Scottish Parliament Cross Party Group on Cancer

Tuesday 21st May, 17:30-19:00

Minutes

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

1) Welcome

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

2) Minutes of Last Meeting

One amendment made and minutes agreed.

3) Speaker, Alex Neil MSP, Cabinet Secretary for Health and Wellbeing:

The Chair introduced Cabinet Secretary for Health and Wellbeing Alex Neil (Cab Sec), Acting Chief Medical Officer Aileen Keel (Acting CMO), and Head, Strategic Planning/ Clinical Priorities Team Liz Porterfield.

The Cabinet Secretary pointed to several contextual statistics: that those aged 75 or over would rise 60% over 2004 to 2031; 1 in 5 children born in Scotland today will live to 100; 2 in 3 65 year olds have long-term conditions; 60% of all deaths are from long term conditions. In pointing to inequalities as one of the biggest causes of these, including cancer, he advised that from 2016 some 35,000 people a year in Scotland would be diagnosed with cancer; this is a 5% fall amongst men and 8% rise amongst women, but with mortality improvements of 15.5% amongst men and 5% in women. Today there are 165,000 people in Scotland who have had a cancer diagnosis.

The Cabinet Secretary highlighted the Scottish Government's four cancer priorities- prevention; early detection; improving treatments and person-centred care.

He emphasised the increasing body of evidence around diet and exercise helping prevention and reminded of: £7.5m Scottish Government funding for healthy living projects; working with food industry; the Commonwealth Games and Ryder Cup and associated public health work; and a Glasgow pilot where radiographers talk about lifestyle choices during screening.

The Scottish Government's £30m Detect Cancer Early (DCE) campaign was highlighted, along with anecdotal evidence of increased presentations. The secondary benefits of improved referral capacity and guidelines to support the campaign were mentioned. Healthcare Improvement Scotland is looking at new guidelines for cancer referrals.

The aspiration to world-class cancer treatments was highlighted, with £8m being added to cancer networks to support surgery, radiotherapy and acute cancer care, including a 23-hour breast surgery programme in Glasgow. Particular work is being done in improving treatments across NOSCAN, and members were also reminded of the £22m Monklands satellite which will start treating patients within 18 months.

The success of Quality Performance Indicators (QPIs) were highlighted, particularly around breast cancer diagnosis and the Cab Sec reminded of the 3 year rolling programme to revise all. He also highlighted Scottish Government funding of £5m over 5 years for Macmillan Cancer Support's Transforming Care After Treatment partnership.

4) General Questions to Cabinet Secretary

The Cabinet Secretary then answered several questions submitted in advanced, along with some follow up questions/ comments:

i. Womb Cancer Awareness

Whilst the incidence of womb cancer in Scotland is currently lower than that of the UK average, in 2007-2009 the rate was 18.3 per 100,000 or 1,959 women. Overall UK figures show that womb cancer is the 4th most common female cancer. Does the Scottish Government have any plans for a national awareness campaign?

The Cab Sec pointed to broader impacts from DCE, with the breast campaign particularly encouraging women to present to their GPs. The campaign had lead to an increase in diagnostic capacity in general too. The Scottish Government would be closely monitoring impacts in all areas.

ii. Pancreatic Cancer

Does the Scottish Government have any strategy to promote the early diagnosis of pancreatic cancer, and plans to promote and fund this historically underfunded area?

The DCE programme was highlighted again and that it will work through a whole range of cancers in different ways. He added that TV-adverting was not the most appropriate channel for all communications. The Acting CMO reminded members of the difficulty in diagnosing the disease, late presentations, and poor outcomes. She had recently written as Chair of the Scottish Cancer Task Force to all Health Boards remaining- and seeking confirmation- that GPs should all have appropriate access to CT and ultrasound imaging as required. She has not seen any evidence of this leading to over-referring.

He mentioned that Cancer Research UK were at least doubling their funding into pancreatic cancer as one of their four identified cancers of unmet need.

The Cab Sec also highlighted the new Stratified Medicine Scotland Innovation Centre which will in time bring new treatment options for many diseases.

iii. Brain Tumour Guidelines

NICE guidelines for the treatment of people with brain tumours include the recommendation that patients "should be supervised by specialist neurosurgeons who spend at least 50% of their clinical programmed activities in neuro-oncological surgery". Could we have the same guidelines for patients in Scotland?

The Cab Sec advised of the general Scottish Government approach to "take account" of NICE guidance, but adhere to SIGN guidelines. If evidence emerges that these should be reviewed this is examined and considered during regular reviews. The Acting CMO asked to hear of

any of the four neurological service centres not performing/ or variation in performance between them.

iv. Patient Involvement

Where does the Government and Secretary of Health stand on patient involvement in the Scottish NHS? Has his Department looked at approaches (models) of existing involvement? If so, we would like to call to his attention Sandra Bagnal's initiative in establishing a PRG and how it interfaces with SCAN as an effective mechanism which could be extended to the other Cancer Area Networks in Glasgow and Aberdeen.

The Cab Sec stated he did not feel there was enough patient involvement across the whole sector, with no national patient voice for Scotland. He pointed to examples of initiatives aimed at remedying this: integrating Patient Opinion to the NHS; and a pilot in Lanarkshire where a tri-partite management team were promoted across all sites along with contact details for patients to use.

v. Individual Patient Treatment Requests

I wondered if the Minister had any comment on the patchy uptake of the interim guidance for Individual Patient Treatment Requests which has effectively meant some patients have access to life extending treatments whilst others do not based solely on where they live in Scotland? Will he rectify this as a matter of urgency to ensure all patients get the improved access the Minister intended?

The Cab Sec said he expected the new system to work equally across all boards.

AK advised that the new Peer Approved Clinical System (replacing Individual Patient Treatment Request) was still a work in progress. But that the new approval system in general should reduced the need for PACS.

She also reminded that the vast majority of cured cancers - 90% - involved surgery or radiotherapy rather than cancer drugs.

vi. Scottish Cancer Plan

Better Cancer Care was published some 6 years ago with many successes against it since. Equally, many new challenges have emerged in the meantime. What plans does the Scottish Government have to introduce an updated set of cancer priorities, or new cancer plan, for the next period?

The Cab Sec pointed to the fast-moving environment this was in and the huge developments over the last six years, for example around the potential of stratified medicine. A programme of review was underway with a stakeholder event held in March. At the end of this, the strategy would be updated.

vii. Breast Cancer Referrals

One in five women who are being treated for breast cancer is under age 50. NHS screening does not kick in until women are age 50 – some being nearly age 53. Why cannot younger women with obvious symptoms (eg. armpit lumps, neck lumps) be able to self-refer like the over 70s when not being able to get past their GP?

The Cab Sec pointed to the consensus around clinicians and researchers that screening works best in the current age range. New GP referral guidelines were produced in 2007 with those updated to more useable format in 2009. New guidelines are being proposed and consulted on. There are also new guidelines for patients with family history of breast cancer. The Acting CMO did point to dangers of women self-referring for breast cancer, in particular when the symptoms mentioned may be due to other cancers and therefore not being a benefit to self-referring for a specific cancer. To maximise quick and accurate referrals she pointed to raising awareness amongst GPs. Peter Hutchison (PH) Chair of the Scottish Primary Care Cancer Group invited members to pass on any evidence of GPs having not referred.

5) Speakers: Pancreatic Cancer Scotland

Ross Carter (RC) introduced recovering pancreatic cancer patient Graham Carson (GC) who told the group of his experience from pre-diagnosis, through treatment and a strong recovery. He reminded members of the great luck in being diagnosed early and praised all clinical staff involved.

RC pointed to GC being one of the tiny minority who survive pancreatic cancer beyond 5 years. He advised members of it having the 5th highest mortality rate, with only 43% of cases treatable from diagnosis. Public awareness was important, but equally so is the education of GPs. Current guidelines are minimal, amalgamate with other GI disease and refer to late stage symptoms. A RCGP module on this had been completed by less than 1% of practitioners, and he encouraged this was rolled out across Scotland He welcomed the letter sent by and earlier referred to by the Acting CMO ensuring appropriate access to imaging for GPs. He indicated that significant improvements could be made with reorganisation rather than investment.

A discussion and other contributions followed during which it was noted:

That clinical nurse specialists could have huge impacts on patient experience and outcomes. Holistic patient management was crucial as significant weight loss could occur up to treatment. Early detection, often to quick access to imaging, could allow early chemotherapy and radiotherapy to facilitate effective surgery. The efficacy of counseling in some circumstances was highlighted.

Asked about specific early indicators for the disease, RC pointed to two examples: non-responsive dyspepsia; and diabetes in lean middle aged men.

The challenges for GPs referring to the correct specialist areas were discussed. PH invited RC to contribute to future work on addressing these challenges.

6) Scotland Against Cancer 2014

Members were reminded to book before registrations close on Friday 23rd May, and the programme headlines were highlighted.

7) AOB

None

8) Close

Appendix 1: Attendees

Moira	Adams	Trustee, Challenge Breast Cancer Scotland
Emma	Anderson	Bowel Cancer UK
Elspeth	Atkinson	Macmillan
Philip	Atkinson	Chair, Scottish Primary Care Cancer Group
Stuart	Barber	Beating Bowel Cancer
Lynne	Barty	Brain Tumour Action
Lorna	Bruce	SCAN (Audit Manager)
Frank	Buckley	Pancreatic Cancer Scotland
Susanne	Cameron- Nielsen	Royal Pharmeceutical Society
Christine	Campbell	University of Edinburgh
Malcolm	Chisholm	MSP
Maggie	Clark	ABPI Scotland Cancer Industry Group (Novartis)
Lorraine	Dallas	Roy Castle Foundation
Sheena	Dryden	Clinical Nurse Specialist, NHS Lothian
David	Dunlop	Specialist Oncology & Clinical Haematology Services, NHS Glasgow
Jeannie	Erskine	Cancer Patient
Shirley	Fife	NHS Lothian
Adam	Gaines	Prostate Scotland
Heather	Goodare	
Dermot	Gorman	Public Health & Health Policy Directorate, NHS Lothian
Nigel	Graham	ABPI Scotland Cancer Industry Group (Merck Serono)
Peter	Hastie	Macmillan Cancer Care
Peter	Hjertholm	(c/o Christine Campbell @ Edinburgh Uni)
Alex	Holme	SCAN / NHS Lothian dermatology
Leslie	Horne	Edinburgh and Lothians Prostate Cancer Support Group
Peter	Hutchison	Chair, Scottish Primary Care Cancer Group
Gus	Ironside	Brain Tumour UK
Andy	Luck	PCUK
Murdina	MacDonald	NHS Fife
Kate	MacDonald	SCAN (Network Manager)
Sheena	Mackenzie	South East Scotland Cancer Network (SCAN)
Marie	Mathers	NHS Lothian
Gregor	McNie	Cancer Research UK
Karen	McNee	James Whale Fund
Kerry	Napuk	Edinburgh and Lothians Prostate Cancer Support Group
Angus	Ogilvy	SCAN
David	Park	Pancreatic Cancer UK
Kim	Rowan	Pancreatic Cancer UK
John	Sleith	Royal Environmental Health Institute of Scotland
Peter	Smyth	Indigo PR *obo* Beating Bowel Cancer

Robert	Steele	Scottish Cancer Foundation
Gregor	Stevenson	Roche
Gonzalo	Tapia	NHS Lothian
Sandra	Thornton	SCAN
Lucy	Wall	NHS Lothian
Nick	White	Breast Cancer Care
Jim	Hume	MSP
Liz	Porterfield	Head of Strategy and Planning, Scottish Government
Graham	Carson	Pancreatic Cancer Scotland
Ross	Carter	Pancreatic Cancer Scotland
Elspeth	Cowan	Pancreatic Cancer Scotland
Clem	Imrie	Pancreatic Cancer Scotland
Gertrude	Kadzuwa	Pancreatic Cancer Scotland
Alex	Neil	Cabinet Secretary for Health and Wellbeing
Willie	Rennie	MSP
Marion	Donaldson	
Aileen	Keel	Acting Chief Medical Officer
Lorna	Porteous	

Appendix 2: Apologies

Jackie	Baillie	MSP
Karen	Bell	SCRN Senior Research Nurse
Lindsay	Campbell	WOSCAN
Martin	Coombes	ABPI Scotland Cancer Industry Group (Novartis)
Chloe	Cowan	Cancer Research UK Senior Nurse
Dawn	Crosby	Teenage Cancer Trust
Kate	Cunningham	Director, Ochre-the oesophageal cancer charity
Val	Doherty	Clinical Lead, SCAN
Mary	Dunlop	Cancer Research UK
Ellen	Finlayson	Clic Sargent
Liz	Forbat	Cancer Care Research centre
Alistair	Haw	Prostate Cancer UK
Robin	Lester	Edinburgh and Lothians Prostate Cancer Support Group
Kaz	Molloy	Womb Cancer Support UK
Alison	McInnes	MSP
Peter	Phillips	SCAN Urology Group (Patient Rep)
Frances	Reid	Target Ovarian Cancer
Helen	Reilly	BMA Scotland
Katie	Robb	Institute of Health and Wellbeing
Alan	Rodger	Retired
Colin	Selby	NHS Fife, SCAN
Mhairi	Simpson	Nurse Consultant Cancer Care, NHS Lanarkshire
Tommy	Tan	NHS Lothian
Ken	Macintosh	MSP