

Cross Party Group on Cancer in the Scottish Parliament

Meeting, Wednesday 14 March 2012, 5.30pm

Present:

Malcolm Chisholm MSP, Co-convener [Chair]
Nanette Milne MSP, Co-convener

Dr David Linden, Scottish Government
Isobel Neil, Scottish Government
Vicky Crichton, Cancer Research UK
Peter Hastie, Macmillan Cancer Support
Phil Atkinson, Health Policy Scotland
Angus Ogilvy, SCAN Patient Representative
Suzanne Spencer, Cancer Research UK Ambassador
Sheena Dryden, NHS Lothian
Barbara McLaughlan, Novartis Oncology
Leigh Smith, MASScot
Alexander Henzing, Aridhia Informatics
Prof. Bob Steele, Scottish Cancer Foundation
Emma Anderson, Bowel Cancer UK
Dr Colin Selby, NHS Fife
Sarah Muir, Cancer Research UK
Sheila Robertson, NHS Fife
Pat McAulay, Scottish Government
Kerry Napuk, Edinburgh and Lothians Prostate Cancer Support Group
Dr Dermot Gorman, NHS Lothian
Dr Liz Forbat, Cancer Care Research Centre
Valerie Finlay, SCAN
Christine Dodds, SCAN
Carol Colquhoun, NSD
Janice Birrell, NSD
Lorna Bruce, SCAN
Dr Christine Campbell, University of Edinburgh
Hazel Scott, NHS Tayside
Leigh Fell, ISD
Joanna Dunlop, ISD
Prof. David Weller, University of Edinburgh
Maureen Black, Scottish Government
Clifford Hughes, SCAN
Judith Lawson, SCAN
Myles Fitt, Breakthrough Breast Cancer
John Sleith, REHIS
Dr Ron Fergusson, NHS Lothian
John Locke, NHS Dumfries and Galloway
Brain Stannage, GSK
Lucy Colquhoun, NHS 24
David Sinton, Prostate Cancer Charity
Diane Thomson, Pfizer
Fiona Hamill, Janssen
Leslie Horne
Jackie Faccenda, NHS Borders

Greg Stevenson, Roche
Dr Hazel McCutcheon, NHS Lothian
Linda Summerhayes, Cancer Research UK
Alex Holme, SDS Skin Cancer Group

Apologies:

Jackie Baillie MSP
Stuart Macmillan MSP
Gus Ironside, Brain Tumour UK
Bill Paton, NAPP
Val Lee, CIS Oncology
Audrey Birt, Breakthrough Breast Cancer
Professor Alan Rodger
Alisa Patrizio, NHS Lothian
Stella MacPherson, SCAN
Dr Brian Montgomery, NHS Fife
Jane Tighe, NOSCAN
Karen Bell, Cancer Research UK
Dr Paul Baughan, NHS Forth Valley
Hannah Gagen, Boehringer Ingelheim
Michael Clancy
Gail Grant, BMA
Helen Reilly, BMA
Anna Whyte, FSA
Mhairi Simpson, RCN
Suzanne Fernando, Cancer Research UK
Lynne Barty, Brain Tumour Action
Stewart Douglas, MASScot
Mike Shaw, Edinburgh and Lothians Prostate Cancer Support Group
Alison Culpan, GSK
Alistair Haw, Prostate Cancer Charity

Agenda

Malcolm Chisholm welcomed attendees to the meeting.

1 Minutes of last meeting

The minutes were approved as a true record of the meeting.

2 Detecting Cancer Early

Speakers: Dr David Linden, Programme Manager, QuEST Cancer Performance Support Team and Isobel Neil, Detect Cancer Early Programme Director, Scottish Government

Dr Linden began the presentation by considering why cancer survival in Scotland is so poor compared to other European countries. He noted that this could be due to genetics, environment, the molecular composition of cancer, the presence of co-morbidities and lifestyle.

Dr Linden showed data on survival rates and noted that the issue is with one year survival – a higher rate of patients die in Scotland within one year. It was noted that there have been questions about data quality in some European countries which may complicate the picture, but that there is still a gap between Scotland and the best performing countries. These data suggest that late presentation, leading to a later stage at diagnosis may be causing this excess mortality.

Dr Linden noted that a report by Cancer Research UK had praised the Scottish Government's Better Cancer Care action plan, but called for a greater focus on early diagnosis.

Looking at the patient pathway, Dr Linden described the challenges in terms of individual and process and system issues. He noted that work had been done with primary care to look at referral guideline to reduce delays, and that cancer waiting times have addressed some of the issues in secondary care. He referenced work done by the Scottish Primary Care Cancer Group looking at the time from patients noticing to reporting symptoms to their GP, and then for the GP to refer. These data suggest that people often delay visiting their GP, despite multiple awareness campaigns over the years.

It was noted that there hasn't been much change in the last decade in stages of presentation, so recent improvements in survival may be mostly due to better treatments and services. Dr Linden then provided examples of the impact of late stage disease on survival, for example in breast, stage 1 cancer has a 97% 5-year survival rate, while stage 4 disease has just 24%.

Dr Linden then outlined some of the key challenges of the programme. These include a need to close and not widen the deprivation gap by targeting messages carefully and to sustain cancer prevention messages. The programme will initially focus on breast, bowel and lung cancers as these form over 45% of all cases, and all have a steep deprivation gradient. However, it was noted that this is just the start of this work, that some cancers will continue to present at late stages and that the lessons learned from this work will be used to inform work in other cancers. The impact on the NHS was also discussed, and while this is being addressed through additional funding to expand diagnostic services, it was felt that the service will be able to adapt to support this work. The programme also offers a great opportunity to research and evaluate the impact of these interventions.

Dr Linden highlighted that in tandem with the Detect Cancer Early work, the Scottish Cancer Taskforce will continue its focus on other areas such as acute oncology, surgical oncology, Quality Performance Indicators, radiotherapy capacity and transforming care after treatment, where the Scottish Government is working with Macmillan Cancer Support, who have contributed £5m of funding to this work. Dr Linden welcomed the input of the Scottish Cancer Coalition to these areas.

Dr Linden then outlined the main components of the programme: public awareness raising campaigns to influence help-seeking behaviour; primary care referral; increasing diagnostic and screening capacity and maintaining existing cancer access performance. It was noted that the HEAT target has been criticised, but it was felt important to drive change, and the cancer waiting times

had shown this to be possible. The programme will strengthen working across primary, secondary and tertiary care and with the third sector.

Isobel Neil then outlined the importance of the social marketing work. She noted that there is poor uptake of screening in more deprived areas and poor knowledge of signs and symptoms across the population. The West of Scotland Cancer Awareness Project had showed success in improving awareness and willingness to present, and the Scottish Government has learned from the National Awareness and Early Detection Initiative underway in England. However, they were also keen to explore options around addressing the key issues of fear and fatalism, and therefore decided to start with a primer campaign before launching symptom awareness work.

Ms Neil noted the importance of GPs to this work, and that the NHS is currently looking at early access to diagnostics and to better understand referral pattern variation between GP practices. The SPCCG will also be looking to refresh the cancer referral guidelines from a symptoms perspective. The cancer waits become standard from April 2012 and need to be maintained – median wait is now six days. This work has been very secondary care focused, so this new programme will include primary care, and the programme is looking at treatment capacity to ensure there are no bottlenecks in the system. The HEAT target will help Boards to prioritise this work, which will be included in their local delivery plans. Ms Neil stated that the target is ambitious, but will drive improvements.

Malcolm Chisholm thanked David Linden and Isobel Neil for their presentation and opened the discussion up to the floor.

The role of screening in aiding early detection of cancer was raised, and there was felt to be an opportunity to improve both the quality and uptake of the screening programmes, as they are the most effective way of detecting early stage disease. It was also noted that screening can lead to both false positive and false negative results, possibly leading to overtreatment, and increased demand on diagnostic services. It was noted that decisions about screening programmes are guided by the UK National Screening Committee's recommendations. It was also agreed that there is a need to better communicate the benefits and risks of screening. The specific issue of colonoscopy capacity was raised and Ms Neil confirmed that this was currently being looked at.

Dr Linden noted that the Scottish Government is working with the BMA to consider inputting aspects of early diagnosis into primary care contracts.

Questions were raised about the willingness of boards to participate and Ms Neil noted that the programme team had met with boards and they had been broadly supportive and that the HEAT target will drive their work.

There was concern about the message that the campaign is trying to avoid an increase in the 'worried well', and that it should be recognised that there are many complex reasons why people may put off going to visit their doctor. People are often concerned about wasting the doctor's time.

It was noted that the HEAT target seeks to measure the increase in those diagnosed at stage one, and why this should be the case rather than measuring survival. Dr Linden noted that 1 and 5 year survival would be measured as well.

The role of GPs was raised and it was noted that the programme will be looking carefully at the emerging evidence around open access to diagnostics and the 'gatekeeper' role.

It was noted that Boards had highlighted the role of the Keep Well preventative programme, and they are looking at how Detect Cancer Early could work collaboratively with this.

Pleas were made for both prostate and melanoma to be included in the programme. It was also noted that there are particular challenges around diagnosing rarer cancers with often nonspecific symptoms. Ms Neil acknowledged this and stated that lessons would be learned from this first stage in order to improve early diagnosis of all cancers.

3 Scotland Against Cancer

Vicky Crichton advised that some places are still available for the conference on Monday 30th April 2012, in Edinburgh.

4 AOB

Vicky Crichton updated the group on the Standards, Procedures and Public Appointments Committee Review of Cross Party Groups. The secretariat will be providing a response and members were asked to contact Vicky Crichton to feed in any comments.

John Sleith noted the recent news about the impact of the smoking ban on neonatal death rates, and welcomed its ongoing influence on public health.

Sue Spencer highlighted the fundraising work of Nigel Lewis Baker, taking part in a charity walk from John O'Groats to Land's End starting on March 21st. There will be a major fundraising reception in Edinburgh for The Prostate Project 'Love Train' Walk.

Kerry Napuk raised the issue of the recent SMC decision on the prostate cancer treatment, Abiraterone, and the need for further debate on the decisions made by SMC and their impact on patients. This comment was supported by other members of the group and it was proposed that access to cancer drugs should be a topic for discussion at a future meeting.

5 Date of next meeting

The next meeting of the group will be Wednesday 6th June at 5:30pm. The agenda will be circulated to members once it is confirmed.