Cross-Party Group on Brain Tumours

Thursday 4th September 13:00 - 14:00

Minute

Present

MSPs

Finlay Carson MSP
Jackie Baillie MSP
Marie McNair MSP
Miles Briggs MSP
Rachael Hamilton MSP

Invited guests

Speakers
Dr Scott Arthur MP
Chengetayi Pswarayi - Novocure
Kevin Donaghy - Story of Hope and Cancer
Dr Sarah Kingdon - The Beatson and Edinburgh Cancer centre

Non-MSP Group Members

Amie Woodgate – Brain Tumour Research
Dr Joanna Birch – Glasgow University
Hester Lee – Neurological Alliance of Scotland
Jana Abdal Rahman – Brain Tumour Research
Sorcha Hume – Cancer Research UK
Thomas Brayford – Brain Tumour Research
Una Ni Bhriain – Edinburgh Headway Group

Supporters
Aleksandra Kieszek
Alex Kiesel
Cameron Somerville
Claire Cordiner
Dawn Keneddy
Elaine Murray
Jill Rennie
Nadia Majid
Susie Goodburn
Vicky Wright
Weronika Somerville

Apologies

Beatrice Wishart MSP
Jenni Minto MSP, Minister for Public Health
Ben Macpherson MSP
Alexander Stewart MSP
Don McKie
Rachel Mckie

Agenda item 1 - Welcome and Introductions

Finlay Carson MSP, Co-Deputy Convener of the CPG, welcomed attendees to the meeting of the Cross-Party Group (CPG) on Brain Tumours. Finlay extended a particular welcome to speakers at the meeting, who shared their insights and expertise on brain tumour research, treatment, and lived experience.

Finlay Carson MSP explained the importance of the CPG, stating that brain tumours remain the biggest cancer killer of children and adults under 40, yet research and treatment in Scotland are still underfunded and inconsistent. The Co-Deputy Convener reminded attendees that the job of the CPG is to bring together the voices of patients, families, clinicians, and researchers so they are heard in Parliament, and to push for progress on access, investment, and care.

Finlay Carson MSP also explained that the CPG's Convener, Beatrice Wishart MSP, was unfortunately unable to attend the meeting. However, she sent her warm regards and best wishes to attendees, and she looked forward to being updated on the discussions.

Agenda item 2 - Updates from Previous Meeting

The Co-Deputy Convener reminded the group that at the last meeting, attendees agreed several action points which he briefly summarised.

Proton Beam Therapy Clinical Trials

- As Convener, Beatrice has been in correspondence with the Cabinet Secretary for Health on this issue on behalf of the CPG. While there is much talk about the importance of early intervention and preventative healthcare, that is not reflected in Scottish funding for clinical trial placements. The Co-Deputy Convener stated he is working with the Convener on a response to the latest reply from the Cabinet Secretary. He asked any CPG members who are healthcare professionals with clinical case studies that could be presented to the Cabinet Secretary to get in touch.

Genomic Testing

- As an initial follow-up, the CPG is writing to the Cabinet Secretary for Health to outline the situation in Scotland as presented in the previous CPG meeting.

Written Parliamentary Questions

- A series of written parliamentary questions addressing various issues raised at CPG meetings have been submitted by MSP members.

The Co-Deputy Convener thanked members who contributed to progressing these actions.

Agenda item 3 - Address by Dr Scott Arthur MP

- Dr Scott Arthur MP updated attendees on his Private Members Bill, the Rare Cancers Bill. He explained how the Bill aims to address inequalities in treatment and how it could impact patients in Scotland.

- Dr Scott Arthur MP thanked those in attendance and introduced himself as the MP for Edinburgh South West.

- He explained that cancer is a personal issue for him as his father-in-law, Ivor Hutchinson, was diagnosed with a glioblastoma in 2017. He was fit and active at the time but passed away only a matter of months after receiving his diagnosis.

- Dr Scott Arthur MP is particularly concerned with the plight of those who receive a rare cancer diagnosis, as patients are more likely to die of these conditions and treatment innovations have stagnated. The term “rare cancer” is a bit of a misnomer, as less common cancers account for 47% of all UK cancer diagnoses.

- The Rare Cancers Bill specifically seeks to address the current imbalance in resources and attention. This Bill seeks to create a fairer, more future-facing system for those with rare cancers. It will do three key things:

    1. Promote research into rare cancers by placing a duty on the UK Government to act, including the appointment of a national specialty lead to drive collaboration.
    2. Increase patient access to clinical trials by strengthening the “Be Part of Research” registry, and building a central database of willing patients, making it easier for researchers to find participants, and easier to attract trials to the UK.
    3. Trigger a review of orphan drug regulations to encourage pharmaceutical companies to trial both innovative new treatments and the repurposing of existing medicines for rare cancers. Together, these steps will break down barriers, increase the number of trials, and accelerate access to life-saving treatments.

- The Bill will also seek to ensure that technologies like Tumour Treating Fields (TTFields) receive proper regulatory review and equitable access. He states that the Brain Tumour Research are particularly interested in improving access to TTFields, and he fully supports them in this endeavour. TTFields are a pioneering, non-invasive therapy that has shown promise in treating the cancer that killed Ivor, and over 35,000 patients worldwide have now used it. It is already being made available in health systems in countries like the US, Germany, France, Sweden, and most recently Spain. Yet here in the UK, it is not currently available on the NHS and patients can only access the technology either privately at huge cost or through clinical trials. That disparity with other countries is unacceptable, and Dr Scott Arthur MP emphasised no one should have to travel abroad to pay for potentially life-extending treatment, and the review component of this Bill should hopefully end this by bringing in line with the rest of Europe.

- For Scotland in particular, the benefits – if the Bill passes – could be substantial: Scotland has world-class research strengths, from the University of Edinburgh's pioneering work in precision medicine, to the Glasgow Beatson Institute's leadership in translational research. This Bill would help unlock that potential, ensuring more trials come to Scotland, more patients can take part, and more discoveries made in Scotland directly benefit Scottish patients. It is also an economic opportunity. Rare cancer trials could draw investment into Scottish science and healthcare, support high-skilled jobs, and give research institutions a global leadership role.

- Dr Scott Arthur MP noted that the part of the Bill covering the disclosure of patient information for clinical trials only extends to England and Wales. Civil servants in the UK have been speaking to the devolved administrations. It is Dr Scott Arthur MP's understanding that Northern Ireland has already put in a framework to enable the Bill to progress.

- The Bill has lots of support from charities in the sector (around 40). The UK Department of Health and Social Care has been helping to shape the Bill.

Discussion:

The Co-Deputy Convener asked about incentivising future research into brain cancer treatments and whether there needs to be upfront funding.

Dr Scott Arthur MP said the real challenge is bringing more funding in. He said the UK Government set aside £40 million, but by the time of the last election had only spent £2-3 million of this. He stated that there isn't the guiding mind to direct it which needs to change. Dr Sarah Kingdon said the money is held in a consortium and that two research leads in Scotland formulated a group to apply for the grant to establish how it would be spent. Dr Scott Arthur MP referenced ongoing research at the Western General Hospital in Edinburgh into treatments for brain tumours.

Miles Briggs MSP commented that the current interaction and collaboration between Scottish Health, care boards across the country, and NICE is making the process unnecessarily complex as patients in different parts of the country can't get onto specialist trials. He asked whether the Bill would help to simplify these processes.
In response, Scott Arthur MP said that the Cancer Plan recognises the barriers and particularly fragmented nature of the system in England. He referred to the efforts of Siobhain McDonagh MP, Chair of the APPG on Brain Tumours, who has spoken passionately about her personal experience navigating these challenges. He specifically mentioned her attempt to direct funds - raised in her sister's name -

towards establishing a clinical trial for brain tumour patients. Despite her efforts, she encountered significant barriers in the system.

This issue was eventually raised with the Secretary of State for Health, Wes Streeting MP, who stepped in to resolve it. Scott Arthur MP used this example to highlight the scale of effort currently required to overcome systemic obstacles that prevent patients from accessing the treatment they need. He suggested that the Bill aims to address and reduce such barriers.

Miles Briggs MSP commented that the story raises important questions about health inequality, a point Scott Arthur MP agreed with.

Sorcha Hume then asked how the group, along with Scott Arthur MP, can ensure that Scotland is not left behind, given that Parts Two and Three of the Bill only apply to Wales and England.

In response, Dr Scott Arthur MP explained that, during the drafting of the Bill, the Scottish Government expressed the view that they could implement the measures outlined in Parts Two and Three without needing new legislation. However, he stated that having something in law compels action.

Vicky Wright added that across the eight research centres established by Novocure, capacity remains the biggest challenge the industry is facing; from research clinical nurses to consultants and clinical fellows, there aren’t the resources on the ground to deal with innovative, complex clinical trials.

Dr Scott Arthur MP stated that because government aren’t investing in that area, people don’t want to work in it and said that the Bill aims to encourage investment in the brain tumour treatment sector, which will help build capacity, develop necessary skills, and ultimately move closer to effective treatments.

The Co-Deputy Convener raised that on the basic level of interaction between Health Boards there are difficulties, citing concerns about the travel burden faced by patients in Scotland, especially those experiencing side effects from treatment. He noted that a recent report found that the further a patient has to travel, the lower their chance of a positive outcome.

Agenda item 4 - Presentation by Dr Sarah Kingdon, Clinical Oncologist, Tessa Jowell Brain Cancer Mission Neuro-oncology Fellow, Scottish Brain Tumour Research Centre of Excellence

The Co-Deputy Convener welcomed Dr Sarah Kingdon, Clinical Fellow with the Tessa Jowell Brain Cancer Mission, who collaborates with neuro-oncology teams in Glasgow and Edinburgh. Dr Kingdon shared insights from her time at The Beatson and the Edinburgh Cancer Centre, outlining current research themes and reflecting on the challenges of translating scientific discoveries into clinical practice for brain tumour patients in Scotland.

- Dr Kingdon explained that the reason she chose to be based in Scotland is due to the excellent research and treatment for brain cancer. At the centre of her work is to provide every patient with the right care from the right person at the right time.

- She explained that her current work involves:
    - Looking at MGMT testing (Cornerstone for treatment on gliomastoma).
    - Looking at raw data and if there's a better way of using this biomarker.
    - Looking at radiotherapy and the use of peer review in radiotherapy pathways as there's big variation.
    - Looking at steroid treatment for radio-necrosis as a side-effect of radiotherapy.

- Dr Kingdon also highlighted several ongoing clinical research efforts aimed at breakthroughs in glioblastoma treatment:
    - In Edinburgh, the KEYNOTE clinical trial is soon to open
    - In Glasgow a new clinical trial is opening to investigate the use of Niraparib in Glioblastoma
    - Aoife Williamson is using MRI scans to monitor whether glioblastomas change during a six-week course of radiotherapy.

- However, a significant administrative challenge exists: if a patient from Glasgow wishes to participate in a clinical trial based in Edinburgh (or vice versa), a separate, individual request must be submitted for each patient and for each trial. This process requires already stretched full-time clinicians to have time and resource to complete the requests.

- Dr. Kingdon discussed the groundbreaking research by Dr. Robertson and Steve Pollard in Edinburgh. During her PhD, Dr. Robertson identified a common protein switch within glioblastoma cells and found a way to harness it to fight the tumour. This approach has shown success in mouse models and there are ongoing efforts to move this into human trials. This represents a completely novel and potentially transformative treatment. The first step is ensuring safety, with the hope of progressing to trials in Scotland soon.

- In discussing access and equity, Dr. Kingdon reflected on a personal story: Her aunt, diagnosed with a low-grade brain tumour in Devon, received genomic testing as part of the diagnostic process, which identified a higher-risk profile and led to her receiving radiotherapy. If the same diagnosis had occurred in Scotland, her aunt would not have had access to this testing at present. This highlights the current inequity in diagnostics between countries.

- Dr. Kingdon stressed the importance of trial availability: If many patients have actionable mutations but no corresponding trials exist, it suggests a clear need for those trials. It is frustrating that patients in Scotland often cannot access the trials such as the 5g trial and Dr Robertson is applying for additional research funding to overcome this as a temporary measure.

Discussion:

Rachael Hamilton MSP asked what politicians could do to reduce the bureaucratic burden around clinical trial access. Dr. Kingdon responded that while a clinical trial-finding platform exists, an attempt to implement it was rejected due to data-sharing concerns. Too often, she said, clinicians face a flat “no” instead of constructive solutions. The technology to utilise AI to track and match trials with patients exists – it just isn’t being implemented.

Finlay Carson MSP asked whether Dr. Robertson’s research could aid early diagnosis. Dr. Kingdon clarified that it is primarily a treatment for both newly diagnosed and recurrent glioblastomas. However, early detection remains critical since current treatments are inadequate. The therapy involves using a viral vector to deliver the transcription switch directly into the tumour, ideally before surgery, as a treatment rather than diagnostic tool.

Susie Goodburn, the mother of a brain tumour patient, asked what would happen once Dr. Kingdon leaves Edinburgh.

Dr. Kingdon explained that she will remain in post until March 2026 and that the projects she leads will continue afterward. She noted that Scotland has excellent clinicians and allied health professionals who will continue to lead an excellent service.

It is the hope of the Tessa Jowell Brain Cancer Mission that the Scottish fellowship programme will continue.

Susie Goodburn urged the group to ensure continuity of Dr. Kingdon’s work and emphasised the need for joined-up thinking across Scotland. She highlighted serious issues in communication between regions and the inconsistent availability of drugs.

Dr. Kingdon echoed these concerns, calling the situation as frustrating for clinicians as patients and caregivers. She acknowledged that the research centres in Edinburgh and Glasgow have different ethos and cultures, which is valuable to patients. However, what's urgently needed is the ability for patients to access care across regions without excessive bureaucracy. For every one patient who can navigate the system, there may be five who cannot.

Agenda item 5 - Presentation by Chengetayi Pswarayi, Director, UK Market Access and Public Affairs, Novocure

Chengetayi Pswarayi, Director of UK Market Access and Public Affairs at Novocure, spoke about the role of innovative brain tumour treatments, the barriers to patient access, and the complexities of securing adoption within the Scottish healthcare system.

Chengetayi Pswarayi explained what the assessments pathways for innovation in Scotland are. They include:

- Scottish Medicine Consortium (SMC) which:
    - Assesses medicine only
    - Is centralised, time-bound and provides mandatory funding if accepted
    - Cancer Drugs Fund supports access while evidence matures

- Scottish Health Technologies Group (SHTG) which:
    - Considers clinical effectiveness, safety, and cost effectiveness
        - Patient/public/professional expert views and social and organisational implications considered
    - No mandated implementation or national budget post-assessment
        - Health Boards and Integration Authorities are 'required to consider'.
    - Potential for unequal access; innovations (for rare or high-cost conditions) often unsupported.

- Assessment of New Innovations for Adoption (ANIA) which:
    - Identifies innovations appropriate for national adoption within NHS Scotland.
        - NHS Scotland national priorities, high-impact, priority health needs
    - Drive national rollout at pace once approved
    - Scottish Government and NHS Scotland Health Boards decide on innovations implemented nationally

Ms Pswarayi explained Tumour Treating Fields (TTFields), a non-invasive treatment that generates an electrical field to stall tumour growth (not a curative treatment). Novacure are creating an awareness briefing on TTFields for clinicians.

TTFields align with the aims of the Scottish Cancer Strategy:
- Improving Cancer survival
    - TT Fields therapy extends survival
- Optimising quality of life
    - Non-invasive, portable, manageable side-effects and ability to maintain daily routines
- Tackling inequalities
    - At-home model may benefit patients in remote or underserved areas
- Workforce sustainability
    - Provision of TTFields does not exacerbate capacity pressures

Ms Pswarayi outlined the challenges for industry:
- Inconsistent national adoption
    - Even when devices are assessed positively, variable uptake across regions undermines equitable access.
        - Cost-effectiveness judged locally, risks making national value invisible in business cases.

    - Technologies not selected for national spread rely on clinician led-business cases

- Evidence generation isn't linked to a defined pathway for commissioning and adoption, stalling innovation.

- No dedicated innovation mechanism or fund
    - Unlike medicines, there is no equivalent fund or fast track process for medicine in rare conditions like GBM.

Ms Pswarayi outlined challenges for patients:

- Delays to or lack of access to some innovative treatments
    - Leads to postcode variation
    - Lagging behind other countries in Europe
    - Lost opportunity to benefit from global advances

- Reliance on individual advocacy or private options outside of Scotland

Ms Pswarayi concluded with what needs to change:

- Need for a clearer, more defined pathway for innovative medical devices
    - Particularly those targeting rare diseases and conditions with high unmet need e.g. glioblastoma
    - Advocate for test cases like brain tumours to improve timely assessment and adoption of transformative treatments

- Need to fix the disconnect between assessment, funding and adoption
    - Champion equitable access to innovation in national adoption policy

- Explore a dedicated innovation commissioning mechanism or fund for rare and under-served conditions like GBM.

Discussion:

The Co-Deputy Convener opened the discussion by noting that politicians often pressure health boards to allocate budgets based on return on investment (ROI), prioritizing treatments for common conditions like hip replacements.

Ms. Pswarayi stated that Novocure is lobbying for the creation of a ring-fenced fund, jointly supported by both the Government and industry, to support treatment and research. The Co-Deputy Convener commented that if the Government invests it gives industry confidence that their investment will have some return.

Vicky Wright highlighted the importance of looking internationally for examples of good practice. She stated that Canada have a recommendation for TTFields and France, Germany and Spain all fund them. She stated it is worrying that innovations come through but take ages to be adopted.

Dr Scott Arthur MP encouraged the group to examine how breakthroughs in other cancer types were achieved, and to apply similar processes and methodologies to rare cancers, which have seen little progress in treatment over time.

The Co-Deputy Convener stated one takeaway is that the panel which only looks at medicines should look perhaps at treatments more broadly.

Agenda item 6 - Presentation by Kevin Donagh, on his book 'Stories of Cancer and Hope'

Kevin Donaghy presented his book *Stories of Cancer and Hope*.

Kevin Donagh began by sharing his personal story of being diagnosed with melanoma in 2019. This was an incredibly difficult time for both him and his family, particularly because his treatment was scheduled to begin in 2020—the same year the COVID-19 pandemic hit the UK. At the time of his diagnosis, he was told that his cancer would be life-limiting. However, thanks to immunotherapy, he was able to significantly extend his life expectancy.

Kevin spoke powerfully about the sense of hope he found through the work of his online melanoma support group. Inspired by this, he decided to collect 20 uplifting and hopeful cancer stories into a book, aiming to help others facing similar challenges feel less alone. Over 60 people worked together to produce the book, all based in Scotland.

It is sold though Maggie's cancer charity online and the book is stocked in their centres across Scotland, while Edinburgh-based Cancer Card were donated 1000 copies of the book to provide with their Comfort Boxes to cancer patients. ScotMid have included the book in their Book Bank initiative. The book is also available to purchase with profits going to Maggie's. Mr Donagh and his collaborators have set up Shandon Publishing, a social enterprise publishing company to publish titles that help people with physical and mental health conditions.

Kevin highlighted the story of Laura Nuttel - the only glioblastoma (GBM) patient featured in the book. Diagnosed at just 18, Laura refused to let her diagnosis define her. She created a bucket list that led her to achieve remarkable experiences, including attending James Bond premieres and meeting Michelle Obama.

Kevin concluded his presentation by emphasizing that every story in the book has an element of hope and it is his desire to have the book in the hands of as many people affected by cancer directly or indirectly. He stressed that early detection is so important in identifying brain cancer and there is need to improve initial diagnosis in Scotland where 70% of diagnoses happen in A&E. He also stressed the need for targeted treatments tailored to unique patient circumstances.

Discussion:

The Co-Deputy Convener thanked Kevin for his heartfelt and personal reflections. Finlay Carson MSP remarked that Kevin's work is a powerful reminder of the human stories behind policy discussions.

Dr Joanna Birch expressed an interest in having the book available in research centres and universities.

Agenda item 7 - Any other business

One of the attendees, who was at the CPG for the first time, spoke about her son Jay who died three and a half years ago after being diagnosed in his first year of university. She is a member of the organisation Angel Mums, which has been working with Tessa Jowell Brain Cancer Mission. They have a passion as parents to be behind this work. She echoed Mr Donagh's comments about this always being about hope, but stated it is frustrating to hear about the challenges being faced. When her son got ill she knew nothing about cancer and was terrified and naïve. She trusted the consultants and did everything she could. She didn't know about genomic testing.

The Co-Deputy Convener thanked the attendee for her contribution and emphasised it is important for her to feel welcome to attend and voice her thoughts as the forum of the CPG is for everyone. He stated the red tape is frustrating and there are barriers to progress which do not reflect a lack of desire on the part of researchers and other stakeholders to help.

Dr Scott Arthur MP stated he was really pleased to have the support of Angel Mums for his Rare Cancers Bill.

Sorcha Hume from Cancer Research UK reminded the attendees that the Scottish Cancer Conference is scheduled for the 10th of November at the University of Strathclyde and that there are free tickets for people affected by cancer.

Sorcha Hume also referenced the minutes from last meeting which talked a lot about how the time for private meetings was over and the want to get media involved and do something publicly.

Nadia Majid stated she has been attending the CPG since the start and is blown away by the information provided and the work everyone is doing. It gives hope and is encouraging.

The Co-Deputy Convener announced Thomas Brayford is leaving Brain Tumour Research and stepping down as the contact for the Secretariat, and wished him well for the future.

Agenda item 8 - Date of Next Meeting

Thomas Brayford stated that work is under way for a meeting in November and that the CPG would be informed of the date of next meeting in due course.

The Co-Deputy Convener stated he would look into the possibility of remote attendance for the next CPG meeting.

The Co-Deputy Convener thanked everyone for their attendance and closed the meeting