A life free from epilepsy is possible
But only through research

SHAPING THE FUTURE OF RESEARCH INTO EPILEPSY

#ALifeInterrupted
Launch Report
FOREWORD

Imagine living with the threat of having a seizure every day. A seizure that can happen at any time and in any place, whether you are driving your car on the M1, playing with your children, or presenting at an event. If you are a person living with epilepsy reading this report, of course you don’t have to imagine. This is your reality.

Epilepsy interrupts lives. Approximately 600,000 people in the UK are living with the disruptive, interruptive impact of epilepsy. For many the stark reality of life with epilepsy results in an ongoing erosion of independence. Losing the ability to drive, be alone or even care for family members are just some of the devastating consequences faced.

Seizures cause interruptions that impact virtually every life choice - education, careers and even the decision to ‘risk’ pregnancy to start a family. Tragically for some, lives are interrupted for ever with 21 epilepsy-related deaths every week in the UK.

Epilepsy Research UK’s launch of the #ALifeInterrupted campaign seeks to highlight the disruptive, interruptive impact of epilepsy and calls on people affected to help drive, enable and shape the future of research.

We know, through research, we can halt the devastation epilepsy causes. But, currently there’s an alarming lack of funding for a condition that affects more people than Parkinson’s disease, multiple sclerosis and motor neurone disease combined. Action is urgently needed to address this, which is why Epilepsy Research UK is publishing this report and launching a major campaign, to raise awareness of this most relentless and interruptive condition.

Epilepsy costs the NHS £1.5 billion a year. At a time when the need to make savings is paramount, there is a compelling case to make to invest more in epilepsy research. The return on investment can lead to substantial cost savings to the NHS and will make an enormous difference to those affected.

As the second largest voluntary sector funder of epilepsy research in the UK (behind Wellcome Trust) we are determined to change the landscape of epilepsy research. We are calling on people with epilepsy to take action now to work with us to shape research that will have the greatest impact for people living with the condition, their families and carers.

Dr Anne Coxon

Maxine Smeaton
Chief Executive
Epilepsy Research UK

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1 SUDEP Action (sudep.org/epilepsy-related-deaths)
2 NICE Guidelines (nice.org.uk/guidance/cg137)
THE HEADLINES

600,000 people are currently living with epilepsy in the UK

87% of people with epilepsy said their condition affects their day-to-day lives³

1,000 emergency hospital admissions related to epilepsy happen every week in England⁴

Yet, despite epilepsy being one of the most common, serious neurological conditions, just 0.3% of the £4.8 billion spent on health-related research is invested in epilepsy research.

In 2018 the UK government invested the following in medical research:

- £82.5 million for dementia (£97 for each of the 850,000 with dementia)⁵
- £34 million for Parkinson’s disease (£234 for each of the 145,000 with Parkinson’s disease)⁶
- £12.8 million for epilepsy (just £21 for each of the 600,000 with epilepsy)⁶

On PubMed, 4.2 million papers were published on cancer, compared to just 230,000 published on epilepsy or seizures.

SHAPING THE FUTURE - OUR ACTION PLAN

STEP 1
Launch our SHAPE EPILEPSY RESEARCH NETWORK and build the UK’s largest ever epilepsy patient population to influence and shape research.

STEP 2
Develop a Research Priority Study to identify key areas of research for people affected by epilepsy.

STEP 3
Using evidence collected from Steps 1 and 2, build long-term partnerships with academic and commercial organisations to accelerate the progress of treatments and lobby government for increased research investment.

TAKE ACTION NOW

There’s strength in numbers. And, in the fight against epilepsy, we need to be strong. We need people with epilepsy to come forward and engage in research in order to secure opportunities for greater investment.

Epilepsy Research UK is launching the SHAPE EPILEPSY RESEARCH NETWORK to provide an opportunity for people with epilepsy to have their say in the future of research into epilepsy.

If your life has been interrupted by epilepsy
You can shape the future of research.

⁴ Neurology Intelligence Network, Hospital Activity Compendium, 2017 (gov.uk/government/publications/neurology-services-hospital-activity-data)
⁵ Alzheimer’s Research UK, 2018 (dementiastatistics.org/statistics/uk-government-investment/)
⁶ UK Health Research Analysis, 2018 (hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/)
INTRODUCTION - A LIFE INTERRUPTED

Epilepsy strikes babies, children, adults and the elderly. Every week 600 people will be given the life changing news they have the condition. Some cases are genetic, some as a result of a brain injury or infection. In the majority of cases, the cause is unknown.

In the UK over 600,000 people live with epilepsy, that’s around 1 in 100. For one third, treatment does not work and they continue to have uncontrolled seizures. This is over 180,000 people for whom research has not yet delivered. For people whose treatment does work, many live with the debilitating side effects of drugs.

The main symptom of epilepsy is repeated seizures that start in the brain. These seizures are caused by excessive electrical activity, the effects and impact of which vary depending on the part of the brain affected.

Shockingly there are 21 epilepsy-related deaths every week in the UK.

A LIFE FREE FROM EPILEPSY

A life free from epilepsy is only possible through research that will provide the breakthroughs needed.

Epilepsy Research UK is the only UK charity exclusively dedicated to driving and enabling a national programme of life changing, life saving research. Our pioneering research is currently being carried out in over 40 universities and hospitals throughout the country, in collaboration with international partners.

We don’t just fund promising projects, we fund promising people too. That’s because securing more scientists into epilepsy research now will have the greatest impact for people living with epilepsy in the future.
THE DISRUPTIVE AND INTERRUPTIVE NATURE OF EPILEPSY

Epilepsy interrupts the lives of ordinary, extraordinary people. It’s invisible, it’s unpredictable, it’s frightening.

Epilepsy can cause chaos and serious life-changing impacts. Repeated seizures can be devastating and result in severe exhaustion, a loss of independence and confidence. Some people with epilepsy can find they are no longer able to be left alone, no longer able to drive, forced to take time off work and miss social activities, or unable to take responsibility for caring for others such as children or family. There is also a greater risk of mortality if the condition remains uncontrolled. All these factors can lead to feelings of isolation, powerlessness, loss and depression.

Claire said: “I was driving my husband to the airport. It was rush hour. While I was in the fast lane of the M3, I felt a sudden, strange empty feeling come over me. It came from nowhere. A sensation was rapidly rising from my legs to my stomach.

“I told my husband I didn’t feel well. The words were barely out of my mouth before I went into grand mal seizure. The next thing I remembered was being in an ambulance. If it wasn’t for the quick actions of my husband who steered the car to the hard shoulder, and the fast actions of the paramedic, I may not be here now.”

At the age of 17, Firefighter Mark was leaving school and all set for his first taste of freedom when his life was interrupted by epilepsy

“Told my husband I didn’t feel well. The words were barely out of my mouth before I went into grand mal seizure. The next thing I remembered was being in an ambulance. If it wasn’t for the quick actions of my husband who steered the car to the hard shoulder, and the fast actions of the paramedic, I may not be here now.”

Claire and Mark’s experiences show the devastating impact of seizures on daily life. How they can turn an everyday situation into a potentially life threatening one. Only around half of people with epilepsy live seizure-free, meaning hundreds of thousands of people live in fear of seizures every day. And seizures don’t actually have to happen to have an impact. Simply living with the constant fear of one can lead many people to feel isolated, scared, anxious and experience mental health problems.

The National Patient Experience Survey by The Neurological Alliance provides strong evidence of how epilepsy interrupts lives. The figures are staggering, with 87% of people reporting that their condition affects their day-to-day lives.

COUNTING THE COST

We know the personal cost of epilepsy is substantial, but so too is the economic cost. The National Patient Experience Survey provides evidence of how epilepsy interrupts employment, with a significant number of people having to either give up or reduce their hours at work. Approximately 70% of people reported that their career development had been negatively affected and nearly 50% said they had not been able to continue to work as normal following their diagnosis.

The economic cost of epilepsy to the public purse is also substantial. Almost 50% of those surveyed reported having an emergency unplanned stay in hospital over the last two years. Indeed, we know epilepsy places a considerable burden on the NHS, with 1,000 epilepsy-related adult emergency hospital admissions in England every week.

INTERRUPTING FAMILY LIFE

Epilepsy can interrupt the very start of life. For many women living with epilepsy the decision to have children can be heavily influenced by their condition. For those who do decide to start a family, sadly for some, the nine months of pregnancy can be dominated by anxiety caused by the risk of seizures. Around one in every three women with epilepsy have an increase in seizures during their pregnancy, putting them and their unborn baby at risk.

87% said epilepsy affects their day-to-day activities
50% admitted to hospital as an emergency over the last two years
48% are unable to continue work as normal after their epilepsy diagnosis
68% missed out on opportunities to develop their career due to their epilepsy

4 Neurology Intelligence Network, Hospital Activity Compendium, 2017 (gov.uk/government/publications/neurology-services-hospital-activity-data)
AN UNBALANCED EQUATION

A LIFE INTERRUPTED - A CONDITION UNDERFUNDED

Epilepsy is one of the most common serious neurological conditions in the world, with 50 million people living with an epilepsy diagnosis. Despite this, it attracts significantly less funding than other conditions with far smaller patient populations. The scale of the problem is quite simply not matched by the current level of research investment.

A FORGOTTEN CONDITION

There is much we still don’t know about the brain and what causes epilepsy, which hampers our ability to diagnose and treat it. The historic lack of funding has delayed progress. Sadly, this underfunding continues today. Investment in epilepsy research compares unfavourably with investment in other conditions, both in the UK and the rest of the world.

In 2018, the government and charities spent a combined £4.8 billion on health-related research. Only £18.2 million of this figure was spent on research into epilepsy, representing just 0.3% of research funded.6

Government spend on epilepsy research was calculated at £12.8 million. This represents just £21 for every person living with epilepsy in the UK. A staggeringly small level of investment, especially when compared to the yearly £1.5 billion epilepsy costs the NHS.

By comparison, in 2018, Parkinson’s disease, a condition affecting 145,000 people, received £34 million in research investment from the UK government. Dementia, a condition affecting 850,000 people received £82.5 million in government research investment in 2018.5

This government research investment represents:

- **£234** per person with Parkinson’s disease (patient population of 145,000)
- **£97** per person with dementia (patient population of 850,000)
- **£21** per person with epilepsy (patient population of 600,000)

Epilepsy research is not just underfunded in the UK, but globally too. In the USA, the National Institutes of Health (NIH) allocated $184 million (£138 million) to epilepsy research in 2018. While this represents almost 11-fold more than what is invested in the UK, it still represents less than 0.09% of the total NIH budget.8

The inequality in research funding continues with a search on published papers on PubMed. In 2020, 4.2 million papers were published on cancer. The number published on epilepsy or seizures was just 230,000. We urgently need to correct this balance.

RESEARCH AT RISK

The UK research environment is experiencing a double threat from the implications of Brexit, and the impact of the coronavirus pandemic.

COVID-19

There is a significant risk to research investment as government funding continues to be diverted to COVID-19 related activities, and medical research charities, such as Epilepsy Research UK, face an estimated 50% drop in income. COVID-19 has caused a delay and postponement of current research and is placing future investment at risk. In March 2020, nearly all ongoing research had to be stopped or postponed as the UK responded to the pandemic. Epilepsy Research UK’s funded research programmes have been put back an average of over 14 months by the pandemic, meaning delays in developing life changing, life saving research.9

BREXIT

Over the last 12 years European Commission funding streams have provided nearly €200 million for epilepsy research across Europe. The implications of Brexit on accessing future funding from the European Commission remains uncertain. Brexit is likely to have an impact not just on how the UK funds scientific research, but also on how easy or hard it will be for scientists to work outside of their home countries. Scientists are traditionally part of an international workforce, with 29% of the UK academic workforce from overseas, and over 50% of PhD students.10

There are also questions around the regulation of medicines and clinical trials which may be different for the UK and European Union. This is important, particularly for rare forms of epilepsy that have benefited from clinical trials run in many countries, to secure enough patients recruited.

POLICY RECOMMENDATION

Epilepsy Research UK is working with the Association of Medical Research Charities to call on government to provide a level of match funding for future charity research over the next three years via a Life Sciences-Charity Partnership Fund.

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5 Alzheimer’s Research UK, 2018 (dementiastatistics.org/statistics/uk-government-investment/)
6 UK Health Research Analysis, 2018 (hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/)
8 Epilepsy a public health imperative, World Health Organization, 2019 (who.int/mental_health/neurology/epilepsy/report_2019/)
9 Epilepsy Research UK Grantholder Survey, 2020
10 UK Research and the European Union, Royal Society, 2016 (myralociety.org/topics/policy/projects/uk-research-and-european-union/)

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THE PROMISE OF RESEARCH

Despite the huge discrepancy that exists in research funding, the global community of epilepsy researchers continues to grow and discoveries are being made. As the second largest voluntary sector funder of epilepsy research in the UK, Epilepsy Research UK is at the forefront of funding and promoting this research. We invest in innovative projects and fellowships. We create partnerships and collaborations. And we help to influence the wider environment within which epilepsy research takes place.

Progress has been made, and we have much to feel optimistic about. Over the past decade we have seen research deliver significant advances in the treatment and care of epilepsy. There are now just over 30 drugs approved for different types of the condition\(^\text{11}\) with more than 50 additional drugs currently in development.\(^\text{12}\) Powerful techniques such as brain imaging are improving diagnosis. And new technologies are being developed to allow easy monitoring of seizure activity away from hospital and to improve the quality of life for people with hard-to-treat epilepsy.

Innovations in genetics are providing researchers with a greater understanding, and in about a third of cases a genetic diagnosis immediately changes treatment. Researchers are discovering many more genes that are the cause of epilepsy. The number of known epilepsy-associated genes has grown to around 1,000. Over 50 genes have been newly associated with epilepsy in the last six years alone.\(^\text{13}\)

Genetic forms of epilepsy also provide clues in the brain pathways which may go wrong in all forms of epilepsy. Excitingly, we are on the verge of starting to treat these types of epilepsy with radical new approaches like gene therapy.

Each and every breakthrough demonstrates the huge potential of research to achieve our vision of a life free from epilepsy. There has never been a better time to harness the recent unprecedented advances in science, medicine and technology for the benefit of people living with epilepsy.

As scientists we know that each increment in knowledge, every marginal gain, when added together can make big differences to the lives of people with epilepsy.

Professor Sameer Zuberi,
Consultant Paediatric Neurologist, Royal Hospital for Children and Honorary Professor at the University of Glasgow

Research equals knowledge and this is how we ensure a better future for people like my daughter.

Gemma Pedder,
ERUK supporter

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\(^{11}\)British National Formulary (bnf.nice.org.uk/treatment-summary/epilepsy.html)
\(^{12}\)Epilepsy Foundation Pipeline Tracker, September 2020 (epilepsy.com/pipeline-listing-page)
\(^{13}\)Wang et al., 2017. Epilepsy Associated Genes. Seizure, 44, pp.11-20
OUR ACTION PLAN
SHAPE EPILEPSY RESEARCH NETWORK

If we are to secure opportunities for greater investment in research into epilepsy, the involvement of people living with the condition is central to unlocking further progress.

We want to build the biggest ever community of people living with epilepsy to influence and shape research.

Our SHAPE EPILEPSY RESEARCH NETWORK will provide an opportunity for people with epilepsy to have their say in the future of research into epilepsy. With the support of this network we will be able to actively pursue new collaborations and programmes, utilising the resources and skills of research partners nationally and internationally.

We plan to involve people with epilepsy in all aspects of epilepsy research, from identifying and evidencing priorities for research that will have the greatest impact for people living with the condition, their families and carers, to making decisions on the research projects we fund. This is known as Patient and Public Involvement (PPI).

This is important because:

- Only by involving people living with epilepsy we can ensure we are funding research that matters most to those affected.
- Building a strong and engaged community group will help us to build productive relationships with research organisations and accelerate the development of new treatments.
- Giving people with epilepsy a voice will enable us to generate evidence to use to lobby government for increased research investment.

YOU CAN SHAPE THE FUTURE OF RESEARCH INTO EPILEPSY

The SHAPE EPILEPSY RESEARCH NETWORK will bring together people committed to working towards a life free from epilepsy, from people living with the condition to scientists and clinicians driving innovations. As part of the network, you can help shape research by:

- sharing the impact of the condition on your life
- helping Epilepsy Research UK choose the best research to fund
- planning and prioritising research areas to focus on
- using your experiences to support research development by informing study design and implementation

As a member of the SHAPE EPILEPSY RESEARCH NETWORK, we will ask you for your views and feedback on research through questionnaires and focus groups. You will also receive personalised emails about recent epilepsy research relevant to you, as well as upcoming research events and advance notice of opportunities for involvement in clinical trials or studies.

A life free from epilepsy is possible. But only through research.

If your life has been interrupted by epilepsy
You can shape the future of research.

SHAPE EPILEPSY RESEARCH NETWORK
JOIN TODAY
Visit epilepsyresearch.org.uk/ShapeNetwork
Shape the future of epilepsy research
CONCLUSION

It is only through research we will be able to stop epilepsy interrupting the lives of those affected. As a major funder of epilepsy research, we are concerned opportunities to accelerate progress are being missed due to lack of investment, not just in the UK, but globally.

To help accelerate this progress we need to address the lack of funding epilepsy research attracts and involve people with epilepsy to identify priority areas and generate the evidence we need to lobby government. The figures shared in this report are stark, funding for epilepsy research lags behind other neurological conditions affecting far smaller patient populations.

Research into epilepsy has a strong track record of delivering new treatments. Yet many recent discoveries have yet to be fully capitalised on.

It is now time to do more. If we don’t act now, epilepsy will continue to interrupt the lives of people with epilepsy.
“I’m pledging my support for the #ALifeInterrupted campaign because…”

- "... epilepsy affects so many people in such a profound way but for many of us it’s a hidden disability, and therefore doesn’t get the profile it deserves.”
  Eleanor Thompson

- "... as a scientist and doctor, I pledge to listen to and work with people with epilepsy, to end the uncertainty and devastation caused by seizures.”
  Mark Richardson

- "... epilepsy is one of the most common neurological conditions. Further research into the causes and treatments of epilepsy will go a long way in making positive changes to people affected by epilepsy.”
  Susan Jacques

- "... I lost my beautiful daughter last year and will continue to raise awareness and help to prevent other families going through the same heartache.”
  Alexandra Matthews

- "... epilepsy needs to step out of the shadows - epilepsy comes with a lot of interruptions and it needs to become the topic of conversation.”
  Sarah Gibson

- "... research into epilepsy will provide the foundation to transform the lives of people with epilepsy.”
  Mike Cousin

- "... my daughter was diagnosed with epilepsy. She hasn’t allowed it to define her. I still however fully support this campaign as research into this condition should be funded appropriately.”
  Colin Cassidy

- "... so much more needs to be done to save and improve the lives of people living with epilepsy.”
  Jo Glenton

- "... my sister has severe Epilepsy and with 87 people diagnosed with a form of Epilepsy every day and with 65% of cases having an unknown cause, it is of paramount importance that we champion research!”
  George Coxon

- "... investment in research will mean that life is about living, not about being in fear of seizures and their impact.”
  Clare Moffat

- "... research into epilepsy gives me hope. My hope being that we will have such an improved understanding of the human brain that we shall be able to provide more effective and preventative treatments for the condition.”
  Torie Robinson

- "... there has never been a more exciting or critical time in epilepsy research for us to pull together.”
  Matthew Walker

- "... we must ensure we are funding research that matters most to those affected.”
  Joe Brice

PLEDGE YOUR SUPPORT
Visit our website: epilepsyresearch.org.uk/ALifeInterrupted/pledge-wall/to pledge your support
EPILEPSY RESEARCH - FUNDING IN DETAIL

In the UK, research funding grants awarded by UK Research and Innovation (UKRI), other government and public bodies, and charity funders are collated and analysed every four years. The UK Health Research Analysis 2018 report, published in 2020, covered research grants that were active during 2018. We used the UK Health Research Analysis 2018 dataset to deliver a picture of UK research into epilepsy.1

The 2018 dataset covers 22,500 health and biomedical research awards that were active during the 2018 calendar year. It is comprehensive in including data from 146 organisations, covering most of the government and charity funded research in the UK. The total portfolio accounts for an estimated expenditure of almost €4.8 billion. Only AMRC member charities that elected to share research funding data were included in this dataset.

With open permission, data from the UK Health Research Analysis is made available for further analysis. Using this dataset, Epilepsy Research UK sought to answer four important questions:

- how much funding is being invested in research into epilepsy
- who is funding epilepsy research
- what is being funded
- where is the work being carried out

METHODOLOGY

A tailored search strategy within the HRCS open database of grants was performed to identify epilepsy related grants. Data was taken from the UK Health Research Analysis 2018.

Stage 1: Open search

185 epilepsy-related grants were obtained using the following search strategy, searching within the UK Health Research Analysis 2018 public dataset:

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<th>NO</th>
<th>SEARCH BOUNDARIES</th>
<th>RETURNED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Award abstract – contains ‘epile’</td>
<td>148</td>
</tr>
<tr>
<td>2</td>
<td>Award abstract – does not contain ‘epile’, does contain ‘seizure’</td>
<td>24</td>
</tr>
<tr>
<td>3</td>
<td>Award abstract – disease categories not identified in 1 or 2</td>
<td>6</td>
</tr>
<tr>
<td>4a</td>
<td>Title - contains ‘epile’ IF award abstract does not contain ‘epile’</td>
<td>4</td>
</tr>
<tr>
<td>4b</td>
<td>Title - contains ‘seizure’ IF award abstract does not contain ‘seizure’</td>
<td>0</td>
</tr>
<tr>
<td>5a</td>
<td>Keyword - contains ‘epile’ IF award abstract/ title does not contain ‘epile’</td>
<td>2</td>
</tr>
<tr>
<td>5b</td>
<td>Keyword - contains ‘seizure’ IF award abstract/ title does not contain ‘seizure’</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>185</td>
</tr>
</tbody>
</table>

‘Epile’ was selected as a search term as it returns fields containing epilepsy and also status epilepticus, epileptogenesis and epileptic seizures. We supplemented this search by searching for specific epilepsy subtypes as listed in the ICARE Epilepsy Portfolio Ontology,3 taking search terms from the 19 disease categories that did not already contain ‘epilepsy’ or ‘seizures’ within the condition name.

Stage 2: Refinement

44 grants (23%) were excluded following further verification by reading the title and abstract. Reasons for exclusion included epilepsy being listed as an incidental reference (for instance mentioned as an exclusion criteria for the funded research) (23 grants), the re-purposing of anti-epilepsy drugs in another disease or condition (three grants), or considered too fundamental or underpinning in nature to be applicable to the study of epilepsy (18).

This resulted in a final dataset of 141 epilepsy research grants being identified for further analysis. Within the UK Health Research Analysis, grants with more than one funder are counted as separate awards with the amount awarded by each funder portioned separately. The 141 projects represented 133 separate grant awards after accounting for co-funded research.

Stage 3: Classification

Central to the UK Health Research Analysis is the Health Research Classification System (HRCS) which is a structured coding system ‘for classifying and analysing all types of biomedical and health related research’.3 We organised the data using the Health Research Classification System that is already applied and available to download as part of the public dataset.

There are two dimensions to the HRCS. (1) The Health Categories dimension of the HRCS captures the area of health or disease being studied. There are 21 separate categories which encompass all diseases, conditions and areas of health. Each of the Health Categories includes research into both disease and normal function. (2) Research Activity Codes classify types of research activity. This dimension of the HRCS has 48 codes divided into eight overarching code groups which encompass all aspects of health-related research activity ranging from basic to applied research.

STRENGTHS AND LIMITATIONS OF THE DATASET AND SEARCH STRATEGY

The HRCS dataset

The HRCS is a comprehensive exercise with very good coverage of UK research funders and is estimated to cover over 90% of UK health relevant expenditure. Based on knowledge of the epilepsy landscape and searching acknowledgement sections of research publications to identify funders, we are confident epilepsy relevant research funders have been identified.

Significant areas not covered by the HRCS are grants awarded from non-UK research funders including European Commission funding, research funded by industry sources, as well as private philanthropic donations made directly to universities. The UK has received a proportion of European Commission funding, as an active member of the European Research Framework Programmes. Epilepsy research in the Sixth, Seventh and Eighth Framework Programmes (respectively FP6, FP7 and Horizon 2020), has reached a total of €197.6 million for 135 different projects over the last 12 years.4

1 UK Health Research Analysis 2018 (hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/)
2 ICARE Epilepsy Research Portfolio Ontology (icarerp.nih.gov/about-portfolio/ontology)
3 Health Research Classification System, UK Clinical Research Collaboration, 2018 (hrcsonline.net/)
4 Epilepsy: a public health imperative. World Health Organization, 2019 (who.int/mental_health/neurology/epilepsy/report_2019/)
Industry and international funding represent significant funders of UK epilepsy research. The decisions for funding in each case sit outside of a national peer review system.

**Search strategy for identifying and defining epilepsy research**

Our strategy for identifying grants based on keyword searches could have omitted grants that did not include our search terms in the title, keyword, or abstract but were still relevant to epilepsy research. This might be likely if searching on grant title alone, but the HRCS is reasonably complete in having full abstracts for most grants.

A more challenging area was deciding the relevance of research grants to epilepsy to include or exclude them in the analysis dataset. Some grants are clearly highly relevant to epilepsy, for instance testing a new intervention in a population of people with epilepsy to control seizures. However others, for instance towards the basic neuroscience end of research have a lower degree of relevance or could be applied to a wider number of diseases. We did not sort to allocate a portion of grant spending to epilepsy in these cases, but included it fully within the epilepsy dataset.

We used the structure of the ICARE Epilepsy Portfolio Ontology when making decisions to include or exclude a research grant in the dataset as ‘epilepsy research’. Where we were unable to apply an ICARE Epilepsy Portfolio ontology to a grant, we used this as a guiding criteria to rule a grant out of the scope of interest.

Overall, we were conservative in taking decisions to include or exclude grants, which may lead to £18.2m being an overestimate of the amount spent on epilepsy. An example of this area was interventional studies in groups of patients with other conditions which are known risk factors for epilepsy, such as stroke or traumatic brain injury. Where these studies measured seizure occurrence or epilepsy incidence, often as secondary outcomes, they were included in the dataset. The ICARE ontology includes a classification on non-epileptic seizures which were therefore included, as they are relevant in differential diagnosis of epilepsy.

**OUR FINDINGS**

**How much is being invested in epilepsy research?**

The final dataset of grants verified as relevant to epilepsy represented £76.2 million total value. To account for different grant duration, the default presentation of HRCS funding is an annualised total where the grant value is divided by the grant duration (in years) to provide an annualised total investment. The annualised value of epilepsy relevant grant awards was £18.2 million.

We identified 141 different awards which represented 133 unique grants after accounting for co-funded grants.

**Who is funding research into epilepsy in the UK?**

We identified 21 different funders of research into epilepsy in 2018. In terms of number of awards made there were four main funders of epilepsy research: Department of Health and Social Care, Epilepsy Research UK, Medical Research Council and Wellcome Trust (Figure 2). The number of grant awards made by charities and government funders was split 50:50, but the government awards were of a higher value (median size of annual award was charity £20k, government £101k) (Figure 3).

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2 ICARE Epilepsy Research Portfolio Ontology (icarerp.nih.gov/about-portfolio/ontology)
WHAT TYPE OF RESEARCH INTO EPILEPSY IS BEING FUNDED IN THE UK?

HRCS disease category
When looking at the health category research spend was associated with, as expected the majority was classified as neurological (£12.2m) (Figure 4). The next biggest category was research of generic health relevance (£1.55m) and mental health (£1.3m). Smaller amounts of funding were allocated in categories where secondary epilepsy to another primary cause may be present included accidents and injuries (e.g. traumatic brain injury) (£1m), reproductive and child health (e.g. foetal valproate syndrome) (£670k), infection (£430k), cancer and neoplasms (e.g. brain tumour) (£300k).

HRCS allows grants to be coded to more than one health category where appropriate. Neurological was assigned in some portion to 121/141 (85%) of the research awards reviewed.

Within the complete HRCS dataset, neurological research represented 9.7% of all research recorded. There were 2,094 awards identified with the disease category ‘neurological’ at a combined investment of £248m. Therefore, research into epilepsy represents about 5% of the total neurological research in the UK.

Figure 4: Health category applied to research into epilepsy

HRCS research categories
The biggest area of investment was in aetiological research defined as the ‘Identification and characterisation of endogenous factors known or suspected to be involved in the cause, risk or development of disease, conditions or ill health’ (38.6%, £6.8m). Underpinning research (category 1) which focuses on understanding normal biological, psychological and socioeconomic processes which form the basis for subsequent research, made up 14.3% (£2.6m) of all funding.

Together, HRCS research categories 1 and 2 often are attributed to more basic research and laboratory discovery research. Therefore, approximately half of all research into epilepsy is more discovery and fundamental in nature. However, this can still include human research identifying causes and mechanisms and is not a measurement of model-based or non-human research.

No research was recorded in the prevention category, which is as expected since the HRCS definition refers to primary prevention of disease and promotion of wellbeing. Diagnostic and treatment development and testing (categories 4, 5, 6) accounted for 35.8% (£6.5m) of all expenditure.

There was relatively low spend in the categories of applied research. Disease management (7.6%, £1.4m) which covers research on individual patient needs and practitioner experiences, including research into quality of life, disease self-management and health services (4.6%, £840k) examines healthcare at an organisational level, including service provision as well as welfare, economic and policy issues.

Figure 5: Percentage total spend by HRCS research activity - kite diagram

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<thead>
<tr>
<th>RESEARCH ACTIVITY</th>
<th>EPILEPSY (£000s)</th>
<th>EPILEPSY (%)</th>
<th>HRCS (WHOLE DATASET %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Underpinning</td>
<td>2,600</td>
<td>14.3</td>
<td>21.7</td>
</tr>
<tr>
<td>2 Aetiology</td>
<td>6,840</td>
<td>37.6</td>
<td>30.6</td>
</tr>
<tr>
<td>3 Prevention</td>
<td>0</td>
<td>0.0</td>
<td>5.9</td>
</tr>
<tr>
<td>4 Detection and diagnosis</td>
<td>2,170</td>
<td>11.9</td>
<td>10.5</td>
</tr>
<tr>
<td>5 Treatment development</td>
<td>1,480</td>
<td>8.2</td>
<td>11.9</td>
</tr>
<tr>
<td>6 Treatment evaluation</td>
<td>2,860</td>
<td>15.7</td>
<td>9.7</td>
</tr>
<tr>
<td>7 Disease management</td>
<td>1,400</td>
<td>7.7</td>
<td>4</td>
</tr>
<tr>
<td>8 Health services</td>
<td>840</td>
<td>4.6</td>
<td>5.6</td>
</tr>
</tbody>
</table>
Grant type
We analysed awards by type of award made eg a training grant (PhD, fellowship), research project grant, or a grant for more underpinning resources or educational support. Only 36 grants (£1.77m) were identified as being aimed at training and career development. This covered four awards aimed at pre-doctoral PhD study, 16 PhD studentships, and 16 post-doctoral fellowships.

The apparent low number of PhD studentships is a concern for the field of epilepsy research where there is a need to build capacity. However, the HRCS data was not collected in a way that allows detailed analysis of this question; for instance, it does not collect the number and career level of personnel employed on grants. This number probably does represent an underestimate as it does not include studentships awarded as part of larger programmes or PhD training centre grants.

<table>
<thead>
<tr>
<th>TYPE OF AWARD</th>
<th>NUMBER OF GRANTS</th>
<th>£ (000s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training and career development</td>
<td>36</td>
<td>1,770</td>
</tr>
<tr>
<td>Research</td>
<td>92</td>
<td>14,140</td>
</tr>
<tr>
<td>Resources and infrastructure</td>
<td>11</td>
<td>2,130</td>
</tr>
<tr>
<td>Educational support</td>
<td>2</td>
<td>160</td>
</tr>
</tbody>
</table>

Geographical location of research into epilepsy
We analysed research spend by geographical distribution. Most of the funding was awarded to centres based in London (61%, £11.17m). Nine different London-based research institutes and universities received funding. As shown in Figure 8 research awards for all health and medical research are not distributed evenly across the country (whole HRCS dataset).

The overall level of investment across the UK was low but there is scope for building additional critical mass of research into epilepsy across the UK. This should be achieved by attracting additional funds into the field.

<table>
<thead>
<tr>
<th>REGION</th>
<th>£ ('000s)</th>
<th>NO GRANTS</th>
<th>% SPEND</th>
<th>% SPEND (WHOLE HRCS DATASET)</th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>11,167</td>
<td>61</td>
<td>61.4</td>
<td>31.8</td>
</tr>
<tr>
<td>Midlands</td>
<td>1,320</td>
<td>11</td>
<td>7.3</td>
<td>21.2</td>
</tr>
<tr>
<td>North</td>
<td>2,502</td>
<td>27</td>
<td>13.7</td>
<td>13.6</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>0</td>
<td>0</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>South</td>
<td>2,186</td>
<td>20</td>
<td>12.0</td>
<td>18.7</td>
</tr>
<tr>
<td>Scotland</td>
<td>651</td>
<td>11</td>
<td>3.6</td>
<td>11.3</td>
</tr>
<tr>
<td>Wales</td>
<td>375</td>
<td>11</td>
<td>2.1</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Epilepsy Research UK is the only charity exclusively dedicated to driving and enabling life changing, life saving research into epilepsy.

A life free from epilepsy is possible But only through research

www.epilepsyresearch.org.uk/ALifeInterrupted
www.epilepsyresearch.org.uk/ShapeNetwork

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