

Cross-Party Group on Cancer

1 March 2022

Minute

Present

MSPs

Miles Briggs MSP (co-convener, in the chair)

Jackie Baillie MSP (co-convener)

Invited guests

Humza Yousaf MSP, Cabinet Secretary for Health & Social Care, Scottish Government

Professor Aileen Keel, chair of the National Cancer Recovery Group

Professor Kevin Blyth, Scottish Mesothelioma Network

Anna Morton, Scottish Mesothelioma Network

Carolyn Macrae, Scottish Mesothelioma Network

Julie Roberts, Scottish Mesothelioma Network

Anna Lewis, Breast Cancer Now

Hannah Maybour, Breast Cancer Now

Non-MSP Group Members

Dawn Crosby, Pancreatic Cancer UK

David Weller, University of Edinburgh

Leigh Smith, MASScot

Benedict Lejac, Young Lives vs Cancer

Martin Coombes, Bristol Myers Squibb

Penny Richardson, Individual member

Ross Barrow, Royal Pharmaceutical Society

Sam Hemmati, AOP Orphan

Dan Cairns, Myeloma UK

Peter Hastie, Macmillan Cancer Support

Christine Campbell, University of Edinburgh

Kim Rowan, Individual member

Sandra Auld, Healthcare Public Affairs

David Cameron, University of Edinburgh

Georgina Giebner, British Dietetics Association

Audrey McNellan, Individual member

Heather Rankine, Exact Sciences

Lesley Shannon, Individual member

Neil MacDonald, Merck Sharp & Dohme (MSD)

Steve Brown, Roche

Karen McNee, Action Kidney Cancer
Nicky McManus, Pancreatic Cancer Action
Mhairi Simpson, NHS Lanarkshire
Lesley Stephen, Individual member
Jennifer Forsyth, Obesity Action Scotland
Stella MacPherson, South East Scotland Cancer Network (SCAN)
Lorna May, Lilly UK
John Kamoto, Leukaemia Care
Brian Forbes, Astra Zeneca
Greg Stevenson, Individual member
Michael Clancy, Law Society of Scotland
Jenni Hampson, Kyowa Kirin
Cathrin Griffiths, NHS Lothian
George Davidson, GlaxoSmithKline
Joe Woolcott, Prostate Cancer UK
Bradley Price, Sarcoma UK
John Macgill, Ettrickburn Limited
Charlotte Poulter, Cancer Support UK
Gillian Hailstones, Beatson Cancer Charity
Alice Clarkson, Pancreatic Cancer UK
Fiona Wardell, Healthcare Improvement Scotland
Rob Murray, Cancer Support Scotland
Clare Morrison, Royal Pharmaceutical Society
Adam Gaines, Prostate Scotland
Stephanie Kleynhans, The Brain Tumour Charity
Anne Gibson, Make 2nds Count
Heather Baxter, Lilly UK
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Edwin van Beek, QMRI University of Edinburgh
Melanie Mackean, NHS Lothian
Ahsan Akram, University of Edinburgh
Jack Feinmann, MHP Communications
Christine Boylan, Aberdeen Myeloma Support Group
Rachel Reel, Scottish Government
Seona Carnegie, Scottish Government
Carolyn Sunners, Scottish Government
David Ferguson, Cancer Research UK (Secretariat)
Michael Heggie, Cancer Research UK (Secretariat)

Apologies

Paul O’Kane MSP
Alison Tait, Individual member
Jessica Potter, Target Ovarian Cancer
Joanna Dunlop, Public Health Scotland
Julie Croft, Individual member
Liz Porterfield, Individual member
Tom Martin, Individual member

Welcome

Miles Briggs MSP opened the meeting and welcomed attendees.

Minutes of the previous meeting

The draft minutes of the meeting held on 1 September 2021 were approved without amendment. Miles Briggs MSP proposed that the draft minutes be adopted, and this was seconded by Jackie Baillie MSP.

Update from the Scottish Government

Miles Briggs introduced Humza Yousaf MSP, Cabinet Secretary for Health and Social Care at the Scottish Government, who had kindly accepted the CPG's invitation to address tonight's meeting. The Cabinet Secretary was accompanied by Professor Aileen Keen, the chair of the National Cancer Recovery Group. The Cabinet Secretary would deliver a short presentation and would then take questions from attendees.

The Cabinet Secretary thanked the CPG for the invitation to speak tonight, and noted that he had recently met, or was due to meet, a number of CPG member organisations. The Cabinet Secretary was keen to meet as many CPG members as possible and said anyone interested in setting up a meeting with him should contact his private office to arrange this (email: cabsechsc@gov.scot). The Cabinet Secretary acknowledged that cancer issues were intensely personal to many people present and reflected on the 1 February parliamentary debate marking World Cancer Day (WCD was 4 February) which Jackie Baillie MSP had secured. This was a particularly important opportunity for MSPs to speak about the impact cancer has had on them as individuals, or people very close to them. It was an important reminder that people are at the heart of any cancer plans and policies, and the Scottish Government would always pursue a person-centred approach wherever possible. The Cabinet Secretary described Covid-19 as the biggest shock the NHS in Scotland had faced in its 73-year existence. He acknowledged that challenges and difficulties concerning cancer services existed before the pandemic and had been exacerbated by Covid. One example was the 62-day waiting time target which had not been met pre-pandemic. Progress has been made lately but performance was still not where it should be. The pandemic made it necessary to take some very difficult decisions, such as pausing screening programmes, and the cumulative impact of these had led to what some third sector organisations had described as a "cancer timebomb." Over the last two years, a number of people had not presented to primary care and this had implications for cancer detection. The Cabinet Secretary referred to the National Cancer Plan and the actions contained, which were backed by over £114m of investment and underpinned by a "Once for Scotland" approach where everyone in Scotland should have equitable access to cancer services. The Cabinet Secretary referred to the Single Point of Contact pilot projects as a flagship initiative and said those would be evaluated and scaled up. He referred to the great work being done by Maggie's Centres on cancer "prehab." On detection and diagnostics, initial data suggested that the Early Cancer

Diagnostic Centres being trialled in NHS Ayrshire & Arran, NHS Dumfries & Galloway and NHS Fife were having a positive impact. A more detailed evaluation is still to come. The Cabinet Secretary said the National Cancer Plan runs until March 2023 and that a new plan would follow on from this. The Scottish Government was currently working with the National Cancer Recovery Group to consider the way forward. There would then be a programme of engagement with the third sector, CPG on Cancer, patients, and cancer survivors. The Cabinet Secretary invited questions from attendees. He would handle questions of policy, and would ask Professor Keel to address question of a more clinical nature.

Miles Briggs thanked the Cabinet Secretary and referred to questions which had been entered into the Zoom text chat by attendees. The first concerned progress with the rare disease action plan. The Cabinet Secretary conceded there had been only limited progress with the rare disease action plan given the need to focus resources on Covid response. Professor Keel said she was a member of the Rare Disease Implementation Board and said the Scottish Government was working closely with other UK countries to ensure consistency of approach across the UK but would also produce actions that are relevant specifically to Scottish patients with rare diseases. She said we could expect to see some further details within the next month or two.

Miles raised a question in the chat asking about targeted lung cancer screening. The Cabinet Secretary understood the desire to see lung cancer form part of the national screening programme. The Scottish Government was guided on this by the UK National Screening Committee which currently did not recommend this approach, but the Cabinet Secretary was keen to look into this matter in more detail. He was open to lung cancer screening in principle. Martin Coombes said he had a personal as well as professional interest in this issue: a close friend of his was dying with lung cancer which could have been picked up by a targeted lung cancer screening programme. Martin warned that if the UK National Screening Committee recommended a screening programme was introduced it would be very challenging to put this into practice. Other parts of the UK had run operational pilot schemes. Scotland needed to ensure it wasn't falling behind the rest of the UK. The Cabinet Secretary said he would consider scope for operationalising a pilot in anticipation of any recommendation. He had no in principle objection to this.

Professor Edwin van Beek said it was essential to plan for the introduction of lung cancer screening. He asked if there was scope for partnerships with commercial entities to get screening up and running as had happened in Wales. There would also be a need to ensure the necessary radiology workforce and screening equipment were in place. The Cabinet Secretary said discussions are taking place about how to respond to any lung screening recommendation, but no timeline was currently in place. He was instinctively uncomfortable about private sector involvement in the NHS but was keen to see what was happening in England & Wales in that regard. It was important to strike a balance between making necessary preparations but not overcommitting resources until it was clear that this recommendation would be made.

Sandra Auld asked a question, in her role as a service user representative on Perth & Kinross Integration Joint Board, concerning breast cancer services in NHS Tayside. In particular there was a perceived lack of foresight and anticipation by the health board of the impact of oncologist retirements and the impact upon services. There were

also difficulties with communications. The Cabinet Secretary said the breast cancer situation in NHS Tayside was not acceptable particularly for those patients who had to travel long distances for radiotherapy. He has met the chair and chief executive of the health board as well as clinicians at Ninewells Hospital. There was an issue with the oncology service across the country, but it was particularly acute in Tayside. He had seen no lack of effort from the health board in terms of recruitment. It had tried to anticipate and address the situation with staff retirements. The Cabinet Secretary had asked his senior cancer official to lead a short life working group to address the oncology workforce issues in Tayside specifically but also Scotland wide. This would look at scope for better mutual aid between health boards, what could be done to improve domestic recruitment, and to look at international recruitment especially from India. It was also important to give the public confidence in the service and to strengthen its reputation. The Cabinet Secretary had asked NHS Tayside to address this.

Professor David Cameron highlighted the growing importance of genomic medicine. He asked if serious consideration could be given to a co-ordinated approach to ensure patients across Scotland were given access to the right tests, that the process wasn't dominated by academics, that it was about both clinical trials and getting genomics into routine services so that all patients could have the right genomic analysis. This would be cost saving as well as lifesaving. A co-ordinated approach was essential. The Cabinet Secretary said the last two years of the pandemic has shown just how important genomics are. Scotland had not been where it needed to be on genomics in the past and there was an ambition to improve. The Scottish Government recently had discussions, led by the Deputy First Minister and involving the Chief Scientist and a range of policy and operational areas, to ensure the Scottish Government was working in a single co-ordinated way and avoiding silo working. The First Minister had made a commitment in the 2021 Programme for Government to invest in genetic laboratories and genetic services. NHS National Services Division (NSD) would be carrying out a review of NHS Scotland's genomic services, identify gaps and advise on next steps. Decisions would be taken by the Scottish genomics leadership group chaired by the Chief Scientist and the NSD Director. The Cabinet Secretary would consider the idea about a single point of contact and would respond subsequently.

Miles Briggs thanked the Cabinet Secretary and Professor Keel for attending. He hoped the Cabinet Secretary would attend another meeting of the CPG on Cancer in the near future. The CPG would gather any questions submitted by attendees which had not been taken tonight and would put these to the Cabinet Secretary in writing. Miles asked CPG members to contact the CPG secretariat (email: crosspartygroup@cancer.org.uk) if they have any additional issues to raise with the Cabinet Secretary. These will be included in the CPG's letter to the Cabinet Secretary.

The Cabinet Secretary reiterated his willingness to meet CPG members and invited them to email his office at cabsechsc@gov.scot. The Cabinet Secretary would write to the CPG to follow up on any actions arising from tonight's discussion.

Presentation by Scottish Mesothelioma Network

Miles Briggs introduced Professor Kevin Blyth who had offered to speak to the CPG about the development of the Scottish Mesothelioma Network and mesothelioma services in Scotland. Professor Blyth began by describing and defining mesothelioma – a form of cancer occurring mainly in the lining of the chest (the “pleura”), driven by exposure to asbestos. The disease had a long latency period, and when diagnosed survival was typically around one year. Scotland was at the epicentre of a global problem: the UK had the highest incidence of mesothelioma in the world, and Scotland had the highest rate of cases within the UK. There were around 200 cases a year in Scotland, with most cases arising within the River Clyde estuary due to the connection between asbestos and shipbuilding. More recently there were increasing numbers of cases due to environmental exposure to asbestos e.g. in school buildings.

Professor Blyth described the process of developing the Scottish Mesothelioma Network. As recently as 2016 there were no specific mesothelioma services. As a rare cancer it was not included in cancer waiting times or audits and there was no incentive for health boards to develop mesothelioma services. The Southern General Hospital in Glasgow had developed local thoracoscopy services in 2010 for the diagnosis of mesothelioma, and this had been followed by a West of Scotland regional mesothelioma multidisciplinary team (MDT) which took forward mesothelioma research. In 2015 the charity Mesothelioma UK provided a funded clinical nurse specialist post, which was the first such post in Scotland. The next big step forward for the development of the Network was a programme of engagement with mesothelioma patients and families, led by his colleague Julie Roberts, which led to a roundtable in Holyrood chaired by Kezia Dugdale. This resulted in a members’ business debate in the Scottish Parliament which was the catalyst for a funding bid for a national network. £1.2m of pump priming funding over three years was made available commencing in 2019 from a consortium of charities (Action on Asbestos, Macmillan Cancer Support, Mesothelioma UK) allowing the Scottish Mesothelioma Network to be formally launched in April 2019. Professor Blyth drew attention to the development by the Scottish Mesothelioma Network and key stakeholders of mesothelioma quality performance indicators (QPIs) launched in June 2019. Health boards are assessed against these indicators, which provides a real impetus to improve service standards. Kevin said mesothelioma in Scotland is the only area in the UK with a direct mechanism for performance-driven service improvement.

The Scottish Mesothelioma Network operates as a “hub and spoke” model, with the hub in Glasgow and spokes in Inverness, Aberdeen, Dundee and Edinburgh. The Scottish Mesothelioma Network funds lead clinicians and mesothelioma nurse specialists in those areas who develop services in these areas. There is a national mesothelioma MDT.

Professor Blyth described the outcome of a major clinical trial – Checkmate 743 – which evaluated the use of nivolumab in combination with ipilimumab compared to chemotherapy in patients with previously untreated malignant pleural mesothelioma. The new treatment had resulted in a significant improvement in outcomes for patients. The Scottish Mesothelioma Network had coordinated the recruitment of trial participants from across Scotland and ensured all eligible Scottish patients were invited to take part. Professor Blyth also drew attention to the Scottish Mesothelioma

Network's website which contained important information for patients. He referred to the patient and carer virtual support group run in association with Maggie's Centres, and a range of educational events for patients and carers and clinicians. The Scottish Mesothelioma Network won the innovation award at the recent Scottish Health Awards 2021.

The Scottish Mesothelioma Network's pump priming funding runs out in April 2022, and discussions are in hand about the transition across to the new Scottish Cancer Network. Professor Blyth concluded by summarising the Cancer Research UK funded "PREDICT-Meso" study which he is leading, and which aims to develop a better understanding of how asbestos-driven inflammation develops into mesothelioma, leading to more effective diagnosis and earlier, better treatment for patients.

Miles Briggs thanked Professor Blyth for a very interesting presentation and expressed admiration for the achievements of the Scottish Mesothelioma Network over what was a relatively short time. Miles asked whether any work was being done on tracing or early screening of people who were at high risk of mesothelioma. Professor Blyth referred to some screening studies conducted in Italy of asbestos exposed workers which didn't find many cases of mesothelioma. Generally, there is no proven benefit from this approach. Miles asked about the impact upon the Scottish Mesothelioma Network of Covid. Professor Blyth said the work had carried on normally throughout the pandemic period. Miles asked about mesothelioma Quality Performance Indicator (QPI) data. Professor Blyth said it was due to be published soon.

Professor Keel paid tribute to the achievements of the Scottish Mesothelioma Network and suggested there was now some hope on the horizon for sufferers of this disease.

Miles Briggs concluded by thanking Professor Blyth for a fascinating session and congratulated him and the team for all their great work and achievements.

Presentation by Breast Cancer Now: secondary breast cancer audit for Scotland

Miles Briggs introduced Anna Lewis, Policy Manager at Breast Cancer Now who would present to the CPG on secondary breast cancer, specifically on auditing. Anna explained that secondary breast cancer, also known as metastatic or Stage 4 cancer, is cancer which has spread to other parts of the body e.g. the bones, liver, brain, lungs. There are around 3,400 people in Scotland with secondary breast cancer. On average people live for around 2 – 3 years. In 2019 Breast Cancer Now carried out a survey of people living with secondary breast cancer. The challenges highlighted in the survey included diagnosis, timely access to support and treatment, and participation in research and clinical trials. The biggest challenge was that there is a lack of data and insight across the UK on this patient group and on details of their care and treatment. This data is not currently collected routinely in Scotland, either at local or national level, and Breast Cancer Now is calling for better data collection and an audit of secondary breast cancer in Scotland. An audit would lead to better data, and to identify what treatment and care is being delivered and whether it is in line with national standards. An audit could also inform national policy, best practice and guidance. Anna said

Scotland already has experience of conducting other audits, and participating in UK-wide audits, so this would be a new concept. An audit could utilise existing data including from the Scottish Cancer Registry, Quality Performance Indicators (QPIs) and the cancer intelligence platform. This would help reduce the burden on clinicians.

Anna said the Scottish Government's 2016 Beating Cancer: Ambition and Action cancer strategy contained commitments around improving data collection on secondary cancers. This commitment was not, however, carried over to the subsequent Recovery & Redesign: An Action Plan for Cancer Services. NHS England and the Welsh Government are taking forward a secondary breast cancer audit in those territories. So far, Scotland has not committed to following suit. Breast Cancer Now will continue to make the case for an audit, will continue to engage with patients and clinicians, and make a submission to the next Scottish cancer strategy document when the time comes.

Miles Briggs thanked Anna for her presentation and said he and Jackie Baillie had raised this issue in parliament over a long period. There was therefore support within the CPG. Miles asked what information had been derived by Breast Cancer Now from Freedom of Information (FOI) requests to health boards. Anna said a 2018 FOI had found around 1,000 patients in Scotland with secondary breast cancer. But only around 38% of health boards were able to respond to the request. This suggested there was a degree of complexity about how this data is being collected and there is no reliable means of determining the needs of this patient population and the impact upon service delivery.

Professor David Cameron completely agreed with the need to obtain such data, but he was not a fan of bespoke audits for a single disease. It's a lot of effort and the data lack longevity. He said there was reasonably good evidence that discussing patients in a multidisciplinary forum when they have a cancer problem is better for their care. He suggested services should discuss recurrent cases at an MDT and use that same conversation to capture the data. This would improve the service for patients and help us understand the data. He said we need this approach for all cancers, not just breast cancer. Anna Lewis said this was helpful, and data collection was the fundamental thing. An audit was just the means by which such data would be collected. Breast Cancer Now would be willing to consider other approaches which would also deliver the desired outcome.

Professor Edwin van Beek noted the lack of research support available in radiology.

Miles Briggs referred to some comments in the Zoom chat function about recording of data and asked whether the Scottish Cancer Registry had capacity to record this data. There was a suggestion in the chat that Scotland could perhaps join in with the work which was already underway in England and in Wales. Anna said the Scottish Cancer Registry doesn't have the data readily available and can only provide a number: the Registry can't provide insights into outcomes etc. She said as a UK wide organisation Breast Cancer Now would support the participation of Scotland in the audit currently being undertaken by governments in England and Wales.

Miles thanked Anna for her presentation and said the CPG's follow up letter to the Cabinet Secretary could incorporate some of the points raised in discussion.

Any other business

No other business was raised.

Miles invited attendees to contact the CPG secretariat if they have any suggestions for future CPG business (email: crosspartygroup@cancer.org.uk).

Date of next meeting

The next meeting is scheduled for Monday 6 June 2022. This would be an online meeting and will take place in the early afternoon, in response to those members who have requested a daytime meeting. Miles hoped that CPG meetings would take place in person soon.

Close

Miles closed the meeting and thanked everyone for their attendance and participation.