



House of Commons
Petitions Committee

**Funding for research
into brain tumours:
Government Response
to the Petitions
Committee's First
Report of Session
2015–16**

**First Special Report of Session
2016–17**

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Petitions Committee

The Petitions Committee is appointed by the House of Commons to consider e-petitions submitted on petition.parliament.uk and public (paper) petitions presented to the House of Commons.

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Publication

Committee reports are published on the Committee's website at www.parliament.uk/petitions-committee and in print by Order of the House.

Committee staff

The current staff of the Committee are Anne-Marie Griffiths (Clerk), Fiona Whiteside (Second Clerk), Emma McIntosh (Petitions and Engagement Officer), Paul Simpkin (Senior Committee Assistant), Sean Harris (Committee Assistant), Pippa Lansdell (Media Officer), Laura Diebelius (Media Officer) and James Millar (Media Officer).

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First Special Report

The Petitions Committee published its First Report of Session 2015–16, *Funding for research into brain tumours* ([HC 554](#)), on 14 March 2016. The Government's response was received on 7 June 2016 and is appended to this report.

In the Government response, the Committee's recommendations are in bold text and the Government's responses are in plain text.

Government Response

Summary

Early diagnosis and treatment of cancer, including brain tumours, is a priority for this Government.

We invest more than £1.7 billion every year into health research and work closely with patients, charities and our world-leading life sciences industry to support further research into this devastating disease.

The role of charities is vital. Through the Association of Medical Research Charities the Minister for Life Sciences, George Freeman has made a comprehensive offer for the views of charities to be heard and for them to be at the forefront of driving research and innovation in the new landscape of life science research co-ordination.

In addition, the Accelerated Access Review is considering how to speed up access to innovative drugs, devices and diagnostics for people using NHS services.

The Government welcome the Committee's report – and accept that action is needed to address the strong concerns expressed in the report and by members of the public who signed the e-petition.

There is insufficient research being carried out to reduce the significant disease burden caused by brain tumours. As he announced in the House of Commons debate on the e-petition on 18 April, the Minister for Life Sciences will be convening a working group of clinicians, charities and officials to discuss how working together with our research funding partners, we can address the need for more brain tumour research.

1. A number of measures are needed to address the needs of brain tumour patients. The first step should be to increase the awareness of brain tumours and to increase the numbers of tumours diagnosed early. It is clear that brain tumour patients are being failed repeatedly. (Paragraph 46)

Government response

- Improving early diagnosis of cancer is a priority for this Government, and was clearly highlighted as a strategic priority in the report *Achieving World-Class Cancer Outcomes: A Strategy for England 2015–2020* published last year by the Independent Cancer Taskforce. The strategy has 96 recommendations which broadly cover six strategic priorities including early diagnosis.
- NHS England is currently working with partners across the health system to establish a new cancer programme to implement the recommendations of the report, overseen by the newly established National Cancer Transformation Board, chaired by the National Cancer Director, Miss Cally Palmer.
- We have committed to implementing recommendation 24 of the report that by 2020, everyone referred with a suspicion of cancer will receive either a definitive diagnosis or the all-clear within four weeks. This standard will be underpinned by investment of up to £300 million more in diagnostics each year by 2020.
- NHS England's Accelerate, Coordinate, Evaluate (ACE) pilots are exploring new models for delivering a diagnosis quickly and effectively, including piloting a multi-disciplinary diagnostic centre, which we hope will be particularly effective for patients with vague or unclear symptoms, although these pilots are primarily aimed at adults in the first instance.

2. Earlier diagnosis could improve survival rates and improve patients' quality of life. Earlier diagnosis could also help to increase the numbers of patients able to take part in clinical trials as well as the diversity of tissue samples available for researchers. Moreover, it would clearly be less distressing for patients and their families if they could be diagnosed before their symptoms become so severe that they present at Accident and Emergency. (Paragraph 47)

Government response

- We agree that early diagnosis is crucial for improving cancer outcomes as a whole.
- It is important to recognise that whilst great progress has been made in reducing the proportion of brain tumours diagnosed as an emergency (a reduction from 64% in 2006 to 53% in 2013), the first symptom experienced by a high proportion of patients with brain tumours would be expected to result in an emergency episode of care e.g. seizure. In these cases, an emergency diagnosis represents wholly appropriate urgent management of a clearly serious health condition. There is therefore always likely to be a higher proportion of patients with brain tumours diagnosed as an emergency than for some other cancers.
- The key is to identify those, such as many of those case studies outlined in the Committee's report, where an emergency admission is avoidable, and we can clearly

do better for those patients. Emergency presentations are a key indicator included in the new Cancer Dashboard, which we expect newly forming Cancer Alliances to use to agree priorities for action.

3. Earlier diagnosis will rely to a large extent on increasing awareness amongst GPs and other front line healthcare professionals about the symptoms of brain tumours. The Committee was impressed by the HeadSmart campaign which shows how guidance can have such a positive impact in a relatively short space of time without over burdening GPs. (Paragraph 48)

4. The Government should provide greater leadership and support to raise awareness of brain tumours amongst GPs and other healthcare professionals in order to increase earlier diagnosis of brain tumours. It should:

- **consider the evidence in this report about the differences between the HeadSmart guidance for GPs and the recently updated National Institute for Health and Care Excellence (NICE) guidelines for the recognition of and referral for suspected cancer in children, young people and adults, and ensure that NICE reconsiders its guidelines.**
- **work with professional bodies and Clinical Commissioning Groups to ensure that GPs and other health care professional receive appropriate training, perhaps as part of their Continuing Professional Development, on the symptoms of brain tumours.**
- **take urgent steps to raise general awareness of brain tumours – either as part of the Be Clear on Cancer Campaign, or as part of other public health awareness initiatives. (Paragraph 49)**

Government response

- In order to continue to support GPs to identify patients whose symptoms may indicate cancer and urgently refer them as appropriate, the National Institute for Health and Care Excellence (NICE) published an updated suspected cancer referral guideline in June 2015. The guideline *Suspected cancer: recognition and referral* includes new recommendations for brain tumours in adults, children and young people. The guideline lowers the threshold for referral, urging GPs to think of cancer sooner. NICE said the revised guideline will make it easier for GPs to think about the possibility of cancer sooner and refer people for tests quicker. This in turn will mean more people receive an early diagnosis and subsequently, more cancers could be cured.
- NICE also addressed generally, symptoms of concern in children and young people, recommending that GPs should take into account the insight and knowledge of parents and carers when considering making a referral for suspected cancer. NICE periodically reviews its published guidance to take account of new and emerging evidence. It is for NICE as an independent body to decide what evidence should be considered as part of this process.
- The guideline includes recommendations regarding when GPs should refer patients for direct access investigative tests – including urgent direct access MRI scan of the brain or CT scan (adult patients). NHS England expects Clinical Commissioning Groups to

enable GPs to follow the guideline. The Royal College of General Practitioners (RCGP) has worked in collaboration with Cancer Research UK (CRUK) on a programme of regional update events for GPs to promote the guideline. RCGP and CRUK have also worked together to develop summary referral guidelines for GPs.

- The Department of Health has highlighted the value of the HeadSmart awareness raising materials with Directors of Public Health, health visitors and school nurses, to encourage their use by professionals in signposting to specialist advice if needed. We are also aware that the HeadSmart campaign website includes an online education module designed to help health professionals improve their knowledge of brain tumour presentation in children and young people. E-learning modules are recognised by the Royal College of Pediatrics and Child Health and other Royal Colleges as part of personal Continuing Professional Development and GPs therefore have the option of completing the e-learning module and using other HeadSmart materials as they wish.
- Royal Colleges have responsibility for developing curricula for doctors, in particular postgraduate curricula and they have also developed a module on 'brain tumours in children'. Health Education England will work with bodies that set curricula such as RCGP to seek to ensure general practice training continues to meet the needs of patients.
- NHS England's National Cancer Transformation Board which has been set up to oversee implementation of the independent Cancer Taskforce's strategy, includes representation from the cancer community and professional bodies alongside NHS England and Health Education England.
- Public Health England's Be Clear on Cancer campaigns aim to improve earlier diagnosis of cancer by raising awareness of the signs and symptoms of specific cancers and encouraging those with symptoms to see their doctor promptly. The decision on which cancers should be the focus of Be Clear on Cancer campaigns is informed by a steering group, whose members include primary and secondary care clinicians and key voluntary sector organisations. A number of factors are taken into account when deciding which campaigns to develop and run, with the main criteria being the scope to save lives through earlier diagnosis and whether the cancer has a clear and specific early sign or symptom that the general public can act upon should it arise.
- We will continue to work with PHE, NHS England and other stakeholders to keep campaigns under review, to see what might be done to increase awareness of other cancers, including brain tumours.

5. Brain tumour research has been seriously underfunded over decades, putting it far behind many other cancers in terms of the improvements in outcomes for patients. The Committee has heard evidence which suggests that there is a correlation between the amount of funding of research into a specific cancer and improved survival rates and/or reduced incidences. It is clear that existing levels of funding have not been sufficient for researchers to be able to make significant advances in their understanding of this devastating disease. Increased investment into research into the causes of brain tumours and into potential treatments is urgently needed. (Paragraph 70)

6. In its response to the petition, the Government has not explained clearly whether it believes that current levels of funding for brain tumour research are adequate.

The response failed to address the serious concerns raised by the petition: the lack of progress in survival rates for brain tumours; the burden of the disease, particularly the fact that it is responsible for the highest number of life years lost compared with other cancers; and the impact on quality of life for those who do survive. We recommend that the Government gives a clear statement of whether it thinks funding levels are adequate and, if not, what it will do to ensure that funding for brain tumour research increases. (Paragraph 71)

Government response

- The Government agree that an increase in the level of brain tumour research is crucial in order to achieve better outcomes for patients and their families. We are committed to work to achieve this in partnership with medical research charities, the NHS and industry. Eighteen major funders of cancer research in the UK work together through the National Cancer Research Institute (NCRI). These funders include the Department of Health, the Medical Research Council (MRC) and Cancer Research UK (CRUK). Through coordinating their research, NCRI partners aim to avoid unnecessary duplication and maximise the impact of research for cancer patients and the public.
- The Department of Health funds the National Institute for Health Research (NIHR) to increase the volume of applied health research for the benefit of patients and the public, drive faster translation of basic science discoveries into tangible benefits for patients and the economy, and develop and support the people who conduct and contribute to applied health research. NIHR cancer research expenditure has risen from £101 million in 2010/11 to £135 million in 2014/15 (the latest available figure). Most of this investment (£111 million in 2014/15) is in cancer research infrastructure where spend on specific disease areas such as brain tumours cannot be separated from total infrastructure expenditure.
- The Department for Business, Innovation and Skills also funds research through the Research Councils, with research relating to brain tumours primarily supported by the MRC. The MRC currently spends around £76 million a year on research directly relating to cancer and between 2010/11 to 2014/15 spent £10.9 million supporting research into brain and pituitary tumours, spanning basic discovery science, translational projects to progress treatments to clinics and early clinical trials.
- Further detail of how the Government is responding to Recommendations 5 and 6 is provided below in our response to Recommendations 9–13.

7. We heard evidence about the barriers that may be preventing increased investment in brain tumour research. Historical funding problems for research into brain tumours and lack of leadership from successive governments in this area appears to have left a gap in the research workforce within the UK; in particular it is increasingly difficult to recruit PhD students and those who complete their PhD often have to change specialisms or work overseas. An absence of co-ordination and awareness has impeded collection of tissue samples, making fundamental research into different tumour types extremely difficult. Coordinated and adequate tissue collection, a quality workforce and ability to get fundamental ‘blue sky’ research applications approved

could significantly improve progress for brain tumours. The Government needs to take a leading role in tackling these systemic problems, to unlock the potential for investment in brain tumour research to be increased. (Paragraph 88)

8. The Government should examine the evidence the Committee has taken and consider what action it can take to address the barriers to brain tumour research described by expert witnesses. In particular:

- The Government should use its powerful influence on funding levels to send a clear message that brain tumour research is a major priority for the UK.
- The Government should ensure that there is adequate support for young scientists who wish to pursue a career in brain tumour research, so that they can stay and progress in their areas of specialism.
- The Government should address the concerns raised by witnesses about the 'red-tape barriers' which may be reducing the opportunities for clinical trials, and explain what it will do to address these, while balancing this with the need for proper safeguards.
- The Government should ensure there is effective coordination of bio-banking and tissue collection, to facilitate brain tumour research.
- In response to the Off-patent Drugs Bill, the Government has said that legislation was not needed to achieve the aims of the bill. The Government should provide a full explanation, with expected timescales, of the steps it is taking to ensure that off-patent drugs in new indications are being made available to patients consistently across the country, providing appropriate safeguards are maintained. (Paragraph 89)

Government response

- The Government are helping to remove the financial barrier commonly faced by those looking to pursue doctoral study, including doctoral study related to brain tumours, by offering loans of up to £25,000. This provides a contribution to the costs of doctoral study for those students who are not in receipt of Research Council funding for living costs. The policy intent is to increase the number of students embarking on doctoral study, reduce the time taken for students to complete doctoral study and strengthen the research base. The policy is part of the Government's commitment to lifelong learning and to stimulate an innovation-led economy by increasing the supply of workers with high-level skills. It will broaden and strengthen the research base, giving students the flexibility to choose where they study, and providing another source of finance for those not in receipt of Research Council funding. The loans will increase the number of students able to study at this level and will also reduce the financial pressure on existing self-funding students.
- Supporting the next generation of research leaders is central to the mission of both the MRC and the NIHR. The MRC provides a range of flexible support mechanisms to support early-career researchers across the spectrum of biomedical science, such as studentships, fellowships and grant funding, targeted at key career transition points of a researchers career. The MRC has recently developed an interactive career framework

to enable early career scientists to explore the career pathways available to them. To make the support mechanisms more flexible, the MRC have removed all eligibility criteria based on years of post-doctoral experience, making it easier to pursue a research career in any field, including brain tumour research.

- The MRC also offers a range of jointly funded awards, as an effective route to encourage applications in specific areas relevant to partner organisations. Current partner organisations include the Brain Tumour Charity, The Royal College of Radiologists, and the Royal College of Surgeons of Edinburgh. In addition, MRC fellowships support recruitment of talented individuals from overseas who are seeking to build their careers and strengthen the UK research base. To reduce the barriers in attracting talented individuals, the Research Councils have worked with BIS and the Royal Society to streamline the Tier 1 visa route for successful applicants from outside the European Economic Area.
- The NIHR has a wide range of measures to support and incentivise researchers in health and social care including those working in the field of brain tumour research. The NIHR has eight types of research programme supporting researcher-led applications. In addition, the NIHR funds research training and career development awards, ranging from undergraduate level through to opportunities for established investigators and research leaders. These award programmes are open to a wide range of professions and designed to suit different working arrangements and career pathways.
- The NIHR Research Design Service is available to help prospective applicants develop competitive research proposals for submission to NIHR itself and also to other national, peer-reviewed funding competitions for applied health or social care research. The service provides expert advice to researchers on all aspects of preparing grant applications in these fields, including advice on research methodology, clinical trials, patient involvement, and ethics and governance.
- The 2014 EU Clinical Trials Regulation 536/2014 (applicable in autumn 2018) has been developed to streamline the authorisation process for clinical trials and harmonise requirements for clinical trials in the EU. A European Medicines Agency database registers all EU-approved clinical trials of investigational medicinal products. Since March 2011 this information has been publicly accessible through the EU Clinical Trials Register (except adult Phase 1 trials) and since 2014 a summary of results is required to be uploaded into the Register within one year of the trial completing. The new clinical trials Regulation (536/2014) provides for even greater transparency in that all data and documents submitted to support authorisation of trials conducted in the EU will be accessible to the public, unless certain confidentiality criteria have been met.
- HRA (Health Research Authority) Approval is the new process for the NHS in England to streamline the regulatory and governance processes for health research. It brings together the assessment of governance and legal compliance, undertaken by dedicated HRA staff, with the independent Research Ethics Committee opinion provided through the UK Health Departments' Research Ethics Service. It replaces the need for local checks of legal compliance and related matters by each participating organisation in England. This allows participating organisations to focus their

resources on assessing, arranging and confirming their capacity and capability to deliver the study. The phased roll out of HRA Approval started in May 2015 and was complete on 31 March 2016.

- The MRC currently supports a UK-wide Network of brain tissue banks which have been set-up around specific disorders and diseases generally to collect post-mortem brain tissue from consented donors. Another source of brain tumour tissue supported by the MRC comes from BRAIN UK which is a partner in the brain bank network and also receives funding from several brain tumour charities. BRAIN UK facilitates access to brain tumour samples for researchers from the archives of 26 of the NHS regional Clinical Neuroscience centres in the UK, effectively covering about 90% of the UK population.
- The UK Clinical Research Collaboration (UKCRC) brings together the NHS, research funders, industry, regulatory bodies, Royal Colleges, patient groups and academia in a UK-wide environment that facilitates and promotes high quality clinical research for the benefit of patients. A consortium of UKCRC funders has established the UKCRC Tissue Directory and Co-ordination Centre to support the work of biobanks by improving access to their human tissue samples for research purposes. The Tissue Directory will enable researchers to discover, search across and contact multiple human tissue and biosample collections to facilitate access. This Directory will encompass all disease areas.
- Ensuring that patients get timely access to any new treatment, including off-label medicines in new indications, is complex and involves a number of organisations and individuals all playing their part. This is why the Department of Health is working to co-ordinate activities and set plans in place that will make this easier. In January 2016, the Department hosted a meeting with medical research charities, including Brain Tumour Research, to look at the barriers and what could help to overcome them. This built on the 2015 roundtable stakeholder event which looked at how evidence for new uses of existing drugs could be used to inform clinical decision making. A series of actions have been identified and these are underway. They include: work to look at more systematic inclusion of off-label uses of drugs in the British National Formulary; development of case studies looking at re-purposed medicines and their pathways from research results into clinical practice; potential partnerships with the pharmaceutical industry; research into clinician attitudes to preventative prescribing; and journal articles to provide better information about drug re-purposing.
- The Department anticipates having further meetings in order to cover aspects of the work plan and it remains very much committed to working with the Medicines and Healthcare products Regulatory Agency, NICE, the General Medical Council, patient and professional groups, and charities to address those areas where we can improve matters. The first of these meetings took place on 22 March 2016 to begin work on development of the case studies.
- Alongside these, the Access to Medical Treatments (Innovation) Act will, in due course, enable doctors to access a newly created database which will provide a mechanism for collecting and sharing information on innovative treatments including off-label drugs and medicines in development. Now that the Act has received Royal Assent the work

to implement its provisions is subject to the Secretary of State exercising the power vested upon him to instruct the Health and Social Care Information Centre to create the database.

- The Accelerated Access Review, independently chaired by Sir Hugh Taylor, will make recommendations to Government later this year on reforms to accelerate access for NHS patients to innovative medicines and medical technologies (including devices, diagnostics and digital). This will cover products that may already be on the market and off patent but are being innovatively repurposed to treat conditions other than those in the remit of the existing Marketing Authorisation.

9. The Committee welcomes the recent commitments by both Cancer Research UK and Children with Cancer to prioritise brain tumours as a cancer of ‘unmet need’. Nevertheless, responsibility for ensuring that gaps in research funding are filled cannot rest solely with the voluntary sector. The Government must take responsibility for identifying unmet needs in research funding and taking action to rectify them. If the Government showed additional leadership on brain tumour research funding, other institutions and organisations would follow. (Paragraph 100)

10. The Government should not leave the prioritisation of research funding only to the voluntary sector. It should consider the burden of disease from brain tumours and take a more active role in setting priorities for brain tumour research funding. (Paragraph 101)

11. The Government must ensure greater oversight of research funding to ensure that it is able to identify, and if appropriate take steps to address, any gaps in funding. (Paragraph 102)

12. Brain tumours are the biggest cancer killer of children and young people. In terms of the number of life years lost, it is the most fatal of all cancers. The unique position of the brain has a huge impact on treatment and quality of life for patients. Its classification as a rare cancer conceals the serious societal impact that brain tumours have. Current levels of funding for brain tumour research are not commensurate with the burden of the disease. The Government should take a greater lead in ensuring that this burden is taken into account when research funding is prioritised. (Paragraph 111)

13. The Government should set out clear criteria for research bodies to follow when prioritising funding needs. In doing so, it should consider whether it would be appropriate for these criteria to take into account the burden of disease, particularly numbers of life years lost; survival rates, and in particular an absence of improvement in survival rates; and historic underfunding. (Paragraph 112)

Government response

- Most NIHR investment in brain tumour research and other cancer research is through research infrastructure. This infrastructure supports translational medicine and the delivery in the NHS of clinical trials and studies funded directly by the NIHR itself and by partners including Research Councils, medical research charities and industry. Investment in clinical studies in a specific cancer site or topic area by a public or third sector partner therefore drives NIHR investment through its infrastructure.

Accordingly, increased investment in brain tumour research by CRUK and other partner organisations will drive increased investment in this field by the NIHR. Commercial studies are supported on a cost recovery basis.

- Clinical cancer research in the UK involves a partnership between the NCRI, the NIHR Clinical Research Network (CRN) and devolved nations' networks, and the NHS. The NCRI is involved in developing and advising on a portfolio of clinical research studies. It is the responsibility of CRN, working with the NHS and Clinical Trials Units, to ensure that the portfolio of studies is made available for recruitment of patients. Thirty brain tumour research studies were open and recruiting patients in the NIHR CRN in 2015/16.
- The NCRI Brain Tumour Clinical Studies Group (CSG) and its subgroups promote the development of clinical studies for adults with brain tumours. This group is actively addressing strategic priorities to enhance the ability to carry out clinical research for these cancers. They coordinate UK engagement with international research partners and have close links with the Society of British Neurological Surgeons to promote surgical trials and provide research training. They have a strong portfolio of radiotherapy trials, open and in development. They are developing a new programme in meningioma research, including a collaboration with US partners to evaluate novel targeted drugs in meningioma as part of the International Rare Cancers Initiative. They work in partnership with other cancer site-specific groups, for example the Lung Cancer CSG, to develop research for patients with cancers originating elsewhere which have spread to the brain.
- Other priorities identified by the Brain Tumour CSG include:
 - to collect linked clinical and biological (especially genomic) data and establish a stratified medicine programme for brain cancer within a 3–5 year time horizon;
 - to establish a translational research infrastructure for adult glioma;
 - to include tumour banking in routine practice;
 - to develop better models for drug development in brain cancer; and
 - to develop strategies to overcome geographical restriction on trial participation.
- Brain and spinal tumours in children bring distinct research challenges. To address these, the Children's Cancer & Leukaemia (CCL) CSG has a permanent subgroup for developing and delivering clinical research in children's brain tumours. Their current Strategy includes:
 - to recruit to open studies, and open several important new trials currently in setup;
 - to complete ongoing development of studies for young children with standard and high risk medulloblastoma, and for gliomas and rare tumours
 - to strengthen the quality of life research dimension of all trials, where appropriate
 - to improve imaging (including novel functional imaging) in clinical trials.

- The NIHR CRN has 15 Local CRNs (LCRNs). In a new initiative from April 2015, each of these LCRNs has designated a senior clinician as the Subspecialty Lead for Brain Tumours. These local leaders are liaising with the national CSGs to help plan development and delivery of the portfolio, identify new research opportunities and areas of clinical need.
- Formed through partnerships between England's leading NHS organisations and universities, 11 NIHR Biomedical Research Centres (BRCs) conduct translational research to transform scientific breakthroughs into life-saving treatments for patients. Staffed by expert investigators and clinicians, BRCs are leaders in translating lab-based discoveries into new cutting edge treatments, technologies, diagnostics and other interventions in clinical settings. The substantial levels of sustained funding which BRCs receive create an environment in which scientific endeavour can thrive, attract the foremost talent and produce world-class outputs. Six of the BRCs are conducting brain tumour research. The NIHR has launched a new, open competition for biomedical research centre funding from April 2017 to March 2022.
- On 31 March 2016, research funded by the NIHR Royal Marsden BRC and the charity Christopher's Smile was announced that will genetically test tumours from children with cancer as part of a new initiative to begin to personalise children's cancer treatment. Around 400 children at 21 hospitals across the country will start to receive the test which is designed to pick up key mutations in the tumours that drive the cancer's growth and spread, by looking for changes in 81 different cancer genes.
- The NIHR also funds 14 Experimental Cancer Medicine Centres (ECMCs) across England in close partnership with Cancer Research UK. ECMCs play a leading role in speeding up the process of cancer drug development and the search for cancer biomarkers that can be used to diagnose cancer, predict the aggressiveness of the disease, or show whether a drug will be effective in a specific patient and at what dose. Applications are currently invited for ECMC status in 2017–22.
- Direct funding of brain tumour research by NIHR, for example through its programmes and fellowship schemes, is driven by the number and scale of successful applications. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.
- The MRC's main funding mechanism is through grants supporting researcher-led proposals which offer a flexible and responsive approach to supporting the highest quality research, capitalising upon the developing knowledge and tools within the field. Strategic investments may be employed to target major research challenges, for instance to bring different disciplines together, or address areas such as stratified medicine and regenerative medicine which can deliver a broader impact across many diseases, rather than target individual diseases.
- Factors such as the burden of disease, survival rates and morbidity are implicitly taken into account during peer review and the final funding decisions when MRC considers investment and research priorities. It is important to highlight that there are other diseases, notably other cancers, that have similarly poor survival rates, exacerbated by late stage disease presentation which is very difficult to treat.

14. The Government should ensure that statistics of secondary brain tumours are adequately recorded so that there is a clear picture of incidences and survival rates for brain tumours. (Paragraph 113)

Government response

- Secondary cancers are a significant event for patients and the NHS. Accurate data on their occurrence will help plan services and understand the effect on people's lives. PHE are undertaking work to investigate how we can use new and existing data sources to identify secondary cancers (including cancer of the brain) and cancer progression more generally.
- The Cancer Services and Outcomes Dataset has mandated collection of secondary/recurrent cancers since July 2015, which will allow direct collection of data on secondary brain cancers. The Cancer Registration and Analysis Service in Public Health England will work with hospital trusts to rapidly feedback on submitted data, to improve data quality.

15. It is unclear who is responsible for making the decision on funding for non-therapeutic drugs. This could be a wider administrative problem which could be delaying the potential benefits of non-therapeutic drugs for patients in the UK (Paragraph 115)

16. The Government should ensure that a decision is made about the use of PharmaMar linolenic acid. It should clarify the procedures for applying for the use of non-therapeutic drugs on the NHS and investigate whether this is a wider administrative problem which could be affecting the availability of these drugs for patients in the UK. (Paragraph 116)

Government response

- In the absence of guidance from NICE on a particular product, it is for commissioners and providers, not for Government, to make decisions on clinical matters. Commissioners have a role in deciding what treatments they will fund, based on advice from clinicians and assessment of a product's clinical and cost effectiveness. Drugs & Therapeutics Committees take decisions about adding products to local formularies.

17. For too long, funding for brain tumour research has been inadequate and not given sufficient priority. Britain has dedicated researchers in this area but is losing young, talented people because they are unable to access research funding. The country is losing the chance to be a world leader in this area and is letting down patients and their families. (Paragraph 117)

18. The Committee has heard throughout this inquiry that patients with brain tumours are failed at every stage – from diagnosis and treatment to research funding. There has been little improvement in the prognosis for brain tumour patients over the last 30 years. Brain tumours are often considered to be rare, but they are the biggest cancer killer of children and the most fatal cancer in terms of life years lost – and the incidence of brain tumours is on the rise. The number of life years lost ought to be a major factor in allocating research funding, but it is not given sufficient consideration. Where there has been significant investment into research, the outcomes for sufferers

of other cancers, such as breast cancer and leukaemia, have improved dramatically. No one who took part in this inquiry wanted funding to be taken away from other cancers. What they wanted was an equal chance for some progress. (Paragraph 118)

19. Funding for site-specific brain tumour research comes mostly from the voluntary sector. Charities have done incredible work to fund brain tumour research and we commend them for that. However, they face difficulties in fundraising, not least because of a lack of public awareness. The Government must not leave charities to tackle this devastating disease alone. (Paragraph 119)

20. Sole responsibility for deciding on priorities for medical research and for identifying diseases with unmet need should not be left to the voluntary sector. The Government could and should take a greater lead: by playing a role in identifying gaps in funding, by setting priorities for research and by supporting the development of the research workforce required to give those suffering with a brain tumour some hope for the future. (Paragraph 120)

21. Maria Lester: “For too long fundraising has been driven by the cancer community and the Government must step up and invest its fair share. There is no time to waste. It is too late to save my little brother and I will have to live with that loss for the rest of my days, but with improved funding just think how many other brothers, sisters, fathers, mothers, friends and children could still be saved. (Paragraph 121)

Government response

- The Government agree that a greater level of brain tumour research is urgently needed so that patients can experience better outcomes. Our response to the Committee’s recommendations sets out our commitment to working with patients, charities, the NHS, academia and industry to further develop and sustain a health research environment where brain tumour research can thrive and increase.
- As announced in the House of Commons debate on the e-petition on 18 April, the Minister for Life Sciences will be convening a working group of clinicians, charities and officials to discuss how working together with our research funding partners, we can address the need for more brain tumour research.