

Cross-Party Group on Cancer

Tuesday 18th September 2024, 18:00-19:00,
Virtual Meeting via Microsoft Teams

Minute

Present

MSPs

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

Invited guests

Neil Gray MSP, Cabinet Secretary for Health and Social Care
Janis McCulloch, Myeloma UK
Carol McGachie, Patient Advocate

Non-MSP Group Members

Sandra Auld, Healthcare Public Affairs
Kelly Blacklock, University of Edinburgh
Tracey Bowden, J & J Innovative Medicines
Fiona Brown, Pancreatic Cancer Action
Lorna Bruce, South East Scotland Cancer Network (SCAN)
Jennifer Cameron, Royal College of Occupational Therapists
Dawn Crosby, Pancreatic Cancer UK
Kate Cunningham, Ochre
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Sally Darnborough, Beatson West of Scotland Cancer Centre
Ryan Devlin, Individual member
Tonks Fawcett, University of Edinburgh
Helen Fleming, Individual member
Brian Forbes, AstraZeneca
Carol Gray Brunton, Edinburgh Napier University
Lily Green, Scottish Government
John Greensmyth, CLL Support
George Guy, ICUsteps
Roseann Haig, Circle of Comfort
Emma Hall, Make 2nds Count
Peter Hastie, Macmillan Cancer Support
Michael Heggie, Cancer Research UK (Secretariat)
Emily Hindmarch, Cancer Research UK (Secretariat)
Juliet Jarvis, Teenage Cancer Trust

Natasha Johnston, Pancreatic Cancer UK
Alison Keil, Scottish Government
Jude Kilbee, AMLo Biosciences
Murdina MacDonald, NHS Fife
Neil Macdonald, Merck Sharp & Dohme (MSD)
Lisa Macleod, Scottish Cancer Network
Liam Mac Lua-Hodgson, The Brain Tumour Charity
Rosa Macpherson, Individual member
Stella Macpherson, South East Scotland Cancer Network (SCAN)
Lorna May, Lilly UK
Kira McDiarmid, Breast Cancer Now
Gregor Mcnie, Scottish Government
Nicola Merrin, Alcohol Focus Scotland
Mairi Morrison, Cruse Scotland Bereavement Support
Ian Pirrie, Cancer Card
Esmé Pringle, Ettrickburn Ltd
Jessica Potter, Target Ovarian Cancer
Andrew Reynolds, Young Lives vs Cancer
Douglas Rigg, Scottish Primary Care Cancer Group
Graeme Rose, Novartis
Marion Sauvebois, Myeloma UK
Edwin van Beek, University of Edinburgh
Emma Walker, House of Hope
Helen Webster, British Dietetics Association
Catherine White, Alcohol Focus Scotland
Jo Williamson, Individual member
Alison Wright, Prostate Scotland
Billy Wright, Scottish Government

Apologies

Jackie Baillie MSP (Co-Convener)
Christine Campbell, University of Edinburgh
George Davidson, GlaxoSmithKline
Fiona Fernie, Clan Cancer Support
Georgina Giebner, British Dietetics Association
Jen Hardy, Cancer Card
Doreen Miller, Cruse Scotland Bereavement Support
Lorna Porteous, Scottish Primary Care Cancer Group
Johnstone Shaw, Fight Bladder Cancer UK
Mhairi Simpson, NHS Lanarkshire

1. Welcome & Minutes

Chair, Miles Briggs MSP (MB) opened the meeting and welcomed members. MB briefly described the meeting etiquette and the agenda. Minutes for the previous meeting on 23rd April 2024 were then approved without any amendments.

2. Update from the Cabinet Secretary for Health and Social Care

MB introduced Neil Gray MSP (NG), Cabinet Secretary for Health and Social Care, who had kindly accepted the CPG's invitation to provide an update to the group on the progress of the Cancer Action Plan. This follows the publication of the Scottish Government's (SG) 10-year Cancer Strategy in June 2023.

NG began by noting that the SG published its first annual Cancer Action Plan Progress Report in July. NG said that cancer remains a national priority for SG and across NHS Scotland. NG noted that SG's strategic aim is to improve cancer survival and provide excellent equitably accessible care. He said that SG's overall vision is that more cancers are prevented and that cancer services are providing excellent treatment and support, and as a result improving the outcomes and survival for people with cancer. NG noted that the first annual report covers the progress made up to March 2024 on the delivery of the action plan. He added that the actions and the work to develop headline indicators were at variable stages of progress, as at the date of publication of the progress report it was only ten months into the three-year plan. NG added that it is a welcome starting point in assessing potential indications of change in highlighting planned analysis to demonstrate early progress and the impact in the future. He thanked the range of individuals and organisations across SG, the health service, as well as the community and voluntary sector who have been working tirelessly to help deliver the 136 actions in that action plan.

NG noted the importance of prevention and supporting people to live healthy lives. With lung cancer continuing to be the most common cancer in Scotland, NG noted that he was hugely supportive of the publication of the tobacco and vaping framework last November. He welcomed the four nations' public consultation which ultimately led to the publication of the UK wide Tobacco and Vapes Bill. He noted that the SG have had very good collaboration with both the previous UK Government and the current UK Government on the Bill. The Bill will increase the age of sale for tobacco products and provide legislative powers on vape products, and NG noted that this presents an opportunity to create a smoke free generation and reduce the harms caused by smoking and vaping. NG also noted that following evaluation of the implementation of alcohol minimum unit pricing, he was glad that the Scottish Parliament voted to approve its continuation and increase its positive impact on public health with the new level of pricing coming into effect on 30th September.

NG stated that early diagnosis is hugely important for people with cancer to have the best possible outcomes and that's why SG continue to invest in their detect cancer earlier programme. The vision of the programme is to reduce later stage disease and focus on reducing the health inequalities gap. NG noted that SG continues to invest in optimal cancer diagnostic pathways and are activating an additional rapid cancer diagnostic service this year, bringing the national total to six. He added that these services provide primary care with access to a new fast track diagnostic pathway for people with non-specific symptoms suspicious of cancer such as weight loss and fatigue. NG highlighted the effectiveness of the rapid cancer diagnostic service. He also highlighted the re-run of SG's 'Be the Early Bird' campaign in August, which he said is important in encouraging people who are concerned about unusual symptoms

to face their understandable anxieties and fears and visit their GP. NG added that people living in the most deprived areas of Scotland are more likely to develop cancer than those living in the least deprived areas. He noted that it is therefore crucial that SG target this campaign at those aged over 40 from areas of deprivation.

NG stated that safe and effective treatments are critical to improving outcomes for each person with cancer and improving overall quality of life. He noted that the Scottish Cancer Network published the first three cancer clinical management pathways in September last year for breast, lung, and neuro-oncology. The work is ongoing for the next two around head and neck, as well as prostate. NG said that these new pathways clearly outline the patient journey from diagnosis onwards and guide consistent decision making across Scotland on optimal treatments available across the patient pathways and support shared decision making.

NG noted that chemotherapy and immunotherapy services continue to see demand rise year on year mainly due to the increasing number of diagnoses, of medicines being approved, and increased complexity of treatment. This has a knock-on effect on cancer services and as a result SG have committed to additional funding for these services on a phased approach reaching up to £10 million a year by 2026/27. He added that SG has released £4.6 million for this financial year and that funding will support the increased regional working, workforce recruitment, and maximise capacity across the existing workforce through initiatives like the non-medical prescribing and treatment closer to home. NG noted that SG have also mobilised the oncology transformation programme and work to progress this is moving at pace. He added that an oncology task and finish group has been established to develop a new service model for oncology on population basis that will be delivered by NHS Scotland through territorial boards.

NG said that the cancer strategy is about people with cancer, their families and carers. SG recognises the need for people with cancer to be central to all decisions involving them, ensuring that they have the support they need and that their voice is heard. NG notes that the 2024 Scottish Cancer Patient Experience Survey results show that 95% of people are positive about their overall experience. NG noted there is work to be done and mentioned feedback from patients regarding treatment times. NG added that the overall experience of people living with cancer and the experience that they receive from the NHS is positive, and that is down to the work of staff, clinicians, and all those that work in the health service. NG noted that SG will continue to drive improvements and continue to work in partnership with the likes of Macmillan to improve the service offered to people with cancer through the Transforming Cancer Care (TCC) programme, which is worth £27 million. NG said that agreements are in place for Scotland-wide coverage of the programme.

NG also discussed SG's Single Point of Contact (SPoC) approach which he said is the epitome of person-centred care. He highlighted SPoC projects in the Western Isles and NHS Lothian, as well as further support of over one and a half million pounds for all the twelve SPoC projects during this financial year. NG noted that the SPoC programme of work has improved the experience for people living with cancer through easing anxieties related to their care and treatment plans. He added that it has also demonstrated how clinical nurse specialist time has been freed up, allowing them to focus on more complex and role specific work. NG said in a recent visit to

Stornoway he heard how rural services are considering how they can best provide holistic care using initiatives like SPoC and the TCC Programme. NG noted that he is looking forward to working with Healthcare Improvement Scotland this year to consider how they can best scale up the SPoC programme so that all in Scotland can benefit from it.

NG stated that research and innovation are a core part of the NHS and central to reforming and improving healthcare services. He added that that research and innovation plays a key role in improving earlier diagnostic rates that enable access to new treatments and improving experiences. He noted that embedding research and innovation in all services is a key outcome in the cancer strategy. NG welcomed the Equity of Access to Cancer Clinical Trials report and said that he looks forward to seeing the expert group address how best to deliver against the report's recommendations. He noted that SG also continues to fund the Cancer Medicines Outcome Programme, which has developed a process to understand the effectiveness and safety of cancer medicines and routine care. NG also noted that the capture, analysis, and use of data are fundamental to understanding the whole system of cancer control and care. He further noted that SG has committed over £1 million this year to Public Health Scotland to strengthen and further develop the Scottish Cancer Registry and Intelligence System. NG added that SG must continue to identify and address data gaps aligned with our strategic aims and translate that into improved equitable treatment and care for people with cancer.

MB thanked the Cabinet Secretary for the update and then moved to the Q&A.

Q1: Dr Douglas Rigg (DR) – Scottish Primary Care Cancer Group

Clear and efficient communication is a key for optimal health care and cancer care in particular. This applies to communication with patients, with other clinicians, and management systems. There are digital and IT solutions that would make for a much improved patient experience, as well as reducing potential clinical issues. Will health care IT and digital innovation be prioritised to achieve these cost-effective benefits for patients, clinicians and the system as a whole?

A: NG said that we need to see greater improvement and investment with regard to IT and digital innovation. NG noted that SG's capital resources are limited but continuing the work on the 'digital front door' and having better data sharing across systems is going to be critical for seeing a health improvement and reform in health and social care. NG noted that SG will continue that work and he will try to push for it to be as fast as possible but capital restraints make that more difficult. NG added that he sees it as essential to see improvement in this area for the reasons DR set out.

Q2: Edwin van Beek (EvB) – University of Edinburgh

Lung cancer screening was formally approved for the UK Government last year and central funding was allocated. Can the Cabinet Secretary provide an update on the roll out of lung cancer screening in Scotland with particular emphasis on infrastructure and workforce?

A: NG acknowledged the UK National Screening Committee's (UK NSC) recommendations and noted that SG continues to work towards them to implement a targeted lung cancer screening programme in Scotland. He noted that SG are part of

the four nations group that was established by the UK NSC to explore some of the significant issues that must be worked through before a full lung screening programme can be implemented. NG added that SG has also established its own Scottish Expert Advisory Group (SEAG), and the remit of the group is to provide advice on the scope, implementation, and establishment of a targeted screening programme. NG said he can't provide any timelines regarding implementation until the SEAG completes its business case which they are working towards.

Q3: Kira McDiarmid (KMcD) – Breast Cancer Now

Can the Cabinet Secretary provide an update on the progress of action 44 in the Cancer Action Plan to carry out a clinically led review of latest data and evidence and determine whether there is merit in specific additional or alternative cancer waiting times standards for different types of cancer and cancer treatment?

A: NG stated that the work is ongoing and some of that has been explored in some of the discussions on reform and improvement around making sure that we have the right measures in place to adequately assess what good looks like within the NHS. NG offered to provide KMcD with a written update on the progress of this action.

Q4: Andrew Reynolds (AR) – Young Lives vs Cancer

In light of the Programme for Government's announcement that another rapid cancer diagnostic service will be established to reduce waiting times, whether the Cabinet Secretary can provide information on whether there are any plans to also fast-track the diagnostic pathway for people under the age of 18 with symptoms raising non-specific suspicion of cancer, such as weight loss and fatigue? Because we know that children and young people with cancer often have to visit their GP 3-5 or more times before getting a referral/diagnosis, which is more than adults.

A: NG noted that the rapid cancer diagnostic service is predominantly for those over the age of 18 but we would expect any young person that's presenting with potential cancer symptoms to be assessed as quickly as possible. NG added that there is an ongoing clinical refresh of the Scottish Referral Guidelines for Suspected Cancer and that's to make sure that the right person is on the right pathway at the right time, supporting earlier diagnosis. NG said that this will be published next year and it will include the updated guidance for children and young people suspected of cancer and the development of new non-specific symptoms referral guidelines.

Q5: Jessica Potter (JP) – Target Ovarian Cancer

Would the Cabinet Secretary please be able to provide an update on the steps being taken to reduce waiting lists for cancer surgery? Target Ovarian Cancer have been working with women diagnosed in Scotland who have experienced significant delays accessing vital surgery, with many having to go private to receive this treatment.

A: NG commended Target Ovarian Cancer's interactions with SG on this specific issue, as well as the work the charity is doing to support those that have been diagnosed with ovarian cancer in Scotland. NG stated that his expectation is that there should be cross-border referrals available. He noted that regional cancer networks have undertaken improvement work to reduce ovarian cancer surgery waits. NG noted that the multidisciplinary nature of the surgery for ovarian cancer means that scheduling can be challenging for some health boards, but actions have

been taken. This includes increasing the dedicated theatre capacity and improving joint working across theatre teams and surgical teams. NG added that SG will continue to monitor those activities and explore alternative actions that could help.

Q6: Nicola Merrin (NM) – Alcohol Focus Scotland

The Cancer Action Plan acknowledges alcohol as a risk factor for cancer and took several actions to reduce alcohol consumption and increase public awareness of this risk. Can the Cabinet Secretary update on progress against the actions to consult on more detailed proposals on alcohol marketing restrictions and to give consumers useful information on product labels?

A: NG stated that he is committed to this issue and that he wants it to be an evidence led process. NG highlighted his recent update to Parliament regarding plans to commission Public Health Scotland (PHS) to carry out a review of the evidence on the range of options to reduce exposure to alcohol marketing. He also noted that he was disappointed with some of the coverage around this announcement. NG noted that the review will narrow down the focus regarding what will make the difference in reducing problematic drinking and dependency, which leads to too many deaths. He stated that SG will consult on recommendations from the PHS review next year and will then bring forward any actions thereafter.

Q7: Doreen Miller (DM) – Cruse Scotland Bereavement Support (NB: MB read out the question on behalf of DM who wasn't in attendance.)

Given the increase in cancer cases and in the number of clients requesting assistance from Cruse Scotland Bereavement Support, can the Cabinet Secretary please agree on the importance of this free support and counselling and the urgent need of future funding to sustain this valuable service.

A: NG praised the work of Cruse Scotland particularly their helpline. NG noted that SG is to deliver on the funding agreement for 2024/25 that comes through the Children, Young People and Families Early Intervention and Adult Learning and Empowering Communities Fund. NG also highlighted other grants that are available. He added that SG is currently facing financial challenges, and the utmost importance has been placed on balancing their budget, but also in ensuring that they are taking decisions that are going to make the greatest difference to people. NG noted that despite those financial pressures SG provided over £200,000 this year to Cruse Scotland and will continue to review funding each year.

MB thanked NG for his time and for answering the questions of our CPG members. MB noted that the secretariat would gather any questions submitted by attendees in the meeting chat function that had not been taken and would put these to NG in writing. NG's response to the letter will be circulated to CPG members in due course.

3. Myeloma UK: Presentation on the In Mye Own Words campaign

MB introduced the second session of the meeting which was a presentation from Myeloma UK regarding their 'In Mye Own Words' campaign. He then handed over to

Janis McCulloch (JMcC) who is Head of Campaigns at Myeloma UK and Carol McGachie (CMcG) who is a Patient Advocate.

JMcC said that every day sixteen people will be told that they have the incurable blood cancer myeloma, and most will never have heard of it before their diagnosis. She noted that at any one time there are around 24,000 people living with myeloma in the UK. While all of those people can be treated, none of them can be cured. Treatment aims to control the disease, relieve complications and symptoms, and it generally leads to periods of remission. However, patients will inevitably relapse, and they will require further treatment. JMcC noted that myeloma has one of the longest times to diagnosis of any cancer and a third of those diagnosed will have visited their GP at least three times before diagnosis. A third of people will be diagnosed through an emergency route. JMcC said that current NHS targets for improving early diagnosis of cancer are mostly based on staging and this is more complicated for blood cancer. She added that we're still waiting on a target to be set around, reducing the number of cancers diagnosed through an emergency route, although this has been promised in the Cancer Strategy. JMcC said that myeloma mainly affects those over the age of 65, although it has been diagnosed in those much younger. Myeloma is 2-3 times more common in black people than in white people.

JMcC stated that Myeloma UK is the only UK charity focused on myeloma and is here so that no one faces the disease alone. JMcC highlighted some of the ways Myeloma UK supports people who are affected by the disease including securing access to treatments, funding research and improving early diagnosis. JMcC highlighted some of the most common symptoms of myeloma including pain, easily broken bones, fatigue, and recurring infections. These are often known as vague or non-specific symptoms and they can be dismissed as other conditions or signs of ageing, and this means that for many people their myeloma progresses, leading to further harm and lasting complications. She noted that the quality of life impact for people who have a delay in diagnosis can be extremely significant.

JMcC explained that because of the huge delays around diagnosis, Myeloma UK always runs at least one campaign that raises awareness of the signs and symptoms of myeloma. JMcC noted that the language people use to describe symptoms is often very different to the language used by medical professionals. Myeloma UK reached out to their supporters, fundraisers, and people who have been affected by myeloma and asked how they would describe their symptoms. This is how the 'In Mye Own Words' campaign was born. JMcC noted that the campaign was designed to bring to life the real words used by people who are living with myeloma in the hope that they would resonate with people. Myeloma UK took these descriptions and turned them into animations designed to emphasise the feelings that are associated with those symptoms. JMcC said that they had a series of animations covering each of the main symptoms and CMcG voiced one of the videos. These videos were shared across social media and used by the traditional media, and they encouraged people to check the Myeloma UK symptom translator.

JMcC noted that people who saw the campaign videos and were experiencing symptoms were encouraged to download the symptom translator and take it with them to their GP. JMcC then gave an overview of the symptom translator. Myeloma UK consulted people who have myeloma, GPs, and other healthcare professionals,

when developing the symptom translator. JMcC noted that the symptom translator was designed to make everybody's lives easier. She added that GPs are short of time and that it's really hard to go to your GP and describe what might seem like vague and unrelated symptoms, so the symptom translator makes this easier for patients. JMcC added that Myeloma UK encouraged their supporters to download a copy of the translator and to take it to their GP surgery. JMcC highlighted some of the positive feedback that Myeloma UK have received from people who took the translator with them to medical appointments. JMcC noted that the symptom translator was downloaded more than 2500 times in one week and the charity is currently carrying out mapping work to see which GPs they still need to reach out to. She added that the translator has been well received by Myeloma UK supporters, as well as GPs and healthcare professionals who have received it.

JMcC introduced CMcG's story which featured on the BBC as part of Myeloma Awareness Week in June and her story led to around 800 downloads of the symptom translator. JMcC asked CMcG to tell everyone about the first symptoms she remembers experiencing and what they felt like. CMcG said that her first symptoms were back and hip pain which would come and go, but it then got to a stage where it just wouldn't go away. CMcG then contacted the GP, which was during the Covid lockdown. The GP ruled out sciatica and told CMcG just to take some pain relief and to attend physio, which she did for months. CMcG explained that there was no improvement whatsoever and then she started to get pins and needles in her hands. CMcG said that she had a low B12 in the past and so they did a B12 blood test which showed it was fine, and there was no more follow up after that. CMcG then moved house which complicated the situation. CMcG had shingles twice, a chest infection, urine infection, and then went back to the GP again because the tingling had then moved to her feet. CMcG was referred to neurology where they did a blood test and found that she had paraproteins. She was then referred to haematology. CMcG noted that the whole process was probably about 8 to 10 months before she received her diagnosis. JMcC said that putting all the symptoms together is difficult because they all seem unrelated which CMcG agreed with.

JMcC asked why CMcG decided that she wanted to help raise awareness of the signs and symptoms of myeloma. CMcG answered the reason was to help with myeloma being diagnosed earlier. CMcG noted that myeloma isn't a well-known cancer and people often confuse it with melanoma, so there needs to be better awareness. CMcG added that her GP's awareness of melanoma has increased due to her case, but also the symptom tracker which has helped a lot. JMcC highlighted the amazing job CMcG has done in helping to raise awareness by sharing her story. JMcC asked CMcG if it would have helped having something like a symptom translator the first time she went in with her symptoms. CMcG said that visible examples that bring it all together would help the patient and GP to come to a conclusion. CMcG noted explaining symptoms in layman's terms helps and would have helped in her situation. MB thanked JMcC and CMcG for their presentation, particularly CMcG for sharing her own personal experience. MB also highlighted all the positive comments from meeting attendees in the meeting chat regarding the presentation and the campaign.

4. AOB

MB noted that this year's Scottish Cancer Conference, delivered by Cancer Research UK on behalf of the CPG on Cancer, will take place on Monday 25th November at the Edinburgh International Conference Centre. The theme of this year's event will be: 'Unlocking the power of health innovation'.

MB added that the event will explore how innovation within our health systems has the potential to transform cancer outcomes by preventing more cancers, diagnosing more cancers at an earlier stage, and providing equitable access to kinder and better treatments. He noted that registration will open shortly.

5. Close of Meeting

MB noted the next meeting date is still to be confirmed but will take place in December and will be the group's AGM. The secretariat will be in touch with more details on the next meeting agenda and how to register.