

Cancer Service for the People in Wales Questionnaire

Name of Respondent	Dr Jane Hanson
Are you responding on behalf of an organisation?	Yes however the comments in this reply do not represent a corporate view, please see note below
If so please give the name	Cancer Services Co-ordinating Group
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<p>The comments included in this reply do not represent a corporate view: CSCG is an advisory structure consisting of many individuals representing organisations, professions and patients involved in cancer services throughout Wales. The questionnaire was sent out to members of our advisory board, who were invited to respond. Many of our advisory board members represent organisations that have been asked to input into this review via other routes, and a limited response was received, some of which will be duplicated when responses are sent in through these other routes, and other members have indicated that they will respond exclusively via another route, the responses given here therefore cannot be taken to be a fair balance of members' views. In addition given the broad membership of our board, some of the views expressed may be at odds with each other and the responses have not been taken to the board to be discussed or agreed. This document is simply a collation of all the responses received, in no particular order. The comments have been anonymised for this submission and may represent the views of individuals or larger groups/organisations, for the latter we are unaware what process of sign-off, if any, was undertaken. Given this however, the comments received here are from a service and patient point of view and require careful consideration.</p>	

1.	How can information technology be used more effectively to track and facilitate the patient's journey?
Response	<p>Comment 1 The cancer treatment pathway is often a complex clinical, journey that involves many departments within hospitals and more commonly different hospitals and other organisations. If the pathway is to function appropriately within the timescales and efficiencies expected then IT has to play a part. Development of a single electronic record is key as well as systems that are able to 'talk' to each other across hospitals and national boundaries. Neither are fully available at this time.</p> <p>Comment 2 Develop software that will register and track by day on pathway all patients with suspected or diagnosed cancer. Need to be able to run weekly reports and flag those patients likely to breach targets.</p> <p>Comment 3 Practice direct booking via proformas.</p> <p>Comment 4 The CaNISC system can enable that. WCISU are able to turn suitable data into useful information using our statistical and GIS expertise e.g patient flows, access. Detailed work would require CaNISC data, most of which feeds into WCISU. We collaborate</p>

	<p>with clinicians on such analysis.</p> <p>Comment 5 the importance of the roles of the Wales Cancer Intelligence and Surveillance Unit cannot be underplayed because of the need to monitor cancers' incidence and survival and to assist in the quality assurance of health service activities e.g. screening, new technologies and practices in surgery, chemotherapy and radiotherapy.</p> <p>Comment 6 use of a single electronic cancer health record accessible to all healthcare professionals providing care for the patient.</p> <p>Comment 7 A system that allows patient records and information to be electronically transferred between primary and secondary care is an imperative.</p>
2.	How effectively is research and good practice being integrated with service delivery? What can be done and by whom to improve this?
Response	<p>Comment 1 Medical research is being integrated and introduced rapidly especially following the introduction of the internet. Sufficient financial resource is the only real issue that would speed this up. Qualitative, non medical research is limited and this is in part due to poor quality of research or research that is related to morbidity rather than mortality and thus seen as less vital. A more integrated approach between academia and the service would I believe promote and speed up the non medical based research.</p> <p>Comment 2 Some progress in this area in units where WCTN have supported Trials nurses. Possibly requires higher priority by steering groups and cancer networks.</p> <p>Comment 3 No not at all. No direct funding for head and neck</p> <p>Comment 4 The have been good developments both in WCTN and disseminating knowledge via NHS network and Web links for clinicians. The development of Multi-disciplinary site specific teams are key</p> <p>Comment 5 translating research evidence into clinical practice is difficult due to the constraints of the commissioning processes (see 3 below). 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.</p> <p>Comment 6 integration limited by lack of resources and recognition by managers and clinicians of the need for change</p> <p>Comment 7 There is a need for a 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 remove bureaucracy.</p>
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?
Response	<p>Comment 1 Commissioning of cancer services in Wales is hampered by a lack of expertise within LHBs and HCW, and a lack of capacity within the same organisations. It is further hampered by having too many commissioners and Trusts who are loathe to give up their statutory function when it is clear that a shared approach is required. Networks are well set up to play a bigger part in commissioning but fail due to having</p>

	<p>no statutory function or budget. Fundamental to this is 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. Arguably this latter point is unlikely to succeed when individual organisation shave statutory duties that could be compromised through being part of a Network.</p> <p>Comment 2 This is a shambles. LHBs have too small a population to commission cancer services effectively. At very least 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, as it is largely historical, confusing and out-dated.</p> <p>Comment 3 Yes very much so. LHB should be taken out of the equation. Top slice funds HCW to Cancer Networks.</p> <p>Comment 4 LHB and HCW seem to be failing to manage the cancer comissioning process. The 22 separate LHB do not have the necessary expertise or experience and the HCW only cover certain specialised cancers. Should be done at Network/Regional level or All Wales for specialised cancers. Needs high level cancer intelligence support from WCISU.</p> <p>Comment 5 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.</p> <p>Comment 6 There is insufficient quality clinical and managerial information to inform the commissioning process</p> <p>Comment 7 This process must be simplified by making the networks responsible for commissioning the more costly elements of cancer treatment.</p>
4.	What evidence is there of the value of screening and immunisation?
Response	<p>Comment 1 Screening for breast and cervical cancer has a strong evidence base. Immunisation has less evidence. The value of screening may be challenged in that the infrastructure could be more efficient. However this does not challenge the place and value of the service in terms of detecting early cancers.</p> <p>Comment 2 None at present for lung cancer, although trials looking at effectiveness of low dose screening CT Thorax are still on-going.</p> <p>Comment 3 Dental screening has shown to give early presentation</p> <p>Comment 4 Well documented scientific evidence</p> <p>Comment 5 the most common cancers in terms of new cases and causes of death are female breast, lung in both sexes, colorectal in both sexes, and male prostate. There is a national programme for breast cancer screening because there is sufficient knowledge of the natural history of the diseases, the test meets the relevant criteria, and the facilities for diagnosis, treatment, care etc. have been organised. 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</p>

	<p>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.</p> <p>There is no national screening programme for prostate cancers because their long natural histories mean that many cancers will not cause symptoms. There is no test that meets the relevant criteria and there is insufficient evidence about the most effective treatments comparing surgery, radiation, chemotherapy, or watchful waiting.</p> <p>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, et alia.</p> <p>Comment 6 site specific answer here, colon good evidence, prostate jury still out</p> <p>Comment 7 My observation as a patients representative and a carer would be that 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.</p>
5.	<p>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?</p>
Response	<p>Comment 1 Wales has difficulty financially and this cannot be ignored. As important is the difficulty with recruitment and retention. In addition Wales also suffers from devolution in that often delays can be found due to required policy change/discussion following devolution.</p> <p>Wales needs to look forwards 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.</p> <p>Fundamentally Wales needs to have a long term strategy for cancer care and make a commitment to it now and prepare for the future. The main risk is inability to recruit and it needs to consider a significant national training programme within certain specialties.</p> <p>Comment 2 This usually relates to funding new technologies and drugs. Further development of horizon scanning may help planning. Rapid assessment of new therapies by All Wales Medicines Group / NICE is required. All Wales policy developed to try and support Trusts & LHBs and prevent postcode prescribing during interim period.</p> <p>Comment 3 Wait for England before moving. No pre-emptive</p> <p>Comment 4 There needs to be early warning "radar" - horizon scanning - resources and expertise needed to model consequences - the WCISU have useful data and statistical expertise which help. There need to be (1) clinically rich data from CaNISC in WCISU database; (2) investment in statistical resources in WCISU</p> <p>Comment 5 Barriers include –</p> <ul style="list-style-type: none"> - 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 - need for greater clarity over the roles of the National Public Health Service for Wales in advising providers and commissioners. <p>Comment 6 information (clinical audit) on how patients are being managed and to what standards, and of course resources.</p> <p>Comment 7</p>

	Perhaps a solution could be to give clinicians the ability and resources to introduce new and effective technologies and therapies.
6.	How can the NHS and the voluntary sector work together more effectively to deliver services?
Response	<p>Comment 1 In terms of cancer both sector already work well together. The voluntary sector however could I believe work better by a) being less competitive between themselves and b) supporting the NHS not just through investment but also shaping policy.</p> <p>Comment 2 Try to agree common agenda and goals and the rest may follow. Are voluntary bodies represented at Network level?</p> <p>Comment 3 N/A</p> <p>Comment 4 Several points. Better communications between NHS and patients and carers/relatives. More data on various burdens of cancer, QoL perceptions, fears and practical issues such as travelling and parking costs</p> <p>Comment 5 these collaborations would be helped by a Government framework that established the policy and strategy and improved the commissioning processes (see answer to q3 above)</p> <p>Comment 6 joint access to better patient information, electronic information sharing</p> <p>Comment 7 The need to involve voluntary and statutory organisations in cancer services is self explanatory and is already being implemented but could be coordinated in a better way.</p>
7.	How can the collection and use of data on where the terminally ill spend their last weeks or months be improved better to inform service provision for those people?
Response	<p>Comment 1 Broadly speaking we know where individuals die, the question is what can we do to provide more choice. The recent Tebbitt Report on Palliative Care in Wales highlighted the fact that too many people were dying in hospital. However it also highlighted major resource deficits in community services. If patients are to die at home, where they want to be, the worst thing we could do would be to leave them there without adequate support. We need to address the deficits in Tebbitt first. This should be a major priority for Wales as the aging population and levels of chronic disease suggest the pressure on palliative care is potentially greater than any other cancer related specialty.</p> <p>Comment 2 Further development of Palliative care and Community services which are at present fairly patchy across Wales. Can CaNISC bridge the IT gap with the Palliative care module?</p> <p>Comment 3 No response given</p> <p>Comment 4 This is really important. Many people wish to "die at home" but lack of palliative care support makes this impossible. Past experience suggests provision is likely to be patchy. WCISU would like to help in this analysis.</p> <p>Comment 5 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.</p> <p>Comment 6</p>

	<p>electronic data allows wide communication and facilitates analysis</p> <p>Comment 7 Data collection for those who are dying should be provided if most professionals are implementing the pathway for life.</p>
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?
Response	<p>Comment 1 Organisations that employ the 'prescribers' should be more prescriptive of what can and what cannot be prescribed. This control can then be use to an advantage by excluding post code prescribing and introducing earlier new cancer drugs in a controlled but accessible way.</p> <p>Comment 2 I am not aware that this is a problem in managing patients with lung cancer.</p> <p>Comment 3 No response given</p> <p>Comment 4 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 - similar issues</p> <p>Comment 5 Inappropriate drugs – involvement of commissioners, providers, and patients to identify explicitly strengths and weaknesses of prescribing decisions. Formularies can be more effective when all these stakeholders are involved in decision making.</p> <p>Comment 6 all-Wales national guidance, statutory body with high percentage of clinicians, specialist nurses and senior NHS staff</p> <p>Comment 7 The issue of drugs is especially contentious and must be debated openly with all parties to ensure safe effective use, good trials, fast tracking and honest information.</p> <p>Comment 8 presupposes that there is prescribing of inappropriate drugs. Is there? By whom? Which drugs? Who says it is inappropriate?</p>
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?
Response	<p>Comment 1 Yes as long as the full cost of the additional services are met i.e they might for a drug privately that also has added implications for pathology. This cost should also be met by the patient who wishes to pay. We have the information available to charge them appropriately.</p> <p>Comment 2 Yes as long as the drug is liscenced, although you could argue that they also pay for any additional monitoring and scans etc if required because of this treatment.</p> <p>Comment 3 (response is unclear but reads as follows): Network Education.</p> <p>Comment 4 Personally, I think so but this raises ethical and other issues. Cochran said all effective treatment should be free. Should not be necessary</p> <p>Comment 5 Private payment – this is a complex and contentious issue. Inequalities will persist if the decisions are made locally so a Government policy should determine the issue.</p> <p>Comment 6 No, this is messy and raises huge ethical issues.</p>

	<p>Comment 7 The issue of drugs is especially contentious and must be debated openly with all parties to ensure safe effective use, good trials, fast tracking and honest information.</p> <p>Comment 8 No</p>
8(iii).	<p>Do doctors, pharmacists and other health professionals have adequate access to independent advice and guidance on the prescribing of drugs?</p>
Response	<p>Comment 1 Yes - a plethora, but they are also subject to early release of data on drug trials from pharmaceutical companies and also to media/patient pressure for treatment with "new wonder drugs"</p> <p>Comment 2 Yes. Non-evidence based prescribing is a dying art and I think has become much less of an issue now that patient management is discussed and agreed at MDT.</p> <p>Comment 3 Yes</p> <p>Comment 4 yes</p> <p>Comment 5 Independent advice – if there was greater clarity over the roles of the National Public Health Service (NPHS) in advising providers and commissioners then the NPHS would be well placed for independent advice and guidance.</p> <p>Comment 6 can't answer this</p> <p>Comment 7 The issue of drugs is especially contentious and must be debated openly with all parties to ensure safe effective use, good trials, fast tracking and honest information.</p>
9.	<p>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</p>
Response	<p>Comment 1 I don't believe services are centered around the patient as much as they could be. However in recent years the Cancer Networks have gone out of their way to consult with users. The issue is that the NHS is limited to how much it can change to really meet the a patients needs, some changes would simply be uneconomic or under utilised. The other problem is that meaningful user involvement is extremely difficult to develop especially as it goes against this historic culture of the NHS and its patients. Fundamentally user involvement needs to be more focused.</p> <p>Comment 2 Moving in the right direction, but could become more patient friendly. Difficult to involve lung cancer patients due to poor prognosis, but I feel we have made significant progress in S Wales over recent years. It takes time to develop and change culture and this has to be more of a long term goal.</p> <p>Comment 3 Yes</p> <p>Comment 4 No not really - more goos surveys</p> <p>Comment 5 most NHS Trusts appear to discuss issues with patient/service user groups. However the extent that these discussions influence decisions by the Trusts needs to be researched.</p> <p>Comment 6 It is easier to provide & manage institution based care, this does not support joined up care on multiple sites, which is the pattern of modern cancer care. A single, electronic patient-centric cancer record which is used by primary, secondary, tertiary & palliative care services would be a major improvement.</p>

Comment 7

My own experience in this field is considerable and I can say that it is now much better and patient groups are being involved at all levels i.e. strategy, local and national but there is still a need to bring all of the separate strands together in a more cohesive way. To ensure less duplication and effective communication in conclusion 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.