



The APPG on Brain Tumours

A record of the minutes for the meeting on the Independent Cancer Strategy 2015-2020
Committee Room 10, Houses of Parliament
9 December 2015, 16.15-18.15

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Chair

Rebecca Harris MP (Con, Castle Point) was elected to Parliament as the MP for Castle Point in May 2010, and currently serves as the Chair of the APPG on Brain Tumours. She is a member of the Regulatory Reform Select Committee and also serves as the co-chair of the APPG on Fuel Poverty and Energy Efficiency.

Guest Speakers

Emma Greenwood is responsible for Cancer Research UK's policy development across a wide range of public policy issues – including public awareness of signs and symptoms of cancer, early diagnosis of cancer, NHS services and cancer strategies, access to effective treatments, and the UK research environment. Recently, Emma was the Programme Lead for the Independent Cancer Taskforce that developed 'Achieving World Class Cancer Outcomes: A strategy for England 2015-2020'.

April Watkins was treated for a brain tumour in her early 20s. She is a supporter of Brain Tumour Research and a Young Ambassador for The Brain Tumour Charity, and is a carer for people with learning disabilities.

Dr Ahmadur Rahman is currently a Consultant Clinical Oncologist in Neuro-oncology at Queens Hospital in Essex.

Dr Rahman is a member of the Society of Neuro-oncology and the British Neuro-oncology Society. He has been involved in international brain clinical trials and has a special interest in novel radiation techniques, research and new technology in improving patient experience.

Gala Rowley was diagnosed with an inoperable Pontine Glioma brain tumour 7 years ago and after radiotherapy treatment the tumour remains dormant in her brain stem. Gala has been a volunteer fundraiser and ambassador for the Brain Tumour Charity for 2 years.

Attendees

The following MPs were in attendance.

- Caroline Ansell MP (Con, Eastbourne and Wallington)
- Mark Durkan MP (SDLP, Foyle)
- Andrew Stephenson MP (Con, Pendle)
- Stephen Pound MP (Lab, Ealing North)

Minutes

The Chair of the APPG on Brain Tumours, Rebecca Harris MP introduced the meeting, and each of the individual speakers.

Emma Greenwood talked about her role on the Secretariat of the Independent Cancer Taskforce earlier this year. The process that the Taskforce went through to produce the strategy document was discussed, and how patient groups and patients were involved in its production.

She highlighted some recommendations in the strategy document of particular relevance to the brain tumour community. In particular, she noted that measures to drive earlier diagnosis would be a real opportunity to shift survival rates and quality of life.

Additionally, Emma identified the need to invest in workforce and equipment in order to improve cancer care, and making sure that the NHS had the ability to support research as two of the more challenging initiatives that needed to be implemented.

April Watkins focused on a few recommendations in the cancer strategy, based on her own experience of being diagnosed and treated for a brain tumour as a young adult.

April talked about the difficulty in transitioning from children's services to teenage/young adult services, noting how she had been placed on a ward with much older people in her first visit to hospital. Despite being

moved to a solitary room, April stated the view that the facilities had not been appropriate to her age, and had felt isolated as a result.

Secondly, April discussed the challenges of entering the workplace following treatment for a brain tumour. As a result of her diagnosis, she had to drop out of university and lost her social circle of friends that had been built up in Plymouth.

Finally, she argued that every young adult with a brain tumour should have the opportunity to take part in research, highlighting the desire for those personally affected to take risks and access new treatments.

Dr Ahmadur Rahman talked about two key areas relating to the Independent Cancer Strategy – the importance of patient experience and research.

Dr Rahman noted that there had been a cultural change in how patient experience was seen in the NHS. He said that there was a tendency for clinicians to see a patient as a set of symptoms rather than a whole person, noting statistics from the National Cancer Patient Experience Survey (NCPES).

Following on from this, he welcomed the focus of the strategy on incentivising measuring patient experience at a local level, saying that the metrics comparing the performance of hospitals would encourage them to prioritise this issue and drive improvement in services.

However, he also emphasised the need to measure patient experience in primary care, noting how the patient journey often started in a GP setting and the difficulties as a clinician of making decisions about the treatment of patients when trying to understand the pathway to diagnosis.

Additionally, he called on the NCPES to measure the cancer experience of young people under the age of 16 in future editions, and to make more of an attempt to engage people from black and ethnic minority backgrounds.

With regard to research, Dr Rahman said that there is a real desire from clinicians to conduct research, drawn from a care towards their patients, and the knowledge that patients want to be offered something better.

However, he identified some of the barriers to research, with clinicians facing an increasingly busy workload, and research often being conducted in their own time. Additionally, he noted the challenges of setting up clinical trials and how clinicians needed to be empowered with time to conduct research.

Gala Rowley talked about her own experience of care following her diagnosis with an inoperable brain tumour seven years ago. She stated how it had taken three years for a GP to refer her for an MRI scan, after suffering from severe headaches over this period.

Gala expressed her disappointment at newspaper articles which indicated that CCGs were encouraging clinicians not to refer patients for MRI scans due to cost pressures. In order to counteract this, she argued that NHS England should mandate direct access to investigative tests.

She highlighted the importance of shared decision making and involving patients in decisions about their treatment, reflecting on the lack of choice she was given about having a biopsy in hospital.

Gala also reflected about how she had not been offered rehabilitation support following treatment, saying that this had contributed to her suffering from stress and affected her ability to find permanent employment.

Noting the poor improvements in survival rates for brain tumours compared to other cancer types, Gala argued that without greater investment, it would be difficult to reduce the inequalities faced by brain tumour patients in diagnosis, treatment and outcomes.

Discussion – Key Themes

Multi-Disciplinary Teams (MDT) for Brain Tumours

- One attendee described a lack of coordination in a hospital MDT care, resulting in someone with a brain tumour being discharged without adequate support.

- With regards to MDTs, Emma Greenwood noted that there are pockets of best practice but a lot of variation. She said that Cancer Research UK would shortly conduct some research on this issue, looking at ways to make MDTs more effective.
- In addition, Emma stated her view that the new Cancer Dashboard, which will compare hospital Trusts with others across England, will increase accountability and drive improvements in care. She explained that Cancer Alliances would be part of this process, and that their membership would include patient representatives.

Access to rehabilitation and support services

- One attendee talked about the lack of provision for psychological support that was available following treatment for a brain tumour.
- Another attendee described challenges in accessing information about support for people with brain tumours, and how the uncertainty of decisions around access to welfare payments can have a significant impact on her quality of life. Patients are often treated as a diagnosis rather than a person.
- Dr Ahmadur Rahman commented that there was a scarcity of access to neuro-rehabilitation services, especially physiotherapy. Rehabilitation services are cost-effective, reduce hospital stays and as a result, place less pressure on the state.
- Emma Greenwood emphasised the importance of the whole healthcare system to place quality of life and patient experience on a par with clinical outcomes. She added that there was a real need to develop metrics to measure these things, and by linking them to incentives and funding, this would drive change in the quality of care.

Workforce/Education

- It was argued that there is a lack of “critical mass” in neuro-oncology expertise in the UK. At a recent Society for Neuro-Oncology (SNO) Conference in Texas, there were fewer than 20 delegates from the UK in attendance. Training of medical oncologists for brain tumours is insufficient, and does not cover areas like rehabilitation.

Access to new technologies/Radiotherapy

- It was suggested that industry is not prioritising new drugs for brain tumours, and that regulation around clinical trials at an EU level also presented a barrier. On a wider level, it was argued that the UK is resistant to introducing new technology, such as Electric Field Therapy which is available in the USA but not in the UK.
- Dr Ahmadur Rahman also made reference to Electric Field Therapy, saying that he had recommended a patient who may be suitable for the treatment, but that cost had been an issue. He added that new technology with the potential to benefit patients needed to be brought to the UK faster, and recommended that new equipment could be focused in one or two specialist centres.
- Emma Greenwood commented that the conversation around innovation and new technology was often confined to drugs, and that radiotherapy was not seen as a priority in the same way. She expressed the view that the publication of the strategy, and the work of the Accelerated Access Review should help to increase the focus on how to get new technologies (not just drugs) to patients in a timely manner.

Rebecca Harris MP concluded the meeting by drawing out some of the key themes of the speakers and audience discussion.