Cross-Party Group on Cancer

Wednesday 18th December 2024, 18:00-19:00, Virtual Meeting via Microsoft Teams

Minute

Present

MSPs

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

Invited guests

Emily Eagles, Cancer Research UK
Kathleen McHugh, Macmillan Psychological Support Project
Helen Moffat, Macmillan Psychological Support Project
Jennifer Cameron, Macmillan Psychological Support Project
Laura Challinor, Blood Cancer UK
Josh Hill, Blood Cancer UK
Kate Keightley, Blood Cancer UK

Non-MSP Group Members

Ahsan Akram, University of Edinburgh
Sandra Auld, Healthcare Public Affairs
Ally Boyle, Individual non-member
Fiona Brown, Pancreatic Cancer Action
Matt Bull, Exact Sciences
Anna Campbell, Edinburgh Napier University
Dawn Crosby, Pancreatic Cancer UK
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Caroline Donoghue, Myeloma UK
Brian Forbes, AstraZeneca
Calum Goodfellow, Leukaemia Care
Georgina Giebner, British Dietetics Association
Roseann Haig, Circle of Comfort
Michael Heggie, Cancer Research UK (Secretariat)
Sorcha Hume, Cancer Research UK (Secretariat)
Sharon Kelly, Individual non-member
Jude Kilbee, AMLo Biosciences
Neil MacDonald, Merck Sharp & Dohme (MSD)
Liam Mac Lua-Hodgson, The Brain Tumour Charity
Janis McCulloch, Myeloma UK

Kira McDiarmid, Breast Cancer Now
Heather McVicars, NHS Lothian
Doreen Miller, Cruse Scotland Bereavement Support
Daisy Parsons, Lilly UK
Ian Pirrie, Cancer Card
Norman Pratt, NHS Tayside
Gozde Ozakinci, University of Stirling
Andrew Reynolds, Young Lives vs Cancer
Johnstone Shaw, Fight Bladder Cancer UK
Tom Steiner, Pancreatic Cancer UK
Emma Walker, House of Hope
Helen Webster, British Dietetics Association

Apologies

George Davidson, GlaxoSmithKline
Craig Davies, Individual non-member
Christine Campbell, University of Edinburgh
Sharon Cowell-Smith, NHS Lothian
Fiona Fernie, Clan Cancer Support
Helen Fleming, Individual member
Nele Gewert, Anthony Nolan
William Greenhill, AbbVie
Victoria Hayes, Kyowa Kirin
Mhairi Simpson, NHS Lanarkshire
Edwin van Beek, University of Edinburgh
Alison Wright, Prostate Scotland

1. Welcome & Minutes

Chair, Miles Briggs MSP (MB) opened the meeting and welcomed members. MB noted the meeting etiquette and the agenda. Minutes for the previous meeting on 18th September 2024 were then approved without any amendments.

2. AGM

Miles Briggs MSP and Jackie Baillie MSP were re-elected as Co-Conveners, and Cancer Research UK was re-elected as the Secretariat. MB explained the group's Annual Return Form would be submitted following the meeting.

MB then noted work has begun on the CPG's workplan for 2025 and said if members have ideas for topics that the group should focus on at future meetings, they should get in touch with the group's Secretariat.

3. Sequencing Success: Genomics for cancer research and care

MB introduced the first session of the meeting which was a presentation from Cancer Research UK (CRUK) regarding their new policy report [‘Sequencing Success: Genomics for cancer research and care’](). He then handed over to Emily Eagles (EE) of CRUK.

EE noted CRUK funds a lot of genomic and genomically enabled research such as the work of the CRUK Cambridge Institute who are driving cutting edge genomic tools into clinical practice. She explained genomics is the study of someone’s complete set of DNA, called a genome, and is key to our understanding of the fundamental nature of cancer.

Genomics offers the opportunity to better prevent, detect, and treat cancer by:

- Identifying increased hereditary risk of developing cancer.
- Diagnosing cancer more accurately.
- Getting cancer patients into the right clinical trials based on their specific disease Helping match patients to targeted treatments.
- Gathering data from genomic testing that can be used to speed up research into cancer biology.

EE added that genomic testing is becoming faster and cheaper, so it's becoming more common for cancer patients to receive this as part of their care.

Regarding the Sequencing Success report, CRUK looked at the genomic health and research environments in each of the four nations of the UK. EE highlighted the recent genomics strategy publication in Scotland, and the new or updated strategies due in England, Wales, and Northern Ireland. In developing the report, EE said that they spoke to 71 external stakeholders and 75 people affected by cancer. This included a range of stakeholders in Scotland.

EE then gave an overview of the structure of the report and its seven overarching ambitions. She noted the breadth of findings across the report and touched on a few:

- Delivery of testing varies significantly within and between the nations of the UK.
- Patient referral for genomic testing and for participation in trials varies depending on staff engagement with genomics.
- Research relevant genes aren’t always reported on, hampering recruitment to genomically enabled cancer trials.
- There is a big opportunity to maximise use of genomic data but currently things are very disconnected.
- Digitalisation of genomic healthcare is reliant on system wide upgrades to IT infrastructure and workforce capabilities.
- Genomically enabled innovations offer exciting opportunities but cannot be maximised without addressing issues with funding, infrastructure and capacity.

EE gave an overview of the genomics structure in Scotland, and she then pulled out some of the Scotland specific findings from the report. EE noted that the report found that there are a number of opportunities and concerns relating to genomics in Scotland. The opportunities include:

- The publication of the Scottish Genomic Medicine Strategy.
- A commitment in the strategy to improve genomic workforce literacy and expertise.

- A joint sharing model for patient data between GPs and health boards has improved data availability.
- The opportunity to implement models of consent for research in pathways.

Concerns from the report include:
- A need for a sustainable funding and commissioning model.
- The absence of clear and clinically meaningful pathway guidance
- Cases of restricted patient access to Scottish Medicines Consortium (SMC) approved medicines.
- A lack of data collection on the uptake of surveillance colonoscopies.

EE noted some of the report's key recommendations for Scotland, including:
- That the Scottish Government must allocate funding to implement the full five-year genomic medicine strategy.
- Setting up a national directory of Lynch syndrome testing and set out an implementation plan for Lynch testing.
- That NHS Scotland need to act to better embed research into the design of clinical pathways.
- That staff should be supported to upskill on genomics, with dedicated time for professional development.
- That NHS Scotland should work to ensure optimal access to more harmonised genomic data and implement a model of consent for research in testing pathways.
- That the Scottish Government must support Medicines and Healthcare Products Regulatory Agency (MHRA) and SMC capacity to horizon scan for new genomic technologies and work to improve alignment with other HTA bodies across the UK.

EE briefly discussed how CRUK involved patients in the development of the report. EE said that some key themes emerged that they wanted to embed in the report. The first of those being enthusiasm from patients for genomics to be included in patient pathways. Also, patients want to know how their results inform clinical decisions and have a real interest in how their data is being used for research as well. EE also noted patients wanted an in-person introduction to genomics, which should be complemented with written resources. Another theme to emerge is patients want to be informed when AI tools are used. EE then discussed the next steps following the publication of the report which includes engagement with a range of stakeholders, including the Scottish Government and Scottish Cancer Coalition.

MB thanked EE for her presentation and then opened to questions from attendees. Regarding genetic analysis, Anna Campbell (AC) asked whether the focus is on Lynch syndrome and BRCA, and if epigenetics and treatment sensitivity is being looked at. AC also said that she is part of Generation Scotland and UK Biobank and asked if researchers have access to the data from these projects. Regarding the question around Lynch and BRCA, EE said the report looked at hereditary risk identification earlier along the pathway and said that this testing can be used within the pathway to help more precisely diagnose people's tumours. EE offered to get back to AC regarding her question on data after the meeting. EE noted CRUK is calling for data sets to be well connected across the four nations of the UK, which is something that's particularly important for children/young people and rare cancers.

MB noted EE's comments regarding the disparity in pathways between the rest of the UK and Scotland and asked for more details. EE noted one example that there are medicines approved by the SMC that require patients to have specific diagnostic tests before they can receive the treatment. She added that capacity issues with the SMC and more broadly has limited horizon scanning so some of those diagnostic tests aren't yet available. This means that patients in Scotland can't access medicine despite it being approved and being available elsewhere in the UK. EE said that the report also explores other areas like variation in access to clinical trials and staff expertise. MB thanked EE again for the excellent presentation.

4. The Macmillan Psychological Support Project: Psychological Support for People Affected by Cancer – Cross-sector Collaboration to Facilitate the Right Support at the Right Time

MB introduced the next session on the Psychological Therapies and Support Framework and the work of Macmillan Psychological Support Project (MPSP). MB welcomed Jennifer Cameron (JC), Dr Kathleen McHugh (KMcH), and Dr Helen Moffat (HM) from the MPSP.

JC explained the project started in June 2023, and they published their final report in November 2024. The aim of the project came about because Macmillan's own scoping work identified inconsistencies and a lack of psychology resource for people affected by cancer, so a project proposal was developed alongside the North Cancer Alliance. JC noted the aims of the MPSP were to:
- Undertake the first national benchmarking of existing services across NHS and partner organisations.
- Identify areas of good practice, and barriers and facilitators to accessing psychological support and therapy.
- Scope level of demand across the 14 Health Board areas using published evidence and prevalence data.
- Engage with stakeholders across all sectors.
- Identify training requirements and opportunities to enhance service delivery
- Develop pathways and recommendations to improve access.

KMcH noted it is now accepted that psychological distress is the sixth vital sign, and we also know that physical health and mental health are directly interrelated. Roughly half of all patients feel their emotional needs are not as well looked after as their physical needs. She said that generally a lot of people feel that they're not getting the emotional support that they would like to get either for themselves or for their family members. More people are surviving and KMcH highlighted that even 10 years after treatment 54% of cancer survivors still suffer from at least one significant psychological issue. KMcH also highlighted the experience of carers and their access to support. She noted it's important to acknowledge that good psychological care is vital to people's overall care experience, but it shouldn't be seen as an add on. If psychological obstacles are not addressed, they can impact on a person accessing tests, investigations, treatment adherence, engaging with rehabilitation, and ultimately impact on physical outcomes. KMcH added that there is a strong economic case for psychological care to be a routine part of healthcare. Psychological therapy reduces physical healthcare costs by an average of 20%. KMcH then discussed the wider policy context behind the project and the various frameworks and strategies that are currently in place. She gave an explanation of the four-tier Psychological Cancer Care Model which comes from NICE guidance that was published in 2004 and is the overarching quality standard for the UK. She noted the four levels are universal support, targeted support, specialist support, and complex support. KMcH explained this is the model that the MPSP used and adapted it to reflect the services in Scotland. KMcH spoke about the stakeholder engagement undertaken throughout the project. This included a mapping exercise to understand what services exist across all four levels in Scotland. They developed a scoping survey which had over 80 responses and gave them a good picture of what was available. The results of this survey confirmed that there's huge variation and availability of services. The survey found that staff weren't always confident about clinical pathways and where they could access support for their patients. It also showed that there's a huge range of training and supervision available to staff but no consistency. They also ran lived experience focus groups as part of their engagement.

HM gave an overview of the responses that the MPSP team received from people with lived experience of cancer in their focus groups. HM noted some people had excellent experiences of support, but about a third of participants reported that their emotional support needs weren't addressed or discussed, and they weren't able to access psychological care or support. Most participants felt that it would be helpful if psychological experiences were discussed routinely, and it was normalised that this was a distressing and challenging emotional experience. People also highlighted the real importance of support for their family members and caregivers. HM noted there are many different entry points needed in terms of psychological support and that revisiting the topic regularly was something that people told them was important rather than a one-off conversation at just one stage in the cancer journey.

HM noted the project's headline findings:

- There is a significant shortfall in workforce capacity and huge inequity in access at this level of support.
- There are also limitations in referral pathways and communication barriers with third sector partners.
- Many patients feel that their emotional wellbeing is not addressed during or after their cancer care.
- There was an inconsistency in whether staff were able to access training and supervision in psychological support.

HM then gave an overview of the Integrated Model of Psychologically Informed Cancer Care outlined in the MPSP report. This model would be aligned with wider nationally agreed policies and structures, as well as Health Board level governance and management structures. Key recommendations based on the model are:

- Integrated cross-system and regional working.
- A focus on training and supervision

- Actions to increase access to specialist psychological assessment and interventions.
- An increased awareness and changes in practice.
- National and local strategic leadership to take this forward.

MB thanked HM, KMcH, and JC for their presentation and opened to questions from attendees. MB flagged a question in the meeting chat from Roseann Haig (RH) asking how Circle of Comfort's findings and experiences can be included in this type of research going forward. MB also noted the MPSP engaged with a range of stakeholders and asked how much engagement there was with smaller organisations/groups. KMcH noted the project team presented to the Scottish Cancer Coalition and that the coalition had a representative on the MPSP steering group. KMcH apologised if they missed anyone out in their engagement. KMcH noted there are now three regional groups for psychological therapies and support, and recommended that anybody interested in this work to link up with these groups. KMcH said that if anyone wants to get in touch to find out more about these regional groups then the MPSP team would be happy to help, which was welcomed by RH.

MB highlighted a question in the chat from Helen Webster, an AHP working in oncology, regarding the best way for individuals and teams to upskill to the correct level for the framework. HM said that within the framework that was published in 2022, there is a training grid which outlines the various training courses that exist, but this is a moving picture. She noted they're hoping there might be some progress regarding NHS Education Scotland (NES) developing resources that can support this work to ensure that people in relevant roles are clear on accessing training.

MB asked if they considered health inequalities, particularly the location of services and getting to them via transport links. KMcH said that this is something they considered in the initial scoping. She noted the importance of integrated services, and this is something a lot of the recommendations have tried to keep in mind.

Anna Campbell (AC) noted the importance of prehabilitation in cancer care, focusing on diet, exercise, and psychological support, and inquired about the effectiveness and pathways of psychological support at the point of diagnosis. HM said that from a psychological perspective, good prehabilitation involves early conversations to normalise emotional experiences and guide people to support. It's a work in progress, with piloting of screening tools, recognising the need for multiple entry points. HM also noted the importance of repetition and ongoing support.

Ahsan Akram (AA) noted psychological support is vitally important. AA works in lung cancer diagnostics and noted the time-constrained system. Regarding the pathways for level 3-4 patients, AA asked if they are mostly self-referred or referred by other healthcare professionals, and how we can improve access. HMcH highlighted the uneven availability of psycho-oncology services across Health Boards. Some areas offer referrals and self-referrals, while others lack services unless third sector options like Maggie's are available. She stressed the need for healthcare teams to normalise mental health conversations to identify and guide patients to appropriate services, which vary by region. Regarding the regional groups, HM noted bringing together third sector and NHS colleagues fosters shared understanding and confidence in utilising resources. KMcH added that they're hoping the regional groups will continue to have adequate representation to help people understand resources. Local teams should build skills, and NES may offer training. KMcH said that it's about the coming together of all these things so that NHS staff will feel more confident in asking questions and to signpost. HM also noted the need for investment and making the case for this. MB thanked Jennifer, Kathleen, and Helen, and noted the secretariat will circulate the MPSP report.

5. Taking blood cancer out of the shadows: The UK Blood Cancer Action Plan

MB introduced the final session of the meeting which was a presentation from Blood Cancer UK (BCUK) regarding the UK Blood Cancer Action Plan. MB welcomed the speakers for the session Josh Hill (JH), Laura Challinor (LC), and Kate Keightley (KK), who were all from Blood Cancer UK. MB then handed over to JH.

JH provided a brief overview of BCUK and its work, noting that blood cancer is the fifth most common cancer in the UK and the third biggest killer, with approximately 17,000 people affected in Scotland. He mentioned that there are around 2,500 new cases of blood cancer each year in Scotland. BCUK is the only charity working across the UK for all blood cancers by funding research and raising their profile. JH noted despite these efforts, too many people are still dying from blood cancer, and the UK is falling behind similar countries in research, outcomes, and survival rates. In 2023, BCUK committed to producing a blood cancer report to improve survival rates. This report serves as a blueprint for their campaigning work for the next few years. Work on the action plan highlighted disparities in outcomes and experiences between blood cancers and other cancers and is based on the National Strategic Action Plan for Blood Cancer developed by the Leukaemia Foundation in Australia. The UK Blood Cancer Action Plan is evidence-based and includes seventeen recommendations aimed at improving survival. It is targeted at decision-makers, policy makers, MSPs, NHS leaders, government, industry, and fellow charities. To ensure the action plan's relevance, a task force with representation across the Four Nations of the UK was formed. This task force was co-chaired by Helen Rowntree who is CEO of BCUK and Prof Adele Fielding from the University of York, and included community representatives, clinical experts, Blood Cancer Alliance staff, and other researchers. JH noted three data projects were commissioned to support the report. An international study led by Prof Claudia Allemani assessed survival across 25 subtypes in over 30 countries. Additionally, studies by Prof Julia Hippisley-Cox examined survival from blood cancer in Scotland and Northern Ireland Prof and Dr Ceri Bygrave looked into blood cancer survival figures in Wales. Key findings from the data revealed that over a 10-year period, one million potential years of life were lost, with one-third of people dying before the age of 65. Survival rates in the UK fall short compared to similar nations, and socio-economic status impacts survival rates. In Scotland, the five-year net survival for all blood cancers between 2015 and 2019 was 65%, with over 128,000 years of life lost among persons diagnosed between 2009 and 2019. More than 10,000 excess deaths were recorded in Scotland over a 10-year period, with 10.8% considered avoidable.

LC noted the report is divided into five key areas: workforce, diagnosis, care, treatments and clinical trials, and data, with 17 recommendations spread across these areas. In the workforce section, it was found that 55% of permanent haematology consultants in the UK will reach the age of 60 in the next decade. Clinical Nurse Specialists (CNS) are crucial for blood cancer patients, but 38% of respondents from Scotland did not know their CNS. Sickness rates among haematology staff are higher than the NHS average and three times higher than the average UK worker. Regarding diagnosis, one in three people with blood cancer visit their GP three times or more before diagnosis, and 27% are diagnosed via A&E. People from ethnic minority backgrounds are four times more likely to experience delays in referral for diagnosis. 13.5% of cancers diagnosed through rapid cancer diagnostic services are blood cancers. Blood cancer symptoms are often nonspecific, such as fatigue and rashes. In terms of care, funding challenges, communication failures, disjointed data systems, and deprivation affect the quality of care for blood cancer patients. In the last five years, 60% of people with blood cancer in the UK faced challenges attending in-person appointments, with travel being a significant issue, particularly in Scotland. Multidisciplinary teams provide tailored treatment plans, but 44% of surveyed people in Scotland were unclear about their role. Clinical trials in the UK are struggling with recruitment and existence, partly due to Covid and Brexit. According to the Scottish Cancer Experience Survey in 2024, only 21% of people with blood cancer discussed research opportunities at diagnosis. Specialised centres for complex blood cancer treatments create significant travel burdens. The report strongly argues for consistent and comparable national data for Scotland. LC noted they commissioned survival data research, highlighting the need for better data. 73% of healthcare professionals support the recognition of blood cancer as a category in the NHS Cancer Registry. Different cancer registries across the UK collect data differently, complicating survival analysis. Not all blood cancers can be staged, affecting national targets for early diagnosis. The recommendations include immediate influencing on access to CNS, barriers to diagnosis, and data collection. Existing projects and coalition work focus on clinical trials access, the decline in clinical academics, and NHS data gaps. New schemes are being piloted for blood cancer awareness, safety netting, and monitoring high-risk individuals. Further research is needed on the haematology workforce and barriers to high-quality care. LC finished by highlighting how attendees can support BCUK with regard to the report.

KK explained she leads BCUK’s information and support services, which are primarily managed by clinical nurse specialists and clinical research nurses. These services include one-to-one support, peer support, and health information available both online and offline. Despite their efforts, these services currently reach only a small proportion of people diagnosed with blood cancer each year. The ambition is to significantly expand their reach so that everyone has access to the information and support they need. BCUK’s goal for the next few years is to reach 75% of those people. Several projects have been initiated to achieve this, focusing on direct referral and clinical trials access. The direct referral project aims to empower patients to manage their care by developing a quick and easy referral mechanism to connect them with services provided by BCUK. KK noted this service is now live in seven hospital trusts/health boards across the UK including NHS Lanarkshire, with 72% of newly diagnosed patients being referred to BCUK, and 85% of those opting for digital support. The plan is to scale up this project significantly over the next few years. Additionally, there are efforts to improve access to clinical trials, which can increase survival rates for blood cancer patients. The BCUK clinical trial support service has been in place for five years, helping patients self-refer and receive detailed information about trial eligibility. The service is going really well, and they have supported over 650 people, and 40% have been enrolled on to a clinical trial. Despite its success, the service needs to reach more people and address the ethnic disparities in clinical trial recruitment. Two new projects aim to redesign and scale up the service using insights and technology, including AI, to ensure broader access and awareness of clinical trials. Given the ethnic disparities observed, a project has been set up to work with Black and Pakistani communities in London. Community researchers have been recruited to conduct Community Co-design research to understand barriers faced by these communities and collaborate with them. The goal is to create and pilot interventions aimed at reducing inequalities and improving access to trials. Over 40 interviews have been conducted with individuals from these communities and healthcare professionals. Thematic analysis of these insights will begin soon to develop recommendations and prototypes for testing with healthcare professionals. The aim is to develop products or services that reduce barriers to trial access.

MB inquired about NHS Lanarkshire being the sole Scottish site involved in the pilot. He asked when data for Scottish patients might be available and whether cancer centres were also included in this work. KK confirmed that currently, NHS Lanarkshire is the only pilot site in Scotland. She emphasized their eagerness to build relationships with other hospitals and health boards in Scotland. KK added that although NHS Lanarkshire is just up and running, they do not have much data yet, but it is being monitored regularly and can be shared when available. MB thanked Josh, Laura, and Kate for their presentation. He said that it would be helpful to receive an update on some of the outcomes of this work at a future meeting.

6. AOB

No additional business.

7. Close of Meeting

MB noted the next meeting date is still to be confirmed but will take place in Spring 2025 and will be the group’s AGM. The secretariat will be in touch in due course with more details on the next meeting agenda and how to register.