Cross-Party Group on Cancer

Wednesday 14th December 2022, 18:00-19:30, Virtual Meeting Via Zoom

Minute

Present

MSPs

Miles Briggs MSP (Co-Convener, Chair)
Foysol Choudhury MSP
Finlay Carson MSP

Invited guests

Lorraine Dallas, Roy Castle Lung Cancer Foundation
David Weller, University of Edinburgh
Edwin van Beek, University of Edinburgh
Ahsan Akram, University of Edinburgh
Phil Hodkinson, NHS Scotland
Cameron Millar, Patient Advocate

Non-MSP Group Members

Lesley Shannon, Individual member
Neil MacDonald, Merck Sharp & Dohme (MSD)
Steve Brown, Roche
Sandra Auld, Healthcare Public Affairs
Tom Martin, Individual member
Alison Tait, Individual member
Douglas Rigg, Scottish Primary Care Cancer Group
Jessica Cuddy, Cancer Research UK
Johnstone Shaw, Fight Bladder Cancer UK
Liam Buckley, Less Survivable Cancers Taskforce
Calum Goodfellow, Leukaemia Care
Caroline Donoghue, Myeloma UK
Jacquie Tosh, Individual non-member
Jennifer Cameron, Royal College of Occupational Therapists
Helen Fleming, Individual member
Emma Hall, Make 2nds Count
Nicola Barnstaple, National Centre for Sustainable Delivery/Scottish Government
Dawn Crosby, Pancreatic Cancer UK
Diane Primrose, National Centre for Sustainable Delivery/Scottish Government
Alex Cruickshank, Scottish Government

Debbie Cavers, University of Edinburgh
Michael Clancy, Law Society of Scotland
Laura Mcglynn, Scottish Government
Martin Cawley, Beatson Cancer Charity
Christine Campbell, University of Edinburgh
Doreen Miller, Cruse Scotland Bereavement Support
Marie Gallagher, NHS National Services Scotland
Anne-Marie Barry, Breast Cancer Now
Melanie MacKean, NHS Lothian
Ross MacDuff, NHS Scotland
Debbie Cavers, University of Edinburgh
Michael Heggie, Cancer Research UK (Secretariat)
David Ferguson, Cancer Research UK (Secretariat)
Emily Hindmarch, Cancer Research UK (Secretariat)

Apologies

Jackie Baillie MSP (Co-Convener)
Karen Bell, Beatson West of Scotland Cancer Centre
Stephanie Kleynhans, The Brain Tumour Charity
Christine Campbell, Cancer Research UK
Heather Baxter, Lilly UK
Jean Paterson, Individual non-member
Ian Pirrie, Cancer Card
Jen Hardy, Cancer Card
Tasmin Sommerfield, NHS National Services Scotland
Penny Richardson, Individual member

1. Welcome & Minutes

Chair, Miles Briggs MSP (MB), opened the meeting and welcomed members. MB explained that the meeting was being held following the postponement of the 14th September meeting, after the passing of HM the Queen and the suspension of parliamentary business. MB then briefly outlined the meeting etiquette to attendees.

Minutes for the meeting on 6th June 2022 were approved without any amendments.

2. AGM

MB and Jackie Baillie MSP (JB) were re-elected as Co-Conveners. Cancer Research UK (CRUK) was approved as the Secretariat.

MB explained that work has begun on the CPG's workplan for 2023, and noted if members have ideas for topics that the group should focus on at future meetings, then to get in touch with the Secretariat at CrossPartyGroup@cancer.org.uk.

3. Roy Castle Lung Cancer Foundation: Lung Screening and Early Detection

MB welcomed Lorraine Dallas (LD), Dr David Weller (DW), Edwin van Beek (EvB), Dr Ahsan Akram (AA), Dr Phil Hodkinson (PH), and Cameron Miller (CM).

LD began by explaining that the focus of the session was to support the discussion around earlier detection of lung cancer including both clinical and patient perspectives, and to discuss whether there are lessons we can learn regarding lung cancer and the potential to improve outcomes that can be shared across the cancer communities.

LD discussed the wider lung cancer context and highlighted that it's a global health problem. She noted that stigma is a factor affecting early detection, research, and awareness. This is linked with tobacco consumption and the health inequalities that impact tobacco dependency and health access. LD noted that there are other risk factors that affect the likelihood of developing lung cancer including air pollution, exposure to asbestos, diesel, and other industrial exposures. She also highlighted that lung cancer patients are less likely to seek support than those with other cancers. Regarding the situation in Scotland, LD noted that lung cancer is one of the most common cancers and it has a poor survival rate. In 2020, 2,385 men and 2,548 women were diagnosed with lung cancer in Scotland. LD acknowledged the impact of Covid on lung cancer but noted there has been some significant work to improve outcomes. She highlighted the work of the Detect Cancer Earlier Programme, work by Scottish Cancer Network on the optimum diagnosis pathway, and the opportunity to build Covid recovery into the new Cancer Strategy. In terms of diagnosis, LD stated that there are challenges for people with the disease including issues around presentation and symptom awareness. LD noted and welcomed the UK National Screening Committee (UK NSC) recommendation to introduce a targeted screening programme. She also spoke about the NHS England Lung Health Check service which has resulted in 1,344 lung cancers being diagnosed, with 61% of these being at Stage 1 and 15% at Stage 2. LD noted the importance of early diagnosis and that this service has been transformative in being able to potentially offer curative treatment to more people. LD then handed over to DW, EvB, and AA to take on the topic from a clinical perspective.

DW noted that we're at an important watershed currently with the UK NSC recommendation and how the Scottish Government responds. DW then brought in EvB to discuss lung cancer screening in more detail, as well as the LUNGSCOT study. EvB began the presentation by highlighting that in the UK there are more deaths from lung cancer than colon, breast, and prostate cancer combined. The lifetime risk is 1 in 13 men, and 1 in 17 women. EvB noted that lung cancer has a poor survival rate and highlighted the importance of early diagnosis in terms of a person's chances of survival from the disease. EvB highlighted that survival according to stage diagnosis has hardly changed since the late 1980s. EvB posed three questions to be answered, 1) How do we diagnose lung cancer earlier 2) How do we ensure the treatment is more effective 3) How to save lives and be cost-effective.

EvB discussed some of the flaws with chest X-rays and added that they're not sufficient for screening as they very often miss lung cancer in patients. He noted that

software can help with detecting lung cancer earlier in some patients. EvB then discussed risk-based eligibility for lung cancer screening. He noted the need to prevent screening of the people who are too low a risk and said that risk-based strategies are more likely to recruit older individuals and groups with diminished life expectancy. EvB highlighted two existing methods of measuring and communicating lung cancer risk and non-screening eligibility to low and high-risk individuals. EvB then discussed some of the recent Europe and US lung screening studies and their outcomes. He noted that all these studies suggest that early detection is feasible, early detection reduces lung cancer mortality by more than 20%, and early detection is cost-effective. He referenced a 2011 study that showed CT scans were more effective than chest X-rays in detecting cases (24.2% vs 6.9%) and as a result translating to better outcomes. EvB also noted a study that showed a reduced mortality with volume CT screening. EvB discussed NHS England's Lunch Health Checks which boost early diagnosis. He said that there are multiple lung screening pilot studies being rolled out across England which are generally mobile scanning facilities in big cities. EvB added that these studies require significant investment which they have in place in England. EvB noted that the UK NSC has recommended introducing a targeted lung cancer screening programme across the UK, for those at high risk of the disease. On Scotland, EvB stated that there isn't screening currently available, we have a high-risk population based on smoking history, and that we have the ongoing LUNGSCOT pilot project. EvB explained that the LUNGSCOT study aims to explore ways of identifying those at high risk of lung cancer with the initial study based in several Edinburgh GP practices. The LUNGSCOT study has had positive results so far, with discussions ongoing about expanding it to Glasgow and the Highlands. EvB noted the difficulty of CT scanner availability and accessibility in terms of expanding the trial across Scotland. Regarding CT screening, EvB noted the shortage of radiologists, the need for investment in infrastructure, and the downstream effects on services. He discussed the benefits of mobile CT scanners, particularly regarding their accessibility and capacity.

In his closing, EvB said, 1) There is general agreement that CT lung cancer screening is cost-effective, enhances patient lives and should be implemented 2) The mode of delivery is under discussion; pilot projects may be required in the first instance before roll-out 3) Opportunities for interaction with AI tools and blood tests are warranted.

With regard to the previous presentation, PH noted that lung screening is the way forward, but to do it properly it must come with the appropriate infrastructure. PH then explained that he will be discussing Scotland's national optimised lung cancer pathway and that he is the Joint National Clinical Lead for Earlier Cancer Diagnosis. PH talked through a table which demonstrated the high volume of lung cancer diagnoses and the proportion of which are at a late stage compared to other cancers. He noted the need to shift lung cancer towards lower stage and less diagnoses at stage 4. PH then noted that cancer can grow during their diagnostic pathway, disadvantaging patients and impacting outcomes, and emphasised the importance of the optimum cancer pathway. PH explained that in 2021 the Centre for Sustainable Delivery's (CfSD) Earlier Cancer Diagnosis Programme Board commissioned the first optimum pathway for cancer with a focus on lung cancer. PH said that they did this by taking expert clinical leadership, undertaking a literature review, looking at equivalent pathway work in England, working with regional managed clinical networks (MCNs), and holding a national event where they came up with a clinical consensus pathway design.

PH discussed the optimal lung cancer diagnostic pathway in detail. PH noted the benefits of the pathway such as improved patient experience and outcomes, faster diagnosis leading to earlier treatment, increased efficiency, and positive patient feedback. Regarding next steps, PH said the pathway has been endorsed by the NHS Board Chief Executives and Scottish Association of NHS Medical Directors (SAMD), funding has been secured, a toolkit has been developed to support clinical and management teams which will include good practice, and the UK Lung Cancer Coalition has been engaged to undertake gap analysis in Scotland to support implementation. PH then discussed what is required to deliver the pathway. PH noted that at a local board level there needs to be a focus on key diagnostic steps earlier in the pathway, job planning for clinical time, and work to address the gaps/inefficiencies in support diagnostic steps. At a regional level, he said they need to ensure there is adequate PET scan availability and develop support for expert interventions. PH said that nationally they will have to train more lung cancer sub-speciality consultants, as well as appropriate advanced non-medical practitioners to co-deliver the pathway. In summarising, PH said that the pathway is the right thing to do and has broad endorsement. CfSD are at the start of an implementation journey with 2023 dominated by working through local, regional, and national level discussions to get to this faster diagnostic process, which will in provide the infrastructure for screening discussions.

Patient advocate, Cameron Miller (CM), said that his story began in October 2019 when he was 52 years old. He was fit, healthy, and a non-smoker. CM returned from a holiday in Japan and was fatigued with a cough. He had endless trips to the GP over a two-and-a-half-month period, three rounds of antibiotics, and two X-rays, and nothing showed up, so they thought it was a chest infection. CM said that he finally got a CT scan, and he was diagnosed with lung cancer which had spread to stage 4. CM noted that this was a shock as he didn't expect to be diagnosed with lung cancer as he wasn't a smoker. A tissue biopsy found that CM had ALK-positive which is a lung cancer in non-smokers. CM noted that 15-20% of lung cancer patients fall into the non-smoking category and younger women are commonly diagnosed with ALK-positive lung cancer. CM discussed his treatment but noted that he is living a normal life and doing well. CM said that the treatments are fantastic but noted the need to diagnose patients earlier. He noted the impact of diagnosing people at stages 1 and 2 as opposed to stage 4. CM spoke about his work as a patient advocate in raising awareness of lung cancer in non-smokers which has included speaking at events. CM then focused on what patients think about early diagnosis. He noted that some patients are quite angry when they're diagnosed at stage 4, particularly if they've been raising an issue with their GP for a long time. CM said that he and other patients got together to create the 'See through the Symptoms' campaign to raise the profile of lung cancer in non-smokers amongst primary care health care professionals and increase earlier diagnosis. CM said that the campaign has received a lot of attention through the website, media coverage, and posters in GP surgeries. The campaign also aims to change the narrative, particularly around the stigma of lung cancer in non-smokers. In his closing remarks, CM stated that there isn't one solution to improving diagnosis rates and highlighted several important issues including links between smoking and deprivation, the Scottish Government's vision of a smoke free Scotland, and the need to tackle air pollution. He also noted the need for more GP training to help recognise the symptoms, as well as more research and collaboration across the cancer sector. MB thanked CM for speaking about his personal story and all his campaigning work.

MB thanked all the speakers for their presentations and initiated the Q&A by asking EvB, PH, and AA whether there is a reluctance from Scottish Minsters to take forward their project because the CT systems are being overwhelmed, and how we get around that. AA said that there is a disparity between what is happening in England and Scotland currently, with 43 sites in England effectively having a lung screening system up and running with funding in place, and this is now embedded in their workflow. AA said some of this has to do with culture and their proactive approach on lung cancer screening, whereas in Scotland there is enthusiasm but resistance from the decision-makers. AA also noted his concern that the disparity between both nations will widen.

Douglas Rigg (DR) said that generally, screening is the way forward particularly with deprivation being a major factor connected to lung cancer, and referenced CRUK's recent deprivation and cancer inequalities report. DR asked EvB, PH, and AA whether there was any information available from the screening pilots about the impact on primary care services, particularly the increase in workload. EvB said that so far, they've seen a limited impact on primary care. DW noted that the impact on primary care is something they will have to be careful about and it's important when information is sent back to GPs it comes with guidance on the next steps. AA said that it's a partnership and noted that Lung Health Checks work closely with primary care. DR noted that when screening is rolled out more widely there will have to be some consideration that GP practices in more deprived areas will see a higher workload and increase existing inequalities. EvB noted that the downstream effect is limited and manageable if the screening setup is properly resourced as it is in England.

EvB said that the optimised cancer pathway is something we all want but that there are some major hurdles. He spoke about the difficulties faced in securing new PET scanners in Scotland, as well as the availability of CT scanners which are currently overwhelmed. EnB noted the need for better infrastructure to avoid delays for lung cancer patients. He also highlighted staffing issues with radiology which is 40% understaffed in Scotland. MB queried the modelling of rolling out a lung cancer screening programme in Scotland and whether we can replicate the England model. PH discussed the complexities of the pathway model and noted the need for additional infrastructure and workforce to handle the demand for a screening programme. PH noted that the UK NSC has created a lung screening committee which will have Scottish representation. The committee will have a Scottish expert group to work through the challenges of rolling out lung screening. PH said that things need to be considered carefully to make sure we don't have unethical screening without rapid pathways in place. He noted that in order to move forward, the screening conversation needs to be matured into a Scottish screening conversation. PH recognised that there is frustration among clinicians that we're not as far forward with screening as England. MB said it's important that priority is given within in the new cancer strategy to this and other screening opportunities and to look beyond recovery from the Covid pandemic.

Johnstone Shaw (JS) explained that he is a patient advocate for bladder cancer and congratulated CM on his inspirational talk. He said that before he became ill, he was working as a GP and noted that his pathway experience was very similar to CM's. JS added that was impressed with the PH's presentation on pathways and how patients access secondary care. He also highted CM's comments on patient experience in primary care and GP awareness should be raised. JS highlighted comments he raised with the Cabinet Secretary at the Scottish Cancer Conference about health inequalities

and access to primary care. He said his concern is that patients with early symptoms are sometimes waiting 6-8 weeks to see a GP through no fault of primary care. JS added that there needs to be some investment and help for frontline primary care. MB echoed JD's points and queried what self-referral currently looks like for patients. PH said that this isn't in place yet, but CfSD would like to test it and they're working on how it might overlap with Rapid Cancer Diagnostic Services. PH noted the importance of primary care in diagnosing cancer earlier and added that self-access needs work. EvB agreed that primary care needs to be strengthened as the only self-referral pathway patients have open to them is to go to A&E which leads to further problems.

EVB spoke about a meeting that took place in Edinburgh in June with clinicians and other people involved in screening in attendance. EvB noted that one of the participants from the screening committee said that it will take 2-3 years to roll out lung cancer screening across Scotland. He said this was a demoralising statement as Scotland will fall further behind. EvB added that he hopes the work on the optimal lung cancer diagnostic pathway concludes in 2023 to benefit people across Scotland. MB noted that as a CPG we'd like to return to this issue and the wider vision on screening.

DR praised CM's presentation and with regard to the campaign to raise the profile of lung cancer in non-smokers amongst GPs, DR noted that part of the issue is that the NICE guidance refers to patients over the age of 40 and suggested that this is where the cognitive bias comes in, as GPs are working not those guidelines. DR added that access to primary care is a huge issue and fundamentally primary care needs to change. He noted the possibility of looking at more self-referral for patients with cancer symptoms and highlighted the need to have realistic conversations about the workload that comes with primary care and what can be achieved given the pressures GPs face.

AA fully agreed that the implementation of an optimal lung cancer pathway is 100% essential, and the evidence is clear. He also said that it's essential that the disease is diagnosed earlier though screening. AA said he's hopeful both can move forward together in tandem, and that Scotland can have a world leading screening programme. Ross MacDuff (RM), who is a practicing radiologist, said that screening and the pathway are the right thing to do, but they need to be planned and centrally driven. MB agreed with RM's points and suggested this work needs to sit alongside the cancer strategy in delivery plans and said it's something MSPs want to see more detail of.

Jacquie Tosh (JT) spoke about her experience as a breast cancer survivor and the difficulties she has recently faced accessing breast screening because she is over 70 years old. JT asked why women like her are in this position. MB said that he has raised this issue in Parliament with Ministers, and self-referral has been the pathway many of his constituents in the same situation have been able to use. MB offered to put her in touch with her local MSP who can follow up on this issue. Michael Heggie (MH) shared MB's email address in the chat box and MB asked JB to get in touch.

4. Look back at the Scottish Cancer Conference

MB looked back at the Scottish Cancer Conference which took place on 28th November. MB said it was great to see everyone in person again and that he and JB were grateful for all the individuals who attended and presented at the conference. He noted that the event focussed on deprivation and cancer inequalities which will

be a focus of the CPG going forward, especially how it will be embedded and tackled in the cancer strategy. MB asked those who attended the conference for their feedback. MB noted that the feedback will help improve and shape next year's conference. He added that CRUK has sent the evaluation form to attendees.

5. AOB

There was no AOB at the meeting.

6. Close of Meeting

The next CPG meeting will take place on Wednesday 15th March 2023, 18:00-19:30. MB added that this meeting will be our first in person meeting since the pandemic. The secretariat will be in touch with the agenda and how to register in the New Year.

MB added that he is pursuing with the Scottish Parliament the potential of developing a hybrid system for CPG meetings to make them more accessible.

MB closed the meeting, thanked everyone for their attendance and wished everyone a Happy Christmas.