

Cancer Research UK Cymru's response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services

Summary

Cancer Research UK Cymru believes that a comprehensive strategy for tackling cancer in Wales, linking prevention, diagnosis, treatment, care and research is essential to ensure that local healthcare providers improve outcomes for all cancer patients in the future.

Such a strategy should include:

- increased co-ordination and autonomy for cancer networks
- a commitment to fund and support both basic and clinical cancer research
- a central point for policy making on public health and screening initiatives
- a mechanism to cost and plan for the introduction of new cancer drugs and other technologies.
- central management and funding to evaluate new equipment needs and address shortfalls
- appropriate workforce planning and support for countrywide specialist training programmes.

Background

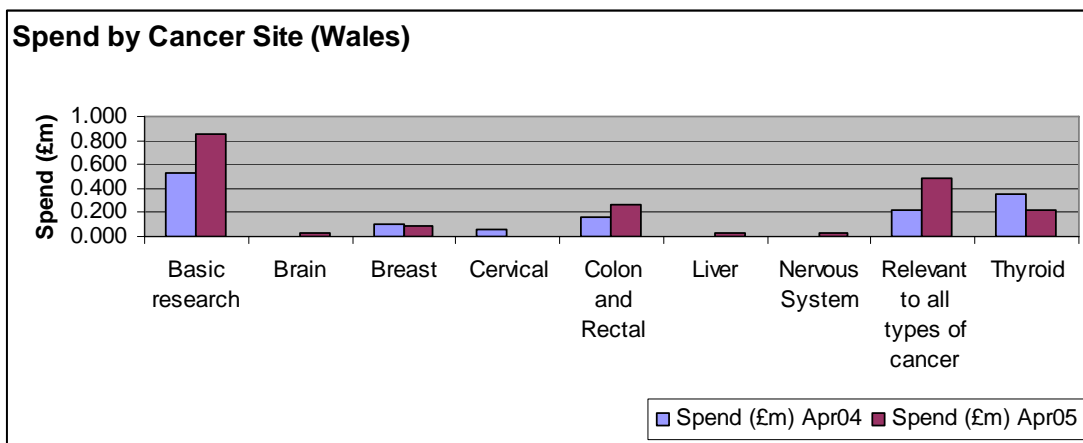
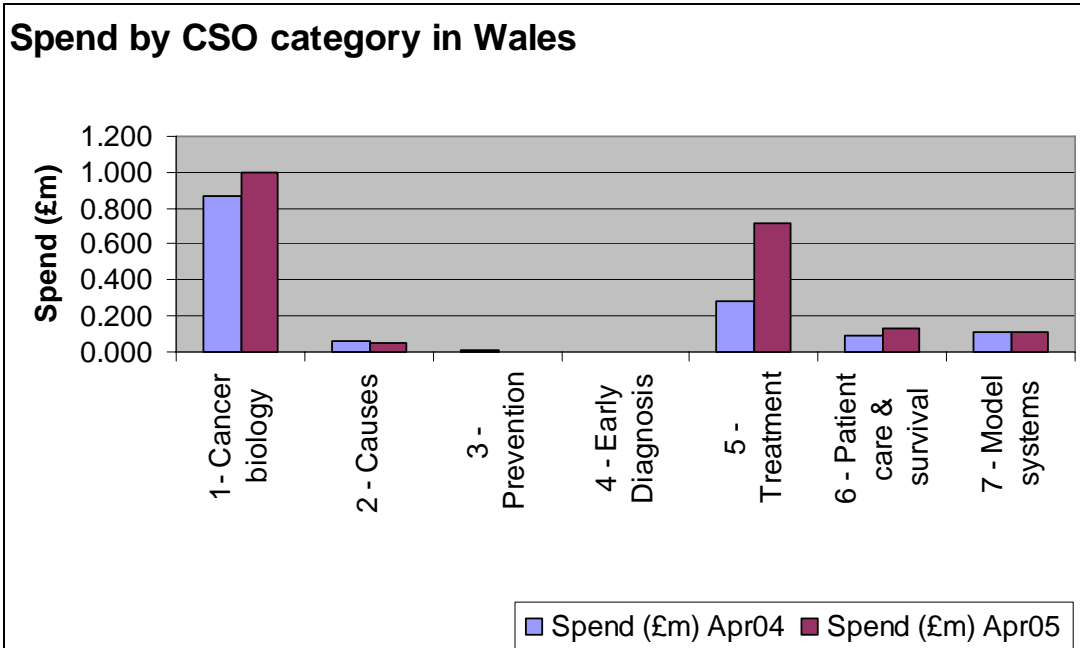
Cancer Research UK is the world's leading independent organisation dedicated to cancer research. We support research into all aspects of cancer through the work of more than 3,000 scientists, doctors and nurses across the UK.

We take an active role in funding research in Wales, awarding over £2m directly to funding research initiatives in Welsh centres in 2004/2005. Cancer Research UK Cymru jointly funds the Wales Cancer Networks and is a major supporter of cancer research through the Wales Cancer Institute.

Most recently, a collaboration of researchers from across Wales has been successful in achieving the status of an Experimental Cancer Medicine Centre, an initiative supported by the Welsh Assembly and funded entirely by Cancer Research UK, bringing with it committed funding in the region of £1.5m over 4 years.

Cancer Research UK Cymru's spend on research by Common Scientific Outline (CSO) in Wales¹:

¹ **Please note that the data do not give a detailed breakdown of the clinical trials in Wales, as this changes frequently depending on what trials are active through the WCTN. What is shown is the funding that we allocate to WCTN in total. In addition, the figures presented do not include recent funding awarded to the Wales Experimental Cancer Medicine Centre.*



Cancer Research UK Cymru plays an active role in supplying information to the Welsh Assembly on issues related to cancer, and provides the secretariat to the Cross-Party Group on Cancer. As the founder of the Wales Against Cancer Conference (www.walesagainstcancer.org.uk), Wales' only annual cancer conference, Cancer Research UK Cymru provides a forum to bring together parliamentarians and all parts of the cancer community to discuss ways in which we can best address some of the issues affecting cancer patients, researchers and health care professionals in Wales.

General Principles

Cancer Research UK Cymru welcomes this review of cancer services in Wales. We are encouraged to see the Committee tackling this important issue which to date has suffered from a lack of strategic oversight. Our response below is indicative of the broad and wide-ranging nature of cancer services, which we believe requires underpinning by properly funded networks to coordinate activities across the health sector in Wales. Importantly we are keen that this review acts as a catalyst, rather

than a distraction, for current work to address the underperformance of cancer services in Wales.

Cancer Research UK Cymru has nominated Professor Malcolm Mason to sit on the expert panel to advise and guide the Assembly Members through this review. We would also be happy to provide additional evidence to the Committee, including oral evidence as required.

Significant progress in cancer services and research has been made in Wales in recent years. The introduction of All Wales cancer expert advisory groups and the drafting of Minimum Standards and clinical management guidelines have been integral to improving outcomes for, and experiences of, cancer patients.

However, services for certain cancers are better organised and resourced than others. Some multidisciplinary teams remain under-resourced and national staff shortages mean that these shortfalls are unlikely to be resolved in the foreseeable future. A lack of centralisation of decision-making about cancer services in Wales can often result in patients being sent to other parts of the UK to receive their treatment, this is not only to the detriment of patients but also leads to increased costs for local healthcare providers.

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. This will also underpin key developments in translational research leading to improved interventions for patients in the future.

Planning and funding for these changes are now needed. We are very disappointed that the Strategic Development Plan developed by the Cancer Services Co-ordinating Group, commissioned by the Assembly, has not been adopted. This excellent document addresses the key issues affecting cancer in Wales and makes 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.

In particular we believe that Welsh cancer services would benefit from increased co-ordination and autonomy for cancer networks. This is particularly important for the cross-health authority role that existing networks have and the future role for cancer networks in commissioning cancer services.

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.

Cancer must remain top of the political health agenda in Wales. An ageing population means that the number of people getting and living with cancer will grow significantly in the next 20 years or so. We believe that a comprehensive strategy for tackling cancer in Wales, linking prevention, diagnosis, treatment, care and research is essential to ensure that all local healthcare providers improve outcomes for all cancer patients in the future.

Answers to specific questions

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

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. Cancer Research UK Cymru believes that 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.

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

Cancer Research UK plays a major part in research funding in Wales and is an equal partner with the Welsh Assembly Government in providing funding for the Wales Cancer Trials Network. Cancer Research UK also played a significant part in the establishment of the Wales Cancer Institute and the Wales Cancer Bank. Wales has great potential to be a world leader in cancer research, to the benefit of patients in Wales, and the wider Welsh economy.

In addition to long established strengths in basic and clinical cancer research in Wales, there is now an internationally recognised track record in translational research. Currently focus is on the development of molecular biomarkers for diagnosis, prognosis and prediction of therapeutic response and the identification of new targets for therapy. Examples of the excellent work currently undertaken by the Welsh Cancer Institute can be found on the Institute's website at: www.walescancerinstitute.co.uk/background.html.

We believe that 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.

However, 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.

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?

Cancer services are provided by a wide range of organisations, including the NHS, private, voluntary and independent sectors. 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.

The network model addresses the complexity of cancer services by bringing all cancer stakeholders together in a 'virtual' organisation, with input from a wide range of professional disciplines. 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. It is important that Network Plans are monitored by a strategic organisation to ensure that the local health boards take this responsibility seriously. 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.

There are currently 22 local health boards operating in Wales. Our view is that the existence of this many regional bodies works against the commissioning and delivery of co-ordinated cancer services across the country; they should be reduced in number.

There is a good argument for developing the role of the Regional Cancer Networks and clarifying their relationship with the Welsh Assembly Government regional offices. Both the Network and the regional office should take a far stronger role in overseeing the commissioning process.

Specialised cancer services—those that would not necessarily be provided in every cancer centre—in most cases need to be planned for geographical areas that span more than one cancer network. Specialised services should therefore be planned by consortia of Networks and commissioned on a national basis by Health Commission Wales 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.

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

Screening provides us with the ability to detect abnormalities early in disease. Cancer Research UK Cymru strongly endorses the strengthening of National Screening Programmes in Wales incorporating the 1968 World Health Organization guidelines on screening.

There are two screening programmes currently operating successfully across Wales:

- The national breast cancer screening programme in Wales, delivered by Breast Test Wales, has been a tremendous success, with a take-up rate of 74.3% in 2003². The World Health Organisation's International Agency for Research on Cancer (IARC) concluded that mammography screening for breast cancer reduces mortality. The IARC working group, comprising 24 experts from 11 countries, evaluated all the available evidence on breast screening and determined that there is a 35 per cent reduction in mortality from breast cancer among screened women aged 50 - 69 years old. This means that out of every 500 women screened, one life will be saved³. In Wales, the extension of the screening programme to women aged between 64 and 69, as already achieved in England, should be a priority.

² *Breast Test Wales -Report of the Director, 2003*

³ *7th Handbook on Cancer Prevention; Lyons 2002*

- The cervical cancer screening programme in Wales achieved a take up rate of 79.1% in 25–64 year olds in 2003⁴. Cervical screening programmes have been shown to reduce the incidence of cancer in a population of women. The protection offered to women by a single negative smear, in terms of percentages of cancer that are preventable is shown in the table below:

Percentage of cervical cancer preventable⁵	20-39 years	40-54 years	55-69 years
3-yearly screening	41%	69%	73%
5-yearly screening	30%	63%	73%

The effectiveness of the programme can also be judged by coverage. This is the percentage of women in the target age group (25–64) who have been screened in the last five years. If overall coverage of 80% can be achieved, the evidence suggests that a reduction in death rates of around 95% is possible in the long term.

Cancer Research 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.

Immunisation

The Human Papilloma Virus (HPV), and the Epstein Barr Virus (EBV) are viral infections that have been linked to the development of some cancers. It may be possible that immunisation against these viral infections is eventually brought into use as part of the wider prevention programme.

We recommend that, particularly for HPV vaccination, Wales takes a lead from the National Screening Board in England and their evaluations on the practicalities and cost-effectiveness of introducing such vaccination programmes.

Education and Prevention

In addition to screening, prevention is a vital weapon in the battle to improve cancer services. Prevention lies not only within the remit of the local health boards, but also with the Welsh Local Authorities, and other Health Education organisations. In addition, some areas of health education cut across policy areas (for example, healthy diet and exercise feed into a number of policy areas). 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.

⁴ KC53/61/65 statistical report 2004–2005. Cervical Screening Wales

⁵ *Sasieni, Adams, and Cuzick, BJC 2003*

Cancer Research UK is currently running a campaign to improve the public's understanding of prevention activities which may help reduce an individual's risk of developing cancer and we would gladly provide advice from our experience in this area to the Assembly on such initiatives. More information on this campaign can be found on our 'Reduce the Risk' website at:

<http://info.cancerresearchuk.org/healthyliving/reducetherisk/>

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?

The number of cancers per head of population (incidence per 100,000) is higher in Wales than England and Northern Ireland, and above the average for the UK⁶. Given these worrying statistics 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 will play an important part in this 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.

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?

The Network model proposed above is based on the principle that the patient should be at the centre of the planning process. It promotes multi-disciplinary expert team working within cancer services, so that care and treatment is the product of a holistic approach to patient care. 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.

For more information please contact Andrew Stallard, Wales Public Affairs Officer for Cancer Research UK on 02920 640 815 or email Andrew.stallard@cancer.org.uk

⁶ <http://info.cancerresearchuk.org/cancerstats/incidence/commoncancers/>