UNDERSTANDING THE BARRIERS TO DIAGNOSIS OF BRAIN TUMOURS IN SCOTLAND – A Roundtable Discussion
A project led by The Brain Tumour Charity and Dxcover: February 2024

Over 1,000 people are diagnosed with a brain tumour in Scotland every year and for many of them, diagnosis simply takes too long. Brain tumours are hard to detect. Symptoms are usually vague and non-specific, and brain tumour patients are most likely to be diagnosed via A&E.

It must also be acknowledged that GP services are overstretched and at maximum capacity. By improving current referral pathways available to GPs, we can support them in ensuring that patients with vague or non-specific symptoms receive the care they need. With new innovations and technologies continuously arising there are reasons to be hopeful that novel intervention may become available in the near future. Particularly to help primary care practitioners identify the patients that might have a brain tumour.

In the meantime, while such a novel intervention tool, such as a blood test, is not currently available, we need to ensure that diagnostic pathways in Scotland are appropriate for those affected by brain tumours. They must also be ready for when a diagnostic tool does become available. As a result, The Brain Tumour Charity and clinical stage, liquid biopsy company, Dxcover, co-sponsored a roundtable discussion with relevant stakeholders including GPs, NHS representatives, researchers and representatives from the Chief Scientist’s Office, to understand the current barriers to a brain tumour diagnosis and how referral pathways can be improved.

From the roundtable, eight key areas were identified as areas which could have the most potential for improving the diagnostic pathways of those affected by brain tumours. The discussions resulted in twelve recommendations to NHS Scotland and the Scottish Government on the changes that are required to ensure current pathways are effective for those affected by brain tumours and could be benefitted by the establishment of a diagnostic/triage tool.

Disclaimer: This report should not be taken as any of these individuals or organisations opinion and rather reflects the discussion as a whole, and further desk research conducted after the event.
Rapid Cancer Diagnostic Services (RCDS): Throughout the roundtable the potential of the RCDS pathway was highlighted. RCDSs were established to investigate patients with vague symptoms that may be related to cancer, and to fast-track patients to receive a diagnosis. Though they are still in the pilot stage, there are now five RCDS pathways across Scotland: NHS Lanarkshire, NHS Borders, NHS Fife, NHS Dumfries and Galloway, and NHS Ayrshire & Arran. The final report on the performance of the RCDS published by the University of Strathclyde in March 2024 suggests there were no brain cancer patients diagnosed within the RCDS pathways. This is a result of there currently being no symptoms related to brain tumours on the referral list for RCDS pathways. Thus, it is vital that the list of symptoms is expanded to include generic symptoms related to brain tumours, so that the service can become more widely available for referral for suspected brain tumour patients. Symptoms related to brain tumours include in the National Headache Pathway (NHP) include “new headache plus personality or cognitive changes, new headache plus seizures and new headache plus sub-acute progressive focal neurology” which could be added to the referral list for RCDS.

During the roundtable concern was raised that the RCDS pathways do not cover the whole population yet and therefore shouldn’t be solely relied upon. Overall, however, it was noted that the service could benefit from the development of a diagnostic or triage tool. If the necessary changes to the referral lists were implemented and shown to positively benefit those affected by brain tumours then RCDSs could eventually be a useful testbed for trialling these technologies in a more general setting.

Recommendations:

• The Centre for Sustainable Delivery (CfSD) must expand the non-specific symptoms list that warrants referral to RCDSs to include symptoms of brain tumours. Considerations should be taken as to whether the symptoms associated with brain tumours that are used within the NHP could be added. Alternatively, the NICE guidance for direct MRI access which is “loss of central neurological function (progressive, sub acute) in adults could be included”.6
• The CfSD should also explore whether a diagnostic/triage tool could be used effectively within RCDS settings.
GP Direct Access and the National Headache Pathway (NHP):

Attendees broadly agreed that GP Direct Access for CT Head Imaging could be improved. Current Scottish referral guidelines for brain tumours states that all NHS boards have pathways for investigation of headaches. It adds that these pathways should include primary care direct access to imaging. In 2020, a Scottish CT Special Interest Group was created to identify if GPs within their health board were permitted to refer for CT Head Imaging. It was found that all areas, except four, did have Direct Access. However, due to current data limitations, we cannot, with full certainty, understand how effectively this pathway is being used and how many people with vague brain tumour symptoms are being referred via GP direct access.

Within the discussion, the launch of the NHP was mentioned. The NHP has been developed to aid with the diagnosis, assessment and management of common primary headaches. It provides guidance for when HCPs should consider secondary headache disorders.

Within that pathway there are guidelines for access to imaging in headache. The NHP notes that patients with ‘red flags’ be referred as emergency / urgently to secondary care for appropriate assessment / investigation – this includes patients with a headache which could be a result of a brain tumour. This is rather than referring them directly for a CT scan. It was generally agreed that this was appropriate – particularly due to the current waiting lists for both CT and MRI scans. Waiting times could potentially be reduced through the implementation of a diagnostic/triage tool.

The NHP uses Positive Predictive Values (PPVs), which are a combination of symptoms to provide a better indicator of a potential brain tumour diagnosis. The PPVs that are included in the NHP are new headache plus personality or cognitive changes, new headache plus seizures and new headache plus sub-acute progressive focal neurology.

GP attendees observed that in most cases of headache they would advise the patient to return within a couple of weeks if their headaches persist or worsen. This is a particular area where long delays can cause more problems further down the line. In areas such as this, interventions such as Dxcover’s liquid biopsy test or other triage/diagnostic tools could be beneficial and aid primary care clinicians.

Nevertheless, clear information, such as what has been developed with the NHP, was noted as being helpful. Primary care physicians need to have clearer referral routes for where to send patients with a possible brain tumour.

Recommendation:

- Public Health Scotland must ensure data is publicly available for GP Direct Access and the National Headache Pathway so it can be understood as to how effective these pathways are for the diagnosis of brain tumours.
Continuity of care:
Another common point of discussion throughout the roundtable was the importance of continuity of care, including the ability for the patient to consistently see the same GP. It was shared that continuity is important for recognising changes within a particular patient. For example, if a GP had seen the same patient continuously over a particular timeframe then they would be potentially be quicker to identify any changes.

The potential benefits of continuity of care were highlighted through the patient voice where one attendee shared how a relative had seen five different GPs before receiving a diagnosis. They continued by asking whether their relative would have received a faster diagnosis if they had seen the same GP during that timeframe, who could have recognised any cognitive changes in them.

The Royal College of General Practitioners (RCGP) defines it as a critical element of general practice. But unfortunately, it was highlighted that it is becoming increasingly difficult for GPs to provide continuity of care. It was noted that workload pressures have a huge impact and patients have difficulty in being able to see the same GP on repeat visits. Reducing pressures on primary care professionals through improving patient pathways, increasing the workforce and by providing new innovations will go a long way to helping continuity of care to become more of the standard.

Recommendation:
- NHS Scotland must develop and provide guidelines for improving continuity of care and raising awareness of its benefits amongst patients.

Safety Netting:
Safety netting was a frequent area of discussion brought up throughout the roundtable by attendees. According to Cancer Research UK, safety netting is a way to ensure a patient is monitored throughout the diagnostic process until their signs and symptoms are explained or their symptoms are resolved. Different GP practices can utilise different safety netting systems to empower patients to return. Doing so largely through asking a patient to return in a certain timeframe if their symptoms do not improve or get worse.

When discussing Clinical Vignettes of patients who presented with symptoms potentially related to a brain tumour, the use of safety netting was continually noted. It was generally agreed that a diagnostic/triage tool, such as a blood test, could be used alongside safety netting in order to triage people not to refer to secondary care.
Furthermore, it was also highlighted that safety netting is not discussed enough in Secondary Care. Attendees agreed clear guidance is required to inform when and where a patient should return if their symptoms do not improve.

**Recommendations:**

- NHS Scotland should undertake research to identify how a diagnostic/triage tool could aid GPs in the use of safety netting and to determine any potential role it could have in this regard.
- NHS Scotland should establish clear guidelines on the use of safety netting in Secondary Care for those with symptoms that may indicate a brain tumour.

**Involvement of Optometrists:**

During the roundtable, attendees discussed the role Optometrists have in the diagnosis of brain tumours. Some types of brain tumours may affect a person’s field of vision or eye-muscle coordination. Symptoms such as blurred or double vision, particularly if associated with a headache can also be common. As a result, some people will book an appointment with an Optician before their GP. Similarly, GPs noted how they may refer people to optometry when they present with certain types of headaches or if they are associated with ocular symptoms. However, it was added that this is not always a reliable solution. As an example, an advocate at the roundtable shared that their relative was diagnosed with a brain tumour after several GP visits, and had previously had their symptoms missed at their opticians.

The Scottish referral guidelines for brain and central nervous system cancer specifies that cancer pathways should exist in all NHS Boards for optometrists to refer directly to secondary care for people with optic discs suspicious of papilloedema.\(^\text{13}\)

However, it was highlighted that in some regions across Scotland, opticians are only able to refer to ophthalmology and unable to refer directly to neurology. For this pathway to be as effective as possible for those presenting with a possible brain tumour, differences across regions must be addressed.

**Recommendation:**

- NHS Scotland must ensure that opticians can directly refer to neurology if the optometrist is presented with a patient with a potential brain tumour.
**Raising awareness:** Attendees highlighted the benefits of awareness campaigns. It was acknowledged that awareness campaigns play an important role in ensuring the public are aware of signs and symptoms of diseases. They are also necessary in informing the public on when to visit a GP or A&E if they are worried about certain symptoms.

However, there was general agreement that there is a responsibility to ensure that campaign materials are messaged appropriately. This means raising awareness of signs and symptoms in a way that empowers people to seek evaluation when necessary, while avoiding language that could cause unnecessary worry. It is something that charities and NHS awareness campaigns should always be considerate of.

**Recommendation:**
- For those responsible for developing symptoms awareness campaigns to ensure that messaging is clear and delivered in a manner that does not increase general anxiety amongst the public.

**Rural and remote communities:**
A key area for where new diagnostic/triage tools, such as blood tests, could be most beneficial is for those who live in more remote and rural areas. It was discussed that in some rural areas and island communities there are no MRI or CT scanners. This means that if a patient is referred for a scan, they must undertake a potentially stressful and time-consuming journey to their nearest centre to attend an imaging appointment. This is partly being addressed through mobile scanners, though these are not readily available and are less relevant for emergency appointments.

During the discussion, participants agreed that if a diagnostic/triage tool, such as a blood test, became available it would mean that those in these rural areas would receive a diagnosis a lot faster. A blood test can be carried out rapidly, even on site at a GP practice, meaning those in more remote areas would potentially not have to travel vast distances to attend a CT or MRI scan.

**Recommendations:**
- NHS Scotland should assess how easy and feasible it would be to ensure rural settings have access to a diagnostic/triage tool like a blood test when available.
- Pilots should then be undertaken to understand the potential benefits of a diagnostic/triage tool in more remote areas.
Innovation is needed: During the roundtable Dxcover presented their novel liquid biopsy approach for brain tumour detection and attendees discussed the potential impact on the patient pathway that a blood test could facilitate. In general, there was an agreement that innovation such as this is needed to aid earlier brain tumour detection.

In The Brain Tumour Charity’s Manifesto for the Scottish Parliamentary Elections in 2021, they called on the next Scottish Government commit to reducing the proportions of brain tumours diagnosed in the emergency department and to pilot the Dxcover blood test in primary care across Scotland.14

Recommendations:

- For Scottish Government and NHS Scotland to work together to pilot a diagnostic/triage tool such as the Dxcover blood test across Scotland as soon as possible to explore its potential to
  - Triage those with possible symptoms and diagnose brain tumours earlier.
  - Improve patient experience.
  - Provide swift reassurance to those who do not have a brain tumour.

Conclusion from the discussion:

Improving current pathways for those affected by brain tumours will be challenging and it is vital to ensure that diagnostic pathways will be ready for when new innovative tools become available. Diagnostic and triage tools, once established, will make a significant difference in the faster diagnosis of harder to detect diseases such as brain tumours and other less survivable cancers.

This roundtable and the areas discussed was a first step in identifying opportunities for improvements and where in the healthcare system a diagnostic intervention could be implemented.

There have been positive steps already undertaken in Scotland. One example is the creation of the National Headache Pathway and its use of Positive Predictive Values (PPVs). The pathway and its clear guidance was warmly received by attendees.

It would be extremely beneficial if similar rationale was developed for other pathways with clear guidance for primary care doctors. Similarly, new guidance for how and when new diagnostic/triage tools could be effectively used, would allow the system to be ready for the next stage of technological advancements.
**Recommendations:**

We need to see an audit of the current referral pathways that exist within Scotland to identify the following:

- How they can be optimised for those who present with a suspected brain tumour through discussions around the Scottish referral guidelines
- How a diagnostic/triage tool can be established when available within specific pathways.
- Areas of current best practice within Scotland.

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**Information on co-sponsors of the roundtable:**

**The Brain Tumour Charity:**

The Brain Tumour Charity is the world’s leading brain tumour charity and the largest dedicated funder of research into brain tumours globally. Brain tumours are the biggest cancer killer of children and adults under 40. Committed to saving and improving lives, The Charity is moving further, faster to help every single person affected by a brain tumour. We’re set on finding new treatments, offering the highest level of support and driving urgent change. And we’re doing it right now. Because we understand that when you, or someone you love, is diagnosed with a brain tumour – a cure really can’t wait.

Find out more at: [thebraintumourcharity.org](http://thebraintumourcharity.org)

**Dxcover:**

The Dxcover® Brain Cancer liquid biopsy is a simple blood test combined with artificial intelligence that can rapidly fast-track patients suspected to have a brain tumour for further treatment. Typically, diagnosis requires several GP visits before specialist scans and can take up to eight weeks or more to fully diagnose.

Dxcover is a spin-out from the University of Strathclyde, based on world leading research and fronted by an award-winning team dedicated to translating this technology into the clinic.

Dxcover’s blood test is fast, inexpensive and only requires a blood sample. The doctor sends the sample to the lab for analysis with infra-red light. Dxcover’s ‘drop, dry, detect’ technology provides results in minutes and is powered by artificial intelligence and trained to detect the signs of cancer.

Through the Dxcover® Cancer project, the company is targeting earlier detection of rare and common cancers. Earlier diagnosis results in significantly higher survival rates compared to late-stage diagnosis, with treatment options and the chances of recovery and quality of life hugely increased. The blood test allows doctors and clinicians to prioritise and fast-track patients for further treatment.
Participants List:

Paul Brennan (Chair) – Consultant Neurosurgeon at the University of Edinburgh and NHS Lothian  
Prof Matthew J Baker – Chief Executive Officer, Dxcover  
Dr James Cameron – Clinical Programme Manager, Dxcover  
Dr Mark Hegarty – Business Advisor, Dxcover  
Dr David Palmer – Chief Technology Officer, Dxcover  
Dr David Eustace – Operations Director, Dxcover  
Dr Alan McNair – Chief Scientist Office  
Catherine Calderwood – former Chief Medical Officer for Scotland  
Carolyn Steeds – Director, Value Communications, Valid Insight  
Dr David Hogg – GP and Patient Representative  
Garth Funston – Clinical Senior Lecturer in Primary Care Cancer Research, Wolfson Institute of Population Health Queen Mary University of London  
Glenn Campbell – Patient Representative  
Sharon Peoples – Clinical Lead, Scottish Adult Neuro-Oncology Network (SANON)  
Miles Briggs – MSP for Lothian (Region) and Co-convenor of the CPG on Cancer  
Dr Sineaid Bradshaw – Co GP Lead for Cancer and Palliative Care in Lothian  
Stephanie Kleynhans – Policy & Campaigns Manager, The Brain Tumour Charity  
Dr Victoria McBride – GP, Occupational Health Specialist and Patient Representative  
Cameron Miller – Policy & Strategy Director, The Brain Tumour Charity  
Liam Mac Lua-Hodgson – Policy & Campaigns Officer, The Brain Tumour Charity  
Dr Philip Hodkinson – Clinical Lead for Lung Cancer and Co-clinical Lead for Earlier Cancer Diagnosis and Performance, NHS Scotland  
Richard Rawcliffe – Patient Representative  
Dr Ewan Gray – Health economics consultant, Dxcover  
Dr Brian Nicholson – GP and Associate Professor, CRUK / University of Oxford  
Dr Lorna Porteous – GP Lead for Cancer and Palliative Care in Lothian  
Marie Gallagher – Programme Manager, Scottish Adult Neuro-Oncology Network (SANON)  
Karen Roberts – Programme Manager, Cancer Performance & Earlier Diagnosis

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References:


