

Cross-Party Group on Cancer

Wednesday 30th April 2025, 18:00-19:00, Virtual Meeting via Microsoft Teams

Minute

Present

MSPs

Jackie Baillie MSP (Co-Convener, Chair)
Foyso Choudhury MSP (Member, Chair)

Invited guests

Dominic Butler, Bowel Cancer UK
Dr Iain Phillips, Edinburgh Cancer Centre

Non-MSP Group Members

Sandra Auld, Healthcare Public Affairs
Anna Campbell, Edinburgh Napier University
Laura Conaghan, Cancer Research UK
Lorraine Dallas, Roy Castle Lung Cancer Foundation & Cancer Card
Peter Hastie, Macmillan Cancer Support
Michael Heggie, Cancer Research UK (Secretariat)
Paul Howard, AMMF
Sorcha Hume, Cancer Research UK
Stella MacPherson, South East Scotland Cancer Network (SCAN)
Neil MacDonald, Merck Sharp & Dohme (MSD)
Lorna May, Lilly UK
Kira McDiarmid, Breast Cancer Now
Doreen Miller, Cruse Scotland Bereavement Support
Suzanne Muir, Beatson West of Scotland Cancer Centre
Katie Robb, University of Glasgow
Johnstone Shaw, Fight Bladder Cancer UK
Linda Sherwood, NHS Lothian
Tom Steiner, Pancreatic Cancer UK
Tristan Loraine, Lobular Moon Shot Project
Helen Webster, British Dietetics Association

Apologies

Edwin Van Beek, University of Edinburgh
Miles Briggs MSP (Co-Convener)

Jennifer Cameron, Royal College of Occupational Therapists
Fiona Fernie, Clan Cancer Support
John Greensmyth, CLL Support
Gillian Hailstones, Beatson Cancer Charity
Josh Hill, Blood Cancer UK
Jill Rennie, Individual member
Douglas Rigg, Scottish Primary Care Cancer Group
Mhairi Simpson, NHS Lanarkshire
David Weir, Gilead Sciences
Jo Williamson, Individual member

1. Welcome & Minutes

Foyso Choudhury MSP (FC), who chaired the first half of the meeting in place of Jackie Baillie MSP (JB), opened the meeting and welcomed members. FC noted the meeting etiquette and the agenda. Minutes for the previous meeting on 18th December 2024 were then approved without any amendments.

2. Finding the missing 95%: Unlocking the potential of Lynch syndrome services in Scotland

FC introduced the first session of the meeting which was a presentation from Bowel Cancer UK (BCUK) on unlocking the potential of Lynch syndrome services in Scotland, which was delivered by Dominic Butler (DB).

DB explained that Lynch syndrome is a genetic condition raising bowel cancer risk to up to 80%, and also increases risk for endometrial, ovarian, and urothelial cancers. It accounts for 1 in 30 UK bowel cancer cases, many in people under 50. It is estimated that around 200,000 people in the UK may have Lynch syndrome, yet fewer than 5% have been diagnosed. This highlights the need to identify the undiagnosed 95% to ensure access to care.

The condition is caused by inherited genetic variations in mismatch repair genes, which are responsible for correcting DNA replication errors. When these genes are faulty, errors accumulate, increasing cancer risk. Lynch syndrome follows an autosomal dominant inheritance pattern, meaning there is a 50% chance of passing it on to children. This makes cascade testing, screening close relatives of diagnosed individuals, particularly important.

Diagnosis typically follows a three-step pathway:

- Reflex testing of all newly diagnosed bowel cancer patients for molecular features of Lynch syndrome.
- Genetic counselling, which addresses the implications for both the individual and their family, and ensures informed consent.
- Genetic testing, which confirms the diagnosis.

Once diagnosed, patients receive comprehensive wraparound care, including psychosocial support and signposting to organisations such as BCUK. Risk-reducing strategies include daily aspirin, which can reduce cancer risk by up to 50%, and

regular surveillance colonoscopies, which can reduce the risk of dying from bowel cancer by up to 72%. Colonoscopies are typically offered every two years from age 25 or 35, depending on the specific genetic variant. Additional benefits include access to targeted treatments such as immunotherapy and the option of preventive surgery.

DB also highlighted existing clinical guidance. NICE has issued several recommendations, including for bowel cancer and further guidance for endometrial cancer. While Scotland does not formally follow NICE guidance, equivalent standards have been developed and endorsed across Regional Cancer Networks.

He then introduced findings from Bowel Cancer UK's 2024 report, Finding the Missing 95%, based on Freedom of Information (FOI) requests submitted between April and July 2023. These requests assessed whether health boards:

- Follow relevant clinical guidance
- Provide comprehensive wraparound care
- Offer timely surveillance colonoscopies
- Conduct cascade testing
- Have a designated Lynch syndrome champion within bowel cancer multidisciplinary teams (MDTs)

The findings, published in January 2024, showed significant progress in reflex testing. In Scotland, 91% of health boards now offer reflex testing for all newly diagnosed bowel cancer patients. This represents a substantial improvement from 43% in 2018. DB noted that more recent data suggests this figure may now be closer to 94–95%. DB addressed the variability in the management of Lynch syndrome services across Scotland. While progress has been made in diagnostic testing, concerns remain regarding the downstream pathway following diagnosis. One key issue identified was the lack of designated Lynch syndrome champions within bowel cancer MDTs. A Lynch champion is a named individual responsible for overseeing the Lynch syndrome pathway, ensuring clarity of accountability and consistency in patient care. This model, already in use in countries such as Finland and the Netherlands, has proven effective and is something BCUK would like to see adopted more widely in Scotland. Comprehensive wraparound care was another area highlighted for improvement. While there may have been some ambiguity in how this was interpreted in FOI responses, the importance of patient-centred care is well recognised in Scottish health strategies. Embedding this support within Lynch syndrome pathways remains a priority. Scotland performed comparatively well in cascade testing, although the data was limited and used a proxy measure. Nonetheless, Scotland scored highest among UK nations, suggesting some progress. BCUK advocates for a more systematic approach to cascade testing across all UK nations. A significant concern was the provision of high-quality and timely surveillance colonoscopies, which are considered the gold standard in reducing mortality from bowel cancer. BCUK identified this as a key priority for improvement in Scotland.

There is currently a “postcode lottery” in service provision, with the quality of care varying significantly depending on geographic location. For example, NHS Dumfries and Galloway scored one out of four on key indicators, while NHS Tayside scored four out of four. Although these scores are not definitive, they reflect broader

systemic variation. This reflects a fragmented system. The absence of up-to-date national guidance has led to the use of multiple guidelines across health boards. The lack of consistency creates gaps in standards of care and contributes to inequities in access and outcomes. The inconsistency extends to information systems used to manage Lynch syndrome. Effective IT systems are essential for managing surveillance colonoscopy schedules through call-and-recall mechanisms. The report found that there is a variation in IT systems used by Scottish health boards, and this variation opens the door to unequal service provision. DB emphasised the need for improved auditing and performance measurement to identify and address inequalities.

DB summarised the report's key recommendations:

- A more strategic / national approach to managing Lynch syndrome in Scotland, including a national framework and oversight.
- Development of a national patient database to unify data collection across health boards, improve auditing, and enable linkage with demographic and QPI data to monitor outcomes and address inequalities.
- Delivery on existing ambitions to improve services, including building capacity in endoscopy and pathology, and securing sustainable funding for equitable genomic services.
- Continued development of a comprehensive cascade testing system.

DB emphasised that, despite challenges, strategic investment and coordination can significantly improve Lynch syndrome services in Scotland. A key barrier identified was limited capacity across the health service in Scotland, particularly in endoscopy and pathology, as well as within the genomics workforce. This is compounded by inconsistent data collection and fragmented information systems, particularly in genomics. These issues highlight the need for national data solutions to streamline care and improve outcomes. DB noted a lack of national coordination on improving Lynch syndrome services. Through conversations with various health boards, it became clear that a unified approach is needed before presenting a business case to the Scottish Government. He also referenced the broader issue of the policy implementation gap in Scotland, where ambitions often fail to translate into action, partly due to fiscal constraints. Despite these challenges, DB highlighted existing strategies, such as the Scottish Cancer Strategy and the Genomic Medicine Strategy, which contain relevant and actionable commitments. He emphasised that Scotland does not need to start from scratch. Existing tools, such as the lower gastrointestinal surveillance database, could be adapted and improved upon, despite their current limitations.

DB also pointed to the convening power of the third sector. BCUK will be hosting a consensus roundtable in Edinburgh in June, focused on the potential of national data solutions to improve Lynch syndrome management. The event will bring together clinicians, academics, policymakers, and other stakeholders to explore how a national database could support better call-and-recall systems for surveillance colonoscopies and improve the overall management pathway. The goal of the roundtable is to build consensus and momentum toward a national policy position on a genomics database for Lynch syndrome in Scotland. This would include assessing feasibility and developing a business case to support implementation. DB concluded

with a call to action for attendees. FC thanked DB for his presentation and then opened to questions from attendees.

Sorcha Hume (SH) welcomed the discussion and offered support from Cancer Research UK for the upcoming June roundtable. She shared updates from the Scottish Cancer Network Steering Group and the Scottish Cancer Strategic Board, highlighting discussions on aligning national clinical management pathways, particularly for bowel cancer, with optimal pathways. She also referenced recent work by the Scottish Strategic Network for Genomic Medicine on guidance for managing cancer risk conditions such as Lynch syndrome. DB expressed interest in continuing the conversation. He indicated he would follow up by email to explore opportunities for collaboration.

Professor Anna Campbell (AC) shared a personal connection to Lynch syndrome and asked whether the SIGN guidelines should be revised and updated. She also asked for clarification on DB's earlier comment regarding national screening in England and why it was not applicable in Scotland. DB agreed that updating the SIGN guidelines would be a valuable and achievable step. He explained that England has integrated Lynch syndrome into its national bowel screening programme, but this may not be feasible in Scotland due to structural and funding challenges.

Linda Sherwood (LS) expressed strong support for a systematic recall system for Lynch syndrome patients. She highlighted concerns about follow-up for high-risk patients post-discharge, particularly the need for regular two-yearly colonoscopies. She emphasised the importance of a national database to ensure consistent care. DB agreed that establishing a systematic approach to surveillance which is a strategic priority for BCUK. He reiterated the importance of the upcoming roundtable in setting direction and addressing current gaps in care.

Professor Katie Robb (KR) asked whether there were international examples that could inform improvements in Scotland. DB responded that Nordic countries, particularly Denmark, Finland, and Norway, offer valuable models due to similarities in population size and rural demographics. He noted ongoing conversations with experts in these countries, including a Lynch syndrome registry lead in Copenhagen, to draw on best practice. FC thanked DB for his presentation and invited any further questions to be sent via email.

3. Improving Outcomes for Less Survivable Cancers

FC introduced the next session on improving outcomes for less survivable cancers by Dr Iain Phillips (IP) consultant oncologist at the Edinburgh Cancer Centre. He then handed over to IP who began his presentation.

IP explained that the focus of his session would be on less survivable cancers, particularly lung and pancreatic cancers, and how outcomes for patients with these conditions might be improved through the use of prehabilitation. He began by sharing a recent case which involved a previously fit and well patient who had developed a persistent cough and subsequently experienced a rapid decline in health, including significant weight loss, chest wall pain, and breathlessness. IP

highlighted that one of the major challenges in managing lung cancer is the early diagnostic phase, during which patients often deteriorate physically while awaiting investigations. He noted that respiratory teams typically have only a short window to deliver a lung cancer diagnosis and outline the treatment pathway, which can be overwhelming for patients.

IP presented data underscoring the severity of lung cancer as a public health issue. Lung cancer remains the leading cause of cancer-related death in Scotland and globally. It also contributes significantly to unscheduled care admissions. IP highlighted data based on 4,000 patients in Southeast Scotland, revealed over 15,000 unscheduled care episodes and 8,000 hospital admissions in the final year of life for these patients. This illustrates the high burden lung cancer places on both patients and the healthcare system. He highlighted comparative survival statistics which showed that while five-year survival rates for breast and prostate cancers are approximately 85% and 90% respectively, with the figures for lung and pancreatic cancers markedly lower at around 20% and 10%. However, IP noted that recent advances in treatment, particularly immunotherapy and targeted therapies, have significantly improved outcomes for some patients. For example, nearly one-third of patients with stage 4 lung cancer who are fit enough for immunotherapy are now surviving five years post-treatment, which is a substantial improvement. Despite these advances, only about 60% of patients with metastatic lung cancer and good performance status receive active anti-cancer treatment. IP emphasised the need to increase this proportion and proposed prehabilitation as a potential solution.

A pilot project in Edinburgh was launched to explore whether improving patients' fitness and symptom management during the diagnostic phase could increase treatment uptake and improve outcomes. The pilot was designed to run in parallel with the diagnostic process. Patients with suspected lung cancer were seen by a respiratory physician and then referred to a palliative care consultant, a physiotherapist, and a dietitian. The intervention was based on Macmillan's prehabilitation framework, which includes three domains: psychological support, nutrition, and physical activity. The aim was to provide timely, individualised support to help patients maintain or improve their fitness and manage symptoms such as pain and breathlessness.

The results of the pilot were promising. Hospital admissions during the first six weeks of diagnosis were reduced by approximately 75%, with the average length of stay falling from eight days to just two and a half. This translated to a saving of over 400 hospital bed days per 100 patients. Preliminary data also suggested a survival benefit, with median survival increasing from five to nine months. Patient feedback was overwhelmingly positive, with all participants reporting the intervention as useful and recommending it to others. Following the initial two-year pilot, the project was paused. During this time, hospital admissions and time spent in hospital increased again. However, with renewed funding from Macmillan and the Scottish Government, the project was restarted, and the earlier improvements were once again observed. IP noted that while more data is needed to assess the impact on treatment uptake, the reduction in emergency admissions and hospital stays is a meaningful outcome, particularly for patients who may not reach treatment. IP expressed a desire to expand the model to include all patients with stage three and four lung cancer who

are fit for treatment, and to explore its applicability to other less survivable cancers such as pancreatic and biliary cancers.

IP discussed the potential for integrating the prehabilitation model with existing services. He acknowledged that patients with lung cancer often do not engage with these services, possibly due to a perception that they are not relevant to them. The goal is to create a continuum of care that includes both prehabilitation and rehabilitation, tailored to individual patient needs. He also highlighted the importance of specialist input, noting that experienced clinicians can make rapid and effective adjustments to care plans, such as modifying pain management strategies or dietary recommendations. The model could also serve as a triage mechanism, directing patients to appropriate services based on their fitness and symptom burden.

IP concluded by noting that further data is needed to assess the impact of prehabilitation on treatment rates. He also suggested that the model could support research into conditions such as cancer cachexia, where patients experience severe weight and muscle loss. The intervention, being simple, cost-effective, and deliverable in district general hospitals, has the potential to be scaled up across Scotland. He expressed a strong interest in securing further funding and collaborating with others to expand the project and share its findings more widely. IP extended his thanks to NHS Lothian, the University of Edinburgh, MSD (who supported the initial joint working project), Macmillan, the Scottish Government, and the Roy Castle Foundation. He acknowledged the collaborative effort involved in delivering the project and reiterated his openness to further discussions and partnerships.

FC thanked IP for the excellent presentation and then handed over to JB who took over chairing duties. JB then opened to question from attendees.

Paul Howard (PH) highlighted that a significant proportion of cholangiocarcinoma patients, approximately 80%, are not eligible for surgery at the time of diagnosis. He asked whether there was any existing patient involvement from those with biliary tract cancers and offered the support of AMMF's in facilitating this. He also enquired about the project's funding timelines, noting that AMMF's current funding round had just closed but expressing interest in future opportunities. In response, IP welcomed the opportunity to discuss future funding and acknowledged the challenge of the project sitting between service delivery and research. He explained that the EASE project is likely to be classified as a quality improvement initiative, which could generate data to support future clinical trials. He confirmed that there is currently no patient representation but anticipated the formation of a steering committee, which could provide a suitable avenue for involvement.

AC expressed strong support for the project, referencing her own earlier work with others on prehab and noted how perceptions have shifted, when encouraging patients to be active before colorectal surgery was met with scepticism. She mentioned her involvement in new UK-wide guidelines, due for publication in the summer, which reflect the growing evidence base. She emphasised the cost-saving potential of prehabilitation and the need for simple, affordable implementation. She also highlighted the value of clinical exercise physiologists, who can both prescribe exercise and screen for chronic conditions. Referring to a trial, which offered holistic

support to cancer patients, she proposed a further discussion with IP to explore funding for implementation science. IP agreed on the importance of involving clinical exercise physiologists and acknowledged the challenge of demonstrating cost savings. He noted that scaling up the intervention could yield broader financial benefits and reiterated that simplicity is a key strength of the current approach. He welcomed the opportunity to continue the conversation offline.

Helen Webster (HW) noted that while there is significant interest among dietitians in Scotland, particularly those involved in national prehabilitation groups, the lack of resources limits their ability to deliver services effectively. She highlighted the importance of proper funding from the Scottish Government and offered support from the dietetic community, referencing a group that is actively promoting the prehabilitation agenda. IP agreed with HW's assessment and acknowledged the difficulty in accessing dietetic support for many patients. He shared data indicating that early dietetic intervention significantly increases the number of patients receiving nutritional supplements. He also noted that cancer patients, particularly those with lung cancer, often seek dietary information independently but may not voice their concerns. He emphasised the importance of expert dietary advice and the significant impact that dietitians can have on patient outcomes.

JB thanked IP, confirmed the circulation of presentation slides after the meeting, and encouraged ongoing dialogue on this issue to apply political pressure where needed.

4. AOB

Dr Johnston Shaw (JS) from Fight Bladder Cancer highlighted that May is World Bladder Cancer Awareness Month. He emphasised the importance of early diagnosis, noting that Scotland has the worst bladder cancer survival rates in Europe. He explained that early-stage cancers are often underreported, and that late-stage diagnoses lead to complex and costly treatments. To raise awareness, stickers highlighting early symptoms are being placed in Scottish Parliament toilets, and he encouraged MSPs to support the initiative.

SH, speaking on behalf of Nicola Merrin from Alcohol Focus Scotland, flagged that Cancer Prevention Action Week is from 23rd to 29th June, focusing on alcohol and cancer. She highlighted some of the planned activity in the Scottish Parliament around Cancer Prevention Action Week. SH also mentioned an upcoming policy webinar in May focusing on the future of biomedical research in the UK.

Tristan Loraine (TL) of the Lobular Moonshot Project highlighted a cross-party campaign backed by 340 MPs, urging £20 million in government funding for invasive lobular breast cancer research. He noted a prior commitment under the 2024 Women's Health Strategy, but a decision from the current UK Government Health Secretary, Wes Streeting, is pending. TL emphasised the cancer's diagnostic challenges and shared that his wife has lived with it for 13 years. JB offered to raise the issue with Wes Streeting.

Tom Steiner (TS) of Pancreatic Cancer UK highlighted a prehabilitation project for lung cancer funded by MSD Pharmaceuticals. He expressed support for similar

initiatives targeting less survivable cancers and encouraged attendees to get in touch if they were aware of related projects.

5. Close of Meeting

JB noted the next meeting date is still to be confirmed. The secretariat will be in touch in touch with more details about the next meeting agenda and how to register.