

FEEDBACK FORM

Thank you for taking the time to contribute to the Better Cancer Care discussion. Please refer to the prompting questions under the 'Issues to Consider' at the end of each section within the document. You do not need to answer all the questions. All responses will be considered. Please use a separate sheet if necessary, clearly indicating the section to which your comment relates. Thank you.

You may download or complete this Feedback Form online at: <http://www.scotland.gov.uk/Topics/Health/health/cancer> or you may request an electronic version by emailing: bettercancercare@scotland.gsi.gov.uk

NHS Lanarkshire Response

In drafting this response NHS Lanarkshire sought the views of patients, the public (through patient partnership forums), professionals in primary and acute care, hospice, support centres and the voluntary / third sector. This resulted in a range of comments which are reflected in this response.

NHS Lanarkshire has recently established a new post of Head of Cancer Services with the intension that this post will pull together disparate cancer services including NHS services, third sector and the hospices. The post will also lead on the development of a cancer centre for Lanarkshire.

The Challenge for Scotland

The introductory chapter misses out on two key issues which are central to the context of the entire Cancer Strategy.

The first issue is the actual and projected increase in the burden of cancer due to increased incidence – principally as a consequence of increased longevity. This was identified in a chart summarising the recent trend and the projections from Cancer in Scotland: Sustaining Change: Cancer Incidence Projections for Scotland (2001 – 2020) – An Aid to Planning Cancer Services. Scottish Government: 2004.

The importance of this observation is that much of the investment in cancer care in the last ten years has been needed to maintain services for the increased demand (the new provision of linear accelerators is a good example of this) and continued future investment will also be needed to maintain the same level of service for the future demand. Cancer is not like many other aspects of health care where one can envisage alternative care pathways such as self-management. Cancer surgery needs surgeons and theatres; radiotherapy needs linear accelerators and highly specialised staff; chemotherapy needs an exemplary standard of quality in all aspects of its preparation and delivery.

In general, survivorship for all cancers (especially in the very long-term e.g. 15-25 years afterwards) is becoming more common and service responses to this are consequently more important. This issue has barely been mentioned in this document and needs highlighting.

The second issue referred to at several points in the discussion paper is the inequality in cancer incidence and outcomes. It is well illustrated in Figure 4 of the consultation document. Notwithstanding the improvements in cancer mortality noted in the text, the figure shows how the inequality ratio has increased. The wording round about this graph was confusing. It gives the

impression that the inequalities gap has in some way decreased, whereas the figure clearly shows that this is not the case.

This increase in the incidence of cancer could be regarded positively as cancer is a disease primarily of old age and the increased incidence is occurring because people in Scotland are surviving those diseases that lead to premature death.

Similarly, in relation to blood cancers the incident is increasing and the reasons are two-fold – a real increase and also an increase in the older population where the incidence is higher. Figures illustrating improved survival highlight the extent to which the outcome for patients with blood cancers have improved and this improvement will continue in the future. This is already impacting on the number of patients surviving cancer and impacting on clinic follow-ups – previously many of these patients were discharged but late-effects of treatment are becoming more widely recognised and there is a need for a planned approach to managing cancer survivors (e.g. partnership with primary care or nurse-led follow up). Many of the problems are not directly related to relapse as such or even second tumours but are cardiovascular or endocrine in nature.

SECTION 2 : PREVENTION

Please provide comments / suggestions on *Prevention*

Issues to consider from Better Cancer Care

- **How can we take full advantage of the opportunities for cancer prevention provided by the Scottish Government's programme to help people sustain and improve their health?**
- **What more can we do to improve public awareness about the risk factors associated with cancer and encourage lifestyle choices that mitigate against such factors?**
- **What more can we do to address inequalities in terms of both access and outcomes?**
- **What further opportunities are there for taking this whole agenda forward through cooperation and collaboration between the NHS and its partners, e.g. the third sector?**

Scottish Government's Programme for Cancer Prevention

NHS Lanarkshire welcomes the recognition that much can be done to prevent cancer and that this needs to be embedded in overall programmes to improve diet, increase exercise, helping people stop smoking and reducing alcohol intake. Many of these programmes (exercise and reducing alcohol intake for example) will have a moderate impact on cancer incidence but will have a much larger impact on mortality and morbidity from other non-malignant causes.

In Lanarkshire health improvement is integrated within the Community Health Partnerships. There are existing frameworks which will support health promoting activity across the different settings mentioned e.g. health promoting schools and nurseries, Health Promoting Hospitals. These frameworks should be utilised in order to ensure an integrated and systematic approach.

There is a need to consider what is effective in supporting prevention through the evaluation of initiatives.

In relation to skin cancer enhanced local collaboration between dermatology services, public health, schools and cancer charities are increasing the awareness of skin cancer and its risk factors particularly targeting children via health awareness education sessions in schools. An electronic triage pathway should be rolled out to all GPs allowing easier access and timely surgery. Sun bed usage should be regulated by the Scottish Government, with the banning of unmanned tanning booths and a block on the provision of sun beds in local authority leisure facilities.

In relation to haematology there are as yet no defined preventative factors specific to blood cancers but some evidence that Lymphomas are higher in socially deprived groups (possibly some through late presentation and this has been thought to be a real issue in Lanarkshire) so a full part in the general drive to improve awareness of cancer and reduced deprivation is essential.

Legislative back up and action is required, for example smoking campaigns had limited effect but the legislation smoking ban had a major impact. Government action on the selling of cigarettes is required.

Improving Public Awareness

There is a need to both continue to raise public awareness of risk factors associated with cancer and encourage lifestyle choices that mitigate against such factors. Awareness can be raised through:

- Links with media particularly local papers, having "health matters" type regular features/ health slots. This would use the expertise of Health Board communication staff and use simple language
- Young people could be targeted using internet, health centres, clubs
- There is a need to overcome the public view that "it won't happen to me"
- Use patients talking about their experience
- Use of brief personal interventions by GPs
- Take awareness raising, smoking cessation and screening checks to supermarkets and shopping centres (there is experience of this working well e.g. World Diabetes Day). This enables people who are "too busy" to be targeted. Permanent shop fronts could be developed in local shopping centres, possibly provided in conjunction with other agencies

- The use of role models of people who are involved in the life of the public (e.g. sports persons, TV soaps) to raise awareness of participating in screening and prevention of cancer and overcoming cancer
- Increase physical activity in schools
- The media should avoid supporting gimmicks, inappropriate diet information and promoting size 0 in order to help young people withstand peer pressure

However, there is also a need to support people to make lifestyle changes. People need to see the benefits of making lifestyle changes through positive messages, raising awareness alone is not enough. There is the difficulty that people only go to their GPs when they feel unwell. Lanarkshire has particular difficulties of patients presenting late, due to cultural ethos – people “accept” ill health.

There is responsibility for action at a Government, NHS and individual level. There is a need to provide evidence based approaches to health promotion across a range of topics, guidance and support should be provided by the Scottish Government on the approaches to be taken.

The opportunities that are afforded to improve health within workplaces through the Healthy Working Lives programme should also be recognised

While health improvement should be on everyone’s lips and the public should be encouraged to take the opportunity of all screening programmes, people with a mental health issue need to be more supported and enabled to attend screening sessions. For example, cervical screening could be a traumatic experience to someone with a history of sexual abuse, also a diagnosis of cancer although devastating for anyone could exacerbate an already existing mental health condition.

Related to the above, there is a need for ensuring up to date knowledge of risk factors and skills development (e.g. brief intervention) across the NHS and partner agencies, particularly local authorities, in order to enable staff to feel confident to raise awareness of cancer risk factors and to encourage and support people to make positive lifestyle changes.

There are examples of effective services which can build on:

- The Lanarkshire Big lottery cancer information service
- Haven Centres in Blantyre and Forth which are accessible enabling people to drop in
- Smoking Cessation groups, however these have limited capacity
- Keep Well
- Bowel Cancer Awareness Project

Addressing Inequalities

Much of this chapter is given over to the important issue of tackling inequalities. It is however slightly disappointing that the text here emphasises the importance of geographical influences, age and sex and equalities legislation. It is noted that, for example, the incidence of early cancer is significantly increased in people with a learning disability and the third sector can play a key advocacy role in facilitating access to care. However, it is important to emphasise that deprivation has the most pervasive impact in affecting incidence, mortality and survival.

Prevention measures need to be targeted at specific groups in the population and it is known that generic health promotion messages do not have an impact particularly in materially deprived areas. The “Keep Well” initiative which targets deprived areas with proactive screening and checks should be built on. There is a need to address the perception that a healthy lifestyle is expensive.

Partnership

Initiatives which target specific populations of need, such as deprived areas, should be considered in order to maximise use of limited resources. Opportunities to link initiatives through Health Living Centres should be explored.

Educational settings are important for health promotion and the Government should specify a standard, consistent level of health promotion in the curriculum, starting early in primary school and

continuing into secondary school. Examples of good practice within education were noted but these were not felt to be uniformly in place. The roll out of the new cervical cancer vaccine provides such an opportunity and children could be taught about aspect such as self examination.

There is a need for consistent advice from NHS, other professionals (such as social workers and teachers) and the media for example about the impact of diet and dietary supplements.

SECTION 3 : SCREENING

Please provide comments / suggestions on *Screening*

Issues to consider in Better Cancer Care

- **How should we develop our approach to screening in Scotland?**
- **What more can we do to raise awareness, encourage participation and reduce inequalities in uptake of existing screening programmes?**
- **What does the research base tell us about how to derive greatest value from future screening programmes in Scotland?**
- **What more can we do to ensure cancer genetics services are positioned to play their full part as technology develops and knowledge grows of the impact of genetics in prevention, diagnosis and treatment of cancer?**

Approach Screening

Screening for cancer in Scotland should continue to be developed in a co-ordinated way focussing on UK National Screening Committee policy. Support from the National Services Division is valued highly. Where national funding can be made available for enhancements to programmes/ new programmes, this is very helpful to boards.

The Scottish Public Health Network may be able to contribute health improvement approaches to address the issues raised in Better Cancer Care.

Screening leaflets are available through NHS Health Scotland and should continue to be free to boards: they are currently but it is unclear how long this will be continued. There needs to be funds available to ensure that we can have adequate access to leaflets and other resources freely available for patients for these statutory programmes. Innovative funding solutions could be considered e.g. sponsorship.

Greater integration of screening IT and existing systems is mandatory if screening is to be viewed as credible e.g. as yet there no integration of SCCRS (Scottish Cervical Call and Recall system) and the local GP clinical systems such as GPASS and NCCIAS (National Colposcopy Clinical Information and Audit system). Although some work is ongoing in the area of the GP clinical systems, there is no timescale for linkage, nor update on the NCCIAS.

Awareness, Participation and Inequalities

As noted above, awareness should be raised through linking with existing settings based approaches (Health Promoting Hospitals, Healthy Working Lives) and community health programmes.

In particular the opportunities to link with local workplaces to promote awareness of screening programmes should be further explored. Consideration should also be given as to how to reach workplaces that are not registered for the Healthy Working Lives programme.

There are opportunities to link with community health projects to explore the potential of training local people as community health educators. Such initiatives have been developed at a local level in relation to breast and cervical screening and have evaluated positively. This model may be particularly useful in promoting the introduction of the bowel screening programme.

Incentivising through the GMS contract needs to be adopted by the whole of the UK and this may help reduce inequalities. Existing payments for GPs for cervical screening can encourage exclusion of the recurrent defaulter population; this population is strongly linked with deprivation and is at greatest risk of cervical cancer. Cervical screening uptakes are falling nationally and require attention. Also cervical screening uptake has been recently removed from HEAT targets-the message this sends is not helpful. Financial support to practices to tackle recurrent defaulters would be welcome, bearing in mind informed consent issues. The GMS contract should do more to encourage practices to register vulnerable groups such as homeless/ travellers etc.

Efforts to achieve full informed consent must be maximised. It requires a variety of methods and additional support will be required to attempt to reduce inequalities. Models like the community health educator have had some impact in this area in ethnic minority and deprived communities. More research into this and other methods is needed support areas such as bowel screening where we recognise that deprived populations and males have significantly poorer uptakes.

The third sector has an important role as it enables greater ownership of issues and maybe more integrated into communities.

Education is very important. Children need to learn about their bodies and understand how disease arises. Fatalism and the view that even if one presents late, things can still be 'fixed' is very strong. Engagement with most deprived communities may be complicated by issues which affect learning and education.

Greater support for marginalized and excluded children is required and interventions to increase self worth can improve ability to learn in the first place and affect awareness and knowledge and informed consent on range of health issues.

In order to promote screening there is a need to balance encouraging attendance with not scare mongering. There is need to address the public's perception that by attending screening this provides them with protection. Screening is not an end in itself, regular checks are required. People also do not attend screening due to fear of either what will be found or concerns that the screening will be painful (e.g. mammograms). In addition patients report that they are reluctant to undergo intimate physical examinations particularly male doctors for woman patients.

A mobile bus used in rural Clydesdale provided a good model by offering information on cancer as well as access to computer training (i.e. do not just provide one service). Also, breast screening vans are viewed as a good model by going into communities and providing a convenient service.

Awareness raising for screening should be similar to prevention health messages with:

- Use of more conspicuous advertisements, not just in GP's and outpatients
- Use of well known personalities to break down barriers e.g. glamorous role models
- Individual targeting – Smear reminders
- Consistent and constant awareness raising rather than one off campaigns
- Use of examples of patients who presented late with poor outcomes and emphasise the positive side of early diagnosis and treatment using cancer patients
- Target local opportunistic events e.g. fashion shows, social interest
- Positive messages of cancers which can be effectively treated
- Use of school immunisation programmes to promote health messages
- Well woman/man clinics
- Ensure GP appointment availability
- Target non- attendees

Deriving Greatest Value from Future Screening

Advancements in screening have and will drive advancements in diagnostics and service provision. Coupling of these through clinical standards is helpful. It is not helpful or logical when standards for screening programmes appear to be disconnected from those of symptomatic services such as the 62 day wait for symptomatic bowel cancer where this does not directly apply to colorectal cancers detected by the screening programme where the yield is far higher.

Cancer Genetics Services

Communication with the public is vital with regards the advancement of cancer genetics services. For example, are the public aware they can request a risk assessment and how has this been communicated. Further training or guidance is required for primary care staff in order that they will consistently offer this service to appropriate patients. Ethical issues around genetic screening need to be simplified and made understandable by GPs and other clinicians who are in the front line with patients and advising on genetic testing.

In breast cancer, screening for genetics / family history patients needs to be adequately funded. Currently there is no funding for MRIs although NHS Lanarkshire has been screening family history patients with mammography for years.

At present patients with familial melanoma have no access to cancer genetic services as these are not funded but are research projects. As these patients fall in the high-risk group, further funding is needed in this area of research.

Specific Cancers

Skin Cancer

Screening for melanoma is difficult but there is some evidence that annual checks could identify unsuspected disease. This could be addressed by the primary care quality outcomes framework or by having annual checks for people in high-risk groups such as the transplant group and people with familial disease.

Breast Cancer

Cancer survivors who have undergone radiotherapy are a group making an increased call on the services of the Breast Screening programme.

Haematology

Although there are no plans for screening for blood cancers, the actual increase in 'routine' blood counts is leading to an increase in the number of people (rather than patients) being picked up with early chronic lymphoproliferative disorders (e.g. Chronic Lymphocytic Leukaemia). There are capacity issues arising for haematology departments and GPs in dealing with these people, most of whom need no treatment other than watchful waiting.

Bowel Cancer

The Bowel Cancer Awareness Project which was implemented in selected deprived area in Forth Valley and Lanarkshire may have paved the way for improved uptake in the bowel screening programme in Lanarkshire through its community development work and awareness raising with the public and key members of staff.

SECTION 4 : DIAGNOSIS AND TREATMENT

Please provide comments / suggestions on *Diagnosis And Treatment*

Issues to Consider from Better Cancer Care

- **How do we continue to improve diagnostic and treatment services?**
- **How should we support the future development of surgical skills within NHSScotland's workforce?**
- **What are the future priorities to ensure safe and effective radiotherapy, chemotherapy and drug treatments across Scotland?**
- **What more can we do to ensure cancer genetics services are positioned to play their full part as technology develops and knowledge grows of the impact of genetics in prevention, diagnosis and treatment of cancer?**
- **How do we balance the need to ensure local access and convenience with the need to maintain specialist expertise and capacity?**

Improving Diagnostic and Treatment Services

Skin Cancer

There is a need for appropriate capacity for skin cancer clinics and these should be multi-disciplinary with input from medical staff, cancer nurse specialist, audit department, cancer trackers and psychologists, with links to plastic surgeons. These should be one-stop clinics with the cancer staff grade performing a surgery list alongside the clinic so patients have access to treatment when necessary. There are models of good practice, with patients being referred electronically and triaged to routine clinics (if no cancer), cancer clinic urgently, dermatology surgery urgently or to the plastic surgeons and NHS Lanarkshire is working to extend this. There should be nursing input from the cancer nurse specialist by providing return appointments for review patients, counselling and screening.

Breast Cancer

NHS Lanarkshire's outpatient capacity for breast referrals is at saturation given the updated referral guidelines, 62 day targets and proposed outpatient targets. In order to meet these challenges there is a need to expand outpatient clinics on all sites with radiology support.

Diagnostic equipment is paramount in breast cancer care and equitable access needs to be available regionally and nationally to support waiting times guarantees.

Haematology

There are existing examples in non-cancer realms where hospital managed but community delivered services work extremely well (eg AntiCoagulant monitoring), and similar arrangements would be feasible to manage cancer patients requiring oral and i/v chemotherapy, supportive care in community clinics or hospitals (including blood transfusion), and long-term patient follow-up.

There is a need to progress electronic assistance in chemotherapy prescribing and administration to reduced clinical risk and improve communication within secondary care and out to primary care.

Development of Surgical Skills

To meet the 31 day surgical targets, NHS Lanarkshire will need to maintain elective breast lists whilst on call and expand the consultant compliment to rotate and cover the clinics and lists. The NHS needs to ensure there are adequate consultant numbers to support these lists and clinics.

Balancing Local Access with Specialist Expertise and Capacity

Lanarkshire has an overall infrastructure model for cancer services with local outpatients, diagnostics and chemotherapy services on all acute hospital sites, a cancer centre planned for Monklands Hospital and increasing palliative care provision particularly in people's homes.

Transport for treatment is viewed as problematic. There are patients who choose local access over more specialised treatment whilst others will travel if they think they get a specialised service or if

they will be cared for by staff they are familiar with. Socio-economic issues affect patient's ability and or desire to travel. Patients may need to access travel expenses up front. There is a need to improve the travel infrastructure between acute sites in Lanarkshire. The Cancer Care volunteer driver service is viewed as excellent. This takes patients and carers to hospitals (the Beatson as well as internally within Lanarkshire). This service is dependent on fund raising and would be placed on a more substantial basis by accessing mainstream funding.

There is a need to consider what treatment can be delivered in patients' homes. The process of treatment in hospitals can be very time consuming with people waiting. There is a need to keep patients fully informed and to streamline the care process as much as possible particularly in relation to the administration of chemotherapy and related blood tests.

SECTION 5 : PALLIATIVE CARE

Please provide comments / suggestions on *Palliative Care*

Issues to Consider from Better Cancer Care

- ***There are numerous examples of excellent palliative care in Scotland. How do we ensure that this happens more systematically?***
- ***What are the key issues for people with cancer and their carers when considering palliative care services?***
- ***How do we balance the need to ensure local access and convenience with the need to maintain specialist expertise and capacity?***

There is a misunderstanding of the term palliative care amongst health professionals as well as the public. Conversations raising palliative care can be difficult. Better Cancer Care identifies palliative care primarily with end of life care however palliative care can contribute greatly earlier in patients' treatment for example through pain control and psychological support.

Palliative care is not a common term outside hospitals and hospices and patients and health care professionals have advised that the misconceptions of palliative care is a barrier to patients accessing these services. There is a need to educate both patients and other care professionals. People also still think hospice is "end of life" and fear them, whereas they can offer positive aspects such as health promotion and symptom management throughout the whole of a person's illness. Better Cancer Care does not mention palliative care's contribution to control of disease and education about disease. Palliative care needs to be considered as a joint venture with curative treatment. Similarly, the public does not know the term "MacMillan."

There is need to increase access to specialist support (e.g. specialist nurses, MacMillan, clinics supporting pre treatment, recurrence and counselling) in hospitals to enable patients to access to advice faster. There is also a need for additional overnight care to support people to stay at home including non malignant patients and to increase the capacity for respite hospice to get people home.

Palliative Care should be available for people living with cancer and non malignant diseases as reflected in NHS Lanarkshire's draft Palliative Care Strategy. The expansion of the Marie Curie recently agreed with NHS Lanarkshire will play a part in addressing the issue of equality of access to Palliative Care regardless of diagnosis.

Much of the value of palliative care services comes from the third sector so it is not surprising that there is inequity in the distribution of access and quality because there is inequity in the charitable giving power of different communities.

In addition, there is limited information on the variation in specialist palliative care across Scotland. All hospices should sign up to a single information system as there is no information currently on the characteristics of patients using Scotland's hospices. This is essential as on the one hand a hospice bed is as expensive as an intensive care bed and yet there is no system similar to the SMR system for the patients in those beds.

It is noted that there will be a plan soon for the improvement of palliative care across Scotland as well as a report from Audit Scotland concerning palliative care. A part of this plan should include an agreement with all hospices on a single information system.

It is appropriate that the SPPC report "Palliative and End of Life Care in Scotland" informs that palliative care plan. NHS Lanarkshire's draft Palliative Care Strategy highlights that people should end their life in their preferred place of care and this strategic direction is reflected in NHS Lanarkshire's agreement with Marie Curie.

Probably the key distinction between providing palliative care for those suffering from cancer and other life limiting illnesses is pain. Thus as set out in Better Health Better Care, the Better Cancer

Care plan should refer to implementation of the Liverpool Care Pathways and Gold Standards Framework, to ensure good delivery of palliative care and a good quality of end of life care.

An underlying principle is that the great majority of palliative care interventions can be given in the community (home or care home) setting: better coordinated working and support in the community can reduce inappropriate hospital admissions. Although hospice/specialist palliative inpatient care is a requirement of a network of interventions, the hospices can also form a crucial hub of the local Palliative Care Network to provide advice to all practitioners in the community together with training.

The development of the Maggie's Centre in Lanarkshire is welcomed and although the main centre will be at Monklands Hospital it might be appropriate and possible to retain a satellite centre at Wishaw General Hospital.

Palliative Care is also not just for cancer and much of the palliative model can be used for other illnesses. The main thrust planned in Lanarkshire for the next five years is to extend palliative care out to non cancers. It is recognised that there are specific issues for cancer particularly in relation to pain; palliative care must also stay integral part of cancer care. There can be a differentiation of two terms, "specialist" palliative care and "generalist" palliative care approach.

Thus, it might be that Better Cancer Care should consider those things which are distinctive for people with cancer and of this the outstanding difference between cancer and other life limiting illnesses is pain. Aspects which can address pain are:

- Gold Standards Framework and Liverpool Care Pathway
- emergency access to opiates
- information sharing (e- care potentials)

There is need to support patients after treatment and to consider survivorship. Palliative care can create independence and self management and this can impact positively on quality of life.

Excellent models of palliative care should be shared through networks and standards of best practice should be developed and implemented, taking account of local needs.

Issues for people with cancer include receiving consistent and timely information on their prognosis and care plan and having a contact point/person that they can approach throughout their care pathway for further information or referral to other services.

It is important to note that inpatient, local palliative care facilities are available and funded - to complement charitably funded hospice care.

There is only one palliative care dietician in Scotland at present, based in Fife. Because food and fluid are an essential for living, the reduction in someone's ability to take them can be extremely stressful for the individual and their families. Therefore it would be useful to see a recommendation on the development of specialist posts in this field in health boards which the other dieticians can link with to provide equity of care to support individuals and their families and provide the best care possible.

SECTION 6 : ASSURING QUALITY OF CARE

Please provide comments / suggestions on *Assuring Quality Of Care*

Issues to Consider from Better Cancer Care

- ***Which aspects of the suggested quality assurance programme should be prioritised to ensure continuous improvements in the speed of access to and quality of care for people with cancer? What more needs to be done to eliminate variations in practice across cancer centres and/or specific tumour services?***
- ***How might we best formalise a publicly reported quality assurance programme for cancer services using comparative clinical audit?***
- ***Is there a need to look at the way cancer audit is organised in Scotland and determine if the current configuration will enable us to meet the challenges to cancer care over the next few years?***
- ***What information should be routinely available to the patients and carers to allow them access to data on service quality and how should this be presented?***
- ***How could we encourage greater participation in clinical trials?***
- ***What further opportunities do you see for taking this forward through cooperation and collaboration between the NHS and its partners, e.g. the third sector?***
- ***In looking at options for new cancer waiting times targets, how could efforts be targeted to be more inclusive and meaningful for clinicians and patients, secure rapid access to diagnosis and treatment and at the same time ensure sustainable, equitable and qualitative improvements in cancer care?***

Priorities for Quality Assurance Programme

Local, regional and national Managed Clinical Networks enable the sharing of good practice. These require management support as well as motivated individuals. They should possibly be more prescriptive to ensure buy in for all to drive change. They should also support a shift in care and be less focussed on acute care. They can support profiling pathways to ensure that all staff groups aware of these e.g. GPs, Allied Health Professionals. Quality of care can be improved through considering patient and staff experience, audits, service redesign, reviews and benchmarking.

There have been improvements in multidisciplinary teams meetings (MDTs) in Lanarkshire but further work is required to ensure consultant pathologist input. Effective structures are required so that they become an integral part of the patient pathway e.g. patient management cannot proceed without the MDT happening. This may have resource implications.

Multidisciplinary Teams meetings need to have standard constitutions and are ideal for groups to ensure the output is appropriate. All professional groups should be represented to ensure treatment plans are optimised.

Clinical audit should be focussed on both targeting quality and waiting times. There is a need also to understanding bottleneck in tumour specific pathways and to improve pathways and communication. There is a need to understand demand and whether there is capacity to against each modality. The way to address this is to identify and manage the individual patient pathway and this has significant resource implications. Access to good research and trials should be further promoted across Lanarkshire, targeting areas of good practice and deficits. Regular reviews of achievement against SIGN guidelines and QIS standards should be undertaken leading to education and training to improve staff competence.

Work on waiting times has been impressive for urgent cancer referrals. Ideally such pathways and timelines need to be regarded as the norm for all patients, regardless of mode of referral and rolled out to all tumour types not just the major groups selected. However, this will require significant additional resources and would need to be managed to ensure that progress achieved to date is not undermined

Also, in relation to waiting times there is a need for sustainable investment linked to long term care and decentralised services. There are positive messages about reduction in waiting times but

negative impacts due to the impact of league tables. The practical implications of waiting times management need to be considered. For example most patients with cancer are elderly. Patients are carers too and this leads to practicality difficulties in how they can attend appointments. There are implications of diagnostic demands (threshold) as there are low cancer numbers from 'urgent' referrals.

There is need for greater education of public and professionals to ensure appropriate referrals. There need to consider referral pathways with specialist vetting and appropriate filtering. There is a need for greater integration with local authorities and improved communication.

Greater emotional and psychological care of individuals and family should be provided and this should include financial support.

Organisation of Cancer Audit

In Lanarkshire since 2002, the audit data sets have expanded significantly, to include additional clinical information, such as detailed follow-up for survival analysis, data on recurrence, etc. As well as this additional level of detail, the cancer audit staff are now responsible for the collection and management of audit data for the full range of tumour types

- Breast
- Lung
- Gynaecological, Ovarian & Endometrial
- Colorectal
- Head and Neck
- Upper GI (2 components)
- Urological (3 components)
- Dermatological
- Haematological

In addition to undertaking more detailed audit in an expanded range of tumour types, the requirement for quarterly waiting times reporting has continued to increase, with additional time pressures due to the decrease in turnaround time for the submission of data.

The methodology for reporting and verifying waiting times has also changed. Waiting times data is now subject to an increased level of analysis internally, prior to submission to ISD. Cases breaching the 62-day target in particular undergo detailed scrutiny, and are subject to a multi-stage sign-off process by clinicians, service and divisional management. To facilitate this process, the audit staff provide a very detail analysis of the patient's pathway, highlighting any documented delays and the reasons for them.

The audit staff also check and validate the full cancer analysis (not just the waiting times component of the audit) reported by other organisations e.g. WOSCAN. Despite this increase in workload, there has been no corresponding increase in staffing complement.

A team of cancer trackers has been established within NHS Lanarkshire over the past year and there are currently 12 cancer trackers in post.

Both teams of audit and trackers are involved in monitoring, for different purposes, broadly the same groups of patients. There is a degree of overlap in some of the data collected, and it would be useful if the Scottish Government considered the issues of:

- Ensuring that waiting times audit data is complementary
- Overlapping data requirements leading to a degree of duplication in data collection is minimised
- Shared IT systems support the collection and reporting of audit / tracking / waiting times data
- Consistent and clear national guidance from ISD and SEHD is provided around data definitions and their application
- Level of audit support staffing keeps pace with increased workload over the past four years

The NHS must also ensure that audit data which identifies areas of concern in cancer treatment are not compromised and delayed by waiting times data collection.

Greater analysis support from ISD is required. For example local invasive cervical cancer audit is carried out at health board level but it has proved challenging to get ISD analysis time to support the aggregation and analysis of these data on a national basis.

Participation in Clinical Trials

The Scottish Cancer Research Network (SCRN) was established in 2003 to fulfill directives set by the Scottish Executive to promote and increase recruitment in cancer clinical trials. Large body of evidence to suggest that patients participating in cancer trials have enhanced outcomes however there challenges in enabling cancer patients to be offered a trial including:

- the EU Directive in 2004 requiring anyone conducting clinical trials have to comply with all new legislations – GCP, CTA, Pharmacovigilance etc (this leads to additional time/increased documentation)
- Obtaining the necessary Ethics and Trust approvals (increased paperwork)
- Busy clinicians with limited time to discuss clinical trials
- Large cancer trials run mainly from cancer centres – not open to patients locally with patients being unwilling to travel, preferring local treatment
- Lack of research nurses

The SCRN is pivotal in overcoming these barriers and some of the funds have been used to employ research nurses and / or data managers to help with the processes involved in clinical trials.

NHS Lanarkshire has a small, but very good team of four cancer clinical trials support staff. Since team's inception, the number of cancer trials conducted within Lanarkshire, the number of patients offered the opportunity to participate, and the number of patients recruited to cancer trials has increased. Currently NHS Lanarkshire has:

- Approx 17 open Hematological trials with 2 pending
- Approx 17 open solid tumour trials (all tumour types) with 9 pending
- Approx 23 closed trials in follow-up

It was recognised in 2006 that one of the main limiting factors in the further expansion of recruitment into trials was the small size of the Cancer Clinical Trials Team and a further Data Manager post was filled towards the end of 2007.

There are pressures on the current service:

- Many trials have sub-studies attached which more and more clinicians wish to participate in. This includes the growing area of Translational Research – this involves collection and coordinating blood and tissue samples – very time-consuming but extremely worthwhile.
- Maintaining the present high standard of both recruitment and data collection – the biggest limiting factor is the accumulative effect of trial follow-up. Many of the trials are in follow-up for 5-10 years so even when they close the service is still regularly collecting and collating data to send to the coordinating centres
- The cancer types for trial in expanding, there has always had a major input into haematology trial recruitment and increased activity is taking place on solid tumour trials, including lung, colo-rectal, breast and this means that there is increased travel between sites and an ever-increasing workload

If the volume of recruitment is to increase, it will be necessary to increase the level of support provided to the cancer specialist clinicians through further expansion of the Cancer Clinical Trials Team. Lack of sufficient support of this type was recognised by the WoSCRN as being one of the key barriers to recruitment, and pump-priming of these teams in the West of Scotland Boards has brought demonstrable improvements.

In relation to differing recruitment rates into trials among different tumour types this would be helped

by increases in Cancer Clinical Trials Team capacity, allowing targeted support for low recruiting areas / tumour types. It should also be noted that this may also, in part, be a function of the availability of suitable trials – this is, an issue that falls within the remit of the WoSCRN.

In order to encourage greater participation in clinical trials there needs to be local clinical trial staff on site, appropriate infrastructure and awareness and education for professionals as well as removal of restrictions to allow clinical trials (e.g. on site oncologist support during delivery). The Clinical Nurse Specialist role should be to ensure plain language used and to distil a clear message for patients. This should help to reduce the fear of experimentation. There is a need to differentiate between trials and studies of proven drugs and it needs to be clear what type of study or trial is being offered.

Clinical trial should be established to suit patients' lifestyles, i.e. be near work and home.

SECTION 7 : PUTTING PATIENTS AT THE CENTRE

Please provide comments / suggestions on *Putting Patients at the Centre*

Issues to Consider from Better Cancer Care

- ***How can we further improve the experience of patients with cancer?***
- ***How can we further improve the information that is available to support patients, their families and carers? What information gaps exist at present for public/patients and how are these best addressed?***
- ***How can we work more effectively with the third sector in meeting these objectives?***
- ***How could the model of self care management be implemented across the pathway of care?***
- ***What approaches need to be considered to deliver the services required to meet the survivorship needs of patients living with cancer and patients living with cancer as well as other long term conditions?***
- ***How can we further improve rehabilitation for people with cancer and how can their needs be better supported?***
- ***How do we ensure better integration and continuity of care?***
- ***Have you had any recent personal experiences that might help shape and inform future actions across Scotland?***

Putting patients at the centre of care is essential and it is disappointing that this topic is presented late on in the Better Cancer Care document. Support for patients and families is required as early as possible (e.g. pre-diagnosis from first approach to the GP) and as locally as possible. Well informed patients and families, aid compliance and aid planning (of events or trips). Continuity of care is required to build and maintain patient confidence.

Patients require early assessment and support addressing their expectations and to reduce anxieties. The Clinical Nurse Specialist has an essential role in this and should be present in the room during diagnosis. The Clinical Nurse Specialist can provide accurate information to facilitate decision making and choice. It is vital also to support the family. Patients should be made aware of the pathway and of trials. To do this additional nursing support is required.

There is a need to reduce the public's fear of treatment and hospitals and to design services around patients needs better e.g. evening services. Improved bereavement skills are required.

Improved end of treatment care is required to support patients to live with cancer. This requires robust, positive support and follow up. The model for this should be considered in relation to who, where and when this is done. A similar model to long term condition case management might be appropriate. Primary care involvement is essential in this.

Self management is a real challenge in Lanarkshire but well-directed efforts at supporting patients by both acute and primary sectors can have good results. New patients with cancer need time with medical and nursing staff often together, and benefit greatly from the same individuals following up on initial messages to clarify understanding. Having sufficient staff in these roles is essential.

There is also a need for dedicated support for getting patients back to work.

Communication is a vital component of a patient's care and this is particularly important when a variety of services are managing different aspects of an individuals care. While care management can ensure the coordination of services for some, softer issues are also important and robust communication between acute and primary care is required to ensure that the patient experience is positive.

Good communication skills should be mandatory / a top priority for consultant staff and feedback on

this can be gained from patients and carers, family members. There is a need for a greater focused involvement on cancer by care by allied health professionals as well as up skilling and integrated cancer care in generalist areas. Access to support and advice out with 9 to 5 is essential.

SECTION 8 : DELIVERY

Please provide comments / suggestions on *Delivery*

Issues to Consider from Better Cancer Care

- ***How could cancer networks be developed further to ensure efficiency and effectiveness of cancer care? Is the current balance optimal? What further steps do you think should be considered? Are you aware of duplications of work which could be eliminated?***
- ***Is there a need for a new lead clinician role to drive change and support clinical leads and networks across NHSScotland?***
- ***Which aspects would you prioritise to maximise efficiency and effectiveness of cancer services?***
- ***What are the most important factors which should be taken into account when considering the optimum use of resources? How should we engage people in these decisions?***
- ***What further opportunities do you see for taking this forward through cooperation and collaboration between the NHS and its partners, e.g. between and across cancer networks?***
- ***What should we do to ensure continuing focus on e-health and tele-health to support clinicians and to underpin continuous improvement in cancer services?***
- ***How can the new e-health strategy better support quality assurance and help make best use of available resources?***
- ***Which key performance indicators would best focus NHSScotland on continuing to ensure the most efficient and effective cancer services possible?***

It is essential across Scotland that there is strategic focus on improving the outcomes of cancer surgery, almost certainly by concentrating surgery in the hands of an increasingly small number of surgeons and individual units. Currently, inconsistencies in care are possible for almost all non common forms of cancer. For example, someone with a potentially curable oesophageal or gastric cancer has almost a random chance of having their case discussed by a multi-disciplinary team, a similar random chance of being seen by a clinical nurse specialist and most crucially, if they are operated on in a unit doing only small numbers of surgical resections, their chances of dying post-operatively are increased from less than 10% to up to 50%. Although the last five years has seen enormous strides in the improvement of non-surgical cancer services - radiotherapy and chemotherapy.

In relation to Lead Clinicians there is a need for a National Lead Clinician who is very senior and aware of all good examples across NHS Scotland. This should reduce variation in practice and quality.

Optimisation of resources could be addressed by nationally by targeting drug costs to lower prices from pharmaceutical companies and locally to encourage ways to reduce waste and sharing resources e.g. managing expiry dates.

There is need to ensure equity of access to effective treatments across Scotland and the NHS should not deny treatments with a sound evidence base (although there is need to recognise limits). For new drugs, there is need for further refinement of the mechanisms for gaining authorisation to use these.

Key performance measures should include: peer review, timed patient pathways, and use of one stop clinics, quality audit and avoidance of duplication. Managed Clinical Networks should have a role in reviewing these.

There needs to be integrated planning at a national and regional level as at times there appear to be gaps between regional planning groups and regional cancer advisory groups. For blood cancers a case can be made for reducing the regional networks to one and this should be explored.

For Lanarkshire there is cumulatively sizeable impact on the service due to repatriation of patients from the Beatson. This is impacted on by capacity and space limitation on local services. For

haematology, there are plans to concentrate the inpatient provision at Monklands Hospital allied to the new cancer centre.

In relation to e-Health, there is an urgent need to expand electronic data handling for cancer across the health system in Scotland linking referrals, clinical records, and rapid communication to GPs and support services.

Better Cancer Care makes no mention psychological aspects and support for people with cancer and the current services for this are limited. It would be helpful to be clearer about the level of need (e.g. Clinical Depression, Anxiety, PTSD etc) associated with patients, what can be done to prevent psychological illness associated with a cancer diagnosis, what level of planning is needed to begin to look at this, and as a consequence what NHS resources may be required to address the level of need.

The services that exist at the moment such as Macmillian and Haven have been developed opportunistically, and there are gaps, especially in the community. There is a lack of audit on level of need, nor are there any plans for sustained development in counselling/psychological services.

The new Maggie's Centre will address this in part but there is a need for this type of support to be accessible in patients' own homes. There is a need to screen and diagnose depression and anxiety. Currently cancer care professionals often address "technical" aspects of care but not patient's emotional needs.

Issues of equality and diversity must continue to be considered to ensure there is an equitable access to treatment. For example, considering access difficulties for patients with learning disabilities.

The current and potential role of the voluntary (third) sector should be recognised and acknowledged in this opening chapter as many cancer charities and voluntary groups make a significant contribution to early detection of cancer and to improving patients and carers experiences.

GENERAL COMMENTS / SUGGESTIONS YOU WOULD LIKE TO MAKE

RESPONDENT INFORMATION FORM

Please complete the details below and return it with your response by Monday 5th May 2008. This will help ensure we handle your response appropriately. Thank you for your help.

Name:	NHS Lanarkshire
Postal Address:	14 Beckford Street, Hamilton, Lanarkshire

1. Are you responding: (please tick one box)
- (a) as an individual (go to 2a/b and then 4)
- (b) **on behalf of** a group/organisation (go to 3 and then 4)

INDIVIDUALS

- 2a. Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government website)?
- YES (go to 2b below)
- NO, not at all We will treat your response as confidential
- 2b. **Where confidentiality is not requested**, we will make your response available to the public on the following basis (**please tick one** of the following boxes)
- Yes, make my response, name and address all available
- Yes, make my response available, but not my name or address
- Yes, make my response and name available, but not my address

ON BEHALF OF GROUPS OR ORGANISATIONS

3. The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government website). Are you content for your group's or organisation's **response** to be made available also?
- YES
- NO We will treat your group's or organisation's response as confidential

SHARING RESPONSES/FUTURE ENGAGEMENT

4. We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Government to contact you again in the future in relation to your consultation response?

YES NO

**Please return your completed Feedback Form
and Respondent Information Form by Monday 5th May to:**

Better Cancer Care Feedback
Cancer & Genetics
Scottish Government
St Andrew's House
Regent Road
Edinburgh
EH1 3DG

Thank you for your feedback