

Scotland Against Cancer Conference 2009



Glasgow Royal Concert Hall
Friday 20th March 2009

Conference Report

Together we will beat cancer

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The annual Scotland Against Cancer conference, held in Glasgow on 20 March 2009, attracted 140 delegates from across the cancer community in Scotland for a day of lively discussion and debate.

The conference focused on setting the agenda for the update of the cancer strategy for Scotland and identifying the key issues for inclusion.

The conference provided a forum for politicians and policy makers, clinicians, patients and researchers to discuss cancer policy and services, and to make recommendations for the future. Recommendations from Scotland Against Cancer play an important part in influencing discussion on cancer policy in the Scottish Parliament.

We are particularly grateful to our conference chairs, Malcolm Chisholm MSP and Nanette Milne MSP, Co-conveners of the Cross Party Group on Cancer in the Scottish Parliament, for chairing the day, and encouraging wide ranging debate on a number of issues. We are also grateful to other Scottish Parliamentarians, speakers and cancer charity representatives who supported the conference by facilitating the discussion forums.

A number of recommendations were made which we hope the Cross Party Group on Cancer in the Scottish Parliament will take forward over the next session.

The conference was organised by Cancer Research UK. We would like to thank the members of the steering group: Macmillan Cancer Support, Myeloma UK, Breast Cancer Care Scotland and the Scottish Cancer Foundation for providing advice on the agenda, and in supporting the conference. We are grateful to the Scottish Cancer Industry Group of the ABPI and Novartis Oncology for their generous sponsorship of the event.

Richard Davidson

Director of Policy and Public Affairs
Cancer Research UK



Contents

Introduction	3
Malcolm Chisholm MSP	
Health Secretary Address and Questions	3
Nicola Sturgeon MSP Cabinet Secretary for Health and Wellbeing	
Keynote Address:	7
Professor John Frank, Director, Scottish Collaboration for Public Health Research and Policy	
Discussion Groups	9
Health messages – turning knowledge into action	
Appraising treatments	
Living with and beyond cancer	
Diagnosing cancer earlier	
Reducing cancer inequalities	
Appropriate care	
Measuring quality and improving outcomes	
Innovation and improvement	
Expert Panel	13
Closing Remarks	16
Nanette Milne MSP,	

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Introduction

Malcolm Chisholm MSP

Co-convener, Cross Party Group on Cancer in the Scottish Parliament

Malcolm Chisholm MSP introduced the Scotland Against Cancer Conference and welcomed all delegates. Mr Chisholm thanked the conference sponsors, without whom it would not be possible to hold the conference, and the steering group members for putting together a full and interesting programme. Mr Chisholm also thanked Cancer Research UK for planning the conference and providing the secretariat for the Cross Party Group on Cancer.

Mr Chisholm noted that ideas and suggestions expressed during the conference would be included in a report to be sent to the Cross Party Group on Cancer, and considered in the forming of future policy. Mr Chisholm thanked delegates for their willingness to participate in the conference and wished them a productive day.

Health Secretary Address and Questions

Nicola Sturgeon MSP

Cabinet Secretary for Health and Wellbeing

Ms Sturgeon opened by saying that was a pleasure and privilege to address the conference and highlighted the high standards of work in Scotland in the cancer field, expressing the Government's commitment to use events like Scotland Against Cancer to ensure constant improvements to the services and support that is provided for cancer patients in Scotland.

The Cabinet Secretary then went on to outline the eight topics to be covered in the later discussion groups, and comment on the Government's views, policies and intentions regarding each of these.

With regard to the first of these eight topics, *health messages: turning knowledge into action*, Ms Sturgeon highlighted the substantial progress in cancer prevention, and pointed out that in Better Cancer Care the Government committed, among other things, to reduce smoking levels in Scotland. Ms Sturgeon referred to the launch of the Government's smoking prevention plan last year, which is supported by nine million pounds of investment over three years, and is designed specifically to discourage children and young people from starting to smoke and thereafter becoming regular smokers. She also pointed out that Parliament are about to embark on the process of new legislation to control the availability and promotion of tobacco by introducing a registration scheme for tobacco retailers, and by measures to restrict the display of tobacco products in shops, something that many people believe has to now happen in order to ensure that the previous ban on tobacco advertising is having the desired effect. Ms Sturgeon expressed her confidence that these measures do have the potential to make a real impact on smoking levels in Scotland.

Ms Sturgeon also referred to the link between alcohol consumption and some cancers, including oesophagus, breast and large bowel cancers. She reminded delegates that details were published about the next steps the Government wants to take to help tackle alcohol misuse in Scotland. The framework will seek to encourage people to adopt positive attitudes and positive choices around alcohol intake and also seek to improve the support and the treatment that is available to help tackle alcohol misuse. Ms Sturgeon said she was pleased to see the Chief Medical Officer in England join the CMO in Scotland in saying that these kind of measures are the right way to go, and stated that the Government would work very hard over the next period to persuade people in Parliament and throughout the country that Scotland must be prepared to take action. She also stated that the Government was prepared to make a financial commitment to tackle this issue, having made a record investment of £120 million over the next 3 years to help tackle alcohol misuse. The money will enable significant investment both in preventing alcohol-related problems occurring in the first place, and also in the treatment and support for those who have already developed



problems with alcohol use. The Government recognises that some more vulnerable groups require a much more targeted approach.

The Cabinet Secretary also alluded to other examples where successful investment and progress has been made, which will help to prevent cancers in the future. These include the introduction of the HPV immunisation programme and the plan published covering a range of areas from healthy eating to physical activity to tackle obesity in Scotland. The Scottish Parliament has also passed new provisions to regulate the use of sun beds. These provisions come into effect later this year with a particular focus on protecting those under the age of 18.

The second topic the Minister discussed was *appraising treatments*. She stated that through the Scottish Medicines Consortium, Scotland has very robust arrangements to review new drugs so that they are available on an equitable basis, and that where new treatments and drugs offer demonstrable improvements for patients, they are made available on the NHS to all those who need them. Ms Sturgeon stressed that it is very important that these arrangements are regularly reviewed in order to ensure that they remain robust, and, where any opportunity to improve them is identified, that the relevant action is taken as quickly as possible. Following the report of the Scottish Parliament Public Petitions Committee Inquiry into the availability of cancer drugs in Scotland, the Government's key priority has been a focus on improving access to all new medicines that are cost and clinically effective. One key action has been to ensure greater understanding of the decision-making process regarding the introduction of new medicines, accessibility and consistency of the processes which operate at national, regional and at local levels.

The Cabinet Secretary expressed her personal interest in the third topic, *living with and beyond cancer*. A new living with cancer group is currently being established under the chairmanship of one of the newly appointed national cancer clinical leads, Dr. Bill O'Neil. That group will include members of the Scottish Cancer Coalition, NHS Scotland, COSLA, directors of social work, and it will report directly to the Scottish Cancer Taskforce. One of the early areas of work for this new group will be the development of different models for engaging with patients who are living with and beyond cancer.

In discussing the topic of *diagnosing cancer earlier*, Ms Sturgeon stated that Better Cancer Care highlighted the importance of improving public awareness of common cancer symptoms and of reporting these as early as possible. There are a number of extremely effective screening programmes already in place for breast, cervical, and bowel cancer. Ms Sturgeon pointed out that although most people are aware that early detection and diagnosis of cancer mean better chances of survival, far too many people may have symptoms for a very long time before they present these to a health professional. Ms Sturgeon expressed her wish to make progress on this issue, and stated that the Government would be issuing a quick reference guide, which is a shortened, user-friendly version of the existing referral guidelines, which would be sent to all GP surgeries, as well as being available online.

Ms Sturgeon stated that *reducing inequalities* in health is a key priority for the Government, and the report published last summer, *Equally Well*, sets out a range of actions which will have a significant impact on reducing the inequalities in health outcomes across the country. People living in the most deprived areas of Scotland have the highest risk of being diagnosed with cancer, but they also have the lowest chance of surviving cancer. This group of people have experienced an incidence rate for all cancers which is 40% above the Scottish average, and a mortality rate which is 75% above the Scottish average. There is evidence that this situation is still getting worse in relative terms. Lower levels of awareness, lower levels of uptake of screening, variations in access to cancer services, differences in circumstances and lifestyle choices all contribute to these significant inequalities. The Government's new patient experience programme *Better Together* will for the first time gather a range of information about GP, inpatient and long term condition specific services, allowing investigation of the particular experiences of communities and different groups of individuals and the development of Government's understanding of the cancer risks for people with low levels of literacy or educational attainment, those from minority ethnic communities or possible different levels of awareness and access to screening services of those in lesbian, gay, bisexual or transgender groups.

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Health Secretary Address (contd.)

Addressing the issue of *appropriate care*, Ms Sturgeon pointed out that children and young people have specific needs which require services which are appropriate for them. The national delivery plan for children and young people's specialist services (including cancer care) was launched in January. One of the key outcomes of this review programme was to ensure that, in the future, services provided for children and young people in Scotland with cancer delivers treatment and care that equals comparable European countries. The national managed clinical network for children and young people specialist services in Scotland, known as CATSCAN, has now been established to improve the quality of cancer services for children, young people and their families.

The Minister stated that *measuring quality and improving outcomes* is a priority area in Better Cancer Care. The cancer taskforce has placed quality high on its agenda, and a national cancer quality group will report to the taskforce to provide particular focus on quality improvement. The Institute of Medicine described healthcare quality as having six main dimensions: safety, effectiveness, access, efficiency, equity and patient-centeredness. This last dimension is reflected in the clear feedback from Better Cancer Care, that there is a need to do more to improve the non-clinical aspects of cancer care. These include physical, psychological, social and spiritual care, and will require a focus on compassionate and caring approaches by all healthcare professionals. The Better Together patient experience programme will also gather information which will allow the Government to measure progress across a number of these key dimensions of quality to prioritise improvements. In Better Cancer Care the Government announced two new waiting times targets. These are firstly to achieve a maximum 62 day target for treatment for all patients referred urgently with a suspicion of cancer, and secondly a 31 day target to treatment for all patients diagnosed with cancer, irrespective of the route of referral.

In addressing *innovation and improvement*, the Minister concluded that in order to make significant changes in outcomes for people with cancer, it's vital that we continue to invest in research and the development of new technologies and treatments. Some current Government actions on this include a further investment in radiotherapy machines of over £20 million, investment in improved access to PET scanning and the establishment of a new Scottish collaboration for public health research and policy. This collaboration will establish a new interface between researchers and policy makers to ensure the efficient translation of research findings into practice and will be supported by a contribution by the Government of over £1.75 million over the next few years.

Ms Sturgeon concluded by stating that if the actions set out in Better Cancer Care are progressed, improvements can be made in cancer prevention, detection, diagnosis, treatment and the care that people get when they're living both with and beyond cancer. She emphasised very strongly that the discussion sessions participated in at the conference really do provide a unique opportunity to take forward some of the thinking required to identify some further areas for improvement, and delegates' contributions are essential in enabling the Government to do that. She ended with a declaration of personal commitment to continue to drive forward the Governments work to improve cancer care, and by thanking all delegates and organisers.



Questions

Q. Heather Goodair, a cancer survivor, suggested that the 62 day target is very unambitious (compared with Europe, for example) and suggested that we shouldn't have a one size fits all target for slow and fast-growing cancers. She asked if it might be possible to establish a system of prioritisation that would be acceptable to patients as well as health professionals.

A. The Cabinet Secretary pointed out that waiting time targets are maximum times. Individual patients should be taken on clinical grounds, so if patients need to be seen earlier than the maximum waiting time targets they should be seen earlier. She stressed the importance, nevertheless of having maximum waiting time targets to allow a clear limit on how long we expect any patient to wait. She applauded everybody in the NHS in Scotland for having worked together tremendously well to reduce waiting times and referred to steps in Better Cancer Care to reduce even further the time that people are waiting.

Q. Leigh Smith from the Melanoma Support Group thanked the Cabinet Secretary for her quick response following a previous request for melanoma to be included in Better Cancer Care, and asked when we can expect a suitable sun awareness campaign to cut the incidence of skin cancer, which would save money for the NHS as well as lives.

A. Ms Sturgeon indicated that Ken Macintosh MSP pioneered the measures that the Government took around sun beds and pointed out that the use of sun beds increases somebody under 35's risk of skin cancer by 75%, showing how important it is to have taken this action. She conveyed her willingness to discuss with Melanoma Support what further we can do to raise peoples' awareness around both the causes and the early symptoms of cancer.

Q. David Howie, on behalf of Macmillan Cancer Support explained that he was diagnosed with cancer when he was young, and is interested in the use of support camps in America. He asked whether the Scottish Government could provide a travel fund, or any other support for kids to attend these camps.

A. Ms Sturgeon agreed that services for children, both clinical and other aspects of the care children need, need to be improved and said that the approach the Government is taking as a result of the review will do that. She commented on her own visits to children's hospitals, particularly cancer wards, and on the amazing provision that's there already. The issue of camps and subsidised attendance and travel to camps is something that's been raised with the Cabinet Secretary before – ultimately that would be for individual health boards to respond to but she would be more than happy to consider if there's more that can be done in that respect.

Q. Susan Jenson from the Cancer Surveillance Team in ISD Scotland asked how well the Cabinet Secretary felt that the Government is doing currently in setting personal examples of health lifestyles.

A. Ms Sturgeon conceded that there's a leadership role for anybody in public life, particularly politicians, and particularly health ministers. She owned to spending a fair amount of time telling other people to drink less, not to smoke, to eat more healthily, and therefore tries to lead by example, and believes that if politicians do that then they can convey messages more effectively.

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Keynote Address (sponsored by the Scottish Cancer Foundation)

Professor John Frank

Director, Scottish Collaboration for Public Health Research and Policy

Professor Frank stated that his task was to summarise what we know about socio-economic inequalities with regard to cancer, for which there is excellent Scottish data. Professor Frank commented that public health professionals often face the problem of crude data on the health of the population, but that luckily cancer is one of the few diseases to be measured when it occurs, as well as in terms of mortality rates. He applauded this as a great accomplishment.

He asked whether it is possible to change inequalities by socio-economic status in a reasonable timeframe (of less than a decade) by deliberate action, and addressed some lifestyle and risk factors associated with the incidence of cancer. He stated that there is a conventional wisdom amongst epidemiologists that most deliberate health policies in developed countries only seem to reduce a broad category of mortality, like all cancer or all heart disease, very very slowly.

In addition, there are certain features of socio-economic differences which are virtually always present. There is a gradient between rich and poor in any health outcome, which tends to be there no matter how many categories we divide the socio-economic variable – income, education, occupation, into.

Professor Frank praised the report of the Scottish Government's Health Inequalities Taskforce, but said the data in it showed similarly stark evidence of this gradient in relation to various issues, for example, alcohol related mortality. He demonstrated that while there is has been a drop in cancer mortality, the gap between rich and poor has not changed at all.

Professor Frank showed a series of graphs of incidence and mortality divided by deprivation status for some common cancers. While some cancer don't exhibit obvious gradient by deprivation (for example, breast, bowel and brain), other show significant differentials where the poorer you are, the more you get of the disease, for example, cervical and lung.

He mentioned that with cervical cancer, almost every western country has this pattern, which is the poorer women are, the more they get it and the more they die of it, and the gap between the lines, which is the survivorship, shows that they actually have worse survivorship too, because they have later diagnosis, and less effective coverage by screening in more deprived communities. He stated that even without HPV vaccination this is fixable and there are countries where there's no difference between survivorship because they have extremely well organised screening programmes with registries or public health nurses who go out and find women who haven't had a test or have had an abnormal test and didn't go back for colposcopy or follow up. However, we need to have the will to do that, and to spend the resources.

Lung cancer stats show little difference in survivorship by deprivation, reflecting a very poor survivorship with current treatment technology. What's different is the rate at which people get the disease and that's due to the residual effect of smoking, or successful quitting of the upper classes and failed quitting, or failure to try quitting, perhaps, of the lower classes throughout the western world.

There is a third pattern where the more affluent communities show a higher incidence rate (for example prostate and skin cancer). With prostate it's likely that the increased recorded incidence is an artefact of increased case finding, possibly by PSA testing in less deprived communities. The legacy of sun exposure has an impact on skin cancer rates where holidays in the sun were once the preserve of the wealthier, and so they now have increased melanoma rates. In both prostate and skin cancer, however, there is no differential in mortality rates across deprivation categories.

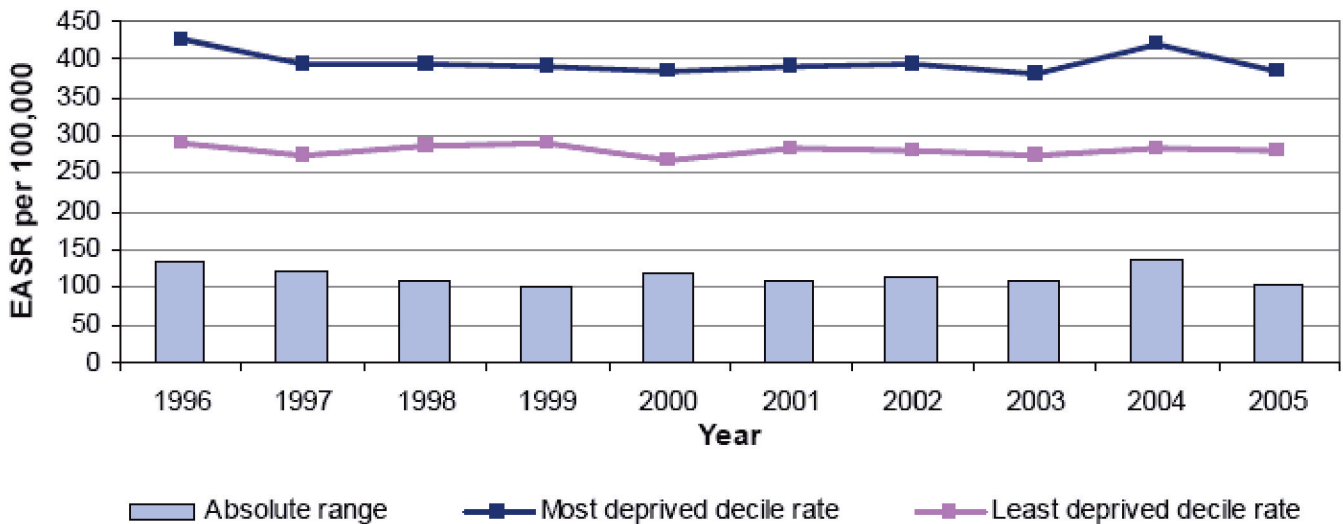
Professor Frank noted that action on cancer inequalities must be long-term and sustained to show significant improvements.



He concluded that in order to have more sensitive outcomes for public health purposes, we need to do a better job in measuring which people in our society are more less exposed to known risk factors. We do have good data for some of these, for example smoking rates. He stated that the most interesting thing from the point of view of knowledge transfer from research into policy or programmes, is that the studies that mattered most for showing the health consequences of smoking were done between 1950 and 1965, and that smoking did not decline seriously until well after 1975. This is called “knowledge transfer lag”, and the important message is that we need to be in it for the long haul because there are no quick wins - it took at least 25 years after the science was in place to change smoking. Sometimes that means that we don’t see the effects on a disease very easily. He asked delegates not to be discouraged, but to be realistic about how best to achieve lasting change.

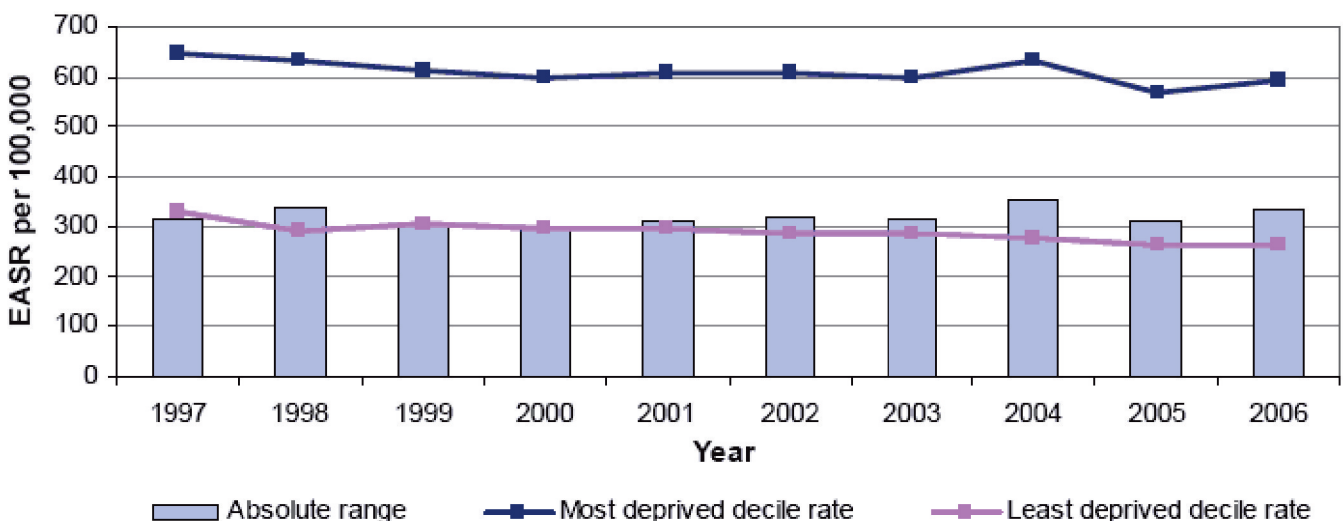
Incidence

Absolute range: Cancer mortality 45-74y - Scotland 1997-2006 (European Age-Standardised Rates per 100,000)



Mortality

Absolute range: Cancer incidence <75y - Scotland 1996-2005 (European Age-Standardised Rates per 100,000)



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Discussion Groups

Health messages – turning knowledge into action

Key points:

- *The public often focuses on smaller, less well known risk factors rather than big factors*
- *Government's main responsibility is education (as well as simply legislation)*
- *Soap opera storylines can be very powerful*
- *Community pharmacists are an underused resource*
- *Currently GPs don't divert from the main issue the patient visits them for - in obesity issue this is a missed opportunity*
- *There is a gap after treatment where healthy lifestyle messages might be powerfully communicated*
- *Perception of risk is crucial*
- *How can we factor in personal choice?*
- *Sun exposure – mixed messages cause confusion*
- *Socio-economic inequalities - most affluent turn awareness into action because these issues are higher on a priority list.*
- *People need to take responsibility for themselves / their own children*
- *There is still a problem between awareness (theory) and transition to lifestyle changes (practice / action)*
- *Problem of "fate", especially in young people*
- *Workplace – lunchtime seminars, doctors' checks, "Healthy Working Lives", work incentives might work*
- *Be aware of irritation of constant "nanny state" lecturing to eat well, etc.*
- *Denial – "it won't happen to me"*

Appraising treatments

Key points:

- *Variations in prescribing across Scotland e.g. in some drugs*
- *Patients are puzzled about why there is a postcode lottery*
- *Health boards should be monitored, to assess compliance with SMC advice, and to find out why there is variation*
- *A consistent approach is required across Scotland*
- *We need to redefine "exceptional"*
- *There should be greater transparency*
- *More open discussion of health "rationing"*
- *Equity considerations*
- *Does QALY capture quality of life?*
- *Health economic measures fraught with difficulty*
- *Will SMC look at "modifiers" like NICE?*
- *More targeted (and more expensive) treatments will compound this issue*
- *Media generates false expectations of "life-saving" drugs*
- *More research needed on societal values*
- *Disinvestment of existing technologies – research, same scrutiny needed*
- *Should we consider extending patents?*
- *Radiotherapy and surgery postcode prescribing gets less of a lobby than drugs*



Living with and beyond cancer

Key points:

- *Psychological issues, depression, stress*
- *Changed person, changed life idea*
- *Getting back to work, financial issues*
- *Communication between healthcare professionals and patients on non-medical issues*
- *Access to good information at the time when you need it*
- *Putting patients and carers in the centre and working around their needs*
- *Self-management strategy for Scotland*
- *Partnership between NHS and charity sector*
- *Challenge of ensuring charities aren't "doubling up" – partnership working*
- *Changing face of cancer - learn lesson from chronic conditions*
- *A feeling of being "put out of the door" post-treatment*
- *Childhood cancer - awareness of late/long term effects*
- *Educating and encouraging NHS staff to be aware of support organisations*
- *Good practice examples need to be shared*
- *Key worker role need for assessment and signposting*
- *Recognition of long-term impacts and side effects*

Diagnosing cancer earlier

Key points:

- *Lack of awareness of rare cancers among GPs*
- *Lack of resources – can't refer everyone who presents with very common symptoms, e.g. cough*
- *Fear (of confirmation of illness i.e. denial)*
- *Patients' lack of confidence / persistence in re-presenting*
- *Waiting times don't take into account time before diagnosis*
- *Need system to feed back to GPs on referred cases: how many were "right" to be referred (i.e. auditing of referrals)*
- *New guidance on patient referral has recently been published – will this help?*
- *Variety in how obvious symptoms are, e.g. breast cancer is relatively "easy to diagnose"*
- *No point producing leaflets if you can't get people to read them*
- *Improve transition from public awareness of cancer symptoms to actual action (i.e. present to GP with symptoms; healthy lifestyle, etc.)*
- *Responsibility of charities to balance shock tactics (used to raise awareness) with psychological damage of scare-mongering*
- *Shift of resources from treatment focus to early awareness, early detection and early diagnosis*
- *"Safety net" – following up patients with consistent symptoms; inform patients to come back if symptoms persist*

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Discussion Groups (contd.)

Reducing cancer inequalities

Key points:

- *Information provision not targeted appropriately*
- *Assumptions are being made e.g. stereotypical prejudices / priorities in life*
- *Fatalistic attitude*
- *Parental / community / generational influences*
- *Access for rural communities to specialist services but perhaps benefits from the model of community working*
- *Training of staff on assessing peoples' information requirements / style, and resources to respond to those needs*
- *Use of demographic data to ensure appropriate information / support – need to use all the information available*
- *Smoking – obvious incidence factor – need new bold thinking to tackle it*
- *Some people don't want to know – won't attend follow up for screening*
- *Need more resources for health promotion activities, not just screening*
- *Inequality is much wider than health – need social solutions?*
- *Paradox that screening / health promotion increases inequalities*
- *Rural patients – transport expensive*
- *Co-morbidities – wider health status*
- *Top-ups – creates two tier system but still better than before*
- *Language can create inequalities*
- *Lack of consistent ethnicity data*
- *Need to oppose the lobby against sharing data*
- *Need to evaluate interventions in the longer term*

Appropriate care

Key points:

- *Needs to be age appropriate*
- *Physical environment*
- *Skilled workforce to support*
- *Psychological environment should be taken into account and supported*
- *Delivering service as locally as possible but recognise the need for centralisation of specialist care*
- *Productive use of network – across health, public, private, voluntary for the good of the patient*
- *Communication about treatment, diagnosis, pathway, bad news should be reinforced/revisited/tailored to individual patients and families*
- *Leadership required to implement this joint vision across Scotland*
- *Desire to roll out best practice*
- *Can't provide equity of service, but should strive to be inclusive*
- *Impact on family life – finance, education, employment, friendships*
- *Youth Cancer Forum Scotland – support for each other*



Measuring quality and improving outcomes

Key points:

- Objective vs. subjective
- Need to measure how quality of life is affected
- Should measure how involved patients are in decision-making
- Most clinicians want to know about outcomes – are treatments working?
- Most patients want best treatment despite issues of travel or toxicity
- Need to better utilise existing data
- Patient reps are not always very representative
- No data available to public on quality and outcomes
- Tougher regulation in England – financial penalties
- Waiting times tend to take focus away from outcomes / survival and they push audit abilities to breaking point
- Waiting time focus has helped drive improvements
- Positive patient journey should be measured (is not at the moment)
- Need to look to Europe to see how they reach better outcomes (but data quality must be taken into account)
- Political vs. clinical priorities need balanced (NHS can't become a football)
- Existing standards on quality need to be reported on and recorded
- Political debate on quality is needed
- Understanding and acting on what is important to patients (especially clear communication)

Innovation and improvement

Key points:

- Need to ensure Scotland is competitive
- Impact and complexity of funding streams
- Infrastructure to support clinical trials, especially late stage, complicated trials
- Experimental cancer centres present an opportunity
- Radiotherapy trials – difficult because of availability of machines
- Importance of strong research base – impact on patient outcomes
- Need strong campaign to support participation in clinical trials
- Human Tissues Act will increase cancer research
- Data protection concerns - generic consent would help
- Bureaucracy - delay but for safeguards – is it proportional?
- Need to support trial capacity in NHS: time and space
- Good science and academic base in Scotland but under pressure
- More discussion needed between service delivery side and research side
- Better communication needed about realities of therapies?
- Universities are sometimes put off taking cancer charity funding because overhead costs aren't paid

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Expert Panel questions and answers

The expert panel was introduced and chaired by Nanette Milne MSP and included Dr. Bill O'Neill, GP Lead, Cancer and Palliative Care, NHS Lothian and the Chair of the Scottish Primary Care Cancer Group; Dr. Aileen Keel, Deputy Chief Medical Officer for the Scottish Government Health Directorate; Kevin Geddes, Director of Self Management for the Long Term Conditions Alliance, Scotland; and Professor Karen Vousden, Director of the Beatson Institute for Cancer Research. Ms Milne then asked for questions for the panel from the audience.

Q. Tracey Loftis from Cancer Research UK referred to lengthy discussions about the importance of clinical trials in the earlier discussion groups, and asked how improved dialogue between patients and professionals regarding clinical trials might be achieved.

A. Dr. Aileen Keel agreed better recruitment into clinical trials is necessary. She also acknowledged that patients who enter trials generally have better outcomes. Professor Vousden stressed the importance of interaction between basic scientists and clinical staff in running clinical trials, and emphasised that Scotland is currently doing well in terms of rates of entering patients into clinical trials. She said that whereas in America around 3 or 4% of patients gets into a good clinical trial, the UK rate is around 10%, and in Glasgow around 15% of patients get into a clinical trial.

Q. A member of the audience referred to Dr. Keel's statement that people who are entered into clinical trials have better outcomes, and asked if that was indictment of usual care, and what could be learnt from people who have been entered in clinical trials that could be transferred to ordinary care?

A. Dr. Keel commended the question, and stated that clinicians have to adhere to rigorous protocols when entering patients into clinical trials. Everything is done in a very standardised way; the monitoring of the patients is done very closely. We could learn from the approach that is taken in clinical trials and try and get a bit more of that systematised into routine clinical care.

Q. Martin Coombes from ABPI cancer industry group referred to the monitoring and capacity issues in the delivery of clinical trials, and asked the panel to suggest how to encourage the NHS and health service to take greater part in clinical trials, when they have so many other priorities in terms of delivering patient care and the pressure that can sometimes bear on current capacity?

A. Dr. Keel answered that effort must be put into tumour-specific managed clinical networks in order to improve trial recruitment.

Q. A delegate asked Dr. O'Neill what he could do to help GPs in referring urgently people who have cancers that are difficult to diagnose. She referred specifically to a friend who was referred very late and was found to have ovarian cancer which had spread by the time she got to hospital.

A. Dr. O'Neill answered that there are very clear guidelines in Scotland for referral of patients where there's a suspicion of cancer. The Cabinet Secretary made reference in her speech to the production of a quick reference guide to be sent to every GP in Scotland, as well as an online version. He pointed out the importance of bearing in mind that in trying to get information to the 1030 practices and over 5000 GPs in Scotland, cancer must compete with heart disease, diabetes, lung disease a whole range of diseases and trying innovative ways to remind people of this information without information overload. He also referred to two recent cycles of audit across practices all over Scotland, looking at referral patterns. Practices had to look back at the pathway that patients went through, whether they'd been referred urgently, according to guidelines, or routinely, or presented as emergencies, and this information is being collated and will hopefully be published. The second part of that recent audit was looking at that all those patients referred when there was a suspicion of cancer, and then looking at those who did turn out to have cancer, to see if there is more information that we can learn from that. He reminded delegates that although there are instances where there has been delay in somebody being referred, which may or may not be explainable, it must be recognised that the symptoms that people present with are often not specific to cancer.



Q. A former cancer patient highlighted the potential problems for patients and their families when receiving chemotherapy as an outpatient, especially when a new drug is used and potential side-effects may be unknown. She suggested that Scotland needs a 24/7 expert on hand to advise GPs and NHS 24 staff when patients experience unfamiliar side-effects at home.

A. Dr. O'Neill referred to the exemplar system in Dumfries and Galloway, where the clinic and nurse specialists involved in the administration of chemotherapy notify NHS 24 on the day a patient has chemotherapy so there is information in place if that patient calls NHS 24. He added that they were not the only board in Scotland to do this, and all of the boards are exploring more efficient ways of communicating information in a timely and appropriately confidential way to NHS 24, so that if a patient contacts them out of hours they are alert to the treatment and the possible complications that they may have. There's also an increasing amount of information being given to patients and in some cancer centres patients get a booklet where the information and the likely side-effects and the doses and names of different cancer drugs are listed so that if they are seen out of hours by the local out of hours service or indeed, by their own GPs in other locations, the information is readily available. He highlighted the importance of electronic solutions to allow this information to be transferred between the different agencies responsible for the care of patients 24 hours a day, 7 days a week.

Dr. Keel also added that most cancer centres where patients are on chemotherapy and therefore at risk of a low blood count and infection, would ask patients to contact them directly in the event of them developing the symptoms in the patient information leaflets. It is very unusual now to have chemotherapy and not be fully warned of side-effects, and given a direct contact number to the cancer centre.

Nanette Milne MSP added that although there is a lot of good practice out there, it's not uniformly adopted, and there is scope for sharing of good practice all over the country.

Q. Dawn Crosby from Teenage Cancer Trust agreed that there is a lot of good practice taking place across Scotland, and asked what commitment we have that this best practice will start being uniform across Scotland?

A. Kevin Geddes was not sure of the possibility of a commitment that it will be uniform across Scotland, but thought one way to try to capture that good practice and have it shared is through working together and working in partnership, work with which the Long Term Conditions Alliance are very much involved. He pointed to the role of the Self-Management Fund, which has been launched to support good work that's already happening in voluntary sector organisations throughout Scotland, but also to encourage new and innovative practice and for that to be shared more widely across groups, conditions, and geographical areas in Scotland.

Dr. Keel stated that what needs to be done across all clinical areas is learn from best practice and promulgate it and managed clinical networks again are one way of doing that. She referred to the quality steering group which will be tasked with looking at outcomes of audits in different tumour areas and different parts of the country, challenge where audit results are different in one part of the country to another, understand the reasons for it and begin to get best practice systematised again across the whole country.

Scotland Against Cancer Conference 2009

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Friday 20th March 2009

Expert Panel questions and answers (contd.)

Q. John Wyke from the Scottish Cancer Foundation pointed out that in the discussion group about research one of the concerns that people expressed was the possibility that more than 80% of research is funded through the voluntary sector, and that in the current climate this might become problematic. Is it thought that some problems might develop in the research portfolio and if so who should be trying to plug these gaps?

A. Professor Vousden agreed that this was a problem. She pointed out that Cancer Research UK has seen a fall in fundraising income, not because people are not donating as often, but because of the falling value of legacies and bequests. She commented that any help from Government in plugging the gap in funding would be extremely helpful. Scotland has developed some outstanding research that spans from basic through translational, into clinical research. The research has been acclaimed as being some of the best in the country, including in Glasgow, which was the fourth best in the UK, so we can be justifiably proud of what we have and should aim to encourage further investment to build on that platform of strength.

Q. Professor Alan Roger, former medical director of the Beatson Cancer Centre referred to Professor Vousden's comments regarding the cooperative work between the Beatson Institute and the Cancer Centre and the quality of the clinical work, going right through from new drug development and phase one to phase three trials. He asked whether anything more could be done to make research in Scotland more co-operative, perhaps through the Scottish Government or the Chief Scientists' Office?

A. Professor Vousden said she thought this was already happening and mentioned Cancer Research UK's centres initiative. However, she also stated that healthy competition within the scientific community helps to keep quality high and helps Scotland to compete worldwide.

Q. Nanette Milne asked whether the recession might be a catalyst for more co-operation when resources are limited.

A. Professor Vousden said that she thought there might be something positive if organisations really think about where they're putting their money, and putting it to the best value and rather than duplicating services they think collaboratively.

Dr Keel agreed and said she is often struck by the number of competing organisations working in the same areas, and she would welcome more co-operation to make best use of resources.

Dr O'Neill mentioned the work of the Scottish Cancer Coalition as an example of organisations working together.

Q. Lara Bennett from AICR asked about the impact of short term grants, typically three or five years, on basic and translational research, and the attractiveness of research as a career.

A. Professor Vousden agreed that this is an issue, but not any more so than has always been the case.

Nanette Milne closed the session and thanked the panel and those who asked questions for an interesting session.



Closing Remarks

Nanette Milne MSP, North East Scotland

Co-convenor, Cross Party Group on Cancer in the Scottish Parliament

Nanette Milne said she thought it had been a very good conference with a wide spectrum of people with interests in cancer attending.

She thanked all the speakers for motivating speeches and all those who took part in, facilitated and took notes at the discussion groups, which were very worthwhile and stimulated interesting debates.

She thanked the MSPs who had attended and particularly Malcolm Chisholm, co-convenor of the Cross Party Group, for chairing the meeting in the morning.

Ms Milne thanked all those involved in the organisation and support of the conference, which provides a useful forum for sharing information and co-ordinating work.

She noted that a report of the conference would go to the Cross Party Group on Cancer for discussion, and will be sent on to Government. She reiterated that the aim of the conference is to generate ideas about how to improve services for cancer patients and that in previous years there have been positive outcomes from the issues raised by delegates, and she hoped that will continue this year.

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