Cross-Party Group on Cancer

Wednesday 15th March 2023, 18:00-19:30, Virtual Meeting Via Microsoft Teams

Minute

Present

MSPs

Jackie Baillie MSP (Co-Convener, Chair)
Miles Briggs MSP (Co-Convener)

Invited guests

Sorcha Hume, Cancer Research UK
Iona Stoddart, Jo's Cervical Cancer Trust
Kate Sanger, Jo's Cervical Cancer Trust
Hannah Wright, Jo's Cervical Cancer Trust
Rachel Reel, Scottish Government

Non-MSP Group Members

Johnstone Shaw, Fight Bladder Cancer UK
Natasha Johnston, Pancreatic Cancer UK
Christine Boylan, Aberdeen Myeloma Support Group
Martin Cawley, Beatson Cancer Charity
Jennifer Cameron, Royal College of Occupational Therapists
Andrew Todd, Myeloma UK
Ian Pirrie, Cancer Card
Megan MacDonald, Pancreatic Cancer Action
Helen Fleming, Individual member
Gareth Inman, University of Glasgow
Douglas Rigg, Scottish Primary Care Cancer Group
Lorna Porteous, Scottish Primary Care Cancer Group
Lesley Shannon, Individual member
Peter Hastie, Macmillan Cancer Support
Anne-Marie Barry, Breast Cancer Now
Dawn Crosby, Pancreatic Cancer UK
Jennifer Forsyth, Obesity Action Scotland
Penny Richardson, Individual member
Karen McNee, Action Kidney Cancer
Christine Mitchell, Individual member
John Greensmyth, CLL Support
Neil MacDonald, Merck Sharp & Dohme (MSD)

Michael MacLennan, Cancer Support Scotland
Ben Lejac, Young Lives vs Cancer
Annie Anderson, Scottish Cancer Foundation
Jessica Potter, Target Ovarian Cancer
Jane Gordon, Scottish Health Action on Alcohol Problems (SHAAP)
Monica Davison, Lilly UK
Doreen Miller, Cruse Scotland Bereavement Support
Greg Stevenson, Greg Stevenson Consulting Ltd
Linda Sherwood, NHS Lothian
Julie Wardrop, CANDU (Dundee Cancer Support Network)
Steve Brown, Roche
George Guy, Individual member
Helen Webster, NHS Tayside
Jennifer Layden, Healthcare Improvement Scotland
Tonks Fawcett, University of Edinburgh
Sharon Cowell-Smith, NHS Lothian
Michael Heggie, Cancer Research UK (Secretariat)
Emily Hindmarch, Cancer Research UK (Secretariat)

Apologies

Jo Williamson, Individual member
Edwin van Beek, University of Edinburgh
Brian Forbes, AstraZeneca
Tom Martin, Individual member
David Cameron, University of Edinburgh
Karen Bell, Beatson West of Scotland Cancer Centre
Hannah Drew, Royal College of Radiologists
Ahsan Akram, University of Edinburgh
Janis McCulloch, Myeloma UK

1. Welcome & Minutes

Chair, Jackie Baillie MSP (JB) opened the meeting and welcomed members. JB then briefly described the meeting agenda and etiquette. Minutes for the CPG on Cancer meeting on 14th December 2022 were then approved without any amendments.

2. Cancer Research UK: Deprivation and Cancer Inequalities in Scotland

JB handed over to Dr Sorcha Hume (SH) who presented on Cancer Research UK's (CRUK) Deprivation and Cancer Inequalities in Scotland Report. SH said that the report offers the first comprehensive picture of deprivation and cancer in Scotland, setting out in detail the inequalities in health and cancer. The report considers three key areas: prevention, early diagnosis, and treatment, to demonstrate the impact that deprivation has on the cancer pathway.

SH noted the need to close the gap, because beating cancer must mean beating it for everyone. SH explained that health inequalities are unfair, avoidable, and systemic differences in health between different groups within society. The scale of deprivation is often quantified using a relative measure called the Scottish Index of Multiple Deprivation. CRUK's report looks at levels of deprivation across Scotland and how it can impact on cancer incidence and outcomes. SH highlighted the variation of levels of deprivation between different Health Boards in Scotland. SH noted that cancer is more common in more deprived populations in Scotland. Cancer incidence rates in the most deprived group are 33% higher than in the least deprived. It is estimated that around 4900 extra cancer cases each year are attributable to deprivation which equates to more than 13 extra new diagnoses per day. There are also more cancer deaths in more deprived populations, with mortality rates 74% higher in the most deprived populations compared to the least deprived.

CRUK's report found that smoking rates in the most deprived populations are much higher in the least deprived populations. On obesity, adults from the most deprived populations are more likely to be obese than those from the least deprived populations. Current projections indicate that the adult obesity prevalence is likely to decrease from 22% in 2019 to 19% in 2040 for the least deprived quintile but increase from 36% to 41% for the most deprived. Obesity rates in children are twice as high in the most deprived compared to the least deprived areas. Over the last 20 years, the proportion of children who are overweight or obese has increased for the most deprived but decreased for the least deprived. SH noted that this could lead to a greater burden of cancer amongst more deprived groups in Scotland.

SH noted that there is a large discrepancy in uptake of screening invitations between more and less deprived groups. CRUK has found that people from the most deprived populations in Scotland are less aware of potential cancer symptoms. The report also shows that people from the most deprived populations are significantly more likely to report barriers to seeking help than the least deprived. This includes facing difficulty getting a doctor's appointment at a convenient time, thinking the symptom was related to an existing condition, and not feeling confident talking about symptoms. SH noted that nearly 1 in 5 people with cancer in Scotland are diagnosed through emergency referral, and people diagnosed through emergency presentation are more likely to have poor survival rates. SH added that data isn't available on emergency referrals by deprivation level in Scotland, but data from other countries suggests that the most deprived populations are 50% more likely to be diagnosed through emergency presentation. The report found that for some cancers, people from more deprived populations are more likely to be diagnosed with advanced stage cancer, which contributes to poor survival. CRUK projections estimate that the difference between the most and least deprived will remain the same by 2032 if no further action is taken to improve early diagnosis. SH noted that available data is limited so these estimates should be interpreted cautiously, but they demonstrate the scale of the challenge over the next decade.

Regarding treatment, SH noted that there is no data available on differences in cancer waiting times by deprivation, but data does show large variation between Health Boards. SH added that there is no routinely reported data on the cancer treatment people receive broken down by deprivation level, however we know that there is variation between more and less deprived populations in other countries.

CRUK's report found that barriers to accessing treatment, such as people living at a distance from treatment centres, are likely to be a significant factor in deprivation-related differences in treatment. Less optimal treatment modes have been chosen or prescribed to some patients to avoid them having to travel. Patients also face barriers to accessing clinical trials, which disproportionately impacts certain groups and can subsequently lead to them being under-represented in cancer research.

SH noted that CRUK's report shows that more deprived groups face significant barriers to good health across the cancer pathway, creating unacceptable inequalities in cancer incidence and outcomes. SH added that these inequalities are not inevitable, and that we must work together across health organisations, governments, communities, and charities in order to achieve progress for everyone. SH noted that the reports three main recommendations are 1) The Scottish Government (SG) and NHS must fund and roll out interventions that tackle the known drivers of inequalities. This includes smoking and obesity, which disproportionately affect more deprived populations. 2) We must take bold action to diagnose cancers earlier and ensure everyone has access to the right treatments for them. This starts with removing barriers to seeking help for all groups, enabling people to get timely access to health services. 3) We must build a much stronger understanding of where inequalities exist and what is driving them. SH explained that to do this, we need to strengthen data collection, infrastructure, and access. In her closing remarks, SH stated that SG must take action to tackle cancer inequalities across the pathway, because beating cancer has to mean beating it for everyone.

JB thanked SH for her presentation and opened to questions from attendees. On the need for better data collection on inequalities, Anne-Marie Barry (AMB) noted the commitment in the draft cancer strategy to include data around race and ethnicity. AMB asked what other data CRUK would be looking for, what the timeframe would be to collect this data, and how this would be achieved. SH noted the findings of the CRUK report regarding the lack of data in this particular area and highlighted that this data is gathered in other countries so it can be achieved. SH pointed towards the upcoming cancer strategy and said the sooner this data is available the better. Douglas Rigg (DR) noted that health inequalities are wider than deprivation (e.g. rurality, race, ethnicity, etc) and said that we shouldn't focus solely on deprivation. DR asked if CRUK had a specific policy regarding how to address the issue of access to primary care, as well as changing health seeking behaviours. SH acknowledged DR's point about health inequalities being wider than deprivation and offered to pick up DR's question after the meeting, as she didn't have the information to hand. John Greensmyth (JG) noted the bowel, breast, and cervical cancer data in the report and asked if any data was available relating to blood cancers. SH explained that this data isn't available and that this was one of the challenges highlighted in the report. George Guy (GG) asked if patient groups were involved with the report. SH said that CRUK's report was data focussed and there weren't patients involved in its development, but noted the importance of the patient voice.

JB thanked SH for her presentation and said the CPG would be interested in hearing about any follow up work CRUK does on deprivation and cancer inequalities.

3. Jo's Cervical Cancer Trust: Preventing and Eliminating Cervical Cancer in Scotland

JB welcomed Iona Stoddart (IS), Kate Sanger (KS), and Hannah Wright (HW) from Jo's Cervical Cancer Trust. IS said that they would be talking about their vision of a day where cervical cancer is a thing of the past. IS added that Scotland is in a strong position to be the first part of the UK to achieve this. She explained that their presentation would discuss this vision, what needs to happen to make it a reality, as well as give an insight into the work of Jo's Trust in Scotland to achieve this goal.

In January, Jo's Trust launched their biggest ever campaign: We can end cervical cancer. During Cervical Cancer Prevention Week the charity visited Holyrood and Westminster, reached hundreds of thousands of people across traditional and social media, released the #WeCan campaign film, and published their latest report. IS noted that this report was on the back of the World Health Organisation's global call in 2020 to eliminate cervical cancer. Jo's Trust looked at what needs to be done in the UK and Scotland to make this happen, so they spoke to over 800 professionals working in cervical cancer prevention and treatment, to find out the challenges and the opportunities to eliminate cervical cancer. IS explained that what they found from speaking to these professionals is that there were key themes around the challenges and opportunities. Some of the challenges included workforce and capacity along the whole prevention pathway, inequalities and barriers to participating in prevention programmes, the need for investment in technology and IT, and a low understanding of HPV and cervical cancer across UK populations. 70% of the professionals spoken to by Jo's Trust identified HPV self-sampling as the biggest opportunity. Other areas of opportunity that were identified included how we use the HPV vaccine, how we can use targeted/risk-based screening, improving IT systems, and better HPV and cervical cancer awareness/education.

IS explained that we have successful HPV vaccination programmes across the UK. Uptake in Scottish schools is 85% compared to around 60% in England, around 56% in Northern Ireland, and around 55% in Wales. However, there is no one team responsible for overseeing the cervical cancer prevention pathway. IS noted that different parts of the pathway come under different teams so there is no joined up approach. Jo's Trust are therefore calling for national strategies and commitments that recognise the importance of the entire cervical cancer prevention pathway and commit to improvements and innovations throughout.

IS noted that cervical cancer elimination should not leave anyone behind, but we know inequalities do exist. Cervical cancer deaths are more common in women living in the most deprived areas of the UK. HPV vaccine uptake is lower amongst those living in areas with high levels of deprivation and those previously excluded or not in school. IS noted that as well as deprivation we know that other inequalities exist and that's also the case when it comes to screening. The Jo's Trust report found that two-thirds of physically disabled women have been unable to attend their cervical screening appointment, almost half of sexual violence survivors have not attended, women living in poorer areas are less likely to participate in the programme, and 80% of women in full-time work struggle to get a convenient appointment time. Jo Trust's existing work in Scotland is focused on informing, empowering, and

supporting underrepresented groups and looking at how to tackle these barriers to ensure that women who are eligible for screening are able to attend appointments.

IS explained that Jo's Trust are involved in a number of national activities in Scotland to represent the voice of women and people with a cervix. IS said that they currently sit on or are involved with the – Cervical Screening Programme Board, Equity in Screening Strategy for Scotland, Core Screening Standards Development Group, Scottish Cancer Coalition, and Scottish Cervical Screening Programme Review.

The groups of women that Jo's Trust are working with in Scotland are those who have been identified as less likely to attend or participate in the cervical screening programme. These are women in ethnic minority groups, menopausal women, women aged 25–29 living in areas of deprivation, women with a learning disability, and those living in rural communities. Jo's Trust are engaging with Health Boards to support them in their existing work. They're also working with Health Boards to look at inequalities and how they can access the target groups living in these areas. IS noted that Jo's Trust are currently working with nine Health Boards. Jo's Trust work with Health Boards includes providing Health Improvement/Public Health team training, running focus groups with the target groups, and sample taker training.

Jo's Trust have also developed new partnerships which is key to reaching the highest number of people. IS noted that Jo's Trust are working with Glasgow City Football Club to raise awareness of their work with social media comms from the club, goal-side banners, as well as awareness sessions with players and staff. IS added that Jo's are also working with Enable Scotland by holding awareness sessions, focus groups and co-producing a new easy read booklet. Jo's are also currently working in partnership with HomeStart and Menopause Warriors Scotland. IS noted that ethnic minority groups have barriers which are specific to their own needs, therefore Jo's have different pieces of ongoing work to tackle these barriers. Jo's are working with Polish women through the West of Scotland Regional Equality Council to produce translated material and hold translated advice sessions. IS said that Jo's also have a partnership with the Health Improvement team in NHS Greater Glasgow & Clyde to produce translated material for the Chinese community. Jo's Trust are also working with a Mosque in Lanarkshire to engage with South Asian women and understand how best to deliver their messaging to that group.

JB thanked IS and initiated the Q&A by noting her comments regarding good screening and vaccination programmes in Scotland and asked what more needs to be done for us to reach the goal of consigning cervical cancer to the history books. IS said that the joined-up approach is key with the different programmes speaking to each other to provide an overall view of the cervical cancer prevention pathway, and Jo's are looking for a commitment from SG that a joined-up approach is a priority. KS spoke about ensuring the workforce across the pathway is supported and well resourced. HW highlighted the need for a holistic approach and noted the importance of increased awareness and education throughout the pathway.

GG noted the importance of translating patient information material and campaign videos in order to reach ethnic minority groups. IS said that Jo's want to engage more with the groups they're working with and echoed an earlier comment from GG regarding listening to and learning from the people they're trying to support. Penny

Richardson (PR) noted that she was a founding member of the cervical smear campaign in Scotland during the 1980s and spoke about its success. DR asked if there was any progress on introducing point of care testing and if it would encourage more people to attend appointments due to the quicker results. KS said point of care testing isn't on the immediate horizon, but research into HPV self-sampling is being progressed. KS also noted Jo's Trust support for introducing self-sampling.

JB noted the positive comments from various attendees in the chat bar regarding the presentation from Jo's Trust. JB thanked IS, KS, and HW for their presentation.

4. Update on New Cancer Strategy

JB welcomed Rachel Reel (RR), Team Leader of the Scottish Government's Cancer Policy Team, to update on the upcoming National Cancer Strategy. JB noted that the new 10-year cancer strategy will replace the current Cancer Recovery Plan. RR explained that it will be a 10-year strategy underpinned by three 3-year action plans. RR said that the idea behind this is to set out a long-term strategic aim, but SG also feel it's important to have 3-year actions plans to take stock of progress, as well as amend or add actions to ensure they're progressing towards their strategic aims. The three action plans will be aligned to the recover, renew, and reform continuum. RR added that the first 3-year action plan will be aligned to the recover phase.

RR gave a brief overview of the current policy environment and noted that several existing SG strategies intersect and highlighted some key existing documents that have fed into the development of the new strategy including the National Clinical Strategy 2016, NHS Recovery Plan 2021, and Workforce Strategy 2022.

With regard to developing the strategy, RR noted that SG underwent a public consultation in April 2022 which received 257 responses from a range of individuals and the analysis of the responses received was published in November 2022. SG held seven focus group sessions with people living with cancer in Aberdeen, Edinburgh, Glasgow, and remotely. SG also held two focus group sessions with third sector organisations, as well as separate meetings with the Scottish Cancer Coalition and Less Survivable Cancers Taskforce. RR noted that there were a number of common themes that emerged from the public consultation and engagement including ensuring equal access to treatment and care, prevention, person-centred approach, research and innovation, workforce, rare and less survivable cancers, the impact of the COVID-19 pandemic, and cancer survival.

With the key findings of the engagement process SG have developed its Outcomes Framework which forms the basis for the strategy. The framework outlines eleven ambitions which feed into the outcomes and the overall strategic vision which is "More cancers are prevented, and a compassionate and consistent cancer service provides excellent treatment and support throughout the cancer journey, and improves outcomes and survival for people with cancer." SG have also adapted the Socio-ecological Model which RR explained through a graphic (five spheres). The model demonstrates how the individual is at the centre and interacts with services and policies. RR noted that many of the components may be influenced but not

necessarily controlled. The spheres are Policy, Community, Organisational/Cancer Services, Interpersonal/Support Structures, and Individual/Patient.

RR again noted that there will be eleven ambitions in the strategy, and she provided an overview of these areas which are: eradicating inequalities, prevention, earlier and faster diagnosis, pre-treatment, treatment, post-treatment, workforce, person-centred care, mental health, research and Innovation, and cancer Intelligence.

RR spoke about some of the challenges and risks that SG foresee for the delivery of the strategy which include service pressures and increasing demand, the fiscal environment, competing priorities, and the ownership and governance of actions. RR added that SG is developing a separate monitoring and evaluation plan which will be underpinned by key theories of change, as well as indicators and targets. Regarding next steps, RR advised that the strategy is waiting to be signed off by the Cabinet Secretary for Health and Social Care, with the publication launched in Spring. RR noted that the SNP leadership contest might delay the publication of the strategy. She added that the publication of evaluation framework will be in the Summer.

JB thanked RR for the update and opened to questions. JB read a question in the chat bar from JG regarding the status of resourcing for Clinical Nurse Specialists, and whether this features in the strategy. RR noted that workforce is a key feature but said she was currently unable to speak about specific actions. PR asked if the strategy would ensure patients are kept informed throughout the cancer pathway. PR specifically noted the need for an easy-to-understand record which patients could refer to. RR referenced the single point of contact pilots which are aiming to support patients in this way. RR noted that the strategy will reflect realistic medicine to ensure clinicians are having conversations with patients about their treatment and providing information material for them to take away. SG are also working with NHS Inform to ensure the cancer pages are up to date and accessible. Jennifer Forsyth (JF) asked if the strategy will have a prevention action plan, and if any of the indicators and targets in the monitoring and evaluation plan will be in relation to prevention. RR noted that prevention will have its own vision in the strategy with several actions sitting under it. RR said that there will be a focus on tobacco, healthy weight, physical activity, alcohol, and cervical cancer vaccines. RR added that prevention is one of the key overarching ambitions in the strategy.

GG welcomed the inclusion of improving the cancer journey in the strategy but noted his concern that there is no mention of peer support anywhere in the plan. RR acknowledged GG's point regarding there being no mention of peer support in the draft strategy and offered to meet with him to discuss it further. Johnstone Shaw (JS) echoed GG's comments on the value of peer support. Following on from PR's question, JS noted his surprise that there isn't more in the draft strategy about communication with patients. He suggested the possibility of training clinicians in speaking to patients about their diagnosis and treatment. RR said that there are actions in the strategy to develop educational tools and ensure clinicians are aware of existing resources that can support these conversations. RR also said JS was free to email her regarding this issue. Helen Webster (HW) asked whether the strategy will bring funding for professionals, such as dieticians, needed to deliver the targeted aspects of prehabilitation. RR said that it won't and noted current financial

constraints faced by the government. RR said the focus will be making better use of current resources and upskilling.

Gareth Inman (GI) noted the lack of plans for an integrated cancer research strategy alongside the overall cancer strategy. RR said that there will be a section in the strategy on research and wider innovations. RR added that the Equity of Access Short Life Working Group recently published a report with a number of recommendations which included developing a cancer research strategy. The new strategy will take into consideration the recommendations from the Equity of Access Short Life report. PR noted that the previous cancer strategy included a promise that a treatment summary would be available for every cancer patient in Scotland and asked what progress has been made so far and will that promise be carried forward to the new strategy. RR explained that this work has been piloted and they're now looking to upscale it. RR added that SG are keen to prioritise this work going forward.

JB thanked RR for her update and for answering questions from attendees. JB added that the CPG is looking forward to the publication of the strategy soon.

5. AOB

There was no AOB at the meeting.

6. Close of Meeting

The date of the next meeting date is still to be confirmed but will take place in June. JB added that the secretariat will be in touch with more details on the June meeting agenda and how to register in due course.