

EU Collaboration in brain tumour research

Background

The UK's decision to leave the EU is likely to have an impact on cancer research, treatment and care in the UK and EU member states. The impact will be particularly acute for rarer cancers like brain tumours which benefit from a critical mass of expertise and knowledge and a wider pool of patients for clinical trials across the EU.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours. We have invested £25 million in research to date and have, in 2016 alone, added a further commitment of £5.2million to our current research portfolio over the next five years. We also provide a range of support services, advocate for policy change and raise awareness of the signs and symptoms of a brain tumour through our HeadSmart early diagnosis campaign.

Rarer cancers

Around 4.3 million people in the EU are affected by a rarer cancer (1). In recognition of the need for collective action rarer cancers have risen up the European policy agenda (2).

The UK is an important scientific partner of the EU in research into rarer cancers, in part because of the resource and ambition of medical research charities. UK based charitable organisations who are members of the Association of Medical Research Charities (AMRC) funded over £1.4 billion worth of medical research in 2015 – continuing a commitment of investments in research of more than £1 billion in each of the past eight years. This is significant given that medical research charities support over 40% of publicly funded research in the UK (3). Investment in research into rarer cancers from UK based medical research charities leads to healthy collaboration across Europe and encompasses a diversity of knowledge, expertise and skills, including EU citizens who take part in clinical trials.

Collaboration in research is essential for better outcomes for people across Europe affected by a brain tumour. There are over 130 different types of brain tumours - it is not one disease. 60% of people diagnosed with a high grade brain tumour will die within one year (4). There are currently few treatment options - since 1971 there has been an overall increase in survival of less than 10% for people with a high grade brain tumour in the UK (5).

There is clear unmet need. Collective European action brings significant added-value in the field of rarer cancers. Rarer cancers benefit from aligned regulation, the inclusion of patients from multiple member states, increased opportunities for researchers, and the networks, ideas and aspirations that grow organically from collective action. As a result, collaboration between the UK and EU member states has brought new opportunities and advances in our knowledge and understanding of brain tumours.

UK based partners have an important role to play in the collaborative effort. We have gathered together several case studies which highlight the benefits of co-operation and the contribution of UK based partners.

Case studies

Further funding

Access to EU grants enables medical research charities to maximise the impact of their investment and build upon the initial findings of their research.

In cases where the outcome of an initial investment shows promise, a research project may receive further funding from other sources. The AMRC disclosed that over a two year period 13 of its members received over £260 million in further funding from the EU (6).

In 2014 for every £1 The Brain Tumour Charity invested, a further £2.30 was leveraged in further funding for this research. Of the further funding in that year, 22% was acquired from the European Union (7). One of the beneficiaries of this additional EU funding has been the Samantha Dickson Brain Cancer Unit, which carries out research into childhood and adult glioblastomas (8).

After initial investment of £1.5 million by The Brain Tumour Charity, the Unit was able to obtain £1.7 million of further funding from the European Research Council, a European Commission funding scheme, which allowed Prof Paolo Salomoni and his team to expand the capacity of research work in the lab.

Some of Prof Salomoni's research findings have been translated into a clinical trial. Work directly funded by the European Research Council has led to the generation of a much needed preclinical model of paediatric glioblastoma that will accelerate discovery and translation into new clinical studies.

Once the UK leaves the EU, UK based researchers may not be able to participate in this sort of funding and almost certainly will not be able to lead on collaborative projects like these.

DIPG trials

Aligned regulation across Europe encourages and facilitates the inclusion of multiple member states and establishes common procedures that can reduce delay, bureaucracy and maximise the impact of investment from medical research charities.

Researchers at Great Ormond Street Hospital are leading on a trial, co-funded by The Brain Tumour Charity along with Cancer Research UK, which tests treatments in children affected by diffuse intrinsic pontine gliomas (DIPG) after dividing them into groups according to their tumour's molecular characteristics.

Jessica Green was diagnosed with an inoperable DIPG at three years old and, as is regularly the case, was given a devastating life expectancy of 9 months. The clinicians could not offer Jessica a cure, only treatment to minimally prolong her life.

"The cruel thing was that Jessica knew exactly what was happening to her little body. This horrendous disease takes away your ability to do everything you usually take for granted but leaves you with your mind. I know Jessica was scared despite our best efforts to comfort her and that is now something we have to live with."

Jessica's mum

This trial will recruit children from across Europe to ensure a sufficient number of participants to give meaningful data. Almost half of the 150 children recruited to the trial over a four year period will be recruited in France.

The International Society for Paediatric Oncology- Europe (SIOPE)

The SIOP-Europe Primitive Neuro-Ectodermal Tumour (PNET) working group aims to increase survival and quality of survival for children with brain or spinal tumours.

Four year old Dylan underwent a total of four operations, 90 rounds of chemotherapy, 31 sessions of radiotherapy and 66 general anaesthetics for treatment of a medulloblastoma – the most common form of malignant brain tumour in children. Despite this aggressive treatment Dylan’s tumour has not been cured. Whether or not it recurs, Dylan faces long-term health problems and reduced life-expectancy because of the disease and its treatment.

One of the SIOPE PNET group’s work streams involves planning, co-ordinating and carrying out clinical trials for the treatment of medulloblastoma across Europe. Given the small number of cases of medulloblastoma compared to more common diseases, European collaboration is key to get sufficient numbers for large-scale, late phase clinical trials.

The data collected from the planned trials will then be analysed by the Cancer Research UK Biomarker programme, which aims to develop new biomarkers^a to assist in treatment decision making, allowing for the stratification of patients according to risk. The Biomarker programme, comprised of over 500 professional practitioners, is also developing further European trials for high-risk and infant medulloblastoma.

Many other trials like these one could not take place without pan-European collaboration and aligned regulation.

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3. AMRC. Medical research charities: investing in research. 2015 Research Expenditure [Internet]. 2015. Available from: <https://brainhtc.org/wp-content/uploads/2016/10/CharitiesInvestingInResearch2015.pdf>
4. Brain, other CNS and intracranial tumours survival statistics [Internet]. Cancer Research UK. 2015 [cited 2016 Oct 10]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours/survival>
5. Cancer Research UK. Cancer survival for common cancers | Cancer Research UK [Internet]. [cited 2016 Aug 11]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/common-cancers-compared#heading-Three>
6. AMRC. Science and technology committee (Commons) EU regulation of the life sciences inquiry [Internet]. 2016. Available from: http://www.amrc.org.uk/sites/default/files/doc_lib/AMRC%20response%20to%20EU%20regulation%20of%20the%20life%20sciences.pdf
7. The Brain Tumour Charity. Researchfish Autumn 2014 report. Unpublished; 2014.
8. The Brain Tumour Charity. Unwrapping genes to find new treatments [Internet]. Available from: <https://www.thebraintumourcharity.org/our-research/research-tumour-type/high-grade-glioma/unwrapping-genes-to-find-new-treatments/>

^a A biomarker is a biological marker. It is a gene, a molecule or some other biological substance in your blood or cells. It can be measured and used to: - diagnose your tumour - work out how severe a disease is likely to be - the likely response you may have to certain treatments.

