able to provide appropriate services for young people who can end up dying in inappropriate places (36).
- ◆ One respondent wrote that there are insufficient services to meet the needs of young people with cancer in Wales (22).

#### **GYNAECOLOGY**

- ◆ Women in Wales with gynaecological cancer are subject to the 'vagaries of referral, indifferent expertise in diagnosis and care'. There is a call for the funding to be top sliced, management to be undertaken by sub-specialty groups and for there to be responsibility and audit of outcomes (2).

#### **PALLIATIVE CARE**

- ◆ Palliative care in rural areas is poor and there has not been equity of access (12). Patients are often referred to acute services due to the lack of availability of 24 hour support at home (28).

#### **OCCUPATIONAL THERAPY**

- ◆ Access to occupational therapy is dependent on where patients receive their care. Not all District General Hospitals have specialist occupational therapy for oncology and palliative care. There is poor access to specialist therapy services outside specialist centres, and poor access for generalist/community therapists to get advice from specialists (22).

#### **PHYSIOTHERAPY**



- ◆ There is a 'grave lack' of therapy services in cancer care. There are also issues around the provision of services which includes aids, appliances and adaptations and which are relevant at all stages. Funding problems, protocols and other considerations need to be explored (23).

## 2. Identify the barriers to good service

### i) IT<sup>1</sup>

- ◆ There is no single, fully developed All Wales clinical data base. There is a need to ensure that all voluntary and statutory providers are linked to one uniform patient administration system (31) (33) Need to electronically link different hospitals/labs by making systems compatible (1) (5) (9) (33).
- ◆ Community pharmacists frequently encounter problems obtaining authorisation for controlled drugs dose adjustments out of hours and on Saturdays because of the lack of electronic access to patient information (14).
- ◆ Many physiotherapists have limited access to IT (23).
- ◆ UK registries do not currently collect data on the number of people living with secondary breast cancer. This lack of data greatly impedes the planning of services for people living with secondary breast cancer (25).

### ii) RESEARCH AND GOOD PRACTICE

- ◆ Occupational therapy research is limited: partly because of the lack of finance/research funding: partly because of lack of specialists in post, expertise and time (22). This is echoed by the physiotherapists who state that staffing levels for physiotherapists is too low for meaningful engagement in research (23).
- ◆ It is a similar story with radiography. There has been slow progress implementing research into routine radiotherapy practice because staffing levels and resources limit what can be achieved (28).
- ◆ Community pharmacists are the only group of health professionals that are not provided with protected learning time or part of the co-ordinated approach to NHS skills development (14).
- ◆ The Welsh Cancer Intelligence and Surveillance Unit (WCISU) is under utilised for monitoring changing cancer incidence and outcome of treatment (4) (9).
- ◆ There is limited support with the paperwork required in order to develop clinical/surgical/national studies (2)

### iii) COMMISSIONING

- ◆ The relative role of all those involved in commissioning is ill defined and there is inconsistency in commissioning across Wales. Commissioners do not have adequate information on case mix and activity.
- ◆ Many respondents reported that there are too many commissioners and that commissioning is overly complicated (4) (6) (10) (15) (16) (23) (27) (32); a 'shambles' (33) There are too many LHBs involved in commissioning (12) (16)

<sup>1</sup> CSCG review of information technology (published recently)

(31) (34) (35). Commissioning is said to be 'significantly hampered by LHBs' (3) and 'worsened' by the involvement of LHBs (6). There is a high level of variance (14) (18) and the quality of commissioning seems to have deteriorated since the introduction of LHBs as specialist commissioning expertise has been distributed thinly across a large number of commissioning organisations (4) (9). Working with multiple LHBs across a region for a regional service like radiography can be complex and cause delays and difficulties (28).

- ◆ HCW 'muddy the water' (5). The lack of capacity and limited cancer specific expertise within LHBs and HCW further confuse the issue (32) (33). This view was also expressed that the central commissioning by HCW has been 'informed and effective' apart from the fact that it is grossly limited by cash constraints (6).
- ◆ A substantial amount of commissioning is for direct medical diagnosis and treatment with little or no commissioning of the full package of rehabilitation and quality of life enhancing services. 'Living well with cancer' and the recognition of cancer as a chronic condition are not yet reflected in the service commissioning. There is under-commissioning of therapy rehabilitation services (22).

### **CANCER NETWORKS**

- ◆ Networks are well positioned to take a more active role in commissioning but fail due to the lack of statutory function or budget (8) (32) (33). They have the knowledge but little power (1). Strategic planning and oversight that is the strength of the Cancer Networks is undermined by their lack of authority over LHBs.
- ◆ Described as 'well meaning' but they have been severely hampered by an inability to implement decisions. NHS Trusts have been able to appoint people such as specialist GI surgeons without reference to the Cancer Networks and thereby undermine any planning for specialisation and centralisation of services. (6) (4) (9). Mechanisms need to be developed to ensure that advice on service configuration is implemented (4) (9).
- ◆ One respondent referred to the 'vagueness' around Networks - they are invariably seen as the individuals working in them or the lead organisations and not the multi stakeholder structures that they suggest. (32) One CHC reported that there is a lack of information about what the Networks are doing (13).
- ◆ There is only one occupational therapist member of the Palliative Care Advisory Group, which supports the South East Wales Cancer Network. There are concerns about the level of advice on therapy service provision that the Networks receive (23).

### **iv) SCREENING AND IMMUNISATION**

- ◆ Screening for cervical and breast cancer have a reasonable evidence base.
- ◆ The development of colorectal cancer screening should now be taken forward. There is a high level of late stage presentations in Wales at present (with resultant high palliative care cost implications).
- ◆ Cervical screening coverage is lower in young women in Wales (50.4% in 20-24 group) (35).
- ◆ The potential of the community pharmacy network to become involved in

population screening is regularly overlooked. They are the most accessible of all health outlets and ideally placed to support population screening e.g. distribution of testing kits for bowel cancer (14).

- ◆ There are unmet support and information needs of people going through diagnostic checks. Patients are not allocated a clinical nurse specialist until a cancer diagnosis has been made, there is no-one responsible for co-ordinating care and patients are handed from one department to the next (18).

## **v) DEVELOPING TECHNOLOGIES AND THERAPIES**

The barriers:

- ◆ The small number of health professionals; little understanding of newly formed agencies; build up of old allegiances (1) and 'clinical conservatism' (29) Lack of human and monetary resources (5) (13) (23) (29) (31) (33). Need for capital investment in technological hardware (10) (20).
- ◆ There are shortages in linear accelerators and a need to ensure appropriate access to CT/PET scanning for Welsh patients. (18) (34). There is 'inertia' in Wales in the development of new medicines and treatments (35). The Assembly Government needs to ensure that Wales does not lag behind new technological developments by moving to more rapidly commissioning new technologies (e.g. PET-CT) (4).
- ◆ Particular professions have problems e.g. physiotherapists have limited resources for IT development therefore access to IT for research and keeping up with technology; NICE guidance etc is limited (23).
- ◆ There is no coherent development of plan/strategy for the radiotherapy services development across Wales. The lack of a robust plan for the service results in difficulty securing resources for new equipment and replacement equipment e.g. Linear Accelerators (28). The lack of a coherent strategy has also resulted in inadequate workforce planning to meet current and future service needs, with a lack of therapeutic radiographers and physics staff to support changing and evolving service needs (28).
- ◆ There are negative perceptions of the pharmaceutical industry and delays in trial coordination leading to low recruitment and less experience of new therapies (27).
- ◆ Lack of co ordination at an All Wales level to agree the process for assessing the impact of new treatments/technologies (7).
- ◆ Delays over the appraisal of new treatments by NICE are commonly reported (25) and there is little scope for investment in new therapies other than NICE appraisals (17).
- ◆ Recent advances in the diagnosis and treatment of cancer have often been costly in terms of acquisition costs and the manpower needed to deliver the service. (19) It was also emphasised that new drugs or therapies have other service consequences which may require additional resources to deliver.

## **vi) NHS AND VOLUNTARY SECTOR**

- ◆ There are a large number of joint specialist cancer and palliative medicine nursing posts already being funded by charity, but funding is not made within a strategic framework (4).
- ◆ There are concerns about time limited voluntary sector projects – it is not clear whether the Assembly Government will provide recurring funding to ensure sustainable services (7).
- ◆ There is concern that specialist posts e.g. those funded by Macmillan, are being affected by the current financial problems in the NHS (18). Also concern that nurses working in the voluntary sector are undervalued or even ignored (20).
- ◆ Gynaecological service is unable to provide basic facilities to allow the voluntary sector to function and support patients, e.g. the inability of the Trust to provide furniture for quiet room for a charity based counsellor (2).

#### **vii) PALLIATIVE and SUPPORTIVE CARE**

- ◆ The evidence base for current and future palliative care policy and practice is weak. More information is needed to guide services more accurately to what patients want and allow services to be developed according to their needs (4) (7) (9) (10) (12).
- ◆ Commissioners are often confused between specialist palliative care services and those in the charitable sector that offer nursing and social care at a generalist level. The needs assessment undertaken by the National Council for Palliative Care should be a starting base for more effective commissioning (4).
- ◆ To date, commissioners have appeared reluctant to be firm about what they will and will not support. Block grants rather than full service level agreements have been awarded to some organisations and political pressures have been brought to bear by Trustees of some organisations to the detriment of others (4).
- ◆ The LHBs act at too local a level to have an overview. They are not able to exert the difficult pressure on the charitable sector partners to alter practice to fit with the needs of an area. (4).
- ◆ The recent Tebbitt Report on Palliative Care in Wales highlighted the fact that too many people were dying in hospital and that there are major resource deficits in community services. If patients are to die at home, where they want to be, it would be unacceptable to leave them there without adequate support. Macmillan were not aware of the actions taken as a result of the Tebbitt Review (18).
- ◆ Palliative care and community services are fairly patchy across Wales (33). Ease of access to palliative care medicines in the community is variable in Wales, especially in relation to out of hours. (19) There is guidance directing LHBs to make provision for accessing palliative care medicines in relation to the All Wales Collaborative Pathway for the last days of life but very few LHBs appear to have complied fully with this (19).
- ◆ The importance of rehabilitation is sometimes lost in the attempt to provide services for the terminally ill (23).

#### **viii) DRUGS**

- ◆ Paediatric oncology has a problem with GPs refusing to prescribe drugs rather

than prescribing inappropriately (1)

- ◆ Many respondents called for regular audits of drug usage by Cancer Networks (3) or by pharmacists (4) (6) (9). Pharmacists in Cancer Networks are said to be in an ideal position to audit these and other local guidelines, but as there is only one of the three Networks which has a funded Network Pharmacist post, it is unlikely to take place under the current arrangements (19).
- ◆ Suggestions were also made for improved data collection and audit through the introduction of electronic prescribing systems e.g. Clinisys Chemocare. (7) Wider use of care pathways should cut down on inappropriate prescribing at the end of life (4).

#### **ix) PATIENT CENTRED SERVICES**

- ◆ There were mixed views about how patient centred services actually are.
- ◆ For some, major steps have been taken to integrate the patient perspective into cancer services and palliative medicine with patient representatives now being an integral part of clinical governance, ethics and R&D committees (4) (13).
- ◆ One CHC said that they believe the professionals' feel the services are centred around the patient, but in the main it is not'. Patients with cancer move around hospitals and teams because they cannot always be dealt with by the consultant. The whole situation is complex and confusing. The setting up of cancer centres within the grounds of acute hospitals would at least mean that patients could visit their surgeon and oncologist at the same time (5).

### **3. Recommend measures to overcome them**

#### **STRATEGIC DIRECTION**

- ◆ There should be a comprehensive long term strategy for tackling cancer in Wales – linking prevention, diagnosis, treatment, care and research (18) (32) (34) and with ring fenced funding and performance targets (18). The NHS Cancer Plan for England is seen as being instrumental in accelerating the modernisation process and reducing delays in accessing treatment (18).
- ◆ The quality of life/living well with cancer agenda needs greater investment (22) (23).
- ◆ A baseline audit against the Cancer Standards is required (23).

#### **i) IT**

- ◆ The majority of respondents called for an electronic patient record to assist clinicians in having far better access to information on the patient throughout their journey. This links to work on the Unified Assessment and both informing social care and informing healthcare strategies (8) (22). All healthcare professionals need access (27).
- ◆ Many respondents said that a single, effective and accurate database of cancer patients is crucial. Cancer Network Information System (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 (34) (4) (6) (7) (9) (15) (17) 20) (28).

- ◆ CaNISC needs to be compatible with other relevant managerial data systems and should be adopted by Informing HealthCare (4) (9) (20).
- ◆ Should be possible to enhance CaNISC to capture data on terminally ill patients (3) (11) (33).
- ◆ Any common data set should include cancer genetic information (15)
- ◆ There was also support for the introduction of an 'Individual Health Record' (14).
- ◆ Community and hospital pharmacists should be included when planning for integration of IT for healthcare (16) (19)
- ◆ There should be increased use of tele-medicine(3) (7), particularly in rural areas (18) and e-health (7).
- ◆ Data is needed on the numbers of women living with secondary breast cancer to ensure the right services are being provided for this group of patients (25).

#### **ii) RESEARCH AND DEVELOPMENT**

- ◆ National standards for research and development should be established to ensure that all patients benefit from research breakthroughs (26) (29).
- ◆ There should be better dialogue/collaboration between Pfizer clinical research and the Welsh Research and Development group (27)
- ◆ Research activity outside the medical profession needs to be enhanced and greater finance needs to be made available for therapist, and other research (22) (23).
- ◆ More financial support and further encouragement from the Assembly Government and WORD to build on the work of the Wales Cancer Trials Network (3) (9) (26). The work of the Network needs to be fully linked to other cancer clinical networks and the CSCG in order for research to be full integrated with service delivery (20).
- ◆ Pharmacists should be recognised as an integral member of the primary care team and as such need to enjoy the same access to training, research and briefing on good practice that is available to other members of the primary care team. The NLIAH should extend their role to include community pharmacists and community pharmacy technicians (14)
- ◆ There is a need to invest in statistical resources at the Welsh Cancer Intelligence and Surveillance Unit (33).
- ◆ There is a clear need to increase the recognition of Cancer Genetics, provided through the Wales Medical Genetics Service, as a conduit for research in genetics (21).
- ◆ There should be a named Minister for Science in line with England and Scotland to raise political profile of scientific research (34).

#### **iii) COMMISSIONING**

The complexity of the commissioning process should be reduced. There is a need to make it more streamlined and standardised with clarity on the roles of commissioning bodies (11).

*Suggestions included:*

- ◆ Reducing number of LHBs – so many regional bodies works against the commissioning and delivery of co ordinated cancer services (34).
- ◆ Regional commissioning by cancer networks (3) (4) (5) (15) (16) (21) (23) (33) or on an All Wales basis (16).
- ◆ Developing strong working agreements with the proposed Regional Commissioning processes and the cancer networks (8).
- ◆ Developing the role of the Regional Cancer Networks and clarifying their relationship with the Assembly Government regional offices. Both the Network and the regional office should take a stronger role in overseeing the commissioning process.
- ◆ Specialised services should be planned by consortia of Networks and commissioned on a national basis by Health Commission Wales (33) in consultation with the Cancer Services Co-ordinating Group. (20) (34) It would be more effective to have a single commissioner for specialist cancer services across the whole of Wales. If an integrated high quality equitable service is wanted, then a Pan-Wales commissioning process would be the best way to achieve this. (6) (31)
- ◆ Capital funding issues for expensive equipment needs to planned on an All Wales basis. (4) (33) e.g. there could be a plan for expensive equipment which had an attached budget with cancer networks signing off requests within the agreed a plan and budget (18)
- ◆ All LHBs should appoint a cancer lead to champion the needs of oncology services and cancer patients, as well as co-ordinating commissioning activity (26) (28) (29).

**CANCER NETWORKS**

- ◆ There should be increased co ordination, autonomy and resources for Cancer Networks (34).
- ◆ The Cancer Networks should receive more adequate involvement from occupational therapists to inform their work (22).
- ◆ There needs to be more multi-professional engagement across Wales with communication and ideas flowing between Networks and services (22).

**iv) SCREENING AND IMMUNISATION**

- ◆ Information about screening should be readily available to women aged 70+ leaving the screening programme (25).

- ◆ A National Screening Programme for bowel cancer is being introduced in England and Scotland and should be introduced in Wales as soon as possible (20) (29) (34).
- ◆ The faecal occult blood screening should be instituted as soon as possible, but ensuring the colonoscopy service is adequately staffed or resourced to deliver increased demand and ensuring a quality assured, adequately funded screening programme is established. (4) (9).
- ◆ Research should be conducted to determine reasons for lower screening rates for cervical cancer (35).
- ◆ Two vaccines for cervical cancer are currently awaiting licence – the Assembly Government should deliver on this earlier and no later than the rest of the UK (35). The vaccination programme needs to be planned to ensure effective prevention with high acceptability for the vaccine without undermining the current cervical screening programme (4) (35).
- ◆ Caution is also noted re the cervical immunisation programmes. The Assembly Government needs to examine questions relating to who and when to vaccinate before embarking on the programme (20) (35).
- ◆ There is evidence to suggest that early intervention is critical. Attention could be focused on those groups who do not present early (27).
- ◆ Education is crucial – needs to be a greater emphasis in the school curriculum e.g. school nurses ideally placed to educate re the risks of diet, smoking and environmental factors. (20).
- ◆ The role of community pharmacies should be better utilised in supporting population screening and the provision of public health advice (14).

#### **v) DEVELOPING TECHNOLOGIES AND THERAPIES**

- ◆ Due consideration must be given to engagement with the public and professionals in managing expectations for new treatments and technologies (16).
- ◆ Need to ensure the right balance between expenditure on cancer drugs and on care (18).
- ◆ Wales needs to look forward and be better prepared for the future. In doing so it needs to adopt the best technologies and look to train staff now for future need. Where ideas and developments are adopted elsewhere in the UK it should have a system of automatic adoption or replication where considered appropriate e.g. NICE. (32).
- ◆ The Assembly Government needs to ensure that NICE delivers on the more rapid evaluation of new technologies and therapies (6) and a faster All Wales response on the guidance for the use of new drugs to avoid postcode prescribing. (8)
- ◆ Following NICE appraisals, there needs to be good predictive models of the uptake in Wales, so that new therapies can be implemented with sufficient cash. Restriction of usage to certain sub-specialists within oncology will be able to



control the flow of the specialist drug usage.

- ◆ Early warning of new technologies and rapid evaluation are vital (6). Further development of horizon scanning may help planning (8) (33) and help ensure that the NHS is able to respond to new technologies and therapies (25). There should be closer collaboration with the National Horizon Scanning Centre (26) and open invites for pharmaceutical industry representatives to discuss horizon scanning or R&D pipeline (27).
- ◆ There is evidence to suggest that commissioners have not always followed NICE guidance, resulting in some patients being denied treatments which NICE has assessed as cost effective. There should be a regular audit of the uptake of NICE-approved medicines by Healthcare Inspectorate Wales, ensuring that areas of continuing weakness can be identified and addressed by LHBs and Cancer Networks. (26)
- ◆ There is a need for a formal strategy for radiotherapy services development in Wales to model service need for the next 5, 10 and 15 years. (28)
- ◆ There should be more engagement with community pharmacists as a member of the primary care team (14).
- ◆ Because of its smallness, Wales needs to be part of the NICE review process and avoid unnecessary duplication of expert review (4) (9). It would be 'intolerably burdensome' to review all new technologies within Wales (6). Changes to the NICE process to have a fast track system are welcomed (6) (9) (16) (26).

#### **vi) NHS AND VOLUNTARY SECTOR**

- ◆ There is potential for the Assembly Government to utilise voluntary sector input, e.g. with an equivalent organisation to the Prince's Trust (2) or with co ordination from WCVO in conjunction with the Cancer Networks (4). The Assembly Government should actively collaborate with the charitable sector in seeking partnerships for quality services it cannot fully fund e.g. provision of level 2 & 3 psychological care for patients with psychological morbidity related to cancer (6).
- ◆ The NHS needs a better understanding about the role of the voluntary sector (5). Many respondents recognised the need for closer working between the voluntary sector and the NHS. Need better understanding of voluntary sector provision, less duplication and facilitation of networks (23) (31).
- ◆ Collaborative work could be helped by an Assembly Government framework that established the policy and strategy and improved the commissioning process (33). The setting up of a taskforce was also suggested with representatives from the NHS and Voluntary Sector to look at the development of partnerships. (25)
- ◆ A clear commissioning intention would ensure that the charitable sector work more closely with the statutory sector (8) and would also avoid developments arising on an ad hoc basis, with pressure then being put on NHS commissioners to fund the running costs. Clear strategic planning is needed to define what the NHS will fund and what is to be left to outside agencies (4).
- ◆ A potential way forward would be direct commissioning of the voluntary sector to deliver appropriate elements of the service (8).
- ◆ Voluntary sector could work better by being less competitive between themselves

(32) and could play a greater role in shaping policy (32) (26).

#### **vii) PALLIATIVE and SUPPORTIVE CARE**

- ◆ A centrally accessible database is needed to collect, store and analysis information about patients wishes and needs when they are terminally ill (4) (10) (11) (13) (19).
- ◆ More investment into studies to identify local needs (7) and more consideration should be given to the wide issue of good practice cancer care and support (18).
- ◆ The deficits identified in the Tebbitt Report on Palliative Care in Wales need to addressed (32).
- ◆ To overcome any confusion between specialist palliative care services and those in the charitable sector that offer nursing and social care at a generalist level, the needs assessment undertaken by the National Council for Palliative Care should be a starting base for more effective commissioning (4).
- ◆ In order for the pharmacy profession to support the needs of terminally ill patients and their families, information sharing across the care setting is paramount. At present, community pharmacy is excluded from information sharing via care pathways, but receives information via the patient or family (16).
- ◆ There is concern that palliative care is not a feature of *Designed for Life (2005)*. The Assembly Government should produce a strategy for palliative care in Wales as part of an overarching cancer strategy or plan (18).

#### **viii) DRUGS**

- ◆ There is a clear need to further debate the issue of whether individuals should have the right to pay privately for treatment not accessible to them on the NHS. One respondent called for the Assembly Government to devise a national policy on this because inequalities will persist if decisions are taken locally (33).
- ◆ Patients can be a powerful group at initiating a review of drugs by asking their doctor if they really still need to take all they are taking. A campaign to raise public awareness could be devised, such as 'ask your doctor' – "Do I really need to take this?" (4).
- ◆ The Assembly Government could take a more pro-active role in negotiating with Pharmaceutical companies for Wales-wide contracts. This occurs in other European countries and helps to keep costs down (4).
- ◆ Most respondents considered that there is adequate access to independent advice and guidance on drug prescribing. However, some respondents contradicted this e.g. (27).

#### **ix) PATIENT CENTRED SERVICES**

- ◆ The patient already has opportunities through the networks to have a say in delivery and configuration of services. This should be extended to commissioning (18).

- ◆ Secondary health professionals need to play a role in providing information to carers. Each Cancer Network should appoint a carer's lead and develop a strategy for identifying carers and advising carers about their rights and services (18).
- ◆ Patient representatives need training to be really effective (11).
- ◆ Although the Assembly Government funds generic patient involvement structures, there is no Assembly funding for cancer-specific patient involvement (18).
- ◆ User involvement needs to be more focused and assessed in terms of its impact to the service development or provision (32). Research should be undertaken to examine the extent to which patient/service user involvement influence Trust decisions (33).
- ◆ Regular surveys of cancer patients should be undertaken to measure patient experience (29).
- ◆ A patient reference group could be developed as a sub group of each Cancer Network and a patient or advocate could represent the sub group on the Network (23).
- ◆ Patient involvement should be maximised in NHS management committees, ethical and research committees (35).

**Members' Research Service  
September 2006**

## **Annex 3**

### **HEALTH AND SOCIAL SERVICES COMMITTEE REVIEW OF CANCER SERVICES FOR THE PEOPLE OF WALES**

#### **Report of the Visit of Committee Members to the Centre François Baclesse, Caen, Normandy, France on 13 July 2006**

#### **1. Introduction**

1.1. On 13 July 2006 three Members of the Committee, Rhodri Glyn Thomas (Chair), Jonathan Morgan and Jenny Randerson visited the cancer centre, Centre François Baclesse at Caen. They were accompanied by Professor the Baroness Finlay of Llandaff, who had facilitated the visit through her working contacts with the Centre, and Dr Andrew Fowell, Chair of the expert reference group advising the Committee on the review.

1.2. 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;

1.3. The purpose of the visit was to establish the way in which cancer services are delivered in France to enable a comparison with the way in which they are delivered in Wales, and to identify areas of good practice that could be applied in Wales.

#### **2. The French Health Care System**

2.1. Organisation of the French health care system is very different from that of the UK, primarily because France has formally integrated the private sector into the organisational structure of healthcare delivery.

2.2. Health care is funded through the public health insurance element of the social security system. It is complemented by private health insurance. Since 2000 people on low income receive publicly funded complementary cover. Health care is not always free at the point of entry. Patients generally have to pay the provider themselves and then claim total or partial re-imbursment of their expenses from their insurance.

2.3. Private insurance also covers medical goods and services when public re-imbursment levels fall below prices.

2.4. Hospital care is paid for directly by the insurance fund. It accounts for 40 per cent of total health care funding, with primary care at 28 per cent.

Hospitals have traditionally been at the core of the system, resulting in specialised, technical and curative care, possibly to the detriment of preventative and community services.

2.5. As a percentage of gross domestic product, health spending in France is higher than the average for other OECD countries. Pharmaceutical spending per head is higher than other European countries.

2.6. France is top of the Euro Health Consumer Index for 2006, with “a technically efficient and generously providing health care system”. In 2000, the World Health Organisation ranked the French health care system number one among the 191 countries surveyed, stating it has “the best overall health care”.

2.7. French hospitals can be public, private non-profit or private for-profit. They can be specialised or not. They are autonomous and manage their own budget. As in the UK the ratio of beds to inhabitants has been reducing. Alternatives to hospitalisation, such as day care surgery or treating people at home, are encouraged. Co-operation between public and private hospitals is promoted to ensure equality of access to treatment and care.

2.8. The way in which French hospitals are funded is changing. Under the old system each hospital discussed its budget with the local authority and was funded in respect of the service provided. There were many non-active small hospitals and overstaffing. The private sector was more competitive.

2.8. Under the new system, known as T2A (Tarification A l'Activité), the more work a hospital does the more money it receives. It will be paid for each stay in hospital. Expensive drugs will be paid for separately in accordance with an official price list. All hospitals have to stay within their budget, voted each year by Parliament. This will be difficult for public hospitals, which accept all patients referred to them. The private sector is able to select its patients. The new system will be phased in over a number of years, with 100 per cent funding under T2A by 2012. The system is designed to bring the social security system back to financial equilibrium.

2.9. Primary care services are provided by doctors, dentists and medical auxiliaries working in their own practices. Most work alone, only 38 per cent are involved in group practices.

2.10 The full cost of prescribing approved chemotherapy drugs, including newly approved drugs, is met in accordance with an official tariff. If the hospital is able to buy the drug more cheaply it is able to keep the difference. Seventy per cent of the cost of a drug is re-imbursed if the drug is given for indications outside the very specific approved indications for which 100 per cent re-imburement is available.

## **Cancer Care**

2.11. A network of cancer centres was established by the French Government in 1945. These are independent, privately run, non-profit making hospitals, specialising only in cancer and nuclear medicine. There are 20 centres across the country and the one in Caen serves the Basse Normandie Region and a small part of Brittany, a total population of 1.5 million.

2.12. The strategic lead is provided by the French National Cancer plan which was launched in 2003 by President Chirac. It sets standards for consultations and advising/ counselling patients on their diagnosis, waiting times for surgery and therapies, increasing provision for palliative care and extending breast cancer screening. The second phase of the plan was launched in May this year, and places greater emphasis on prevention and early detection.

2.13. The Plan also outlines increased means for palliative care.

### **Prevention and screening**

2.14. Cancer prevention and early detection work has not been so developed in France, and work is underway to place greater emphasis on these areas.

2.15. The Government has taken steps to reduce tobacco use, and consumption by male adults has reduced. School pupils are also given advice on prevention of cancer.

2.16. Oncogenetics are used to identify vulnerability to breast and colon carcinoma and some rare cancers. There is a national network for consultation and specific laboratories. The centre at Caen deals with 400 families a year in respect of breast cancer and works with the Rouen centre on colon cancer.

2.17. Screening for breast cancer is now available every two years to women aged 50 to 74. Since 2003 it has received state funding. The take-up rate is below 50 per cent. Since 1996 there have been 125,44 mammographs, 7,486 of which had positive results and 740 were cancerous.

2.18. Screening for cancer of the colon has been piloted and will be available throughout France on a two-yearly basis for people aged 45 to 74 from 2007. In Caen, since June 2004, 165,000 people have been eligible for screening. The response rate has been 40 per cent. There were 2,404 positive results leading to 1,157 colonoscopies revealing 30 cases of cancer.

2.19. Screening for prostate cancer is being evaluated currently.

2.20. There is no national programme for cervical screening, but it is available in five French counties. The results from screening so far justify extending availability.

2.21. The cancer centres undertake less screening, which tends to be undertaken by local hospitals.

## **Diagnosis**

2.22. Diagnosis is carried out through screening, by general practitioners (GP), by private specialists (on referral from the GP or by direct referral), or in a general hospital. Most diagnosis, through radiology, endoscopy, or biopsy, is carried out by private practitioners, (who own their equipment) but some through outpatient departments.

## **Treatment**

2.23. About 50 per cent of treatment is undertaken in the private sector. This is mostly surgery and radiotherapy. Around 30 per cent of patients are treated in university or general hospitals. This is mainly surgery, chemotherapy, neurosurgery and radiotherapy and includes treatment for conditions after the first therapy has failed. Around 20 per cent receive treatment in cancer centres, mostly by radiolotherapy, chemotherapy, surgery or second line treatment.

## **3. Centre François Baclesse**

3.1. The Centre was founded in 1923 and was integrated into the network of cancer centres established in 1945. It is the hub of cancer services and the clinical network for the region, with some services being provided in other hospitals, including the adjacent university hospital, and by private funding. The role of the Centre means that commissioning is less complicated than in Wales.

3.2. The Centre provides the following treatment and services:

- surgery;
- radiotherapy;
- medical oncology;
- radiology;
- nuclear medicine;
- pathology;
- biology;
- nursing; and
- supporting technical and logistical services.

3.3. The centre specialises in cancers of the breast; lungs; head and neck; genito-urinary and digestive cancers; haematology; skin tumours and sarcoma. It is in the top four cancer centres for activity. It has a strong clinical research base with links with the adjacent university and through Groupe Regionale d'Etudes sur le Cancer (GRECAN). However, it has only one university professor and there is a shortage of physicians. This is partly due to a poorer rate of pay than in the private sector. 55 per cent of physicians go into private consultation on qualifying; and only 40 per cent into the hospital sector. Five per cent go into public health or occupational health posts. Only 20 per cent of students see cancer patients during their training.

3.4. There are 750 full time equivalent staff, of whom 60 (mostly full time) are physicians. The Director of the centre is a physician, as is the case for all the cancer centres.

3.5. Doctors receive post graduate university training in chemotherapy and this is followed by a year in the Centre before they are fully certified. Nurses cannot prescribe chemotherapy, but are given post graduate training to administer it.

### **The Care Pathway**

3.6. The provision of psychological care is seen to be a high priority. When a patient is diagnosed they are, by right, offered the services of a nurse to help them understand and cope. A special room is available for private counselling. The Centre has funding allocated for this work.

3.7. The next stage is the drawing up of the care plan. There is a multidisciplinary approach, with each patient having a personal physician. Breast cancer patients should have their care plan within 15 days of diagnosis. This is an iterative process, with the plan being reviewed as treatment progresses. The multi-disciplinary team, including private practitioners, meets fortnightly to progress cases.

3.8. Delays in starting treatment is a recognised problem, partly due to the shortage of surgeons, but sometimes because the patient elects to see a specific surgeon. Waiting times will be one of the criteria for the certification of hospitals required under the French Cancer Plan with effect from January 2007.

3.9. The concept of the hospital at home does not work as well in rural areas as in urban districts. There is a home chemotherapy service in Paris, but it would not be viable in Basse Normandie because of the long distances between patients' homes.

3.10. Levels of hospital acquired infection are low. On touring the hospital it was evidently very clean and uncluttered. Cleaning is carried out in-house.

### **Table 1 - Key Statistics**

new patients in 2004	6,931
number of these with cancer*	4,300
consultations per year	40,000
full hospitalisations per year	11,000
Day hospitalisations per year	9,000
patients per day	400
	<ul style="list-style-type: none"><li>• <i>non-cancers relate mainly to breast tumours and thyroid.</i></li></ul>

### **Table 2 - Capacity**

	No of beds
day medical	18



weekly hospitalisation (not weekends)	30
usual medical services	97
surgical services	51
intensive care unit	7
ambulatory surgery	5
bone marrow transplantation unit	4
brachytherapy, metabolic radiotherapy	10
Total	222

### Table 3 - Technical Activity

external radiotherapy (5 accelerators\*):

treatments per year	2,800
irradiations per year	42,100
irradiations per day	160

brachytherapy :

treatments per year**	280
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Radiology examinations per year:

scanner	10,000
ultra-sonography	5,000
MRI	600
mammography	5,000

\* one accelerator per 150,000 population

\*\* 30 to 40 per cent of patients with prostate cancer are treated with brachytherapy

### Table 4 - Trends

	1980	2000	2005
new patients	2,075	4,211	4,600
Day patients	84,024	52,760	52,760
In patients hospitalisation	5,907	11,154	19,154
median time (days)	14.2	4.7	3.2
physicians	31	47	60
nurses	149	134	134
assistant nurses	198	170	170
technicians	62	58	58
assistants	49	44	44

### Expansion of the Centre

3.11. A 10 year programme of capital improvement works started in 2002 with the aim of modernising and upgrading existing facilities and equipment and expanding capacity. The works will:

- enable new treatments;
- separating out-patients and in-patients thus reducing the risk of infection of in-patients;
- provide better facilities for consultation;
- provide more single bedded rooms;
- improving access for disabled people;
- increasing clinical research and teaching; and

- a palliative care unit.

3.12. A first phase of major building works providing new administration offices, teaching and lecture theatre and library has just been completed and work is now underway to refurbish the existing hospital and building a new day care block, centralised chemotherapy unit, pharmacy, MRI unit; clinical research unit and mortuary. The final phase will centralise consultation, provide new pathology and stomatology units.

3.13. By 2012 most of the hospital beds will be in private rooms and there will be facilities for supportive treatment and psychological help.

3.14. The key to the hospital's ability to undertake the work was having plans on the stocks ready for implementation when funding became available. Funding is mainly from central government sources supporting the Cancer Plan, but the Centre is also raising money through a bank loan.

### **The Incidence of Cancer in Basse Normandie**

3.15. Cancer registries in France cover only 13 per cent of the population. However in Basse Normandie there is a general cancer register for Calvados in the Centre François Baclesse and one covering cancers of the digestive system in the nearby university hospital. There is also a general tumour register covering the Manche Department.

3.16. The registries collect data on morbidity, the evolution of the disease and survival. They provide information on risk factors, evaluation of practices and the impact of public health initiatives.

3.17. Cancer registries are approved and monitored by the National Committee of the Registers. Approvals are reviewed every four years.

3.18. Data is collected from the health services, pathology laboratories and also medical insurance companies. Data is followed up until the patient's death.

3.19. The most common cancers in men in 2000 were prostate, lung and colo-rectal. They represent half of all cancers and 44 per cent of the deaths for men.

3.20. Across France, the incidence of prostate cancer increased threefold between 1980 and 2000, although the mortality rate was stable. An increase in the number of deaths was explained by the aging population. In Calvados the incidence only doubled over the period. The increase in the incidence is largely explained by the improved detection, with endoscopy and guided biopsy, and more recently the use of prostate specific antigen.

3.21. For women, breast cancer is by far the highest, representing two thirds of all new cases and 20 per cent of mortality by cancer in women. Breast cancer is the most frequent cancer when considering the two genders

together. In the last twenty years the number of cases has doubled and the number of deaths increased by 35 per cent. The mortality rate was stable, the increase in the number of deaths is attributable to the aging population. Survival rates significantly increased between women diagnosed with the disease in the two periods 1978 to 1982 and 1993 to 1997. The increased risk is most significant among women aged between 50 and 69. The diverging trend is probably the result of changes in risk and medical practices and is partly due to better survival. Mass screening has taken place in France since the 1990's, but its impact has not yet been evaluated.

3.22. Lung cancer kills more than 27,000 people a year in France. 80 per cent of the cancers occurred in men, but the number of cases among women doubled in the 20 years from 1980, while in men it increased by 40 per cent. During that period the risk increased by 10 per cent for men and doubled for women. In the Basse Normandie region the risk for men is in line with the national average, and is lower for women.

3.23. In the same period the number of cases of colo-rectal cancer in France increased by 50 per cent. In 2000, 54 per cent of cases were among men. Although the disease is more common among older people, the survival rate has improved through early diagnosis and treatment. The incidence in Normandy reflects the all-France picture.

3.24. France has a high rate of lip / oral cavity and pharynx cancers compared with other countries. In the year 2000 there were 15,000 new cases, 84 per cent occurring in men. In women the incidence is low, but increasing. There were 5,000 deaths from the cancer that year. The main risk factor for the tumours are alcohol and tobacco consumption. However, the risk is decreasing due to the reduction in alcohol consumption in France since the 1950s.

3.25. The high rate of oesophageal cancer among men in the region is thought, but not proven, to be linked to the high alcohol content of home brewed calvados.

3.28. Taking all cancers together, the number of cases in France increased by 63 per cent (66 per cent for men, 60 per cent for women) between 1980 and 2000. These changes are attributable to increased population, the changing age structure and changing risks. The decrease in the death rates is partly due to changes in the type of cancer and to improved treatment. Overall the trends in Basse Normandie are in line with the national picture.

### **Computerised Medical Records**

3.29. Under the aegis of OncoCOM (an association of physicians from the private, hospital, clinic and general practice sectors in Basse Normandie), an electronic medical record for cancer patients in the region has been developed. This enables the physicians in all sectors to share information, to which the patient may also have access. The records contain:

- all clinical observations

- operation and histological reports;
- biology from the Centre François Baclesse
- patients' appointments;
- images produced in the centre in the last year.

GPs are able to connect easily and securely through the Internet.

3.30. Initial evaluation has shown that the system is easy to navigate and meets the needs of the doctors who use it. It has highlighted the need for objective reporting, avoiding personal comments and has improved the quality of the hospital medical record. Doctors are able to access record of specific events and laboratory data. Use of the record has lengthened the doctor-patient consultation time as information on the screen is explained to the patient.

3.31. Evaluation of the patients' experience of the record is also positive. They appreciate the more direct dialogue and being able to see the hospital's observations. They also appreciate that the system prevents loss of information and that information can be transmitted more quickly.

3.32. There is now a demand for access to the record from other professions such as radiologists and further development of the system is awaited. It is hoped to have an imaging system at a regional level; a prescription system for chemotherapy; to be able to return information from the GP to the hospital; and to include a nurse record.

### **Clinical Research**

3.33. Clinical research is an important part of the activities of the Centre François Baclesse and the adjacent university hospital. It is carried out in accordance with EU protocols.

3.34. Between eight and 11 per cent of the patients treated at the Centre are involved in clinical studies each year. This work is important in improving standards of care and treatment. There is evidence that patients who are involved in trials do better than those who are not, possibly because of the degree of care and monitoring they receive. The Clinical Research unit is involved in three phases of clinical trials for drugs and therapies; diagnostic studies, prognostic studies and translational studies.

3.35. Currently the Centre is involved in 63 studies at national level, five academic studies at international level and in 38 projects working with industry.

3.36. The Centre is a member of GRECAN which is involved in general population studies, particularly the epidemiology of cancers and its aetiology .

3.37. The unit's staffing budget is 0.64 per cent of the Centre's total budget. Funding also comes through grant from the health authorities, national public

research centres, voluntary organisations and sponsoring scientific companies (without strings attached).

### **Equity in Access to Care**

3.38. France has the highest cancer survival rate in Europe, but nevertheless geographical and social factors such as deprivation impact on survival rates. Breast cancer is more prevalent among more well-off women, but prognosis is poorest where there is deprivation.

3.39. Information on cancer risks show that there are occupational risks from exposure to pesticides, coke, and asbestos which leads to mesotheliomas. Diet and social behaviour, such as sunbathing, consumption of alcohol, all impact on risk. There is little information on the impact of social factors on prognosis, other than the knowledge that there is a correlation between the social gradient and mortality. More work is needed in this area to identify non-clinical factors that affect prognosis.

3.40. Whilst there is equity of access to treatment once there is a diagnosis, there are a number of factors that deter people from taking up screening or treatment.

3.41. Screening for colo-rectal cancer is taken up by 60 per cent of the population in urban areas, but by less than 30 per cent in rural districts. Similarly there is lower take-up of treatment for digestive cancers, which are more prevalent among the elderly. There is also a low take-up of treatment for lung cancer in rural areas. This may be due to difficulty in travelling to treatment centres. The cost of patient transport is met through social security.

3.42. Although there are no figures available on the split between rural and urban take-up of breast cancer screening, there are no mobile screening units in France.

3.52. One theory is that GPs who are near to the Cancer Centre in Caen are more aware of screening services and promote them more aggressively than those who are further away.

3.53. It is recognised that access to services is an issue that needs to be addressed by health care organisations in France.

## **4. Conclusions**

4.1. The main differences between the organisation of cancer services in France and in Wales are:

- the funding mechanisms for health care and capital work;
- the emphasis in France on treatment and care, with less importance attached to screening and prevention than in Wales.

- commissioning is less complex in France than in Wales.

4.2. In Caen, the specialised role of the Cancer Centre with treatment for all cancers being available in the region (of 1.5 million people) means that commissioning is less complicated.

4.3. The Centre also provides a clear lead in networking and effective multi-discipline co-operation. This is also facilitated by the use of computerised records and the way these are shared with GPs. While this is not as comprehensive as the UK single record will be, it is a useful development while the more complex issues around ethics and confidentiality of a single patient record and technical problems are still being addressed.

4.4. The requirement in the French Cancer plan for conveying information on diagnosis, prognosis etc and providing psychological counselling and support in a suitable environment is commendable.

4.5. On a wider front, the cleanliness and uncluttered state of the hospital was very noticeable. Cleaning is undertaken and supervised in-house, and there is a low level of hospital acquired infection.

4.16. There are also important attitudinal differences. Patients in France are free to choose any physician they wish and have the right to self refer to specialists. There is no 'gatekeeping' as such and the notion of waiting to see a specialist via GP referral is not one which is readily recognised in France.

**Members Research and Committee Service  
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