

Scotland Against Cancer Conference 2007

Cancer Research UK

Monday 29th October 2007
The Assembly Rooms, Edinburgh



Conference Report

Together we will beat cancer

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Conference Report

The annual Scotland Against Cancer conference, held in Edinburgh on 29 October 2007, attracted 160 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, Scottish Cancer Foundation, Scottish Cancer Industry Group of the ABPI and the Scottish Partnership for Palliative Care for providing advice on the agenda, and in supporting the conference. We are grateful to the Scottish Cancer Industry Group of the ABPI, Bayer HealthCare, Cephalon Oncology, CIS Oncology, Novartis Oncology and Roche for their generous sponsorship of the event.

Richard Davidson

Director of Policy and Public Affairs
Cancer Research UK

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Contents

Introduction – Malcolm Chisholm MSP	4
Welcome – Harpal Kumar, Chief Executive, Cancer Research UK	4
Health Secretary Address and Questions	5
Keynote Address: Professor Sir Kenneth Calman, Chancellor of the University of Glasgow	8
Expert Panel and Discussion	9
The public health challenge	9
Quality and equality in cancer care	9
The future of cancer research in Scotland	10
The patient experience	11
Panel questions	11
Open Discussion Forums	13
Meeting the public health challenge	13
Improving survival – screening, diagnosis and rapid access to treatment	13
Continuity of care – living with cancer	14
Quality in cancer care	14
Equality in cancer care	14
The future of cancer research in Scotland	15
Learning from the patient experience	15
Closing Remarks – Nanette Milne MSP, North East Scotland	15

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

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 a formal consultation on the updated cancer strategy would be taking place in 2008 and that the views expressed at the conference could feed into that.

Mr Chisholm thanked delegates for their willingness to participate in the conference and wished them a productive day.

Welcome

Harpal Kumar, Chief Executive, Cancer Research UK

Mr Kumar opened by stating that Cancer Research UK is proud to host the Scotland Against Cancer conference, which plays an important role in shaping cancer policy in Scotland and providing an opportunity to work together.

He outlined the challenges, where one in three people will develop cancer in their lifetime and 27,000 cases are diagnosed each year in Scotland, and noted that this figure is set to grow. Smoking, the biggest preventable cause of cancer, has been targeted through the ban on smoking in public places, and Scotland led the way in that. The benefits are already being realised and we will see more in the future.

Mr Kumar stated that progress is being made with more people surviving cancer, but there was still little progress in some cancers, such as lung, pancreatic and oesophageal. In cancers where significant progress has been made, there is still often a poor prognosis where diagnosis is late.

Mr Kumar outlined Cancer Research UK's ten goals for 2020, which specify the impact the charity aims to have. These include specific outcomes on prevention, early diagnosis, reducing treatment side effects, improving survival rates, reducing health inequalities, improving patient information and planning for the future. Mr Kumar explained that he hoped to see the goals achieved by working with others, and that the conference's recommendations for action will help with this.

Mr Kumar went on to outline the portfolio of research that Cancer Research UK funds in Scotland and thanked everyone who has supported this work through campaigning, research or fundraising. He stated that Scotland contributes a significant proportion of scientific advances in cancer prevention, diagnosis and treatment and should be proud of the ground-breaking work carried out here.

Mr Kumar acknowledged that cancer is a political issue and went on to discuss Cancer Research UK's campaigning work. He referred to a study which had shown that over a quarter of people said that cancer is their biggest fear, but many were unaware of how they could reduce their risk. Mr Kumar highlighted the Cancer 2020 campaign, which called on UK Governments to update their cancer plans, and ensure that cancer remains a political priority. Over a quarter of a million petition cards, 24,000 from Scotland, were handed in to the Public Petitions Committee in Holyrood in February 2007. Following the petitions, commitments were given in Scotland and England to update their cancer plans.

Mr Kumar outlined the recently launched Screening Matters campaign, which encourages people to attend cancer screening – breast, cervical and bowel – when they are invited, and asks Government to ensure that these programmes are the best possible.

Mr Kumar closed by stating that Cancer Research UK's vision is that 'Together we will beat cancer', and reiterated the importance that he attaches to working in partnership with others, through the Cross Party Group on Cancer, with the Scottish Cancer Coalition and with individuals and groups across Scotland to achieve this. He thanked delegates for playing their part in achieving that vision.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

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 to see so many people from different backgrounds attending brought home again the passion, commitment and interest there is in cancer and its impact.

This impact is significant because of the burden of illness on the population and the consequent need for ongoing research; in the face of increasing incidence and the resulting demand on services; the need for up-to-the-minute screening programmes, state of the art treatment and the best possible care; and because of the inequalities in access and outcome that are still evident amongst the Scottish population.

She stated that it is the Scottish Government's determination to improve access across all areas. Ms Sturgeon noted that much has been achieved since the launch of the cancer strategy in 2001, with unparalleled increases in the number and range of staff working within cancer and other services. Cancer networks have been developed, bringing the benefits of full multidisciplinary team-working, which is recognised across the globe as a key quality marker for cancer services.

Ms Sturgeon stated that patients can be confident that decisions they make about their treatment and care derive from the collective knowledge and expertise of medical, nursing, pharmacy and other relevant healthcare professionals working together to deliver the best care possible. She noted that feedback from patients indicates that the effort and commitment of cancer teams is of a high standard throughout the country, and said she had seen first hand the unstinting efforts of staff everywhere, and across all professions and disciplines.

All five cancer centres are now equipped with state of the art linear accelerators and the investment programme over the past few years has ensured that old equipment has been replaced, improving safety and increasing capacity. Ms Sturgeon highlighted the Beatson West of Scotland Cancer Centre as an example of a dedicated new facility, with its design and decoration informed by and decided by patients. Most of the other cancer centres have also been extended with additional facilities for patients as well as treatment areas.

Ms Sturgeon referred to improvements in access to imaging and diagnostic services with many patients going 'straight to test'. She also noted that significant inroads have been made in patient information with good examples of hand held records so that patients have the information they want at their fingertips.

Looking to the future, Ms Sturgeon said that Cancer Scenarios projections suggest that cancer incidence will continue to rise, largely due to the ageing population. Ms Sturgeon highlighted the encouraging decline in mortality rates in the under 75s and noted that these are on course to meet the national target to reduce death rates from cancer in this age group by 20% by 2010. Latest figures show an 18.1% reduction since 1995. Furthermore, survival rates have improved significantly with five year survival from prostate cancer at 63% and bowel cancer up to 50%.

Ms Sturgeon noted that the previous month had seen major publications on health and socio-economic inequalities in cancer outcomes in Scotland, and pledged to continue a focus on ensuring that more people seek and get access to the services that are available, highlighting the Keep Well projects as one example of this work. Ms Sturgeon went on to highlight advances in this area, with the national target to reduce the rate of mortality in under 75s in the most deprived communities by 10% between 2003 and 2008 on track to be met, with a 7.5% reduction so far. The Cabinet Secretary also mentioned the Ministerial Task Force on Inequalities which she has set up.

Ms Sturgeon confirmed that cancer remains a top priority for the Scottish Government and said it was vital that the momentum for change and improvement is maintained. The Chief Medical Officer is leading work to develop the broad strategic vision for cancer, and the Government wants to see wide public and patient input to the development of the updated cancer strategy, as well as engagement with healthcare professionals, operational management and the voluntary sector.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Health Secretary Address and Questions (contd.)

Considering the issues for discussion at the conference, the Cabinet Secretary reiterated the centrality of patients to all the work being undertaken, and said that she expected the updated strategy to build on the success of the patient focus and public involvement programmes already in place across the cancer networks. She said she expected networks to take forward key elements, such as systematically tapping into the views and experiences of patient, ensuring accessible and appropriate patient and public information, and demonstrating joined-up patient focused care.

She highlighted the recent development of a model of supported self management, the application of which will give clear signposting, information and support for patients so that they feel better equipped and more confident to become more active in their care.

Another area highlighted by Ms Sturgeon was quality assurance of clinical services and she noted that all three cancer networks quality assurance frameworks are accredited by NHS QIS. Generic cancer standards, as well as tumour specific clinical standards are being developed and there will be public reporting and scrutiny of how services are living up to those measures.

Discussing screening programmes, Ms Sturgeon stated that both the established breast and cervical programmes are showing clear evidence of their benefit in terms of increased survival due to earlier detection and treatment, and in the case of cervical cancer, a clear reduction in the number of deaths. She stated that the Government is committed to extending screening programmes where there is evidence of benefit and will be guided by the recommendations of the UK Screening Committee. The Cabinet Secretary referred to the fall in attendance for cervical screening among young women and emphasised the importance of attendance, and noted the importance of reiterating this message when the HPV vaccine is introduced. Ms Sturgeon confirmed that breast screening will be extended to include two views at every round, and that the introduction of bowel cancer screening will be in place across Scotland by the end of 2009.

Ms Sturgeon explained that the Scottish Government's vision for palliative care was set out in Better Health, Better Care, where they pledged to make the Gold Standards Framework the norm for people nearing the end of their life.

On research, the Cabinet Secretary noted that the Chief Scientist Office spends £12.6m every year supporting cancer clinical research, the Scottish Cancer Research Network and Experimental Cancer Medicines Centres in Glasgow and Edinburgh. She also noted that the Research Strategy for Health and Healthcare will be revised in 2008.

Ms Sturgeon took the opportunity to thank staff across NHSScotland for their contribution to the success of the cancer strategy. She also mentioned meeting with the Scottish Cancer Coalition and their agreement that significant and welcome improvements had been made that they want to see continued. She stated that the Coalition had identified a need for better signposting and access to relevant information, and noted that the supported self management model will be fundamental to making this a reality.

Discussing waiting times, the Cabinet Secretary said there was no doubt that improvements so far are welcomed and made it clear that she expected to see the 62 day target achieved by December 2007, and sustained thereafter.

Ms Sturgeon explained that she wants to consider how to reach more people with more meaningful standards and ensure that patients can rely on the NHS to deliver these standards. She noted that for the strategy to be meaningful it has to be capable of developing to meet emerging evidence and growing needs.

Ms Sturgeon closed by wishing delegates a successful day.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Questions

Q: Moira Adams from Scottish Breast Cancer Campaign commented on primary prevention and exposure to industrial chemicals, and asked that the updated cancer strategy look at exposure; identifying risks and making provision in this area.

A: The Cabinet Secretary said that she agreed with the premise of the question and said that a key theme of the strategy must be primary prevention across a range of fronts, including lifestyle factors such as smoking. She agreed to look into the inclusion of this issue in the strategy. She remarked that there has to be speedy diagnosis and the best possible treatment, but we should never give up on trying to reduce the number of people who get cancer in the first place.

Q: Irene Leigh, a Cancer Research UK skin cancer researcher at the University of Dundee stated that the incidence of skin cancer continues to rise and melanoma often affects younger people. She asked for comments about skin cancer in Scotland and specifically about sunbed regulation.

A: The Cabinet Secretary stated that this rise in incidence is indeed a cause for concern. She said that there is a need to get across the right messages about the dangers of sun exposure, and like other public health messages, this needs to be done on an ongoing basis. She noted that Ken Macintosh MSP has pioneered a Members Bill on the issue of sunbed legislation and that she is keen to work with him to see what progress can be made.

Q: A delegate who is a member of a melanoma support group asked what the Government could do to get the message about sun protection across at an early age, including in nurseries and schools.

A: The Cabinet Secretary agreed that there is a long way to go to get those messages across, and said that while people often understood the need to use sun protection when abroad, they often do not use it in Scotland. She agreed that there is more work to be done to educate people and raise awareness of the damage the sun can do.

Q: St John Hattersley from Macmillan Cancer Support, and Chair of the Scottish Cancer Coalition welcomed the positive comments the Cabinet Secretary had made about working with the Coalition. He also welcomed the focus on patient experience and stated that there is excellent work in this area going on across Scotland, but there is a need for a framework for this at national level. He asked about the CCRC's recent work in this area and what the timeframe might be for reporting on that and taking it forward.

A: The Cabinet Secretary stated that she attached great importance to the work of the CCRC and that the Scottish Government is looking closely at the outcome of its recent research. She added that she wanted to see patient experience, and a focus on the non-clinical aspects of care for cancer patients as a central part of the updated strategy. She added that the updated strategy will, in some ways, be a very different document to the one it replaces as the improvements that have been made in the intervening years in areas such as infrastructure, staffing and technology, mean that other issues, such as patient experience, now have to take a more central role.

Q: Michael Coates, a patient, asked about the possibility of reducing the cost of sun protection, as is the case in Australia, to address skin cancer rates.

A: The Cabinet Secretary stated that it was her feeling that the issue was not so much about the provision of protection, but a cultural and educational issue, but that she would consider his suggestion.

Q: A delegate stated that her experience in America had been of a strong network of local support groups which she had found very comforting and useful, but that she wasn't aware of the same provision in Scotland.

A: The Cabinet Secretary welcomed the point and agreed that these groups played an important role. She said that groups represented at the conference may be able to help in this regard. She noted that on a recent visit to the Western General Hospital in Edinburgh patients had told her about the benefit of meeting others in the same situation and the mutual support that brought.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Keynote Address

Professor Sir Kenneth Calman, Chancellor of the University of Glasgow

Sir Kenneth stated that the most powerful educational experience of his life had been learning from patients. He was involved in setting up cancer support group, Tak Tent, which provided a vehicle for patients to become part of the team and to understand what was required, what could and could not be done, and an impetus for change.

Through a series of cartoons, Sir Kenneth discussed the relationship between patients and professionals. He stated that patients have an enormous amount of courage and tremendous expertise and it is important that they are involved.

Sir Kenneth referred to the 1979 Cancer Services in Scotland report, which he felt was up-to-date at the time, but not a lot happened, and asked why some reports change things and others do not.

The aim of medical professionals is to assist the process of healing. Staff do need to have the right knowledge, skills and attitudes to take that forward, and communication and teamwork are hugely important. Sir Kenneth discussed the 'index of suspicion'. For every 500 patients with a cough or respiratory symptoms, one will have lung cancer. For every 400 patients with digestive or stomach complaints, one will have stomach cancer. An average GP in Scotland will have around 1500 patients. Each year they will see 8-10 new cancer patients. 1 breast, lung and colon cancer every year, stomach every two, ovarian every five, cervical 10, testicular 15 and childhood 20. This is a significant challenge for the primary care team, and it's quite difficult to keep up to date in that period on what to look for.

Sir Kenneth noted that research is fundamental because what we already know about some cancers is not enough. Research councils and charities are vital to this. Scotland punches above its weight in this area. NCRI data show that Scotland gets 13% of the UK research spend, on 8.5% of the population, is a world leader in fundamental research, and contributes significantly to the evidence base. It is also fortunate to have a small, stable population and good cancer registries. But we need to continue this and make existing resources work even harder.

Sir Kenneth discussed the Calman-Hine strategy which emphasised the importance of specialist staff in all disciplines, teamwork and patient involvement. It also considered flexibility of care. There will be times when some operations, therapies or diagnostics have to be done in the tertiary centres, but as expertise develops some can move out, and we need to be prepared for this.

On prevention, there are links to other areas of health as obesity, smoking and alcohol are just as relevant for other diseases. Sir Kenneth stated that there is significant potential for improving health, and we need to implement what we know. Environmental carcinogens are also still an issue.

Sir Kenneth closed by stating that what is needed is political will, clear strategy, tactics, commanders on the ground, logistics and resources. Much could be changed now. He recommended agreeing and implementing the strategy, which will need full political, public and professional support. The public need to take their responsibilities and patients need to be seen as part of the team. There is also a need to develop the research base, professional education and to make links to other health priorities.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Expert Panel and Discussion

The public health challenge

Dr Laurence Gruer OBE, Director of Public Health Science, NHS Health Scotland

Dr Gruer opened by stating that public health has been famously described as the science and art of preventing disease, prolonging life and promoting health through the organised efforts of society. He identified three major challenges for cancer: understanding the impact of cancer on the population in order to provide the correct action; to prevent people from getting cancer; and to organise services to diagnose and treat cancer as effectively as possible.

Dr Gruer noted the importance of epidemiological studies which can help to illuminate the causes of cancer, as was the case with the links between smoking and lung cancer, and HPV and cervical cancer. He also highlighted the importance of monitoring the success of interventions, and stated that age standardised rates were vital as they allow comparison without the effects of an ageing population.

Dr Gruer stated that a detailed knowledge of individual cancers and their causes means that we can do more to prevent cancer. He outlined nine simple rules that would prevent most, but not all, cancers: don't smoke or live with a smoker; eat a diet rich in fibre, fruit and vegetables with only small amounts of red or processed meats; maintain a normal weight throughout life; only drink modest amounts of alcohol; remain physically active; avoid sunbathing and use a high spf sunscreen; do not inject drugs; avoid exposure to asbestos or ionising radiation; and for young females, avoid multiple sexual partners, have children early and breastfeed them. However, he felt that it would be a great challenge to persuade and enable people to live in this way when their appetites, addictions, habits, culture and circumstances may drive them to do otherwise.

Implementing these rules in the real world presents significant challenges, and to date there has been more success with some than others. The reduction in smoking rates is due to a comprehensive approach over many years, including education, increased taxation, controlling advertising and legislation. Conversely, last year's review of the Scottish Diet Action Plan showed little progress over the past decade in encouraging people to eat a healthier diet.

Dr Gruer outlined his top three priorities for action:

smoking remains a priority and Dr Gruer is confident that the Scottish Government will press ahead with measures to help people quit and stop young people starting to smoke;

tackling what we eat and drink – education has an important part to play but major changes in our food and drink industry seem essential to improve public health, and will take great political skill and courage to achieve;

making a success of the HPV immunisation programme which will ensure that the incidence of cervical cancer will steadily decline to almost nothing into the decades to come.

Quality and equality in cancer care

Professor Nora Kearney, Director, Cancer Care Research Centre

Professor Kearney stated that while there was no doubt that the past decade has seen substantial improvements in survival, there are still significant challenges in cancer care. The EUROCARE study showed that Scotland is doing relatively poorly compared to European counterparts and Professor Kearney suggested that where a country shows differences to countries of similar wealth, it suggests that the health system is not functioning as it should. She noted that the UK's poor survival rate has been mainly attributed to late diagnosis.

Professor Kearney noted the socio-economic variations that exist in cancer, where those from more deprived groups have a greater chance of getting cancer, and lower survival rates. She also stated that geography provides huge challenges for Scotland in providing equitable care for those who live in remote and island areas. We need to think differently about delivering care closer to people's homes that is the same standard as that delivered in our major cities. She also highlighted the impact of an older population who have multiple conditions. Current silo services are not geared up to support these individuals, and delayed diagnosis, less frequent tumour staging and under-treatment are common.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Quality and equality in cancer care (contd.)

On the issue of quality, Professor Kearney stated that targets are valuable, and that patients want them, but asked if the targets we set are correct. Over the past three years, the Cancer Care Research Centre has been looking at delivering cancer care that's more responsive to the needs of patients. They engaged with over 2000 people in this work. Some of the major findings include a need to address the public awareness of cancer signs and symptoms, which often results in late diagnosis. Many patients experience excellent or good care from compassionate professionals, but this was not consistent cross the country. Care was felt to be fragmented and partnership working was not effective. Psychological, emotional and financial support was lacking for many, and there was a particular concern that there was no follow through of patients who had finished active treatment.

Professor Kearney closed by stating that it is time to do something quite different. She suggested that there is a need to acknowledge that Scotland lags behind, focus on community-based prevention and capture outcomes, not just on survival, but on the totality of patient experience. She believes that a national strategy for cancer research is needed which includes basic science, clinical trials and patient experiences, and that a new model of care is required which shifts the focus from cancer to the individual.

The future of cancer research in Scotland

Professor Roland Wolf, Honorary Director, Cancer Research UK Molecular Pharmacology Unit, Ninewells Hospital and Medical School

Professor Wolf opened by stating that news of breakthroughs, developments and advances often led to false expectations. He noted that the process of translating a laboratory discovery into clinical practice is still very long, and we should be targeting this.

He explained that having found a new target for cancer, a researcher must find a way of interfering with that target, then demonstrating that this displays potential utility when you get to a patient. The researcher must consider the risks associated with applying that drug to people, how it is metabolised in the body, whether it is in the body for long enough to give a therapeutic effect, and whether it will cause intolerable or unacceptable side effects when used in people. These are all important factors in the regulatory process of licensing a new drug. Once this stage is passed, the drug must take part in a series of clinical trials that define tolerability, toxicity and efficacy. Professor Wolf stated that it is important that the public understand the difficulties and the long road ahead following these discoveries being made.

The last few decades have seen massive advances in scientific understanding, and particularly the sequencing of the human genome. The rate of change is enormous and cancer research benefits from this increase in knowledge.

Professor Wolf explained that cancer is difficult to treat because tumours are unstable. Even within one tumour there will be multiple different mutations and that may mean that part of a tumour will respond to a particular treatment, but not all. Drugs developed previously were targeted at cell division so they attacked healthy cells as well. We are now moving away from non-specific cytotoxic drugs to drugs that are targeted to specific pathways in tumours. However, this strategy will also throw up a series of new issues to be considered, such as how you identify which individuals to target each drug at.

Scotland has pioneered and played a major role in identifying environmental factors and legislating to reduce their impact, and has been at the forefront of leading studies into screening programmes for early diagnosis, particularly in colon cancer. Exciting things are happening in immunisation, such as the HPV vaccine. Professor Wolf reiterated the importance of understanding the factors that cause cancer in order to develop drug and lifestyle interventions.

Professor Wolf stated that new pharmacological and pathological approaches must be developed so that the patient receives the right drug at the correct dose. This would stop patients getting a drug that has no impact but causes all the morbidity of treatment, and which may mean they miss out on another treatment that might work.

Professor Wolf stated that Scottish scientists have made a major contribution to this, and Scotland has exceptional databases and collaborative programmes. There are great opportunities to be world leaders in these fields.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

The patient experience

Jeff Hurst, cancer patient

Mr Hurst outlined his experience as a bowel cancer patient. Having been diagnosed with anal polyps in 1985, he had had regular check-ups and so was able to proceed straight to a consultant when, in late 2002, he noticed significant changes in his bowel habits. In January 2003, a colonoscopy confirmed the presence of a bowel tumour, and surgery was swiftly arranged. Mr Hurst felt that this was the worst period as there was no definite end in sight and he worried about what would happen and what the outcome would be. He told his family and close friends, but no-one at work except his manager. This meant he was able to stay at work and maintain a degree of normality which was the best situation for him. Eight weeks later he was admitted to the Western General Hospital in Edinburgh, and remained in hospital for three weeks as his bowel had gone into shock. Mr Hurst paid tribute to the skill and dedication of the medical professionals, but said that it was still a great shock as he had never been in hospital before.

Following discharge, Mr Hurst embarked on a course of chemotherapy and found it startling to compare his situation to others on the ward. He returned to work after 12 weeks on phased return. Mr Hurst explained how after his final course of chemotherapy, as warned, he was struck by the enormity of what had happened. All his energy had been devoted to the treatment and it was strange to suddenly be left with nothing and go back to his normal life. He coped because he had always believed he would get better, but understands why others sometimes struggle.

Mr Hurst explained that he wanted to put something back and spread the word that cancer can be dealt with, especially if diagnosed early enough. He became involved with SCAN and was recruited as a patient rep on the Cancer Care Research Centre steering group. He has also appeared twice in newspaper coverage of bowel cancer awareness month.

In 2006, Mr Hurst was almost at the stage of being discharged altogether when a lesion was discovered on his right lung which was confirmed on biopsy as coming from the original tumour. It is a setback, but he has coped with the news and everyone has rallied round as they had before. He received another course of chemotherapy – this time orally, which proved challenging as it requires the patient to take the dose at the correct intervals. The three month course ended in January 2007 and the tumour has not increased in size.

Mr Hurst said that he feels lucky. He can live his life without any restrictions. He feels humbled by the fact that so many people have devoted, and continue to devote, their time to him to allow him to lead a normal life. He said he wanted to take the opportunity to thank them all. His message to the conference from his experience is the importance of early diagnosis. Most people, particularly men, do not like discussing bowel habits, but as Mr Hurst has shown, it can literally save your life.

Panel questions

Q: John Wyke from the Scottish Cancer Foundation asked about attempts to engage with schools in order to increase public awareness of cancer risk factors and symptoms. He stated that the Beatson Institute had tried in the past, but had not met with much enthusiasm from schools.

A: Nora Kearney stated that the CCRC research included speaking to children aged 8 and 10 in primary schools, and they were welcomed by the school. The research had looked at the children's knowledge, perception and attitude toward healthy eating and found that while children were aware of the key messages, they often didn't match with their preferred foods, and noted differences between affluent and deprived communities.

Laurence Gruer agreed that engaging with younger people was important but studies show that education projects have minimal impact on behaviour. He also noted that there are huge pressures on the curriculum to get much on health education in.

Jill MacRae from Teenage Cancer Trust stated that TCT have a dynamic education programme that goes into secondary schools across the UK to have frank discussion with children and young people about cancer. TCT find a good response from the children, but often find that teachers are less comfortable with the idea.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Panel questions (contd.)

Q: Jill Hubbard from the Cancer Care Research Centre reiterated the need for genuine multidisciplinary research to encourage partnership working and avoid silo working and asked the panel to comment on how this might be achieved.

A: Nora Kearney noted that the CCRC's work is trying to look at the whole spectrum of care and based on the best possible research from all areas. The new model developed by the CCRC recommends the development of a cancer research strategy for Scotland that brings basic, translational and patient experience research together.

Laurence Gruer agreed that services need to draw on the best available research then apply the findings to people's needs and circumstances.

Q: A delegate asked whether the concept of personalised medicine was logistically difficult or prohibitively expensive.

A: Roland Wolf agreed that this may be the case but that there was a moral and ethical issue that if it is possible to test a patient to see whether they will respond to a particular treatment it's only fair to carry that out. The tests themselves are often not very expensive. He also noted that we are moving towards personalised medicine already with treatments such as tamoxifen and herceptin. However, for some cancers neither tests nor personalised treatments are available.

Q: Ken Macintosh MSP asked what specific recommendations the panel would make to the Scottish Parliament.

A: Nora Kearney asked that the model of care developed by the CCRC be implemented across Scotland.

Roland Wolf said there was an opportunity to implement a co-ordinating approach to prevention, and asked for continued support for the Translational Medicine Research Initiative.

Laurence Gruer asked for continued action to tackle tobacco and for the Parliament to get tough on alcohol.

Q: John Kenney asked about smoking in and around hospitals, particularly by NHS staff, and that it gives a very bad impression.

A: Jeff Hurst agreed with the sentiment.

Q: Euan Paterson, a GP from Glasgow, asked about trying to engage with large companies trying to promote an unhealthy lifestyle.

A: Laurence Gruer said there was scope for engagement with the food and alcohol industries and said there was some signs that there is a recognition within the food industry of the relationship between diet and health. He felt there was a role, mainly at UK and EU level, to emphasise companies' responsibilities to consumers, and where required, to introduce regulations that will diminish the unhealthy side of what they're doing.

Roland Wolf noted that an emerging industry of functional foods is being driven for economic reasons on the basis that they may contain ingredients that may be helpful in preventing disease.

Q: A delegate asked whether it would be possible to see more health education messages written into TV storylines as it does seem to have a good effect.

A: Laurence Gruer agreed that there was a strong argument for increasing the budget for prevention and health improvement, which forms a very small proportion of the NHS budget, and that there was scope for engaging with the media. However, he noted that it is increasingly difficult to get health education messages across in this way due to the fragmentation of the media.

Q: A delegate welcomed the increased focus on patients and carers but noted that it was more difficult to get hard edged outcomes on care, and asked the panel how these could be highlighted or moved up the agenda.

A: Nora Kearney agreed that the evidence is challenging but felt that it is mainly down to perception and that the scientific processes for patient experience research are just as robust. She said that what is needed is to get those who hold the purse strings to believe in the evidence.

Open Discussion Forums

Meeting the public health challenge

Key points:

- *It's not just about cancer, it's about society, empowerment and choice*
- *Need targeted strategies for different groups*
- *Need to invest in education and reach children as young as possible*
- *Awareness of services and engagement is crucial*
- *Positive messages instead of negative - for young, in particular, emphasise their societal benefits of health lifestyles rather than cancer risk of poor habits*
- *Cohesive, needs-led approach*
- *Tackle deprivation through role models*
- *Difference between message getting across and behavioural change*
- *Legislation and taxation have been more effective than exhortation – use this to target alcohol as next aim*

Improving survival – screening, diagnosis and rapid access to treatment

Key points:

- *Short education videos/ books etc. in waiting rooms*
- *Identifying people through screening – imperative to follow through with treatment and care*
- *Need improved GP education and symptom awareness – but generalist by nature*
- *Need better public awareness of symptoms*
- *Rarer cancers – problems of low prevalence and often non-specific symptoms*
- *For screening - must be registered with a GP – if not registered may fall through the cracks*
- *Government targets set in cancer strategy have been met – waiting times much better*
- *Need for inequalities and cultural barriers programmes*
- *Referral guidelines exist but need better linked systems for referral*
- *Resource heavy for monitoring 62 day urgent referral target*
- *Screening and non-urgent referrals not included in target*
- *Sharing of good practice – challenge of getting others to adopt change in practice; professional egos and political imperatives conflict*
- *Some don't want to do the test in case it detects cancer – how do we address this?*
- *Accessibility of screening services – time/ location*
- *Audit of GP diagnosis to help identify trends and patterns – so leading to higher detection rate*
- *Improvement in array and accuracy of test available to GPs – clinical examination and appropriate investigation*

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Continuity of care – living with cancer

Key points:

- *Understanding what people's needs are*
- *Use of technology to connect people together*
- *Importance of support groups*
- *Base model on patients experiences of care*
- *Stop duplication and get agencies working more collaboratively together*
- *Breaking down barriers and implementing supported self care*
- *Improve communications between health care professionals and patients/ carers*
- *Strengthen managed care networks – bring together clinical and care networks*
- *Focus on 'vulnerable points'*
- *Duplication of services – regionally/ locally*
- *Patient champion – signposting to voluntary sector, self-help groups*
- *Evaluation and sharing knowledge is key*
- *Getting people on board very important – often they find their own solutions*
- *Appropriateness of information to suit the individual*

Quality in cancer care

Key points:

- *National standards very important. Can't improve quality without standards*
- *Broad, comprehensive standards that include quality of life*
- *How do we measure/ demonstrate etc.? Need research into 'softer issues/ models of care*
- *Complaints process/ procedures – use as learning/ way of improving things*
- *Recognition that patient is "more than a sum of their illness"*

Equality in cancer care

Key points:

- *Minority groups – information, education, communication - infopack detailing patient journey?*
- *Literacy levels – leaflets in other languages make no difference if people can't read them*
- *Ethnic communities not accessing services in the first place, so won't access helplines etc.*
- *Rural and island communities - having to travel to locations quite far from home for treatment; financial cost; travelling when ill etc.*
- *Need to define barriers – social stigma; travel; stoicism; perception of bothering the doctor; access to preventative and palliative care; faith; language; health board prescribing policies*
- *Use the mobile model with local contacts to bring outreach to communities*
- *Improve spread of GPs through deprived communities – new models for GP practices as primary care centres*
- *Equality between different parts of cancer journey – palliative care often just an add on*
- *Need to raise people's expectations of what they want from their own lives – lack of aspiration*
- *Look beyond just health professionals to communicate messages*

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

The future of cancer research in Scotland

Key points:

- *Joined up approach: research, policy, patients*
- *More clinical staff involved in research*
- *Co-operation and understanding between clinicians and scientists*
- *Location should not discount participation in research and clinical trials*
- *What can the Chief Scientist Office do to facilitate research?*
- *Research to understand what interventions will make a difference*
- *Why so much variation in outcome in a rather homogenous population – Scotland a good place to answer this questions*
- *Trial different interventions (prevention/ diagnosis) in different deprived areas – structured and co-ordinated trial*
- *Need more admin support for clinical trials*

Learning from the patient experience

Key points:

- *Professionals/ practitioners/ patients and carers need assistance to engage*
- *Not always “big” changes*
- *Integration into everyday practice*
- *Medical language can be a barrier*
- *Resource GPs – must be capable of personal support*
- *Aim to bring into NHS the best of what charities supply*
- *Need systems for children as patients and family members*
- *No mechanism for discussing/ complaining/ evaluating care that has a child focus*
- *How do you capture the qualitative experience to inform care?*
- *Every patient’s story needs to be recorded before they leave hospital to ensure instant improvements*
- *Targets/ quality standards attached to patient feedback*
- *What part should carers and families play and how can their views and needs be taken into account?*
- *Difficulty of engaging with those who are not interested/ socially isolated/ deprived – empowerment; time; expectations*
- *When designing services we need to ensure the patients/ public involved reflect the diversity of the population*
- *Need to establish an ethical, robust, realistic process for capturing, synthesising and feeding back information*

Closing Remarks

Nanette Milne MSP, North East Scotland

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

Nanette Milne MSP thanked all delegates for taking part in the open discussion forums, which raised a number of key issues.

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.

Scotland Against Cancer Conference 2007

Monday 29th October 2007

The Assembly Rooms, Edinburgh

Cancer Research UK would like to thank the following organisations for their support, without which the Scotland Against Cancer conference would not be possible. All Gold and Silver sponsors have a medical expertise and a commercial interest in cancer, but have not been involved in the content of this conference.

Gold Sponsor:



Silver Sponsors:



Steering group:

Macmillan Cancer Support

Myeloma UK

Scottish Cancer Foundation

Scottish Cancer Industry Group of the ABPI

Scottish Partnership for Palliative Care

For further information on Scotland Against Cancer, contact:

Vicky Crichton

Public Affairs Officer for Scotland

Cancer Research UK

Unit 1 Quality Court

3a Quality Street

Edinburgh EH4 5BP

Tel: 0131 310 4368

Email: vicky.crichton@cancer.org.uk

Web: www.cancerresearchuk.org

CANCER RESEARCH UK



Together we will beat cancer

CANCER RESEARCH UK

