

Meeting of
Lanarkshire NHS Board
30th April 2008

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**SUBJECT: BETTER CANCER CARE
LANARKSHIRE NHS BOARD'S RESPONSE**

1. PURPOSE

This paper is intended to:

- provide the Board with information on the Better Cancer Care discussion document
- brief the Board on the engagement process undertaken by Lanarkshire NHS Board to respond to this document
- request approval for Lanarkshire NHS Board's response (attachment 1)

2. BACKGROUND AND DISCUSSION DOCUMENT

Better Cancer Care was developed by the Scottish Government as an update to the Cancer in Scotland: Action for Change, 2001 strategy in light of Better Health Better Care. The preparatory work for the document was undertaken with clinical communities.

The Better Cancer Care discussion document was launched by the Cabinet Secretary on 12 February 2008 with a twelve week discussion period. The updated strategy will be published in summer 2008.

The discussion document provides an opportunity for Lanarkshire NHS Board to influence the make up of the final national strategy and the deadline for responses is 5 May 2008.

The content of the discussion document commences with an outline of the incidence of cancer nationally. This identifies:

- there is a current incidence c.27,000 new cases per year
- projected incidence c.36,000 new cases per year by 2020 (Updated *Cancer Scenarios*, 2008 (to be published in the final plan)
- there has been significant improvements in survival over the 25 years to 2004

In effect, this means that more patients and their families are living with cancer, often as a long term condition.

The document requests comments in relation to chapters covering the topics of:

- Prevention
- Screening
- Diagnosis and Treatment
- Palliative Care
- Assuring Quality of Care
- Putting Patients at the Centre
- Delivery

The Lanarkshire NHS Board response is set out on the standard proforma provided by the Scottish Government which reflects these chapters.

Under the delivery section of Better Cancer Care the Scottish Government identifies priority issues and states in relation to these:

- New cancer drugs – NHS needs to ensure the best use of the available resources with the Scottish Medicine Consortium providing advice to NHS Boards on the use of new drugs. Linked to this is the exceptional case process
- Service planning – The current regional cancer networks are felt to have been valuable although Better Health, Better Care makes a commitment to review planning arrangements across NHS Scotland and this will provide further opportunities to improve the operational interface with NHS Boards
- E-health – The new eHealth strategy for NHS Scotland will reflect the progress made in “joining up” e-health systems. The development of the Generic Care System and systems for breast cancer, gynaecological cancers and head and neck cancers is noted as well as the development starting on systems for colorectal and lung cancers
- Clinical leadership -Queries if there is a case for reappointing a national lead clinician charged with engaging clinicians throughout Scotland in the development and delivery of national cancer policy

Although these issues featured in the responses obtained in Lanarkshire from the engagement process it is interesting to note that other priority issues were highlighted locally. A summary of the main issues raised is presented in section 4 of this paper.

3. LOCAL ENGAGEMENT PROCESS

Within Lanarkshire a comprehensive local engagement process was undertaken during the period mid March to mid April 2008.

This included engagement with patients, public (through the Patient Partnership Forums, PPFs), primary and acute care professionals, the hospice, support groups and centres and the voluntary / third sector.

In order to achieve this three open meetings took place at St Andrews Hospice, Wishaw General, Hairmyres Hospital as well as a meeting with the North PPF (the South PPF provided representation at the open meetings). PPFs representatives were also invited to submit written comments. However, these were not available for the development of the Board paper and as a consequence they will be collated separately and appended to the Lanarkshire NHS Board's response when it is submitted to the Scottish Government.

Patient engagement was undertaken in the oncology day units and cancer outpatient clinics.

Written responses were also collated from key stakeholders from acute, primary care, social care, voluntary and patient sectors.

The draft response was considered at the Modernisation Board meeting on 28 April 2008.

During the local consultation process it became clear that providing better cancer care cannot be delivered by the NHS in isolation. An integrated care management system is required to deliver physical, mental, emotional and financial support. To do this it is clear that we must look beyond the traditional boundaries of primary and secondary care and towards a multi agency package of care delivered across health and social welfare systems. Furthermore, it is clear that long term benefits will be achieved by focussing on the need to keep people healthy rather than simply treating illness. To achieve this will require involvement of the education system from nursery onwards. Accordingly, meaningful change cannot be delivered within the current NHS financial envelope but will require alternative national financing solutions.

4. SUMMARY OF KEY ISSUES IN THE RESPONSE

Putting patients at the centre

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. This chapter should be located at the front of the final document. Support for patients and families is required as early as possible (e.g. pre-diagnosis from the first approach to the GP) and as local 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.

Lanarkshire NHS Board has recognised the importance of integrating cancer services and has recently established a new post of Head of Cancer Services with the intention 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.

Cancer survivorship

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 increasingly important. Cancer is becoming a long term condition and more focus needs to be given in relation to longer term disease management. The need to support the carers as well as patients was highlighted during the course of the consultation. As more patients and their carers are living with cancer as a long term condition it must be recognised that most of the disease management is undertaken outwith the healthcare setting. Resources are required to ensure that adequate continuing support is made available. This issue has barely been mentioned in the document and this needs highlighting.

Raising awareness is not enough

During the course of the consultation it became clear that awareness alone does not ensure that individuals will access available healthcare or make the life style changes required for better health. For example, a wide ranging variety of pressures were given which prevent people attending for screening. These were related to time, transport, childcare, finances, and work commitments. This suggests that health is viewed as secondary to other pressures in every day life. Fear was also given as a reason that individuals do not attend for screening or other appointments. Lanarkshire has particular difficulties of patients presenting late, due to the cultural ethos of people "accepting" ill health.

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. However, there is also a need to support people to make lifestyle changes. The way to tackle this is by the multi agency approach outlined previously. A key factor in the success of such an approach will be the need for consistency. For example, the sun awareness programme which is targeted at schoolchildren is delivered by healthcare professionals yet there is currently no government regulation to help reduce the use of sun beds. The Scottish Government could help by banning unmanned tanning booths and blocking the provision of sun beds in local authority leisure facilities.

It has been suggested that health awareness issues should form part of the National Curriculum to instil health awareness from an early age. It has also been suggested that the media could play a key role in disseminating information and using positive role models to demonstrate the benefits of early detection in relation to cancer outcomes. These role models can also let people see that a good quality of life is achievable following a diagnosis of or treatment for cancer.

There is a need to provide evidence based approaches to health promotion across a range of topics and guidance and support should be provided by the Scottish Government on the approaches to be taken.

Deprivation

Much of the prevention chapter of Better Cancer Care covers the important issue of tackling inequalities. However, the text here emphasises the importance of geographical influences, age and sex and equalities legislation. This is welcomed as, for example, the incidence of early cancer is significantly increased in people with learning disability and the third sector will play a key advocacy role in this process. Although socio economic factors are mentioned in the document the impact which they have on outcomes is not given sufficient weight. It is important to emphasise that it is the impact of deprivation which is the most pervasive 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. Initiatives such as "Keep Well" should be built on which target deprived areas with proactive screening and checks. The increased demand which this places in terms of manpower must be appreciated and addressed.

Step change in health improvement

The consultation in Lanarkshire highlighted continually that cancer prevention and health improvement needs to be address across society and partnership across the public, third and commercial sector is required to achieve this.

The Scottish Government's strategic objectives, which tie in health service HEAT targets and local authority Single Outcome Agreements, provide an opportunity to align actions and optimise impact across society.

Better Cancer Care does not commit additional funds and this limits a step change in health improvement. However, working across organisational boundaries could maximise the use of current resources. New ways of funding health improvement could be considered working with the third and commercial sectors.

Effective care and local and specialist access

Lanarkshire has an agreed overall infrastructure model for cancer services with local outpatients, diagnostics and chemotherapy services on all acute hospital sites with the cancer centre planned for Monklands Hospital. This is felt to balance local verses specialist access.

It is essential that across Scotland there is a strategic focus on improving the outcomes of, particularly less common, cancer surgery, almost certainly by concentrating surgery in specialist units. Currently, inconsistencies in care are possible for almost all non common forms of cancer.

Palliative care

The document links palliative care directly with end of life care. This perpetuates the misunderstanding of the term palliative care amongst health professionals as well as the public. Better Cancer Care identifies palliative care primarily with end of life care however palliative care can be wide ranging from assistance with controlling pain and nausea to providing psychological and emotional support. Palliative care can therefore significantly enhance patients' quality of life from diagnosis onwards. The expertise of palliative care physicians is in managing the symptoms and other consequences of cancer.

The consultation highlighted the need for palliative care services to include support for carers. The need for continued support after treatment was also highlighted as patients and their carers report feeling abandoned following initial consultations and treatment regimes. In addition, bereavement support is not widely offered by the NHS and a need for additional staff with bereavement training was identified.

A distinctive issue for cancer patients is pain. National symptom control guidelines for palliative care including pain control should be developed. Improved use of analgesics for breakthrough pain will have resource implications.

The reliance on voluntary and charitable organisations for supportive care for both cancer patients and their carers was highlighted during the consultation. These services are highly valued by patients and their carers. The services provided can range from nursing, emotional and psychological support to assistance with transport and accessing benefits and other financial packages. However, these services have often developed in an ad hoc manner and there is a need to review what is available and to make additional provision to ensure equitable access to such services across Scotland. The roll out and sustainability of these services should be assured by additional centrally provided recurring funding.

Delivery of care

There was a strong commitment across those engaged to the improvement of cancer care and many examples were provided of aspects of services which could be developed, expanded or made more uniformly available. This includes increases in community support services, transport, and improved consistency in the operation of multidisciplinary teams. These improvements will however require additional resources.

Better Cancer Care also makes no mention of psychological aspects and support for people with cancer. It would be helpful to be clearer about the level of need (e.g. Clinical Depression, Anxiety, Post Traumatic Stress Disorder 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.

There is also the need to look at extended opening hours for general health clinics and screening facilities need more Wellman and Wellwoman Clinics as these are non threatening.

The 62 day target for urgent referrals has led to improvements in care delivery. However, further reduction in target times or the inclusion of other patient groups must be undertaken in a controlled manner to ensure that the significant progress so far achieved in reducing waiting times is not undermined by excessive demand on resources. Indeed, it is likely that additional demands will only be achievable with a concomitant increase in manpower. The addition of further tumour types to the 62 day target must be evidence based to ensure that limited resources are allocated appropriately and with maximum benefit for patients.

The advent of the modernising medical careers training programme for junior doctors is impacting on many areas of service delivery. A particular issue for cancer services is the current lack of suitable applicants for staff grade posts. Clarity is required in relation to the role of the 'trained doctor'. Until it is known exactly what role the trained doctor can undertake accurate workforce planning for cancer services is proving difficult.

Improvements in information systems

Greater integration of existing information systems is essential for improved patient care. For example for screening there is 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.

5. RECOMMENDATIONS

The Board is requested to approve Lanarkshire NHS Board's response to the Scottish Government discussion document Better Cancer Care.

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