Scottish Parliament Cross Party Group on Cancer

Wednesday 31st May 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 31st May 2017 were approved by the group without amendments.

3) Annual General Meeting

Miles Briggs MSP and Jenny Marra MSP were re-elected as co-conveners. Cancer Research UK was approved as the Secretariat.

4) The Chair then welcomed Nicola Barnstaple (NB) and Neil Harrison (NH), to give an update on the Detect Cancer Early Programme

NB began by discussing the snapshot of cancer incidence and survival in Scotland. She noted that Scotland's cancer survival rates are lower than many other countries and that late diagnosis is a contributing factor to this. NB noted that the impacts of health inequality were being seen in cancer survival. Prior to the programme mortality rates from cancer in the most deprived areas were around 1.8 times higher than those in the least deprived areas.

Cancer incidence is also increasing with a predicted increase from 30,500 annually in 2008-2012 to over 40,000 in 2023-2027. NB noted that this is, in part due to Scotland's ageing population, with the proportion of over-75's in Scotland projected to increase from 8% in 2014 to 14% in 2039.

NB then noted the history of the programme, which was launched in 2012. She stated that the programme has initially focussed on breast, bowel and lung cancers as these cancers account for 43% of all cancers diagnosed in Scotland. She then added that the programme was agreed to have a whole systems approach to look at primary, secondary and tertiary care, as well as public health campaigns and marketing. The programme was launched with a target to increase cancers diagnosed at stage 1 by 25% by 2015.

NB then discussed the work that has been done on screening, including awareness campaigns, education courses, investment in qFIT implementation and incorporating prevention messages into screening settings. She then explained the work that has been done in primary care to update the Scottish Referral Guidelines for Suspected Cancer and develop a quick reference guide, website and app for the guidelines.

The work to improve diagnostic capacity was then discussed. NB stated that most of the money from the Detect Cancer Early programme has been invested to increase diagnostic capacity. This has been through direct investment in NHS boards, work to look at and assist cancer waiting times performance and to undertake local pilots such as the pilot of qFIT as a first line diagnostic test.

NB then discussed the public awareness campaigns that have been run by the programme. She noted the primary campaigns that encouraged the public to visit the GP as well as targeted campaigns for breast, bowel and lung cancers. She then highlighted other awareness raising work performed such as an awareness-raising roadshow which tours Scotland.

The results of the programme were then discussed by NB. The 25% target has not yet been met, with a 9.2% increase seen so far. NB noted that there have been successes with the biggest rise seen in the most deprived community (17.4%). She highlighted the variation that exists between Health Boards and stated that work is ongoing to better understand this variation. NB also noted some other successes such as a 39.2% increase in the number of lung cancers diagnosed at stage 1, a reduction in the mortality of cancer in the most deprived areas compared to the least deprived from 1.8 times to 1.6 times and a range of attitudinal shifts in the population.

NB concluded by saying that the work so far has shown that targeted interventions can work. She stated that work is moving forward, with melanoma being added to the programme.

NH then discussed the marketing work being undertaken as part of the Detect Cancer Early programme. He noted that fear is still a major issue for the public as a barrier to talking to GPs. He stated that the current marketing strategy focuses on advertising through traditional media such as TV, billboards and the radio working on campaigns across the three tumour types and that these campaigns are supported by the social marketing campaigns such as Wee C and Don't get scared, get checked.

NH explained that the marketing campaigns have a defined primary target audience, namely people aged 45 and above in the most deprived areas. He then stated that the team is looking at how to target the campaigns going forward such as how to extend the use of current assets as well as looking at whether to continue with tumour specific campaigns or whether to use a pan-tumour approach to tackle the fear of cancer.

He then discussed how the programme is looking to tackle the fear of cancer through its marketing campaigns. NH noted ongoing insight research on people's fears as well as the impact of the campaigns to date. He stated that the research has found that people agree with the statement that cancer is less dangerous if caught early but that they feared wasting the doctor's time or perceived that the doctor wouldn't want to see them for what they thought were minor symptoms.

NH finally discussed how the team was trying to cut across the current discussion around cancer. He noted that many people are still fatalistic about cancer and others are more proactive about their symptoms but noted that a large number are somewhere in the middle and that fear plays a big part within this group. He concluded that they are using this to work out how best to get people to present through tumour specific or pan-tumour campaigns.

5) Questions to NB and NH

On whether the updated cancer referral guidelines were just for the 3 cancers targeted by the DCE programme, NB stated that the updates were across all cancer.

On the 25% target and whether there is a new date for it to be reached by, NB stated that there is not a new date for the target. She noted that discussions are ongoing around this target and what the best target should be, stating that a lot of good work has been done but that the 25% increase in stage 1 diagnoses was an ambitious one.

On whether enough weight is given in the referral guidelines to younger women in breast cancer and whether the guidelines are still being updated, it was noted that the Scottish Primary Care Cancer Group keeps the guidelines on the agenda.

On the harms of breast screening, Val Doherty (VD) noted that breast screening is the most complicated of the screening programmes in terms of harms and noted that a system of informed consent is important.

On whether there is a need to regulate for time off to attend screening appointments, NB noted that the public should be allowed time off. NH stated that there is thinking ongoing about raising awareness of this issue in their social marketing work.

On whether pancreatic cancer should be included in the programme, NB noted that the pan-tumour approach aimed to instil confidence in the public to report symptoms across tumour types. She stated that education and awareness raising of the symptoms is being considered. She also highlighted that solutions to help diagnosis of vague symptoms such as the ACE programme and MDCs are being considered, but that this is at an early stage.

On whether there are concerns over the ability of diagnostic and GP services to cope with the increased number of people reporting following an awareness campaign, NB stated that the team is extremely aware of the ongoing workforce pressures. She emphasised that much of the initial budget was spent to increase diagnostic capacity. The smaller budget now means that the team has to be aware of the impact that waiting for a diagnosis can have on people. The ongoing workforce planning by the Scottish Government was also noted.

On whether qFIT is a comprehensive test for symptomatic bowel cancer, NB stated that it was used in the pilot for patients presenting with vague symptoms and that the test was sent in with the referral. This was then used as a rule out test for cancer, reducing the number of scopes needed.

On tying in campaigns on lung cancer with smoking cessation, NH noted that the campaigns have not so far been tied in. Scottish Government campaigns around smoking in recent years have focussed on second hand smoke. Next year the campaigns will focus on cessation and they will look at whether this can be tied in with DCE.

On whether genetic testing and inherited risk-factors for cancers may be included in DCE, NB stated that there are programmes around breast and colorectal cancers for inherited risk factors, keeping affected individuals under surveillance.

6) The Chair then welcomed Val Doherty (VD) to discuss the ongoing cancer waiting times targets review.

VD began by emphasising that the review is ongoing and that there is opportunity for people to feed in comments and suggestions to this review. She noted that the review was established in last year's cancer strategy – Beating Cancer: Ambition and Action, due to an awareness that cancer outcomes are currently worse in Scotland than the rest of the UK.

VD noted that the current 62 days standard for urgent referrals was set up in 2006. She stated that the introduction of the target helped to drive up pathway efficiencies between 2006 and 2009, where the performance increased from 70.1% to 93.8%. She also noted that this 62 day target was arbitrary and that there is no clinical evidence that this period is key for improved outcomes, but that the existence of a target allowed these efficiencies to be created, whilst also driving improvements in the recording of data.

The performance against the targets in recent years was then discussed. VD stated recent performance has been more challenging. Performance in the 31-day standard has drifted down in recent years, but still remains close to the 95% standard (94.9% in Q1 of 2017). She then stated that

the same cannot be said for the 62-day standard where current performance is down at 88.1% (as of Q1 2017).

VD then discussed the considerations that were being made as part of the cancer waiting times standards review. These include considering: which measures are most valued by patients and clinicians; which new or modified measures across the cancer pathway could optimise planning and delivery, and raise the quality of care whilst remaining deliverable; and how the standards can retain reactivity to changing needs such as new diagnostics, new treatments.

It was then noted that there is no evidence to suggest that the outcomes are worse for those whose treatment has been delayed, but that the anxiety caused to patient by such delays is well known. VD then discussed an online questionnaire that had been run by the Scottish Government to collect the views of public and patients, interviewing 1,018 members of the public and 71 members of a patient group. VD noted that the questionnaire found that 27% of the public cohort and 46% of the patient group were content to wait for a month if not urgent. But 62% of the public and 49% of patient group would want to have a test within a week, if urgently referred. She then stated that 49% of the public and 55% of the patient group trusted that health professionals will inform them about test results at the appropriate time. 35% of the public and 42% of the patient group would not want to wait for the results and 8% of the public would like to have time having a test for cancer and receiving the results.

VD then noted that the review is also looking at the urgent referrals process. It is looking at whether there is variance in urgent referrals within primary care and in the triaging of these referrals. It is also reviewing the management of urgently referred patients through diagnostics.

She then stated that the diagnostic and treatment pathways are under review. VD highlighted that new treatments and diagnostics are altering pathways over time. She then mentioned the realistic medicine agenda being put forward by the Chief Medical Office, noting the option of 'watchful waiting' and stating that people should have time to assess their options.

Results from the questionnaire were again highlighted which showed that there is widespread acknowledgement of reasons why it might be necessary to wait for test results. The results also showed that the majority of patients would like to be able to discuss any concerns with someone during this waiting period, either through a helpline or a direct contact at their GP practice. The questionnaire also found that 3 out of 10 cancer patients did not feel that they received enough information about the amount of time they should be expected to wait for test results and to start treatment.

VD then discussed the ongoing analysis of the benefits and adverse effects of the cancer waiting times targets. She stated that they need to understand whether targets have adverse effects on cancer pathways or to other disease pathways. She noted that so far it had been agreed that the standards have improved data collection and cancer diagnosis pathways. However, she noted that not all cancers and patients are the same and that the idea of different standards for different cancers and a range of other options are being discussed. VD also noted that there is a need to improve communication to patients around waiting times.

VD concluded by noting the timelines of the cancer waiting times review. She stated that there will be a further opportunity for comments in October, before recommendations are put forward for consultation in December or January and stated the final report and recommendations are expected to be published in early 2018.

7) Questions to VD

On whether the 62 day waiting time standard is too long for fast growing cancers, VD stated that different tumours have different biology and that it is important to put the right people through the correct pathway. She stated that there is no evidence from outcomes that a shorter waiting time standard should be selected, though the patient concern element has not been measured. She also stated that cancer types where symptoms are easier to diagnose, such as breast, were often referred much quicker than 62 days. However, for cancers such as pancreatic, where symptoms are more complex, the time to diagnose and treat is often longer.

On the role of standards stopping people falling through the net and whether the delays are found in diagnosis. VD stated that once diagnosis is made, most patients begin treatment within a week. However the process of diagnosis includes not only people with cancer, but also people without cancer and those who have other conditions and that it takes time to carry out tests to obtain a cancer diagnosis.

On whether the success of early diagnosis driven awareness campaigns have caused issues in waiting times, VD stated that more people are now being diagnosed than when the waiting time standard was created. NB noted that public awareness campaigns often bring forward a number of people who, after testing, do not have cancer. She stated that the balance between the responsibility to inform the public and the knowledge that any campaign will cause alarm to a certain number of people is considered when campaigns are run.

On the low survival rates of pancreatic cancer due to 80% being diagnosed at stage 4, VD stated that in the review it is being noted that some cancers are less urgent and can be diagnosed over a longer period with no change in outcomes but for others, this timeline is much more urgent.

8) A.O.B

The chair noted that the Scottish Cancer Conference will take place on 20th November 2017 at Surgeon's Hall.

9) MB then closed the meeting. Next meeting 17.30-19.00, Wed 13th December 2017.

Attendees

Group Members

Member
Miles Briggs MSP
Claire Adamson MSP
Macmillan Cancer Support
Prostate Cancer UK
Pancreatic Cancer UK
CLIC Sargent
Brain Tumour Action
Nanette Milne
Circle of Comfort
Beatson Cancer Charity
Cancer Research UK
Scottish Primary Care Cancer Group
Pancreatic Cancer Scotland
West of Scotland Cancer Network
Heads Up Cancer Support Group

Scottish Cancer Foundation
NHS Fife
Novartis
Dr Alan Rodger
Merck
Bloodwise
British Dental Association
University of Edinburgh
Prostate Cancer UK
Heather Goodare

Non-Group Members

Member
Mental Health Foundation
Ettrickburn Limted
Nicola Barnstaple
Val Doherty
Neil Harrison