



Scotland Against Cancer Conference 2006

Cancer Research UK Scotland

Friday 22nd September 2006
Thistle Hotel, Cambridge Street, Glasgow



Conference Report

Together we will beat cancer

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Conference Report

The annual Scotland Against Cancer conference, held in Glasgow on 22 September 2006, attracted 150 delegates from across the cancer community in Scotland for a day of lively discussion and debate.

The conference focused on the future of cancer and how Scotland can prepare itself for forthcoming challenges.

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, David Davidson MSP and Ken Macintosh 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 Scotland. We would like to thank the members of the steering group: Cancerbackup Scotland, Macmillan Cancer Support, Myeloma UK, Scottish 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 Industry Group of the ABPI, Bayer HealthCare, GlaxoSmithKline, Lilly, Merck, Novartis Oncology, Ortho Biotech, Roche and Sanofi-Aventis for their generous sponsorship of the event.

Richard Davidson
Director of Policy and Public Affairs
Cancer Research UK

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Introduction

Kenneth Macintosh MSP, Eastwood
Co-convenor, Cross Party Group in the Scottish Parliament on Cancer

Ken Macintosh MSP introduced the Scotland Against Cancer Conference and welcomed all delegates. He said that there were a number of issues to be addressed, such as cancer incidence, prevention, new drugs and treatments, and the fact that more and more people will be living with cancer.

Mr Macintosh thanked delegates for their contribution to tackling cancer in Scotland, and for their willingness to participate in the conference.

Keynote Speech

Andy Kerr MSP,
Minister for Health and Community Care

The Minister said that he was happy to be speaking at the conference, which he felt had a strong agenda, and looked forward to the outcomes of the discussions.

He began by saying that since the launch of *Cancer in Scotland* five years ago, we have very good cancer services in Scotland, and the policy was contributing to better care in Scotland.

He stated that he anticipated an improvement in lung cancer incidence as smoking reduces, following the introduction of the smoking ban in Scotland, and noted that it was good to see the posters advertising and celebrating the ban.

The Minister discussed participation in the breast and cervical screening programmes in Scotland, and the resultant drop in mortality, as well as the colorectal screening programme which will be rolled out across Scotland from May 2007.

Patients are becoming more empowered and benefit from self-care. However, developing a strategy for services and support of this is essential. There have been service changes via multidisciplinary teams and their embedding in the community in Scotland. This along with the clinical trials and research taking place in Scotland is amazing, innovative and incredible. Recruitment onto clinical trials has surpassed the target, and patient outcomes have improved.

High-tech treatments hold great potential for patients. The Scottish Medicine Consortium must be thanked for the quick flow through of new treatments as their task is not to be envied and they are often ahead of NICE with regard to new treatments.

There have been moves forward with involving patients. Their voices continue to be heard and they have helped contribute to our success to date. The Cancer Strategy has key areas that are still relevant and the debates and discussion on the Cancer Strategy need to involve patients.

However, he warned about being complacent and said that we must respond to the real challenges with a long term strategy that must work for patients and reflect where we are going.

The Minister added that he has a belief in the core values of *Delivering for Health*, and providing services in the community environment, where possible. There are lots of challenges ahead, but everyone should be positive about what has been achieved to date. Success should be celebrated.

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Questions

Q: The use of the new cervical cancer vaccine would protect seven out of ten women. Will the Executive introduce it? Also, with regards to oesophageal cancer, 98 per cent present at palliative stages with an expected eight-month survival. When will it be the turn of oesophageal cancer?

A: The new cervical cancer vaccine has great potential and the Executive must wait and look at the scientific research, the outcomes, take advice and then respond. Great care must be taken not to introduce the vaccine and use it as an excuse not to continue with screening as vaccines could dilute the emphasis on screening programmes.

There is impact from the Strategy around bigger cancers and oesophageal cancer must be brought to the fore. Dentistry is helping to address this but we must ask how oesophageal cancer fits in?

Q: What about quality, queues and waiting times? Quality suffers as re-designs are based on quantity.

A: Quality is key. Waiting times are an issue but the quality outcome is improvements in survival. Meeting waiting time targets must not be at the expense of quality - the balance must be right and changes will happen if it isn't. The key issue is survival but we are duty bound to have reasonable waiting times.

Q: Second to pain, financial difficulty is the biggest issue for cancer patients and cancer poverty needs to be addressed.

A: Financial difficulty relates to benefits, parking, reduced benefits etc. Benefit entitlement awareness could be better. There are systems in place and we are working on these issues.

Q: Workload is a real issue as self care moves the burden to the end of life and makes it worse for the acute/primary care sector. General practice and nursing need to address this.

A: The management, funding and support of self care is there and helps towards better outcomes. A shift of burden does exist with patients entering a hospice setting later and for less time, and the balance of care should be appropriately shared in the workforce – between carers, GPs, occupational therapists, nurses, dieticians and consultants. The task is to get the balance right and the links between them all is key. It is a challenge but Delivering for Health will make a difference to patients.

Q: The end of the appointment of the Cancer Tsar is detrimental.

A: The debate on having a Cancer Tsar is open but we need the evidence to keep the post. The post was required in the early stages of planning to support the networks.

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Q: Decision makers don't have enough knowledge on all cancers to get the correct decisions on benefits. Also, when a carer becomes a pensioner, they stop being considered a carer, and receive no additional support, and this needs to be addressed. Many elderly people are looking after elderly patients, and have no extra income to support them.

Q: There are differing attitudes to support groups in the medical profession. Part of the problem is that support groups vary in quality and that means that clinicians don't always want to support them. I think the support group system needs to examine itself and find out how best it can contribute to change. Patient and public involvement is not just about improving the information that cancer patients get, but their involvement in the whole process of improvement of service delivery.

Q: I have consulted with my MSP colleagues here, and one out of three has had a constituent come and ask for choice. I just have a slight concern that if we concentrate too much on providing choice, and there being a cost in our having to do that, then that might be at the expense of actually providing the kind of care that people want. Or are we unrepresentative in that?

A: Bob Grant. I would hold onto the idea that choice is important, but not at the expense of everything else. I have patients who come in and ask where they might get the best treatment, and it may be that the GPs are getting more questions about this than MSPs, as it may be only where the medical advisory system is falling down that you're getting frustrated constituents coming to you. Patients should have more power and they should have the right to more choice.

In relation to patient support groups, I attended the annual meeting of the Association of Scottish Cancer Support Groups, and I was immensely impressed. We need to support that association; it wouldn't cost much to do so, and we need to support support groups to ensure that they function well, and provide the input into improving care that we also need.

A: Peter Bates. There are some choices that it's very important that we rely on expert clinical teams to make; there are other choices where it's important that patients have the ultimate power of decision making, and perhaps the most controversial issue in Scotland at the moment around choice is where services are provided. We have to look to MSPs to take a real, open, honest leadership role in explaining to the general public in Scotland that it is important, because of patient mass and clinical skill, that some services can only be provided in certain places, but other services can safely be provided more locally, and I think politicians have an enormously important role in creating the climate of public confidence around that.

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Expert Panel and Discussion

The benefits and challenges of a new generation of cancer treatments

How will Scotland ensure access and equality for all patients?

Professor Jim Cassidy, Beatson Oncology Centre and University of Glasgow

Professor Cassidy explained that many new treatments for cancer will be related to molecular knowledge, and that this has implications for the way clinical trials are conducted. Patients would need to be divided into sub-sets based on their potential to respond to certain treatments. It is hoped that by targeting treatments at sub-sets of patients, response rates will be higher, and patients will not have to undergo treatments which are unlikely to be successful.

Current drugs often work by killing dividing cells, and that brings with it all the common side effects of toxicity. However, new treatments often inhibit the processes and behaviours of cancers to halt growth. This may mean that the cancer is not destroyed, but can be lived with. This reflects many of the discussions taking place about cancer being treated as a chronic condition.

There is no doubt that these drugs will cost a lot, and costs will increase as people live longer and are exposed to more therapy. Academics have to work closely with pharmaceutical companies to take these developments forward into drug production, particularly given the high risk and costs involved. This also raises other issues about what molecular diagnostic tests will need to be rolled out to sub-set patients in advance of treatment.

Professor Cassidy discussed the role of the Scottish Medicines Consortium, and said that Scotland is now doing well in terms of horizon scanning and forward planning for drug budgets. There are often other costs to consider with new drugs, for example, the requirement for support in the community for patients using drugs at home that would previously have been dispensed in a secondary care setting. There is also a tension between decisions based on cost effectiveness, and patients being aware of drugs that could potentially help them, but which are not being prescribed by the NHS.

There are issues to be discussed around centralisation and the tension with care delivered in local settings. For example, clinical trials for new molecular drugs would be very difficult to start in a community setting as patients would have to be tested and then allocated to the appropriate trial. However, it may be that they could then be treated in the community.

Professor Cassidy finished by making two suggestions; that patent law could be changed, since increasing the patent life of a drug would reduce the pressure on drug companies to make their money back so quickly, which could lead to a reduction in drug prices; and creating a Europe-wide body like NICE, which would have greater bargaining power with the drug companies to put downward pressure on their costs.

Will patients have more choice and power?

What role can patients play in the development of cancer policy?

Dr Bob Grant, Chair, Scottish Cancer Group, Scottish Executive Health Department

Dr Grant stated that patients having more power is both achievable and desirable. Choice is firmly embedded as a key element in the wider patient focus and public involvement agenda and NHS Boards have therefore been seeking to address this element of choice as part of their wider work. It can be a powerful driver for change and in delivering high quality health services.

However, it was noted that while some choices are already available to patients, services are still in many instances

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geared more to the needs of professionals and providers than those of patients. In addition, there are concerns that promoting choice could be at the expense of equity in access to services. The reality is that the articulate and the educated are already likely to benefit from better access and more choices.

There is a need for professionals to have a better understanding of what the needs and preferences of patients are, while patients need the information to be able to make informed choices and act on them.

There is an opportunity to promote greater choices in primary care, where the majority of contacts with health services occur, and whose importance will increase as we develop more local and community based services. However, for some patients these choices will not be available, for example due to geographical issues such as rurality or restricted GP lists in some urban areas.

The Scottish Cancer Group was reconstituted in 2004 and there are three patients now on the group. Their input has been invaluable. At regional level, and within NHS Boards, efforts are being made to increase patients input, with each board having a nominated director with responsibility for enhancing patient and carer involvement.

Dr Grant also felt that patients welcomed the opportunity to be involved in research projects that may lead to cancer service improvement and development.

As the quality and success of treatment steadily improves, it would be unfortunate if quality of care did not progress at the same rate. The input of patients and carers can ensure improvement in the quality of cancer service provision in the future.

Does the health service have the capacity for what's required?

How can NHS Scotland prepare to meet the resource and capacity demands of the future?

Peter Bates, Chair, NHS Tayside

Peter Bates stated that he believes that the health service has the necessary capacity for the future. He highlighted the commitment of politicians to investing in the NHS in Scotland, and the need to ensure that it is spent as efficiently and effectively as possible.

It is absolutely crucial that clinicians remain the key players in regional networks and local NHS boards in determining priorities, influencing resource usage, and involving patients and carers in those discussions. Clinicians, as a group, must be at the centre of that decision making, and that principle has served Scotland well over the last five years in the regional cancer networks. Mr Bates commended the leadership that Anna Gregor and others have given to the networks, and the need to maintain that.

Quality and waiting times must go together. Mr Bates echoed the Minister's view that waiting matters greatly to patients and their families, but it shouldn't be at the expense of quality.

The NHS, and the four teaching boards particularly, must work closely with universities to facilitate and enable a research climate, and the training of doctors, nurses and other NHS staff.

NHS Boards have to give a very high priority to patient safety, and within that context, they have to ensure that, subject to safety and quality measures being approved by local clinicians, as many services as possible should be provided at a local level, using the value; central when necessary, local when appropriate and safe.

Investment in diagnostics and new treatments must continue, and in a transparent way that reassures the clinical and wider community that money intended for cancer and palliative care is being used for that purpose. NHS Boards

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across Scotland must be open and transparent with patients, carers and local communities about how resources are used, on how new treatments are introduced. Patients and communities respond well to this approach, and clinicians would certainly welcome it.

To ensure that services are fit for purpose and able to respond, boards need to work strategically and operationally with all of the voluntary agencies and other key groups that play such a vital role in cancer care and the patients' journey.

Mr Bates concluded, saying that he had confidence that with leadership, scrutiny, accountability and within a robust performance management framework, NHS systems in Scotland can deliver what is required.

How will the patient journey change?

How can we make the system work for patients?

Bill Clark, Director of Social Work Services, West Dunbartonshire Council

Bill Clark stated that an effective and sensitive service to meet the benefits advice and social care needs of cancer patients and carers has to be in place across Scotland.

In West Dunbartonshire, Macmillan Cancer Support are working in partnership with the Council and NHS, and this has allowed the Council's welfare rights service to promote care and rights services for all cancer sufferers referred to their projects.

Across the UK, more than £126.5m in benefits each year go unclaimed by cancer sufferers, with the highest rate of non-claiming in Scotland. In the UK, 50% of people who die from cancer do not receive any financial support from the benefits system. Cancer patients visit hospitals on average 53 times during their illness and in Scotland they spend double the UK average on travel costs.

Since 2005 the scheme has helped over 500 patients, and has generated over £1m in benefits and grants. 74% of service users who responded to an evaluation reported increases in their weekly income. If these results were repeated across Scotland, between £30m - £40m in benefits would be generated for cancer sufferers.

Palliative care experts confirm that financial concerns are second only to pain. 9 out of 10 households affected by cancer experience increased costs or a loss of earned income. One of the issues is the complexity and stigma associated with claiming welfare benefits. Another area of concern is that many types of cancer do not fit well within the benefit system, for example, breast cancer patients are often denied access to disability benefits until three months after surgery, or are refused disability benefits.

Prescription issues are also worrying. The current system was examined by the Scottish Parliament, but unlike the Welsh Assembly, no programme of abolition of charges was recommended. The trend towards outpatient treatment increases the cost for patients, and the welcome drop in mortality rates has made this a long term cost for some patients. This is a legislative issue that merits attention.

A service model has been developed to cover Scotland, which aims to integrate benefit advice and social care centres across local authorities and CHPs within managed clinical and care networks. The core project would act as a triage point for advice and claims, and as an expert resource.

The range of policy interest in cancer care highlights the problem of political ownership and leadership. Up to seven ministers have a stake in cancer poverty. Any review of the Cancer Strategy should address this issue and nominate a lead Minister for Cancer Poverty. In the interim period the Cross Party Group could well have a role in determining the effectiveness of anti-poverty work streams.

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Panel Questions

Q: We see real cancer poverty in breast cancer, and while it would be marvellous to see better social work advice and benefit advice, there is not a benefit for which they are eligible. We should be looking at legislation to have some form of temporary disability living allowance for cancer patients and others undergoing intensive treatment, but who we hope will go back to being a contributing member of our society.

A: Bob Grant: The system is complex and needs to be revised to be more easily understood and relevant. GPs cannot have a comprehensive knowledge of all the benefits available, but patients look to them for advice. We need a simplified system which responds to the reality of the patient.

Q: Over the last few years, the improvements we have seen in cancer have been put down to a number of reasons, but in terms of policy we have had a Cancer Tsar, a Cancer Strategy, ring-fenced funding and cancer networks. How important have these factors been?

A: Sir David Carter. I think Scotland needs a Cancer Tsar; you need someone who is still engaged with the constituencies, and who can still relate to the Health Department. I think there is a strong argument for having that focal point.

The managed clinical networks have contributed to the choice and equality agenda, and cancer services have taken full advantage of this opportunity to use resources wisely, get the multidisciplinary teams in place and involve patients.

Q: Support groups can be a great help in encouraging patients, carers and families, and feeding their concerns back to clinicians. However, I get the impression that many clinicians consider support groups as a nuisance who interfere with their own decision making and not to be encouraged.

A: Jim Cassidy. I think that the more people that get together, the better. It seems to me that we should have more pressure groups, but unfortunately, with some of the cancers we deal with, patients don't survive long enough to even join a pressure group. I would like to see all cancers represented.

A: Sir David Carter. There is now good emerging evidence of the impact that informed and engaged patients can have, not only on their own care, but on the care being offered by the system.

Q: We've been talking about new drugs being brought in which can give quality of life to people in a palliative situation, but instead of asking how much the drug will cost if we use it, we should consider what it will cost if we don't use it. In many cases people who are given these drugs can return to as full a life as possible; they can provide services to people who are dependent on them, and they relieve a positive burden on the care that they would need if they don't get that drug.

A: Peter Bates. I believe very strongly we should not leave that burden with individual clinicians in face to face discussion with patients. There has to be open and transparent dialogue by boards and politicians, with the public as a whole, and I think the public and patient groups respond to that very well. We have got to make sure in every part of the NHS that services are being redesigned and modernised and fit for purpose to ensure that every penny that possibly can is freed up for patient care.

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Q: Decision makers don't have enough knowledge on all cancers to get the correct decisions on benefits. Also, when a carer becomes a pensioner, they stop being considered a carer, and receive no additional support, and this needs to be addressed. Many elderly people are looking after elderly patients, and have no extra income to support them.

Q: There are differing attitudes to support groups in the medical profession. Part of the problem is that support groups vary in quality and that means that clinicians don't always want to support them. I think the support group system needs to examine itself and find out how best it can contribute to change. Patient and public involvement is not just about improving the information that cancer patients get, but their involvement in the whole process of improvement of service delivery.

Q: I have consulted with my MSP colleagues here, and one out of three has had a constituent come and ask for choice. I just have a slight concern that if we concentrate too much on providing choice, and there being a cost in our having to do that, then that might be at the expense of actually providing the kind of care that people want. Or are we unrepresentative in that?

A: Bob Grant. I would hold onto the idea that choice is important, but not at the expense of everything else. I have patients who come in and ask where they might get the best treatment, and it may be that the GPs are getting more questions about this than MSPs, as it may be only where the medical advisory system is falling down that you're getting frustrated constituents coming to you. Patients should have more power and they should have the right to more choice.

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A: Peter Bates. There are some choices that it's very important that we rely on expert clinical teams to make; there are other choices where it's important that patients have the ultimate power of decision making, and perhaps the most controversial issue in Scotland at the moment around choice is where services are provided. We have to look to MSPs to take a real, open, honest leadership role in explaining to the general public in Scotland that it is important, because of patient mass and clinical skill, that some services can only be provided in certain places, but other services can safely be provided more locally, and I think politicians have an enormously important role in creating the climate of public confidence around that.

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Keynote Address

Dr Anna Gregor, Clinical Director, Southeast of Scotland Cancer Network (SCAN)

What are the main drivers that will shape what cancer services will look like in the next 10-20 years?

Scotland is on track to reduce cancer mortality by 20% as planned. The biggest chunk of this improvement is through better organisation of services, and the implementation of evidence-based care, while only 20% comes from new treatments.

There will be changes in demographics, an increasing number of people diagnosed with cancer, and particularly, people living with cancer. There are big increases predicted in prostate and breast cancer but there will be a significant decrease in lung cancer, and this is hopefully going to get even better providing we continue to stop smoking at the rate that we are doing. There will be more than a third increase in people living with cancer, more than a quarter increase in new patients diagnosed with cancer every year, and the biggest increase is going to be in the over 75 age group. Services will need to change to accommodate this and this will need to be done in the context of a new policy in healthcare, *Delivering for Health*.

Cancer services are well on their way to defining the clinical pathway of care. They are now working on an integrated information pathway, so that every single patient, at every appropriate clinical transaction will know what is going to happen, where, when, who is going to do it, and what the experience is likely to be. Technology can help with this, and it is hoped that a qualitative competency based framework will follow, to ensure that the information given to patients, and the manner in which it is given, is appropriate to the patient's needs.

There is a need for a new approach to the diagnostic pathway in order to target therapies, and pathology is going to be central to this. This will cost more money, and will require an informed debate about the affordability and cost effectiveness of these approaches and the context in which we use them.

So, how has *Cancer in Scotland* over the last five years prepared us for this? It was developed as a policy with an implementation plan attached to it. The key to this was the regional multidisciplinary teams and how they were empowered, not just about the clinical decision-making about patients, but to decide how to spend the resources available. The policy was accompanied by clarity about what the service provision should be and a transparency in accountability about resources, and supported by the key involvement of patients.

In 2001 the Scottish Executive Health Department promised to deliver the new functional structures and working arrangements; develop a quality assurance programme; reduce unwanted variations in access, outcome and process; reduce waiting times; and improve the experience for patients. The three SCAN networks are up and running, and already demonstrating improvements in terms of working arrangements and provision of services for patients. They have all been accredited through NHS Quality Improvement Scotland, there is a very useful technology assessment process through the Scottish Medicines Consortium, a national PET, and radiotherapy expansion. Patient information, communication and involvement is now a reality, multidisciplinary teams are working and access is improving. The establishment of the Scottish Cancer Research Network is one particular success story. The target was to double recruitment to clinical trials from the 2001 baseline, and it has been trebled. What is really important is that more than twice as many patients taking part in clinical trials are now treated locally.

Sustainable benefits need sustained attention. The combination of demographic changes, workforce availability and technology inflation over the next 10-15 years will be a challenge. The work that has been done in Scotland puts it in a place that is perhaps a little more advantageous than others because relationships have been established that will assist stakeholders in tackling some of those difficult problems and develop trust between the various parts of the system in order to have those difficult conversations.

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Open Discussion Forums

What will cancer look like in 2020?

Key points:

- More people will be getting cancer with a more positive outlook but will have greater information needs
- The need to treat the whole person and not just the tumour
- Consider a wider range of risk factors such as lifestyle and environmental factors such as toxicity
- More emphasis should be placed on reversing the upward trend in incidence by tackling environmental pollution
- Need more focus on the patient journey outwith the acute services
- There is a need for more targeted campaigns on awareness of symptoms
- Innovations are required to move from now to 2020 in terms of service delivery
- Social care and health needs should be integrated into one plan
- There is a need for charismatic leaders
- Planning cycles are too short

The benefits and challenges of a new generation of cancer treatments

Key points:

- There is a need for systematic preparation
- There is a need for improved education of patients and of clinicians
- There is a need for an independent review on the national dilemma of the cost of new medicines and technology and the consequences for a cash limited system versus quality of life
- There is a real need for open access to easily available information on drug innovations
- What is informed choice in relation to clinical trials?
- Patients from under-represented groups need to be involved in clinical trials

Will patients have more choice and power?

Key points:

- Information is essential and the form of the information is all important
- There is a need to address deprivation
- There is often poor communication and jargon
- There is a need for patient involvement on two levels – individually and through advocacy groups
- A mechanism is required for feedback to clinicians on the information they provide, and involve all groups in this
- CHPs are showing more commitment to patient involvement
- Patient involvement shouldn't just be limited to those people who put themselves forward for patient support groups
- Best practice in patient involvement should be shared

Does the health service have the capacity for what's required?

Key points:

- There is a need for effective workforce planning
- Delivery of IT strategy is key
- Need more trained people to operate diagnostic services and interpret results speedily
- There is a need for flexible budgets (e.g. to allow community nursing to be adequately funded)
- Collaborative strategic planning is required across all sectors of care
- Diagnostics/ screening need to be improved to enable better targeted, more appropriate treatment
- Investment in equipment, staff, education/ training
- Better communication between the NHS and charities would maximise support to patients

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How will the patient journey change?

Key points:

- There is a need to integrate health and social systems at all levels
- Patient care coordinators would help
- There is a need for more flexibility
- Technology is no substitute for speaking to people
- There is a requirement for planning and resourcing capacity in primary and secondary care, particularly with the emphasis on *Delivering for Health*
- The electronic medical record will help and needs to be introduced fully
- There is a need educate the public about clinical trials and eligibility
- More specialist social workers attached to cancer centres would help

Closing Remarks

David Davidson MSP, North East Scotland Co-convener, Cross Party Group on Cancer in the Scottish Parliament

David Davidson MSP thanked Dr Gregor for her address and all delegates for taking part in the open discussion forums, which raised a number of key issues. Mr Davidson specifically welcomed the input of patients and carers to the conference.

Mr Davidson said that the cancer journey is not a simple or easy one for the patient, or their families and supporters, but there is hope, and the conference has demonstrated that we are on our way, if not yet to conquering cancer completely, then to helping people to live with cancer.

The Minister has asked the Chairs to make sure that he is updated on all the outcomes of the conference and particularly the messages of the different groups that came together today. Mr Davidson thanked all those involved in the organisation and support of the conference, which provides a useful forum for sharing information and co-ordinating work.

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Key Recommendations

Planning for the future

- There is a need to prepare for the future – rising incidence, new treatments, workforce planning, IT etc.
- *Cancer in Scotland* has made a real impact on cancer care in Scotland, but it needs to be refreshed in order to take into account recent developments, and to address future issues
- The post of Lead Cancer Clinician and ring-fenced funding for cancer have helped enormously, and consideration should be given to how this will be taken forward
- Research and clinical trials in Scotland are punching above their weight, but require continued support

Social care

- Consideration should be given to how health and social care can be further integrated to provide a seamless patient journey
- There is a need for consideration of the issue of cancer poverty and what support and advice cancer patients and their families might require, as well as whether legislative changes might be required

Patient information and involvement

- Patients need high quality information in order to make and exercise informed choices
- Services should be provided locally where appropriate, but some interventions will still need to take place centrally to ensure safety and the best possible clinical outcomes
- Patient choice is improving but there is still more work to do, and choice is still limited for some patients (e.g. those in geographically remote areas)
- Patient involvement should be valued, on both an individual level, and through support/ advocacy groups

New treatments and services

- Breast and cervical screening programmes have shown real benefits in reducing mortality rates. The roll-out of bowel cancer screening should be welcomed and supported as it will bring similar benefits
- New treatments may bring greater reductions in mortality but a real debate on affordability and cost-effectiveness is required
- There is a need to improve diagnostics/ screening to enable better targeted, more appropriate treatment
- Consideration must be given to how to treat cancer as a chronic condition, as more people are, and will be, living with cancer

Inequalities

- Waiting times are a key issue but this must not be at the expense of quality
- Inequalities of incidence, care, access and survival still exist and need to be addressed urgently.

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Thistle Hotel, Cambridge Street, Glasgow

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