

Scottish Parliament Cross Party Group on Cancer

Wednesday 1st March 2017, 17.30-19.00

1) Welcome

Miles Briggs (The Chair) opened the meeting and welcomed the attendees and speakers to the meeting.

2) Minutes of the Last Meeting

The Minutes of the previous meeting of the Cross Party Group on Cancer on 7th December 2016 were approved by the group without amendments.

3) The Chair then welcomed the Cabinet Secretary for Health, Shona Robison (SR), to give an update on Scotland's Cancer Strategy and progress on access to Advanced Radiotherapy in Scotland

SR began by outlining that the Scottish Government is determined to address all 200 types of cancer with its strategy 'Beating Cancer: Ambition and Action'. SR then outlined that, in addition to the £100 million investment, the Government is working with the third sector, NHS and patients to ensure the strategy is driven forward.

The issue of deprivation and cancer was then addressed by SR, who stated that Scotland is not unique in this issue but cannot be comfortable while it is the case. To help tackle this issue, SR stated that work is needed to address the lower uptake of screening and later presentation of symptoms which result in later diagnosis and treatment. SR pointed to the successes of the Detect Cancer Early Programme where the number of cases of cancer diagnosed at stage one has increased by 16.3%, with the highest increase in the most deprived areas. The establishment of an NHS Scotland network to allow for the spreading of strategies and learning in screening was also highlighted. SR then noted the £5 million investment that is going into reducing inequalities in screening.

Access to advanced radiotherapy was then discussed. SR stated that the Scottish Government's aim is to make sure advanced radiotherapy techniques are available to all for whom it is clinically appropriate. SR noted the £50 million investment in radiotherapy. SR highlighted investment in radiotherapy physics trainee posts and the strengthening of the radiotherapy working group which aims to create equality of access in Scotland. Progress to date was then noted, with every cancer centre in Scotland possessing the equipment to carry out modern radiotherapy techniques. The importance of staff planning in improving cancer outcomes in Scotland was also raised.

SR then discussed children and young people with cancer. The 200 diagnoses of cancer in children and young people every year was noted. SR highlighted the work of the MSN for Children and Young People with cancer, along with the Teenage Cancer Trust. She stated that the MSN is enabling all of Scotland's cancer centres to work together to ensure access to treatment for all children and young people with cancer. The holistic treatment needs of children and young people with cancer with emphasis on access to clinical trials and psychosocial care was noted.

SR concluded by acknowledging that the first year of the strategy was almost over. She stated that the programme was being managed by a task force and that changing systems can take time. SR stated that the Scottish Government is not giving up on survival, incidence and inequalities in cancer. SR stated that there is increasing momentum, noting the 176,000 living after cancer treatment and 11% reduction in mortality in 10 years. She restated her desire to work with organisations, the NHS

and patients around prevention, research and care and thanked those who helped form the strategy.

4) Questions to SR

Peter Hastie, Macmillan Cancer Support: “The cancer plan mentions Deprivation 27 times. Can you talk about some of the measures you want to put in place to tackle this?”

SR praised Macmillan’s work in Glasgow on inequalities and stated that it is right that the plan mentioned deprivation 27 times. The need to improve screening programmes to reach the most deprived was highlighted. The Fairer Scotland plan was noted as a cross-governmental plan that is addressing inequalities with 50 actions. SR then stated that work is needed to reach the most deprived and men in particular and to engage them with public health messages.

Lawrence Cowan, Breast Cancer Now: ‘What is the timeline for implementation of the Scottish Government’s response to the Montgomery Review on access to medicines?’

SR thanked Dr Montgomery for his work on the review and stated that the recommendations will be taken forward with the SMC and other stakeholders in the next few months. The importance of equality of access was highlighted and the establishment of an appeal panel to ensure equality was noted. SR stated that the system will be adjusted to be more clinically focussed and said that the CPG will be kept updated on progress in enacting the Montgomery Review recommendations.

Emma Anderson, Bowel Cancer UK: ‘Could the Cabinet Secretary provide an update on progress made on the commitments outlined in the Scottish Cancer Strategy to a) increase the number of nurse endoscopists in training by 40% by 2017 b) how much additional capacity they will provide once fully trained and c) to invest in an additional £1 million per annum in additional scopes capacity?’

SR stated that there has been additional funding since 2016 for non-medical endoscopists, noting that this will be an important staff resource. She recognised the skills of nurses to carry out procedures and stated that the training is about assisting current nurses as well as training new endoscopists. She noted that 9 nurses had started training this year and the government is working with NES and the universities to provide training as well as to attract nurses to the training. SR stated that the £1 million was given to the Health Boards.

Leah Miller, Pancreatic Cancer UK: ‘The Cancer Strategy for Scotland sets out the ambition of reducing variation in survival rates for different cancer types, but lacks specific measures to improve survival for those cancers with the lowest survival rates. What action will be taken to ensure the cancer strategy delivers improvements in survival for the most tough to survive cancers, such as pancreatic cancer which has the lowest 5 year survival rate of the 20 most common cancers – just 4.6% in Scotland?’

SR stated that more research is essential for new approaches to treatment, noting that, in February 2016, the First Minister announced £4 million to foster a precision medicine ecosystem. She also noted that funding for a flagship programme for research into pancreatic cancer had been renewed. SR stated that a better understanding of the causes of pancreatic cancer is needed as well as the need to improve diagnosis. She stated that the government will continue to work with the third sector to enable research into pancreatic cancer.

Pat Kilpatrick, British Dental Association: ‘Head and Neck cancer cases are projected to rise by 32% by 2023-27, making this one of the highest growing tumour categories. What steps are Scottish Government taking to engage the support and input from General Dental Practitioners in helping to reduce incidence, drive early detection, improve access to treatment, clinical outcomes and ultimately reduce mortality rates?’

SR stated that dentists are key to the detection of cancer and that work is ongoing to improve access to dentists in Scotland. She stated that the Government had asked for views around oral cancer risk assessments between dentists and patients. She stated a desire to review the oral cancer diagnostic pathway. SR also stated the importance of free dental check-ups where the most at-risk patients could receive the most comprehensive assessment.

Mil Vukovic-Smart, Bloodwise: 'What progress has been made or what are the plans to address the needs of patients with rare and less represented cancers such as blood cancer? Blood cancers are 3rd biggest killer and 5th most common cancer in the UK, the same figures count for Scotland also, but public awareness of the disease is still very low?'

SR noted that some improvement had been seen in blood cancers, stating that the mortality rate of Non-Hodgkin Lymphoma patients reduced between 2005 and 2015. The importance of primary care for all cancers was noted. SR then pointed to the Wee C campaign which encourages patients to present to their GP when symptoms occur. She also stated that the government wants to work further with GPs on diagnosis, especially around young people. A variety of symptoms are in the Health Information Scotland new guideline that have been published. She stated that the cancer plan gives more room to promote the symptoms of blood cancers.

Julie Roberts: 'Motion S5M-02554 'Tacking Meosthelioma in Scotland' achieved cross party support from all 5 parties and was debated in the chamber on 20 December 2016. How you are ensuring that the Scottish Cancer Strategy is taking on board the implications and recommendations of the Mesothelioma UK 5 Year plan?'

SR stated that though not all cancers are mentioned in the cancer strategy, the strategy should help all types of cancer on early diagnosis. The new guidelines have a specific update on mesothelioma and has been sent to all frontline health professionals. The Chief Scientist's Office has invested £250,000 on biomarkers in mesothelioma and **stated that she would send more information.** SR also stated that the group that is considering changes to waiting times is considering adding mesothelioma and others to the cancers that are recorded.

Dr Alan Rodger: 'We have noted that there will be a significant amount of capital funding for radiotherapy equipment. Is this new money for an *expansion of the service* and additional to the funding of the equipment replacement programme that has existed and been supported by successive governments since at least 2000?'

SR noted that the money in the cancer strategy is intended to enhance the radiotherapy service and the equity of access to radiotherapy across Scotland. She stated the amount of money that was given to radiotherapy in the strategy shows how much of a priority it is for the Government. She said that the radiotherapy working group is looking at how to stay ahead of technology advancements but also noted that it is important that the staff resources exist to run the state of the art equipment.

Jo Williamson: 'What will be the Scottish Government's strategy for genetic causes of cancer and specifically rare forms of genetic cancer?'

SR noted the Scottish Government's rare diseases strategy and stated that work is ongoing to implement this strategy. She highlighted a 5 year study that is being undertaken on cancer genomics relating to cancer risk which is being undertaken from funding from the Scottish Government (£4 million) and the Medical Research Council (£2 million).

Neil Pryde, NHS Fife: 'What are the Cabinet Secretary's thoughts on the current development of a Health Promoting Health Service model, and where she would see this in practice by 2020?'

SR noted the importance of health campaigns, noting the success of campaigns around smoking and alcohol misuse. She then stated, however, that issues still exist such as lung cancer levels in women and the link between breast cancer and alcohol. She noted the need for work around obesity, the upcoming obesity strategy and the potential for health professionals to be promoters of public health messages. She also highlighted the need for clear, simple messages to be given the public around public health.

5) The Chair then welcomed Hamish Wallace (HW), National Clinical Director of the Managed Service Network for Children and Young People with Cancer to discuss the progress and plans for the MSN.

HW began by outlining the vision of the MSN to 'deliver a safe, sustainable world class national service for children and young people with cancer.' He stated that the MSN released its 2nd plan to improve care for young people and that the MSN presents an opportunity to work nationally which is often difficult due to competing priorities of NHS Health Boards.

He then addressed survival trends in children's cancers. He noted the encouraging statistics which show that mortality has been steadily decreasing since 1975 but stated that there is more to be done. He also noted that incidence has been increasing within this time. HW then compared the survival rate of the most common childhood cancer, Acute Myeloid Leukaemia, in Scotland to the rest of Europe. He stated that Scotland achieves close to the European average for AML but noted that there are issues with differing standards between cancer registries in Europe. He also, then noted that the trend is similar in brain cancers as it is with AML, though he stated that the registration of brain cancers is particularly problematic. He then noted the overall trend in survival of both children's and teen and young adult cancers which have seen steady improvement in the last 40 years. He noted, however, that this is due to the use of intensive treatments such as chemotherapy and radiotherapy which have a number of risks associated, including the risk of a secondary cancer later in life and that work is needed to address this.

HW then moved on to two examples of how the MSN is planning to improve the care of young people with cancer, noting that there are many more areas that are being pursued. He first gave the example of how the MSN is working to create enhanced electronic cancer registration. First, the importance of an accurate cancer registry was highlighted and HW stated that there is a need to move on from a paper-based registry to an electronic registry. He then highlighted the 5 ambitious Key Performance Indicators that the MSN had set for a registry for children and young people of cancers. 2 of the KPI's focussed on the diagnosis (95% within 3 weeks) and time to begin treatment (95% within 2 weeks). 1 KPI focuses on access to clinical trials, with a target of 30% of those eligible being entered into clinical trials. The final 2 KPIs focus on patient management, specifically around national MDT (95% of cases discussed by a national MDT) and End of Treatment Summaries (100% of patients to receive an end of treatment summary).

HW then discussed the second example of how the MSN is working to improve care, the development of a national service for teens and young adults with cancer. He stated that there are 23 hospitals that treat the approximately 200 young people diagnosed with cancer in Scotland every year and that this means that there are often issues to provide the holistic care this group requires. HW noted that the aftercare working group is looking at the issue of support for Teens and Young Adults (TYA) during treatment. He then stated the MSN's plans to create treatment equality in Scotland for TYA's, saying that 5 specialist treatment centres were needed in Scotland (in Edinburgh, Glasgow, Aberdeen, Dundee and Inverness) to provide the holistic care required by TYA's. He also highlighted the work of the national MDT for TYA's with cancer, who review the treatment of 50% of

patients currently. He stated that the panel is intended to advise where holistic needs could be met further elsewhere in Scotland through, for example, suggesting clinical trials or fertility services that are in a different area of the country,

HW finally discussed how the MSN plans to deliver more autonomy to young cancer patients through an app called My Story Now. The app allows easy access to electronic health records and guides young patients through their journey, allowing the patient to take ownership of their personal record and to share aspects with friends and family. The app was delivered with input from TYA's through asking what they wanted from the app. The most wanted areas were information about their treatment plan, appointments and information about the late effects of cancer treatment. HW stated that the app is currently in the pilot stage and hoped that the app would be fully operational by the end of the year.

6) Questions to HW

MB thanked HW for his presentation before questions were taken from the group. On the subject of the late effects of radiotherapy, HW stated that many in TYA cancers are very cognisant of the problem and that radiotherapy is being removed as a treatment where it can. When asked about why brain tumours are difficult for registries, he stated that recording systems vary throughout Europe and that some low-grade paediatric brain tumours are not included in the registers for some countries making comparisons between registries difficult. HW noted the need for proton therapy closer to Scotland, with patients currently having to travel to Florida for the treatment. On the need for specialist neuro-oncology nurses in Scotland, where there are none currently employed, HW supported the need for specialist neuro-oncology nurses and also the work of CLIC sergeant nurses who work with young people with cancer outside of the hospital. On the challenges of creating a work national MDT, he said that there is a greater appetite to work nationally. When asked whether the My Story Now app might be available to all cancer patients, HW stated that the hope would be that it will be available to all in time. On the challenges of meeting a 5 week treatment time target when the current 62 day target is not being met, HW stated that within TYA cancers this is possible, especially if 5 specialist centres are created. On the barriers to clinical trials, HW stated that regulatory barriers make it difficult for researchers to commit to running clinical trials, particularly if there are only likely to be very few eligible patients.

7) A.O.B

It was asked whether a meeting on pancreatic cancer could be set up. MB responded that pancreatic cancer was one of the topics being planned for future meetings of the CPG.

8) MB then closed the meeting. Next meeting 17.30-19.00, Wed 31st May 2017. The Public Health Minister, Aileen Campbell will be speaking at the meeting.

Attendees

Group Members

Member
Miles Briggs MSP
Anas Sarwar MSP
Macmillan Cancer Support
Breast Cancer Care
Health Policy Scotland
The Brain Tumour Charity

Beatson Cancer Charity
Edinburgh Health Forum
Roche
AbbVie
University of Edinburgh
Brain Tumour Action
Prostate Cancer UK
British Dental Association
NHS Fife
Scottish Primary Care Cancer Group
NHS Greater Glasgow & Clyde
Teenage Cancer Trust
Cancer Research UK
Prostate Scotland
Celgene
Scottish Cancer Research Network
MASScot
Roy Castle Lung Cancer Foundation
Novartis
Pancreatic Cancer UK
Bloodwise
Pancreatic Cancer Scotland
Heads Up Support Group
Challenge Breast Cancer
CLIC Sargent
Breast Cancer Now
Dr Alan Rodger

Invited Guests

Guest
Shona Robison MSP
Manage Service Network for Children and Young People with Cancer
Mesothelioma UK
Scottish Involvement Group
Ettrickburn & Scottish Pharmacist Magazine