

**Response to Consultation on the Better Cancer Care
South Edinburgh Public and Patient Forum – May 2008**

We welcome the opportunity to comment on the consultation paper “Better Cancer Care”.

- It is worth pointing out at the outset that as a “lay” group, we were a bit confused by the term “third sector” which was not unfortunately defined in the glossary. Our assumption is that what is meant is the voluntary sector and our response is based on that premise.

Following the issues on which you sought comment:-

Consultation Questions

SECTION 2- PREVENTION

Issues to Consider

- 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?

Para 3: ‘Exposure to environmental carcinogens’ is only given a brief mention, and radon is not a particularly high risk in Scotland. Far more important in buildings is asbestos, which has recently been flagged as a continuing hazard in far too many Scottish schools. The Scottish TUC and Scottish Secondary Teachers Association have called for an ‘intensive audit’ of state schools. (Source: Adam Forrest: ‘Ticking Timebomb’ *Big Issue* 27 March 2008). We also need to beware of the hazards of nanotechnology and its possible impact on human health in general and cancer in particular (see attached).

Also attention should be drawn to the Public Petition ‘Cancer Causing Toxins’ [**Petition Number PE1089** - Petition by Morag Parnell, on behalf of the Women's Environmental Network Scotland, calling on the Scottish Parliament to urge the Scottish Government to investigate any links between exposure to hazardous toxins in the environment and in the workplace and the rising incidence of cancers and other chronic illnesses.

<http://www.scottish.parliament.uk/business/petitions/docs/PE1089.htm> addressed to the Scottish Parliament by the Women’s Environmental Network Scotland on 20 November 2007 and 19 February 2008, and the recent resolution passed by the European Parliament, with an overwhelming majority of Euro-MPs agreeing to amendments proposed by Green MEP Caroline Lucas to highlight the environmental causes behind breast cancer. University of Stirling scientists believe 24,000 people a year die from cancers caused by their occupations, compared with the figure of 6,000 estimated by the Health and Safety Executive. There are innumerable carcinogens and endocrine disrupters in the environment that are easy enough to modify given appropriate legislation, e.g. formaldehyde, bisphenol.

On the question of alcoholism and binge drinking, action should be taken to ban ‘happy hours’ and ‘student promos’ (advertised on A-boards in the street). Licences should be refused to premises that flout these regulations. (See 2 attached recent photos taken in Edinburgh). We welcome the report from Quality

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Improvement Scotland published on 1 May on Harmful Drinking and support their work which is aimed at informing government policy on alcohol in an attempt to reverse an apparent decline in which the country finds itself.

Food, obesity management etc.

John Prescott's recent revelation about his bulimia has underlined that over-eating is very often a reaction to stress. This is true of all age-groups and both sexes. Psychological help and counselling should be easily available to everybody, from school children onwards, without stigma. Counsellors should be appointed in all schools, colleges and GP surgeries.

A healthier national diet should emphasize the importance of fresh fruit and vegetables, reduction of meat intake, especially smoked and cured foods, and the minimal use of pesticides and insecticides, which are often carcinogenic. Organic farming should be encouraged and promoted.

Healthcare professionals should also be given special help to engage in programmes of weight loss, smoking cessation and healthy living. It is disturbing to patients to see staff smoking outside hospitals, and also to observe that many staff are overweight. Hospital canteens could do a great deal more to encourage healthy diets and ban sugary snacks. Food served to patients should also avoid excessive salt and staff should make sure that fruit and vegetables are readily available. (This will help with avoiding stroke and heart disease as well as cancer.)

Health Education

This must form an essential part of the curriculum, and emphasis should be on both mind and body. Sexual health education must go hand in hand with the education of the emotions. If the HPV immunisation programme is introduced to girls as young as 12-13, this must be accompanied by firm and friendly advice about relationships: it must not be taken as a sanction for irresponsible sexual behaviour, and the point must be made that HPV immunisation does not protect from HIV, AIDS, or STD in general. It was pointed out that there is not agreement and understanding within the general public of the various immunological processes to back HPV immunisation of 12- 13 year olds:the MMR debate for example showed a distinct lack of understanding of the underlying scientific issues. There needs to be plain understandable messages to inform the public. As well as courses in schools, television could be used to convey health education messages. Environmental awareness in schools could start with simple lessons in not dropping litter, recycling etc., to avoid toxic waste that will build up in the environment and cause problems for future generations.

It has been reported that there is substantial evidence that even one unit of alcohol increases the risk of cancer by 7%. As against all forecasts, the gradual introduction of smoking prohibitions led by Ireland, closely followed by Scotland, and now actively considered in Europe, has been largely successful in cutting the smoking habit, it may also be possible to plan and mount a similar campaign against the abuse of alcohol, particularly by the young. Education towards the realization of the dangers of alcohol, not only drunkenness, but also the clinical effects, is essential to bring about an outlook on alcohol similar to that on tobacco. The recent campaign in Armadale (restricting alcohol purchase to over 21s at weekends) seems to have been a success on the vandalism front, so education would gradually have a similar effect on health.

Mental health issues

As the Scottish Government's parallel consultation 'Mental Health in Scotland' points out, bowel cancer is 90% more likely in people with schizophrenia, and breast cancer 42% more likely. People with less severe

mental illness such as bipolar disorder, long-term depression etc. are also more likely to adopt unhealthy lifestyles, with consequences for physical disease including cancer. There is evidence that people suffering from long-term depression are more likely to develop hormonal cancers such as prostate and breast cancer.

* Some psychotropic medications also trigger weight gain. This has three implications: (a) people with mental illness should receive psychological therapies and encouragement to adopt healthy lifestyles; (b) the physical health of those with mental illness and learning disabilities should be regularly reviewed by GPs. (c) Care should be taken to monitor the side effects of drugs.

*Gallo, J.J. et al. Major depression and cancer: the 13-year follow-up of the Baltimore Epidemiologic Catchment Area sample (United States). *Cancer Causes and Control* 2000; 11: 751-758.

SECTION 3 – SCREENING

Issues to Consider

- 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?

General

The development of the approach to screening will depend on its cost effectiveness and expected survival times. Breast cancer groups have campaigned very successfully for screening programmes; it could be argued the success of this is due to the post treatment 5 year survival rate, whereas lung cancer sufferers are much less likely to be around post 5 years to campaign for a screening programme.

There is no doubt there are inequalities in uptake of screening and we need to reach those most likely to benefit. We need to take opportunities to get messages across in as many public places and in as many ways as possible – the GP's surgery, nurseries, community centres, workplaces, schools (if children can take home literature) and so on. This can be by leaflet or poster, but also other methods – local radio, free news-sheets, TV (if financed nationally).

We did question whether the expertise to interpret such a wide and diverse research base needed to be strengthened, either centrally in the research arm of the Scottish Government or within the statistical divisions of Health Board areas.

We considered this to be a difficult issue even for the professionals since only a small percentage of genetic research has yielded information on which specific gene is responsible for which illness. We suggest there is a need for Government to keep Scottish University research programmes well-funded and focused to yield the best chance of understanding mechanisms of prevention and diagnosis.

We also suggest that where possible, GPs should write (or note on a computer record), where known, the details of familial cancer diagnosis. This would allow them to make the connection with their patients

should they present with similar symptoms.

Mention should be made in Better Cancer Care of screening for women with a family history. NB Those with moderate risk, i.e. with a fairly strong family history but not carrying the BrCa gene, need to be kept an eye on by GPs and supported to enter the screening programme where appropriate. (One of our members happened to fall into this category: both grandmothers and an aunt had breast cancer, but apparently this history was not strong enough to warrant genetic testing). The Edinburgh Evening News of 1 May carries the story of a 27 year old having a breast removed due to her carrying the BrCa gene. (<http://edinburghnews.scotsman.com/topstories/I-gave-up-my-breasts.4039481jp>) .Breast screening can also pick up other cancers – for example lymphoma, which is a supplementary benefit.

We suggest that the interval between screening for breast cancer should be 2 years, not 3, to avoid too many interval cancers. Also, safer and more effective scans (e.g. MRI) should be available to women under 50 with a family history of breast cancer. (See also section on Referral Guidelines, below, under Diagnosis and Treatment.)

Bowel cancer

We suggest that the bowel cancer screening programme be extended to those outside the 50 –74 age-group with a family history of the disease.

Prostate cancer

We have heard the arguments against PSA screening for men, but in view of the fact that this is the most common cancer in men, with a death rate greater than that for bowel cancer, we think that this policy should be reconsidered. The PSA test is simple and non-invasive, and the arguments against it could equally well be made for breast cancer (i.e. it leads to unnecessary interventions).

SECTION 4- DIAGNOSIS AND TREATMENT

Issues to Consider

- How do we continue to improve diagnostic and treatment services?
- How should we support the future development of surgical skills within NHS Scotland'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?

General

Improving diagnostic and treatment services is very difficult but we would support the embedding of good training for our health professionals, from the primary care setting for GP practice nurses and the GPs through to the continuing professional development for hospital staff, including consultants. Where possible we need to avoid the loss of professional expertise and to keep effective teams working together. We would like to see consistent and prompt treatment nationally not dependant on a post code lottery.

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In Edinburgh we are fortunate to have a high concentration of expertise on 3 sites, and would not really need the local diffusion of expertise.

Referral Guidelines

There have been recent concerns about GP referral, and we have been looking at the referral guidelines to make sure that they are as helpful as possible. For example the Cancer Referral Guidelines and also the paper on 'management of women with a family history of breast cancer' show inconsistencies with the main document, Better Cancer Care. They recommend 2-yearly mammography for those with a moderate risk under age 40 and annually age 40-50. They say nothing about management of women at moderate risk when they enter the ordinary screening programme. There is also no mention of MRI screening for premenopausal women. We understand that mammography for younger women is only 50% accurate in view of the denser tissue of the premenopausal breast. Also repeated mammography for those in this age group could be harmful in itself, since it exposes the breasts to unnecessary radiation. We are of the strong opinion that the government must review their policy and try to reconcile all their different recommendations.

'Peau d'orange' as a possible symptom of breast cancer has been omitted from the referral guidelines.

Another matter of concern is the difficulty found by GPs in spotting signs of secondary cancer. For example, a woman with a history of breast cancer (even if diagnosed 10 years previously) with a persistent cough should be referred for specialist opinion: it should not be assumed that this indicates a chest infection and nothing else. The same goes for bone pain.

Radiotherapy

Recent papers in the Lancet and Lancet Oncology reporting on the START trial after five years would seem to indicate that hypofractionated radiotherapy (i.e. larger doses given less often) are as safe and effective as the traditional smaller doses given daily. Unfortunately this conclusion is premature: we have clear evidence from patients that long-term problems often only arise *after* five years, and we strongly recommend that Scotland does not fall into the trap (despite what the Cancer Czar has said) of going for the cheaper treatment, which in the long term may increase the health and social care budget that will have to pick up the long-term disabilities that may arise. Patients would gladly go for daily treatment to avoid long-term problems. If necessary, hostel accommodation should be provided for those who have to travel long distances for radiotherapy.

SECTION 5- PALLIATIVE CARE

Issues to Consider

- 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?

Palliative care should start from diagnosis, and not be left to the last months of life. People with cancer need emotional support, information, counselling, and complementary therapies from the outset, and organizations such as Maggie's Centre do an excellent job. Cancer support groups should be given every facility and encouragement.

The “how to deliver excellent palliative care” question is the hardest one to answer as integration is the hardest to plan systematically- costing exercises should be done first so that we have better estimates, and on the ground contributions taken into account as well as top down contributions. In Scotland the uneven distribution of population presents unusual challenges: some services such as chemotherapy could perhaps be delivered locally, radiotherapy could not – but patients could be accommodated in hostels during treatment.

The Gold Standard for care issues should be considered so that conceptualization of palliative care and balance of local access and convenience and maintenance of specialist expertise and capacity is fully taken into account.

SECTION 6- ASSURING QUALITY OF CARE

Issues to Consider

- 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?

Waiting times

The target of 62 days (maximum) from urgent referral to treatment sounds unambitious. We think it could be improved. Also, there are people not referred urgently who should have been: the referral guidelines might be improved here.

It might be more helpful to aim at a maximum of (say) a fortnight from urgent referral to appointment with a consultant, so that at least the patient knows that something is being done, and the necessary diagnostic procedures are set in train. It is accepted that ‘treatment’ may take different forms: surgery, chemotherapy, or even radiotherapy as a first option. Speedier diagnosis may depend on the availability of scanners etc.,

so where there are shortages these need to be given urgent attention. Also, expensive equipment could be used more effectively if working hours of staff were staggered. (See 'Improving Cancer Care', attached.)

Clinical audit is very hard to put in place, to get to function consistently well because practice teams may feel very threatened when league tables are released into the public domain – but on the other hand it may encourage competition for best services and patients wanting to register. Variations of practice depend on popular therapies and the view of the consultant heading up the team, and post code lottery. Our current record for gaining good cancer services is fragmented and this is true for local response – it is difficult to see a way forward for even the next 3- 5 years.

We should always pay the expenses and training courses of volunteers, who often fill gaps left by healthcare professionals. Peer support is just as valuable as professional support after a cancer diagnosis.

SECTION 7- PUTTING PATIENTS AT THE CENTRE

Issues to Consider

- 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?

Safety

The long-term safety of radiotherapy, as well as the short-term, needs to be carefully considered. Cost cutting and economies must *never* compromise patient safety or quality of life.

Information resources such as those at Maggie's Centre (Western General) and the Patient Information Centre at the Royal Infirmary should be available nationwide. Cancer is no longer a badly kept secret: patients deserve to know everything that they wish to about diagnosis and prognosis, when they wish to know. Sometimes information cannot be absorbed all at once immediately on diagnosis, when people tend to be in a state of shock. But booklets, leaflets, contact numbers etc. should be available straight away, to be used when the patient is ready.

The possibility of self-referral for physiotherapy should be widely advertised. After lumpectomy or radiotherapy to the breast where the axilla is affected, exercises will need to be maintained for life to avoid chronic disability. There will be similar examples for other cancers.

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Rehabilitation would be helped by home visits from specialist nurses after discharge from hospital, as in the case of stroke patients.

Patient-held records

We suggest that when so many cancer patients have to travel long distances between hospitals for cancer treatment, patient-held records should be adopted (as in maternity care). These need not be the only record, but should at least have the minimum information needed by the next clinician in the patient journey. They would also have information useful to patients, e.g. about various support services, internet sites etc. It often takes too long for communication between hospitals to be made in an efficient and timely manner, and the patient could well be the messenger. In a trial of this method, patients were found to lose their notes less often than hospitals! (See also 'Improving Cancer Care', attached).

Leeds, together with Glasgow RI, led the way for renal patients to have their own web-based disease management facility. All their details are put onto a secure website, which is accessible by the public for general information about renal disease, but their personal details - patient notes - are only accessible by the patients themselves by means of a "dongle", a kind of electronic security key. The personal part of the web database is frequently updated directly from the various Proton and Clinical Vision systems run by the renal units throughout the UK. The system is Renal-Patient-View (<https://www.renalpatientview.org/>).

Such facilities could of course be available for all specialties - Diabetes and Cancer are probably the most advanced in this direction after Renal. (Renal had the advantage of having had a dedicated system manufacturer for several decades - Clinical Computing Ltd - which built up extensive knowledge of users' requirements and the specialties).

We also suggest

- Have good family support units for patients with cancer and their families.
- Support charities, if necessary with better funding packages to enable them to develop better information-giving facilities, using the expertise of patients, relatives, friends- to form self-help groups. One of our members pointed out that in the 20 years since being directly involved with a self-help group – the number and breadth of funding packages has decreased.
- That the integration of services for those with long term conditions (diabetes, autism, Alzheimer's) and who suffer from cancer is considered. It can produce a level of complexity not usually seen and requires partnership working from various services. There should be special budget provision for such cases in order to give patients a proper service.
- Be bold - try this – more seed money for more charities to build up community support services for local people to be involved.

SECTION 8- DELIVERY

Issues to Consider

- 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?

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- 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?

Scotland is known for its more prompt and generous provision of new and expensive cancer drugs than England. Long may this continue: at the same time, we wonder how long this policy can be afforded. We feel that expenditure on expensive drugs in the last few months of life, which may only prolong life for a few weeks and only add to the misery of toxicity, with terrible deterioration of the quality of life, might need to be reviewed. More honesty with patients about likely outcome is needed. Many patients think that if treatment is being given, there is 'hope': i.e. of a cure, when this is in fact not possible. Clinicians have to learn how to be more honest, while also being compassionate. This is extremely difficult, but in the end both patients and relatives will appreciate the truth, and thus be able to make appropriate end-of-life decisions.

There would certainly seem to be a case for a national lead clinician for cancer services. The present UK lead clinician is obviously finding it difficult to enunciate policy that can be implemented in Scotland, which has different needs and priorities. Clinical leads at the moment are being bombarded with so many needs for change – we need to make sure the need for change does not drive underground actual progress.

There is a general view that much more could be done to improve and link up services in the community. We need to make sure patients participate and are taken into the decision making process – organizations such as the SEPPF has had its problems in common with other PPFs.

Tele-health strategies e.g. 24/7 do not have a good record and seem to be doomed. How can the idea of e-health strategies improve through the use of the internet when there are still many people who cannot access the internet, either because of lack of know-how, or because of a lack of a home access point?

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