Cross-Party Group on Brain Tumours

Thursday 19th June 2025– 13:00 -14:14

Minute

Present

MSPs

Beatrice Wishart MSP (Convener)
Colin Smyth MSP
Alexander Stewart MSP

Invited guests

Dr Mark Brougham, NHS Lothian
Ms Emer Campbell, Royal Hospital for Children Glasgow
Prof. Colin Smith, University of Edinburgh
Dr Joanna Cull, Brain Tumour Research

Non-MSP Group Members

Thomas Brayford, Brain Tumour Research (Secretariat)

Apologies

Jackie Baillie MSP

Agenda item 1

Welcome
Beatrice Wishart MSP welcomed attendees to the meeting and introduced the first speakers.

Agenda item 2

Presentation: Closing the Gap – Genomics and Access to Trials
Camile Goetz introduced the Tessa Jowell Brain Cancer Mission (TJBCM), a convening body of various stakeholders to deliver new programmes and address inequities. TJBCM recently launched their 'Closing the Gap' report on the variations in genetic testing for brain tumours in the UK. This testing has become an essential part of treatment to guide decision making and enable access to clinical trials.

A key finding of the report is that Scotland is behind rest of the UK. TJBCM met with Cabinet Secretary for Health and Social Care and set out a straightforward solution to address this. Disappointingly, the Scottish Government does not intend to take on this solution. This inequity in access to molecular and genomic testing is not an optional extra, it is a key part of treatment and this pressing inequity could be easily addressed. Acting on this is an easy win. The CPG has opportunity to tangibly improve treatment by pressing on this issue.

Dr Mark Brougham, a paediatric oncologist in Edinburgh, NHS Lothian, illustrated the issue with patient case study. 8-year-old Christopher had headaches, vomiting and vision issues. An MRI revealed an aggressive tumour deep in the brain which was inoperable. It appeared to be a high-grade glioma which has a poor prognosis. Biopsy results were consistent with the scan. However, sent to Great Ormond Street Hospital (GOSH) in London for molecular analysis that can’t be done in Scotland. Dr Brougham had a difficult conversation with the parents and planned treatment with radiotherapy and chemotherapy as palliative measure. It took 6 weeks to get further information. The team were getting anxious about tumour growth so started the treatment programme. One day later found out from GOSH it was a completely different type of tumour needing a completely different type of treatment – and importantly, it may actually respond well to treatment. Very surprisingly the scan after treatment showed the tumour had completely gone. 2.5 years later he is well and doing well at school.

These tests are therefore essential to ensure an accurate diagnosis. We already have requisite equipment and expertise to perform these tests sooner. In Christopher’s case his treatment could’ve started sooner. Another concern is that samples can get lost in transit on their way to London and there have been cases of this happening.

Health professionals feel guilty about giving inaccurate information to patients and their families regarding diagnosis and prognosis. This is avoidable.

Ms Emer Campbell, a consultant in paediatrics in Glasgow also gave a patient case study. 10-year old Diago presented with headaches, vomiting and double vision. An MRI showed an isolated primary brain tumour deep in right hemisphere close to the brain stem. He was transferred from Aberdeen to Glasgow where a biopsy was performed. 10 days later the local neuropathology team diagnosed a low-grade tumour to be treated with chemotherapy and radiotherapy. Diago’s headaches got worse and his symptoms indicated a deteriorating condition. He needed brain fluid draining but there was no improvement. Re-scans showed tumour wasn’t growing but his symptoms indicated high-grade malignant tumour. The team began to plan surgery, which came with significant risks including facial paralysis and disability. This was 4 weeks since sent sample to GOSH. The team only got a result by effectively using back-channels to contact the team at GOSH. It proved the tumour was low-grade as initially diagnosed but with certain mutations. These indicated it could respond to chemotherapy, which Diago received. He is now back at school and playing football. If he had had the surgery he would likely not be able to do this due to the impacts e.g. face paralysis, brain injury. It is clear that not having all the information could have life-changing consequences for patients.

Professor Colin Smith from the University of Edinburgh, also a consultant neuropathologist, presented on the proposed solution. He highlighted that the clinical need is clearly demonstrated and that this affects adults as well as children. He gave the example of BBC journalist Glen Campbell who has spoken about the delays in getting all the info about his brain tumour diagnosis as Scotland doesn't get all the molecular testing. Scotland is utterly dependent on another country to provide it, making us one of only three countries in Europe that cannot do this themselves. Looking to implement something already in place across the world. Know there are significant savings to be made as a diagnosis could be provided within 2 days rather than weeks and treatment planning could commence. The Scottish genomic strategy is not working. Issues with the National Service Delivery for NHS Scotland.

There is a huge disconnect as Glasgow and Edinburgh universities are world leading in terms of research. Presented solution to the Scottish Government that universities could provide the testing and information for the NHS. The situation is most acute in brain tumours because molecular tech is ahead of the curve but this problem applies to other types of cancer which rely on sending samples to England. The Scottish Government said that university labs are not accredited but university labs are happy to go through the accreditation process. The inflexible mechanisms that are in place at the moment are obstructing this proposed solution.

Using unis would be cheaper, quicker and get clinicians the information they need to create accurate, targeted treatment.

We are missing out enabling Scottish patients to access clinical trials across the UK.

The Chair invited the CPG to agree to write to the Scottish Government to raise this issue. The CPG agreed.

<u>There followed a Q&A and comments on the presentations:</u>

Colin Smyth MSP asked about the barriers to enacting this.

Professor Colin Smith: Neil Gray was supportive in a meeting but later wrote that Scottish National Genomics Network in place and the university test isn't validated. But the network has been in place for 3 years without action and the test is validated. The point is also that the budget is cheaper than what they are currently planning for. £2-300,000 to cover Scotland.

Theo Burrell, Brain Tumour Research Patron: Paid £5000 to get her tumour sequenced in America. Had no idea that someone could've done the work in Scotland. Met another patient who has just found out that instead of having a high-grade cancerous tumour she has a benign tumour. Her team in the north east Scotland didn't have access to the correct information. She is now living with disabilities as a result of her unnecessary chemotherapy and radiation. Unusual case but illustrates potential harm of this testing not being available in Scotland.

Dr Sorcha Hume, Cancer Research UK: CRUK are presenting similar research to the Genomics Network; offered to work with TJBCM on this issue.

Archie Goodburn: His family had to self-fund his genomic testing to determine what kind of glioma he has, which influences the type of treatment needed. The uncertainty patients go through in this time is indescribable.

Agenda item 3

The Scottish Brain Tumour Research Centre of Excellence – The Story So Far
Presenter: Dr Joanna Cull, Brain Tumour Research
- Centre's establishment and leadership
- Key research themes and translational goals
- Collaboration with clinical and academic partners
- Vision for sustained growth and impact

Dr Joanna Cull gave a presentation on the Scottish Brian Tumour Research Centre of Excellence.

Brain Tumour Research (BTR) funding model focuses on centres of excellence, giving long-term funding over 5 years. The newest addition is a collaboration between Glasgow and Edinburgh universities.

The Scottish BTR Centre of Excellence began in 2022 with a call out for applications for a new centre. A peer-review process chose Scottish centre as the new one. BTR formed a partnership with Beaton Cancer Charity to fund it.

The Centre launched in January 2025. It is co-led by Prof Steve Pollard and Prof Anthony Chalmers and has the largest multidisciplinary team researching glioblastomas in the UK. This is a fast-growing tumour, the most common type of primary malignant brain tumour in adults and has a poor prognosis.

Centre aims to address the 'translation gap'. Historically there has been a lack of funding into this area to turn research into treatments.

Three main aims of the centre are to:

- Develop new effective drugs by developing drugs that target and kill cancer-causing cells.
- Improve how we test medicines in the lab; Testing needs advance models that recapitulate the key features of human diseases, meaning therapies are less likely to fail when moving from lab testing to testing in people.

- Train the next generation of researchers. Key to keep up momentum. 4 nonclinical PhD studentships. Prioritising early career investigators.

Collaboration is at the heart of the centre of excellence. University, Clinical Trial Networks, CRUK Institutes, NHS Regions.

Since the funding began the network has been established – all staff and PhDs have been hired. Large number of novel small molecule drugs have been synthesized which are now starting to be progressed through the rigorous pipeline of testing.

Asks for the Scottish Government:

- To recognise brain tumours as a caner of unmet need.
- To match-fund the Centre for Excellence.
- To support collaborative research.
- expand research capacity
- provide core funding for essential roles such as clinical research nurses and data analysts.

There followed a Q&A and comments on the presentations:

Colin Smyth MSP asked for the asks at the end of the presentation to be circulated to MSP members so they can follow up these asks to the SG.

Colin Smyth MSP highlights that prognoses for have not changed in the last few years.

Dr Joanna Cull responds that the aim is to de-risk investment in research for treatments.

Theo Burrell highlights the work of Steve Pollard to go beyond his work as a research scientist to make the case for funding but points out that she doesn’t think we should have to rely on our scientists to be doing this.

Alexander Stewart MSP asks about goals.

Dr Joanna Cull would like to see research positions funded by SG and expansion to other universities to embed the research.

Professor Colin Smith: Transformation in MND research due to Scottish Government investment. Relatively small investment can have big impact.

Archie Goodburn: This is the start of a process and need to build on this momentum.

Agenda item 4

Advancing Brain Tumour Research – A National Perspective

Presenter: Dr Sorcha Hume, Cancer Research UK
- Overview of CRUK's brain tumour research portfolio
- Key projects and funding in Scotland
- Partnerships and policy engagement opportunities
- How others can collaborate or seek support

Dr Sorcha Hume from Cancer Research UK gave a presentation on CRUK's work on brain tumour research.

Cancer Research funds £415 million of research into all types of cancer. £12 million specifically into brain tumour research.

Research Strategy commits to tackling cancers of unmet need of which brain cancer is one. These cancers have historically fewer research tools and models and historically smaller research communities.

Examples of research funded by CRUK:

- In 90s involved in identifying a new chemotherapy – which is still used today.
- In 200s research developed treatments for children.
- In 2016 research into understanding biology of particular type of tumour.
- 2018 Additional £25 million investment into brain tumour research.

Since 2014 invested over £95 million into brain tumour research. Work with other organizations in the sector to maximise impact. Hold regular brain tumour conferences.

Examples of ongoing research include developing cheap blood test for diagnosis and analysing genes to develop targeted personalized treatments.

Scotland received 25% of CRUK brain tumour research spend in 2023/24. Various research projects.

Work in collaboration with other organisations. As Secretariat for CPG on Cancer in SP ensure it considers brain tumours. Work across all UK parliaments and also have Europe and global teams; look at opportunities to learn from other countries. Asking researchers – these are the biggest questions, what are you going to do to work on finding the answers.

Agenda item 5

The Struggle for Access – Patient Voice on Vorasidenib

Speaker: Archie Goodburn
- Personal story of challenges in accessing vorasidenib
- Broader implications for access to innovative treatments for low-grade gliomas

Archie Goodburn gave a presentation about the unequal access to treatment affecting Scottish patients.

Archie is a 23 year old student who has just completed a masters in targeted drug delivery to brain tumours. Athlete who was competing in high-level swimming.

Been trying to access vorasidenib to treat his brain tumour. Approved by FDA in 2024, it delays the need for chemo and radiotherapy. Patients can maintain brain function and live their lives. Radiotherapy in Archie’s case would cause permanent cognitive damage due to tumour location.

Earlier this year his application for this drug was rejected. Just across the country in Glasgow access has been given. Brutal that drug exists, is working, is in use in the UK but can’t be accessed.

This isn’t the only example; part of a wider pattern in brain tumour care where your postcode can determine your speed of diagnosis, your treatment, and even survival.

Molecular and genomic testing not available in Scotland. Patients in Scotland end up paying privately – inequality.

Low-grade gliomas grow slowly but they do grow. Can become deadly. Delays aren’t just frustrating, they are fatal.

Not asking for miracles. Asking for clear, coordinated approaches so that access to treatments are available to all patients as soon as they exist. Must do better and we must do it now.

<u>There followed a Q&A and comments on the presentation:</u>

Dr Mark Brougham – Familiar issue; have a number of patients in this position, looking for targeted treatments.

Colin Smyth MSP – asked more about the availability of vorasidinab

Archie Goodburn – NHS Glasgow and NHS Tayside are both offering it. Been frustrating knowing his tumour is growing and the drug may be less effective or not work; could have lost years of his life due to this delay. Despite trials finishing two years ago, still not seeing it available. Lessons must be learned from this.

Colin Smyth MSP – Offers to put Archie in touch with Lothian MSPs

Archie Goodburn – want to raise the wider issue of access to treatments for all patients, and all types of brain tumours not just his own.

Agenda item 6

Open Discussion and Q&A
- Questions and reflections from attendees

- Identifying opportunities for policy support and collaboration
- Summary and closing remarks from the Chair

Nadia Majid told the CPG about her son who died in 2018. The answer from GOSH never arrived about what type of tumour he had and he didn't respond to treatment. There was very little information about his tumour type; they felt in the dark. She said it is encouraging there is work going on in research but wonder how much is making its way to patients and stressed the need for faster progress.

The Chair (Beatrice Wishart MSP) agrees there needs to be faster action.

Colin Smyth MSP, Deputy Co-Convenor of the CPG, took over the Chair from Beatrice Wishart MSP, the Convenor.

Dr Sorcha Hume offers to add CRUK voice to Archie's campaign – glacial pace of equitable access to treatments. Thinks that personal stories help make the points to decision makers.

The Chair (Colin Smyth MSP) asked what other actions should be take from today's meeting beyond writing to the Scottish Government on the 'Close the Gap' report.

Professor Colin Smith emphasizing the frustrations we've heard and how they are unique to Scottish patients. English patients are not paying privately for sequencing; they are accessing the drugs. As a professional it is frustrating. The universities are doing the sequencing; have piloted it; all good to go. National Service Delivery are preventing it. Would argue they should be dealing with the national problem of access to drugs. The major pathology labs in Scotland should be doing this; lagging behind; Scottish patients won't be able to access clinical trials.

Theo Burrell Volunteers to go to any meeting to make the points personally. Angry. Unbelievable that these inequalities exist in Scotland when solutions are available.

The Chair (Colin Smyth MSP) – Option to request a meeting is probably a good one.

Elaine Murray introduced herself as a former MSP and Theo Burrell's mother in law. Scandalous that Theo had to pay so much money for sequencing when it could've been done locally. Thinks that could do a media campaign. Journalists who might take this up. If SG think they can get away with sending a letter to fob you off they will continue to do so.

The Chair (Colin Smyth MSP) – Media do like real life stories. Can facilitate and support that; meeting with journalists.

Camile Goetz – New trials are going to be opening in the UK; real risk that Scottish patients will not be able to access them. Ludicrous that research on this takes place in Scotland that Scottish patients may not access.

Archie Goodburn – New clinical trials listed never have Scottish locations listed. Frustrating. Recently looked to put something together with the BBC but didn't end up airing as no clear direction as to call for action as there are so many frustrating aspects. Would work with charities to develop calls for action. Main things – genomics, translational gap from lab to clinical trial, then gap from clinical trial to real world.

Dr Sorcha Hume – Had so many private meetings and things aren't progressing. Now is the time to look at media. Need a specific call for change. Offers CRUK media team.

Theo Burrell – Seen the power of people like Chris Hoy speaking out. BTR have high profile patrons; if they are willing to put their name behind something could raise profile.

Archie Goodburn – Willing to put story out there for a constructive purpose, not a sob story.

Professor Colin Smith – Three clear messages:

- Scottish patients need equitable access to genetic testing for brain tumours;
- Sottish patients need access to clinical trials;
- Scottish patients need access to drugs.

Theo Burrell – Coming up against barrier about taking drugs that have been proven to work; offering to pay for them; but clinician is refusing as outwith NHS protocol. Confusing that patients in Glasgow can pay for this drug themselves but not in Edinburgh. And in this situation it is life or death.

The Chair (Colin Smyth MSP) – Inconsistency across health boards; postcode lottery.

Archie Goodburn – Has been able to access vorasidinib on a case-by-case basis; learned about it yesterday and come about through pushing and raising case and working with Christine Jardine MP to put NHS Lothian on the spot. Far less promising treatment than it would've been 12 months ago.

Susie Goodburn – Pushed like mad to get to this stage; no 23 year old who was due to be in the Olympics should be going through this. Seems ridiculous that has had to go to this extent to get to this point; concern that he may have missed the window for this treatment to be effective. Alarming. If lived an hour away in Glasgow would have been given this treatment a year ago.

The Chair (Colin Smyth MSP) – Need for MSPs to talk through the issues and follow up to make sure we pick up the actions and address the wider issue about raising this in the press. Identify some journalists with interests in health who would take up writing up the campaign.

Thomas Brayford, Brain Tumour Research – Good to have homework from these meetings. Want to be here to do things. Need to collaborate on press. Grateful for all input and ideas.

The Chair (Colin Smyth MSP) – Commit that MSPs will work with group to come up with an action plan for a campaign. Look for opportunities to highlight in parliament as well.

Dr Sorcha Hume – Offer to link up with CPG on Cancer. Has a draft plan for a press conference in parliament that could be used.

Actions:

The CPG agreed to write a letter to the Scottish Government urging the removal of bureaucratic barriers preventing Scottish university labs from gaining accreditation to carry out genomic sequencing.

- University-based sequencing is validated, cheaper and quicker.
- Existing labs in Edinburgh and Glasgow already have the equipment and expertise.
- Accreditation could cost £200,000–£300,000—less than current spending.
- CRUK offered to support this action and coordinate with TJBCM.

The CPG also discussed requesting a face-to-face meeting with the Cabinet Secretary to make representations on the issues raised.

A media campaign to raise awareness of the inequities in sequencing access was supported:

- High-profile patient advocates like Archie Goodburn and Theo Burrell are willing to be involved.
- CRUK offered the use of their media team and a draft plan for a press conference in Parliament.
- Option to coordinate with the CPG on Cancer and develop targeted calls to action.
- Stories from Archie, Theo, and other patients highlight the urgency and personal impact of delayed or denied access to sequencing and treatment.

The Chair (Colin Smyth MSP) closed the meeting.

ENDS