Scottish Parliament Cross Party Group on Cancer

Wednesday 23rd September 2015, 17.30-19.00

Minutes

Attendees and apologies noted in appendices. **Bold underlined text indicates actions/ agreements**

1) Welcome

Malcolm Chisholm MSP ("the Chair") opened the meeting, welcoming all attendees and speakers.

2) **The Chair welcomed Shona Robison MSP, Cabinet Secretary for Health, Sport and Wellbeing (SR) to present.**

SR began by noting that the NHS is facing a variety of challenges, from finding the right balance between primary and acute care, to demographic challenges. In terms of cancer specifically she noted the very positive news that more people than ever are surviving the disease, while noting that this brings its own challenges in terms of coping with the long term effects of the disease and related treatments. Outlining the work the Scottish Government is doing to improve cancer outcomes she referred to the Cancer Patient Experience Survey, developed with the support of the Scottish Cancer Coalition, which will launch next month. She also noted the upcoming National Clinical Strategy which the Scottish Government has begun to work on in collaboration with the Scottish Cancer Taskforce.

She noted that rising rates of cancer in Scotland are partly due to our ageing population, with cancer being increasingly common in old age. However, she noted that there are many things we can do to increase our risk, with 40% of cancers being preventable by lifestyle choices. She stressed that the Scottish Government is working to increase prevention and early detection of cancer, such as with the 'wee c' launched this summer in collaboration with Cancer Research UK. This aims to raise awareness of improvements in cancer treatment and outcomes and challenge fatalistic views of cancer, thus encouraging people to go to their doctor with symptoms. She also referred to the new Cancer Plan which is due to be published next year.

3) **Questions to Shona Robison**

Gregor McNie, Cancer Research UK, on behalf of the Scottish Cancer Coalition: "Could the Cabinet Secretary update on which stakeholders will be involved in producing the new Scottish Cancer Strategy, what the timescales for this will be and the planned publication date?"

SR answered that the Cancer Strategy will be published in spring 2016 and will include as wide a range of stakeholders as possible, particularly taking into account the voices of patients and families.

Nanette Milne MSP: "Which NHS boards will take part in the pilots of the peer approved clinical system and when these will begin?"

SR advised **that she will feed back to the group on this.**

Janice Preston, Macmillan Cancer Support: "Can the Cabinet Secretary outline the Government's plans around access to a cancer nurse specialist?"

SR stated that each NHS board receives £2.5 million for specialist nursing; however this is not confined to cancer but covers all areas of nursing. She noted the importance of post-treatment support, and that there will be a need as part of the development of the new cancer strategy to look at who is best to be involved in this, whether nurses or other professionals. She noted she had seen the importance of post-treatment care during a visit to a Maggie's Centre.

Dr Neil Pryde, Cancer Services Lead, Fife Cancer Services: "Given the aging population and increasing complexity of cancer treatments, what are the Scottish Governments future plans to support Health Boards in meeting this challenge?"

SR stated the need to decide priorities in the development of the new cancer plan, and that these emerging priorities would need to be captured in the forthcoming spending review. She noted that there has already been a lot of investment in infrastructure and services, but that gaps remain and these will need to be identified. It is critical to get the right investment in the right places, and to work to eliminate inequalities across Scotland.

Dr Alan Rodger, CPG Member: "Scotland has, thanks to the Capital Equipment Replacement Programme for radiotherapy equipment the most modern technology for delivering what is now considered internationally to be essential and standard radiotherapy techniques. While our approach to equipment replacement and upgrade is enviable, our cancer survival rates are far from that yet radiotherapy cures more cancer patients than chemotherapy. The equipment is installed across our country but why is Scotland falling behind even rural centres in Australia, most of Europe and all of the USA and Canada and many countries in Asia in failing to be able to offer such treatments to all who require it? Does Scotland need a national Radiotherapy service? Is any effective action being taken by the government based on data and service assessment?"

SR began by agreeing that investment in equipment has been significant. However, she agreed that it is also crucial to have the right staff with the right skills, and that more consultant radiographers are needed. She noted that the Scottish Government is looking at networks to lead in ensuring delivery of key cancer services, especially in the North. She noted that the West and East networks are doing better, also noting the new Beatson satellite in Lanarkshire. However, it is important to ensure that people across Scotland can access high quality treatment. She also noted the Scottish Government's recent focus on head and neck cancer treatment, taking a whole pathway approach.

Mark Parsons, Lead Cancer Pharmacist, NHS Tayside: "Prior to the Independence Referendum, changes to the SMC process were implemented. These followed advice to Health Boards to be more sympathetic to patients' and clinicians' requests for new medicines via IPTR and other processes. The aim of these changes was to increase the availability of new cancer medicines to patients in Scotland. Some of the financial implications of funding these new medicines have been met by the Scottish Government. However, the workforce implications, and their impact on the safe delivery of these additional medicines, have not been addressed by the Scottish Government and this is putting severe strain on service delivery. Clearly, the financial position of Scottish Health Boards is such that service expansion is impossible within the current funding envelope. What provisions is the Scottish

Government making to support the implementation of this change in service provision and its implications?"

SR noted that this is a very reasonable point. However, she noted that the £90 million New Medicines Fund can also be used by Health Boards to cover staffing costs if the new drug requires extra staff support. She noted that not everyone was sufficiently aware of this, and that she would do some work with Health Boards to make sure that they are reminded.

Lorraine Dallas, Roy Castle Lung Cancer Foundation: "We welcome the new treatments being made available for lung cancer via SMC, however it remains the most common cause of cancer mortality in both men and women, with 9.8% 5 year survival achieved by 2011. In the Eurocare 5 study we had the 3rd poorest 5 year survival amongst 29 European countries. What additional steps can we take in Scotland to improve early diagnosis and effective treatment for lung cancer?"

SR pointed out the Detect Cancer Early campaign's focus on lung cancer and particularly its media campaigns with Sir Alex Fergusson, which she said had been particularly useful at reaching out to men of particular demographics. She noted that the Scottish Government would need to continue to build on this. She highlighted some more recent work such as the 'wee c' and forthcoming "get checked" campaign. She also noted the new cancer referral guidelines which have been sent out to all GPs, and we have seen an increase in quick referrals.

Jeannie Erskine, CPG Member: "When will the age for the NHS Breast Cancer Screening Programme be lowered from 50?"

SR noted that screening ages are guided by recommendations from the UK National Screening Committee, who have not recommended that women under 50 should be routinely screened. She noted that there are exceptions for women at higher risk, such as those with a family history of breast cancer. She noted that the greater issue may not be the screening programme, but certain GPs over-assuming that younger women won't have the disease.

Kim Rowan, CPG Member: "Whether Scottish Government has plans to use the Detect Cancer Early campaign to run a public awareness campaign of the signs and symptoms of pancreatic cancer?"

SR stated that this would depend on recommendations by experts, but that any future DCE campaigns will need to look especially at cancers where prognosis is better with early detection.

4) Further questions

Alistair Haw, Prostate Cancer UK: Will the new Cancer Strategy be published before or after the election? SR said that if all work towards it could be completed in time, there would be the aim to publish before although this would have to be before purdah in March. However, she noted that the most important thing will be to get it right. **SR then had to leave the meeting to attend another Scottish Government event. However, it was agreed that further questions would be passed on to her to answer and feed back to the Group at a later date.**

Firstly, a question was asked on home bowel screening kits. It was noted that routine bowel screening is only open to those over 50, but that people much younger than this can be affected by the disease. He asked whether stool testing kits could be made available at pharmacies or GPs

practices so that people not part of the screening programme but who were worried about symptoms could get a home test**.** However, Prof Bob Steele, Director of the Scottish Colorectal Cancer Screening Programme who was present at the meeting noted that this is an approach which is being increasingly discussed, and that NHS Tayside will shortly be embarking on a pilot of a similar scheme, and within six months we should have an idea of whether such a scheme would be viable across the whole of Scotland.

Colette Backwell, CLAN Cancer Support noted that there are many issues of rurality in provision of cancer care and support. For instance, the difficulties of patients travelling from Orkney and Shetland to Aberdeen for tests, which she noted can make the experience even more worrying and stressful for patients. This is something the Scottish Government will need to consider when planning cancer services.

5) Dr Peter Hutchison (PH)

He began by talking about the many years of training required to become a GP, 11 in total, with tough selection criteria. He then stressed the range of issues a GP will encounter as part of his/her career, and how difficult it can sometimes be to spot serious conditions like cancer amongst much larger numbers of more minor ailments which often have very similar symptoms. This is especially difficult when a GP will on average see only eight new cases of cancer a year, out of around 8,000 patient contacts. However, approximately 60% of patients visiting a GP have some symptoms which could be cancer. He notes that GPs have to act as 'professional pessimists' and consider the worst case scenario with any of the symptoms they are presented with.

GPs will see one every year of the three most common cancers- breast, lung and colorectal. They will on average see one every five years of the less common cancers (bladder, kidney, pancreas, oesophagus); one every seven years of ovarian cancer, brain cancer and leukaemia. A GP might only see one case of childhood cancer in their whole career.

PH went on to outline some of the challenges facing primary care, such as the fact that the budget has declined to 9.8% of NHS budget in 2006 to 7.8% in 2013. He noted that the ideal figure would be somewhere around 11%. He also noted that the UK has fewer GPs per 1000 people than Germany, France and Holland. The numbers of GPs in the UK has been declining for several years. He noted there is a marked imbalance between publically stated intentions by the Government and NHS of treating people closer to home, while primary care budget and staffing is declining.

He went on to discuss the unusual position of primary care within the NHS, in that GPs are not technically employed by the NHS but are independent contractors who are running a business, albeit one that is not designed to make a profit. The majority of GPs own their own premises and pay staffing costs, only partially funded by the NHS.

He noted the challenges on GP practices with the average person seeing their GP 5.3 times per year, and with GPs doing more tests than previously. He blamed increased workloads for the fact that many GPs are considering early retirement or working abroad. He also noted that one third of GPs are already approaching retirement age and there is a difficulty of attracting new people. The RCGP estimates that by 2020 Scotland will 900 GPs short. At present, 1 in 6 training posts are unfilled, 1 in

10 GP posts are vacant and many GPs practices are being taken back under local health board control as an emergency measure due to lack of staff.

Going on to look more specifically at cancer, PH noted that GPs are present throughout a patient's cancer journey, particularly at the early stages when a patient first notices symptoms and is diagnosed, and again at the later stages of follow-up care, late effects of treatment and palliative care.

PH then gave some case study examples, showing how a GP tries to work out a diagnosis and action from a range of symptoms given, and noted some very common symptoms such as fatigue.

He finally noted how primary care could be made as effective as possible. He put forward the need for more doctors to go into primary care; more practice nurses, and more money for community physiotherapy and counselling services; a simplification of the GPs contract, and finally he urged against any privatisation of the NHS.

6) Questions to Dr Peter Hutchison

Firstly PH was asked what progress has been made in communicating the new cancer referral guidelines (including on pancreatic cancer) to GPs. He advised that every GP has received a copy of the referral guidelines, as have all pharmacists and dentists. He noted that in reference to pancreatic cancer specifically, because the symptoms are generally so vague it is unfortunately not practical to refer all patients suffering from, for instance, fatigue for testing for pancreatic cancer, as the symptom is too vague and almost all patients visiting their GP complain of fatigue. He also commented on the proposed development of better GP access to CT scans for patients presenting with vague symptoms.

PH was then asked whether patients had been consulted in the drafting of the referral guidelines. PH noted that large numbers of patients had been consulted. He was then asked about the absence of constipation as a referral symptom for bowel cancer. He replied that this was a very unusual symptom of bowel cancer and usually only appeared when the disease was already advanced, therefore it would be harmful to refer all those suffering constipation for endoscopic investigation. However, it was noted that GPs should refer on anyone whose constipation is prolonged and does not go away with normal remedies.

He was then asked about making more time to spread preventative messages about helping to prevent cancer through a healthy lifestyle. PH replied that it would be very difficult to do this in the consultation itself, as there is limited time to spend with the patient, and generally it needs to be spent on the issue the patient has come to the GP about, not on other health messaging. However, he noted that public health departments of Health Boards need to do more to get these messages across.

PH was then asked about the rigorous selection process he had described for appointing GPs. Given the falling numbers of people applying and the shortage of GPs in many parts of the country, is there a temptation almost to take anyone, in order to fill vacancies? PH replied that this was not the case, and that all applicants are subject to the same intensive training as before, and if they are not suitable they will not be able to get through. He noted that much of the focus is on the applicants'

ability to listen to and communicate with people, including intensive use of analysis of video consultations as a teaching tool.

In a related question, PH was asked why so few doctors are looking to become GPs in the UK, when the position does seem to be popular in other countries, and so many British doctors are seeking positions abroad. PH noted that he believes this is largely as a result of increasing GP workloads and a worsening balance between work and personal life. He also blamed attacks on GPs in the press and the lack of funding for the service, noting that the number of hospital consultants is rising.

PH was then asked if he believed there are other symptoms missing from the cancer referral guidelines. PH noted that lots of work is being done to assess this and referred to the system of positive predictive value whereby if a symptom has more than a 3% chance of being cancer it should be referred for further testing. He also noted that unfortunately mistakes are still made and cancers are sometimes missed.

A question was then asked about holistic needs assessment for cancer patients, and whether this could be done by social care. It was noted that this is being trialled in Glasgow.

The final point was raised, which noted that GPs are having to respond to lack of time, and will inevitably cut corners. This is part of the environment that GPs are in, and is a structural problem that needs Government action.

7) **Minutes of the last meeting were approved**.

8) A.O.B.

A point was raised on the need for more patient advocates who could help patients who might struggle to speak concisely to a doctor within their 10 minute consultation period. PH noted this is a good idea and already happens in some cases.

The Chair then referred to Gregor McNie to talk about the Scottish Cancer Conference. He noted that it will take place on the 16th November at the Radisson Blu Hotel, Royal Mile, Edinburgh. The conference is nearly fully booked but there are some places remaining which can be booked online at http://www.scottishcancerconference.org.uk/.

Anthony Chalmers (AC) then thanked the group for the action taken on pushing the Scottish Government to publish data on access to radiotherapy. He noted that these figures would not have been published had it not been for the work of the CPG and would be the first step in tackling inequalities of access to advanced RT. The Chair advised that he saw this sort of activity as very much part of the CPG Cancer's role, that it would continue on this issue, and others in the future.

The Chair then closed the meeting. Next meeting: 17:30-19:00, Wed 19th Dec, 2015

Appendix I Attendees

John	Allen	
Collette	Backwell,	CLAN Cancer Support
Simon J.	Barclay	
Lynne	Barty,	Brain Tumour Action
Karen	Bell,	Cancer Research UK
Angela	Blake,	Pfizer
Chris	Booth,	Scottish Government
Tracey	Bowden,	Pfizer
Prof David	Cameron	Edinburgh Cancer Research Centre
Christine	Campbell,	University of Edinburgh
Malcolm	Chisholm	MSP
Maggie	Clark,	ABPI
Lawrence	Cowan	Breast Cancer Now
Lorraine	Dallas,	Roy Castle Lung Cancer Foundation
Eilidh	Dickson,	Indigo PR
David	Dunlop,	Scottish Government
Jeannie	Erskine	
Tonks	Fawcett,	University of Edinburgh
Shirley	Fife,	NHS Lothian
Marie	Gardiner,	SCAN
Heather	Goodare	
Gail	Grant	
Gillian	Hailstones,	Maggies Centres
Fiona	Hamill	
Peter	Hastie,	Macmillan Cancer Support
Alistair	Haw,	Prostate Cancer UK
Peter	Hutchison,	NHS Dumfries & Galloway
Rob	Lester	
Gordon	Macdonald	MSP
Stella	Macpherson	
Alex	McCaffrey,	Heads Up Cancer Support
Colin	McFarlane,	Indigo PR
Karen	McNee,	James Whale Fund
Gregor	McNie,	Cancer Research UK
Nanette	Milne	MSP
Francis	Norton,	Heads Up Cancer Support
Angus	Ogilvy	
Mark	Parsons,	NHS Tayside
Gillian	Phillips,	Cancer Research UK
Peter	Philips,	
Rachel	Pont,	Cancer Research UK
Liz	Porterfield,	Scottish Government
Janice	Preston,	Macmillan Cancer Support

Katie	Robb,	University of Glasgow
Katie	Robertson,	NHS Forth Valley
Shona	Robison	MSP
Alan	Rodger	
Kim	Rowan	
Colin	Selby,	NHS Fife
Ewan	Shannon	
Lesley	Shannon	
Peter	Smyth,	Indigo PR
Suzanne	Spencer,	Cancer Research UK
Greg	Stevenson,	Roche
Diane	Thomson,	Pfizer
Hamish	Wallace,	University of Edinburgh
Nicolas	White,	Breast Cancer Care
Norman	Wilson,	Pancreatic Cancer Scotland
Keri	Wyatt,	Bloodwise

Appendix II Apologies

Michelle	Armstrong,	Cancer Research UK
Lorna	Bruce,	NHS Lothian
Lindsay	Campbell,	WOSCAN
Ian	Campbell,	
Maggie	Clark,	Novartis
Emilia	Crighton,	NHS Greater Glasgow & Clyde
Val	Doherty,	SCAN
Mary	Dunlop	
Tonks	Fawcett,	University of Edinburgh
Dr Dermot	Gorman	NHS Lothian
Janice	Malone	Macmillan Cancer Support
Dr Marie	Mathers,	University of Edinburgh
Alison	McInnes	MSP
Kaz	Molloy,	Womb Cancer Support UK
Gillian	Phillips,	Cancer Research UK
Helen	Reilly,	BMA
Hazel	Scott	NHS Tayside
Rebecca	Scott,	Cancer Research UK
Mhairi F	Simpson,	NHS Lanarkshire
Leigh	Smith,	MASSCOT
Morag	Stocks,	Cancer Research UK