

2020 Paediatric **Epilepsy**
Research Impact Report

 **Young
Epilepsy**

Great Ormond Street 
Hospital for Children
NHS Foundation Trust


GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH



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Introduction

I am delighted to present the very first Research Impact Report for the Young Epilepsy, Great Ormond Street Hospital (GOSH) and University College London - Great Ormond Street Institute of Child Health (ICH) Research Partnership.

Young Epilepsy exists to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected, and their ambitions realised. Under our four key offers as an organisation, we coordinate and fund research into the causes, treatments, and impact of childhood epilepsy.

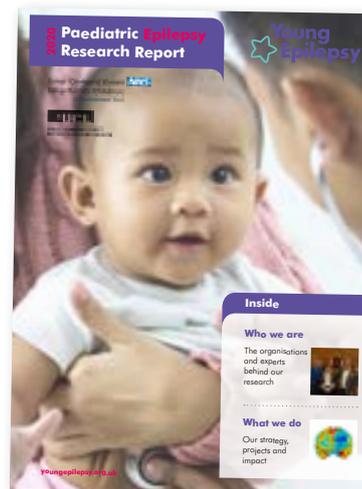
Our research partnership brings together multiple domains of knowledge relating to childhood epilepsy and aims to find solutions to one of the most complex and disabling set of conditions. 2019/2020 marks the 15th year of operation for the partnership and we present what we have achieved over this time alongside a special focus on the impact of our work in the last year (July 2019 to June 2020).

The successes of the year are thrown into sharp relief when the challenges are considered, such as the impact of Brexit on research funding and collaborations and, even greater still, the changes to all lives and pursuits due to the COVID-19 pandemic. We are proud to have contributed to the strategies and advice for continuing epilepsy care and research during the pandemic, as well as supporting families during this difficult time.

We invite you to help us continue to provide better outcomes for children with epilepsy by sharing this document, supporting our work through fundraising, or sharing your experiences with us to shape the future of childhood epilepsy research.



Professor Helen Cross OBE
The Prince of Wales's Chair of
Childhood Epilepsy



This document is produced in tandem with the annual Paediatric Epilepsy Research Report which outlines the research projects in more detail. The Research Report is available online and in print from Young Epilepsy.

The Prince of Wales's Chair of Childhood Epilepsy

In 2001, Young Epilepsy (then the National Centre for Young People with Epilepsy, NCYPE), UCL GOS - Institute of Child Health (then UCLICH) and Great Ormond Street Hospital, embarked on a major fundraising appeal which successfully raised £2 million for the first-ever Chair in Childhood Epilepsy, under the patronage of His Royal Highness The Prince of Wales.

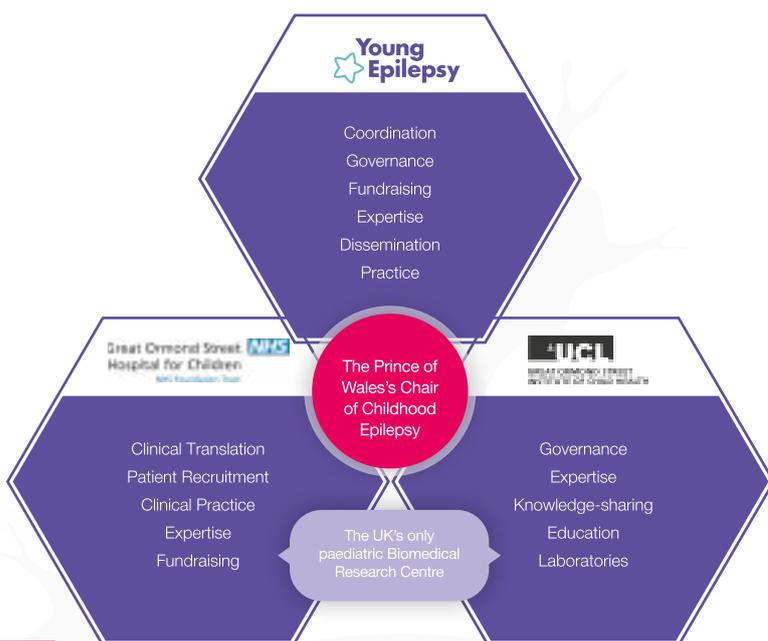
In 2004 the late Professor Brian Neville became the first incumbent of The Chair with Professor Cross succeeding him on his retirement in 2008.

The overarching focus of research under The Prince of Wales's Chair of Childhood Epilepsy is to improve outcomes in complex childhood epilepsy.

Enormous strides have been made in the field of childhood epilepsy over the course of this 15-year partnership and our research team, led by The Prince of Wales's Chair of Childhood Epilepsy, has remained at the forefront of discovery and implementation. For many children and families, the future is much brighter because of this research.

In addition to her role as The Prince of Wales's Chair of Childhood Epilepsy, Professor Cross holds a myriad of additional international leadership roles in childhood epilepsy which ensure maximum collaborative, translational and developmental opportunities for our research partnership.

We know that children and young people with epilepsy face systemic and needless challenges in many areas of their lives, including cognitive and behavioural challenges, mental health issues, stigma and lack of understanding. Through clinical research, real advances are being made in our understanding of the underlying causes of epilepsy, as well as how they affect all aspects of a child's life. Research presents a real opportunity to improve outcomes. However, health services can still be inconsistent in terms of access to specialist services, speed of diagnosis and adequate face-to-face support. This must change. Our world-class research has already begun to change outcomes but there is much work still to do.



Research Strategy

GOAL 01

Gain a better understanding of the medical causes of epilepsy

22% projects currently contribute to this goal

GOAL 02

Gain a better understanding of how epilepsy affects development and behaviour

23% projects currently contribute to this goal

Workstream 1: Understanding Childhood Epilepsies

Around half of people diagnosed with epilepsy never learn the cause of it. This is concerning from both the personal and clinician perspective. The more we know about what causes epilepsy and how else the underlying cause is affecting the individual patient, the better clinicians can manage and treat, and the better the patient may understand themselves.

Workstream 2: Outstanding Treatment

Epilepsy treatments have not changed very much over recent years and the process of finding the right combination of treatments for each patient can take a long time. This is very hard on patients, and their families. Continued advancement of imaging, surgery, dietetics, genomics, targeted treatment, and new medicines is therefore crucial in the quest to effectively treat and one day perhaps cure every epilepsy.

GOAL 03

Improving diagnosis and treatment to determine the benefits of early interventions in improving long-term outcomes

28% projects currently contribute to this goal

Workstream 3: Outstanding Support

This workstream is set to tackle the wider challenges associated with growing up with epilepsy and in treating childhood epilepsies. It is important to know what epilepsy is, and how to treat it, but if the systems and supports are not in place to act on this knowledge then patients cannot benefit.

GOAL 04

Gain a better understanding of barriers to learning and determine the benefits of educational interventions.

5% current projects contribute to this goal

GOAL 05

Make life better for children and families and make support systems more effective

18% projects currently contribute to this goal

GOAL 06

Develop a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners

5% projects currently contribute to this goal

Past Impact

Some of the key achievements of the research partnership to date

2001

Appeal to fund Europe's first Chair in Childhood Epilepsy Launched by Young Epilepsy, UCL GOS – ICH and GOSH with support from HRH The Prince of Wales

Overseen research in **NEW NEUROIMAGING TECHNIQUES** which has resulted in an increase in the number of children considered for epilepsy surgery

Identified significant **SLEEP DIFFICULTY**, and risk levels for **STRESS, ANXIETY AND DEPRESSION IN MOTHERS** of children with epilepsy

Overseen several studies determining outcomes from epilepsy surgery and promoted surgery as an intervention both nationally and internationally

Established a **SUCCESSFUL EUROPEAN REFERENCE NETWORK**, a network of centres specialising in care of individuals with rare and complex epilepsies across Europe



LAUNCH OF YOUNG EPILEPSY'S EDUCATION RESEARCH PROGRAMME to highlight the impact of epilepsy on learning and the urgent need to develop new strategies and interventions

Hosted a **DARZI FELLOWSHIP**, jointly with UCL-ICH, UCL Partners and Whittington Hospital NHS Trust. **IDENTIFIED CRITICAL GAPS IN CARE PATHWAYS** and developed national recommendations for future provision of epilepsy services

Established the first evidence base for the use of the **KETOGENIC DIET** (a high fat, low carbohydrate diet) and widened its use in children and infants with drug resistant epilepsy

Contribution to the **DEVELOPMENT, AND HOSTING OF, THE WORLD'S FIRST WEARABLE MAGNETOENCEPHALOGRAPHY (MEG) SYSTEM FOR CHILDREN**, in collaboration with UCL Institute of Neurology, Magnetic Shields Ltd and the University of Nottingham

Pilot work in the health economics of epilepsy strongly illustrated the need to explore further the real cost of childhood epilepsy in order to aid service provision and commissioning

Research into how **SLEEP** and **DEVELOPMENT** contribute to a better understanding of the causes of cognitive impairment in epilepsy



Professor Helen Cross OBE appointed The Prince of Wales's Chair of Childhood Epilepsy

2008

Contribution to the **EPILEPSY12 NATIONAL AUDIT**



Ground-breaking research evidencing the extent of **EDUCATIONAL DIFFICULTIES** and the high rate of cognitive and behavioural problems in school age children with epilepsy

Epidemiological studies into the **INCIDENCE, CAUSES, TREATMENTS AND IMPACT OF EPILEPSY IN INFANCY**

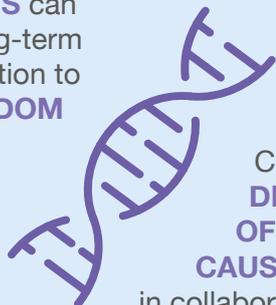


Contributed to the **DEVELOPMENT OF BUCCAL MIDAZOLAM** (one of the most widely used emergency epilepsy medications) and implemented training on its administration

Participated in the national commissioning of the **CHILDREN'S EPILEPSY SURGERY SERVICE (CESS)**

Established vital genetic collaborations through gene discovery and contribution to cohort studies

Demonstrated that **REAL IMPROVEMENTS** can be seen with long-term follow-up, in relation to **SEIZURE FREEDOM AND WEANING FROM MEDICATION** following epilepsy surgery



Continued **DISCOVERY OF NEW GENETIC CAUSES** of epilepsy in collaboration with UCL Institute of Neurology

2009

Opening of award-winning **Neville Childhood Epilepsy Centre** in Lingfield, which hosts our rehabilitation, diagnostic, and assessment services

First annual **Young Epilepsy Paediatric Epilepsy Research Retreat** held to foster national research collaboration

2011

Professor Helen Cross becomes the first woman elected, in its 100+ year history, to **President (2021-2025)** of the **International League Against Epilepsy**

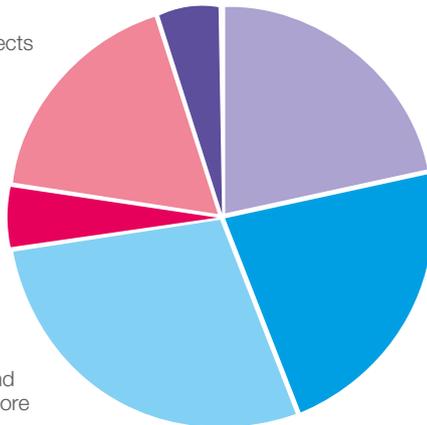
2019

Current Impact

Key outputs of the partnership between July 2019 and June 2020:

45 live research projects

- 22% of projects contributed to understanding the medical causes of epilepsy
- 23% of projects contributed to understanding how epilepsy affects development and behaviour
- 28% of projects contributed to improving diagnosis, treatment and early intervention
- 5% of projects contributed to a better understanding of barriers to learning and the benefits of educational interventions
- 18% of projects contributed to making life better for children and families and support systems more effective
- 5% of projects contributed to developing a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners

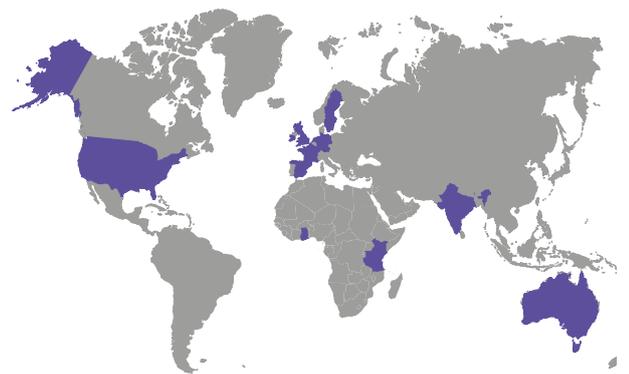


34 Principal Investigators
(senior leaders of research)



19
PhD students

37 international active Research Collaborators

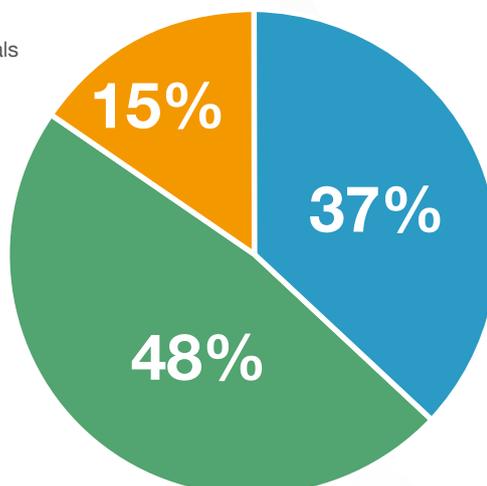


Geographic reach of Principal Investigators and Active Collaborators

Percentage number of projects contributing to each workstream

(weighted by number of goals per workstream)

- Workstream 1: Understanding Childhood Epilepsies
- Workstream 2: Outstanding Treatment
- Workstream 3: Outstanding Support



Over **£24million** secured in funding across the partnership

The partnership published

62

primary research papers

By November 2020

- These papers had been cited by a further 989 research articles
- These research papers had achieved the highest Altmetric Attention score* of any year of work produced by the team
- There were nine high impact papers underlying this success.

These papers:

- ▶ are cited in a further 847 research publications
- ▶ were referenced in 5 international policy documents
- ▶ mentioned by 455 international news outlets, 167 blogs, 4214 Tweets, 35 Facebook pages, across more than 70 countries

* The altmetric attention score is produced by an independent bibliographic data organisation, Dimensions (<https://app.dimensions.ai/>), and is calculated based on the public attention that an individual publication has received across news articles, social platforms, and policy documents.

28

review papers

5

chapters in books

Young Epilepsy was delighted to announce our first joint funding initiatives for epilepsy research:

EPILEPSY RESEARCH UK & YOUNG EPILEPSY FELLOWSHIP AWARD

£300,000 Fellowship Award for research into childhood epilepsy to be awarded in 2021 by Epilepsy Research UK and Young Epilepsy

Young Epilepsy AUTISTICA EPILEPSY RESEARCH UK
epilepsy and autism joint award

£30,000 to create a dossier of evidence to better understand autism
Awarded in 2020 by Autistica, Young Epilepsy and Epilepsy Research UK



Held the 10th and largest Annual Paediatric Epilepsy

Research Retreat to date – with 106 researchers coming together to share knowledge and discuss 34 projects

Established the UK's first patient involvement network for childhood epilepsy research with nearly...

140 members

Conducted important research into the experiences of people with epilepsy during the COVID-19 restrictions in the UK



Translation of research outcomes into the

development of the **Young Epilepsy Online Guide for Schools**

youngepilepsy.org.uk/guide-for-schools/

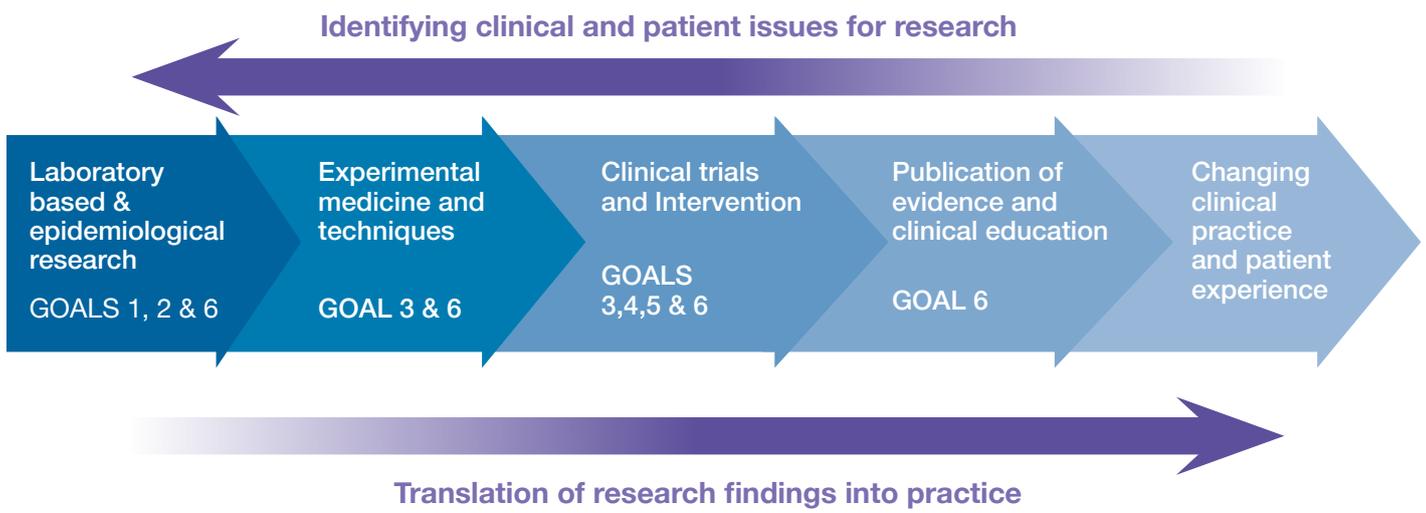


Researcher and research supported content published on **The Channel**, Young Epilepsy's online

information resource for young people with epilepsy
thechannel.org.uk

Meeting our research goals

Our research originates from the identification of clinical problems and feedback from patients. Ideas are then developed into project plans for which funding is sought and an expert team assembled. The end result is to publish results as original research which has stood up to the review and critique of independent experts – a process known as peer review. This ensures robust evidence on which we can implement changes and/or conduct further research.



The number of research projects within the partnership increases year on year (Figure 1) and we track the contribution of active projects to the three workstreams and six goals (Figure 2). We are historically strongest in addressing Workstream 1 and 2 – *Understanding Childhood Epilepsies* and *Outstanding Treatments* (Figure 3). Given our clinical origins this is not surprising, but over the last few years, we have also grown research under Workstream 3, *Outstanding Support*, through educational, psychosocial, and service-based research.

Figure 1: Number of research projects per year

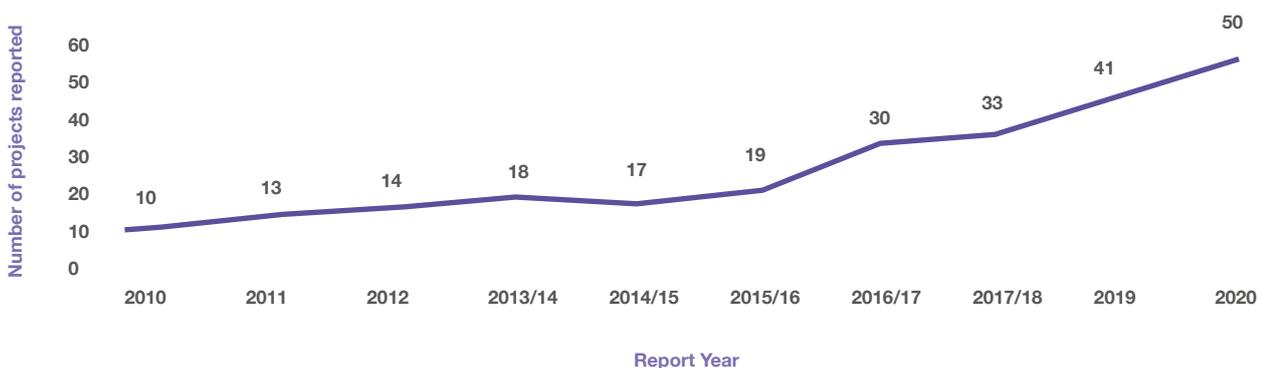


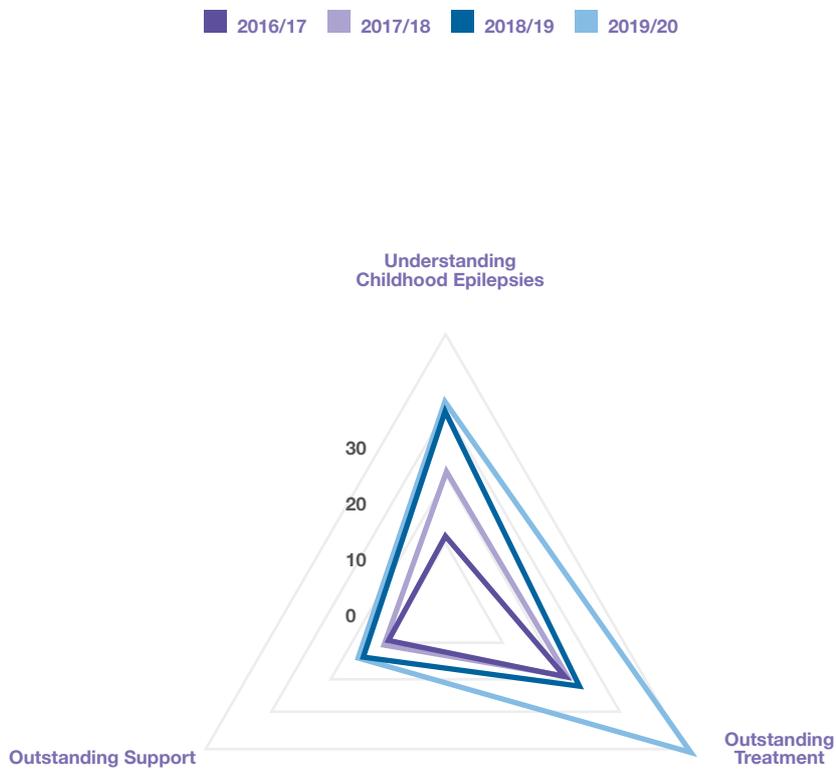
Figure 2: Number of active projects contributing to research goals

Many projects contribute to more than one workstream and/or goal



Figure 3: The relative work under each workstream year by year

(Number of projects contributing to each workstream annually, weighted by number of goals per workstream)



The strength of the evidence we publish

Over the past 10 years, our research programme has grown from having four Principal Investigators (the leaders of research units and laboratories, often Professors), to having 34 Principal Investigators supervising 19 PhD students and working alongside an additional 37 international collaborating researchers (Figure 4). This growth is reflected in the number of research projects and publications produced across the unit each year (Figure 5). 2020 has seen a dip in number of publications which is likely due to the delays and challenges caused by the COVID-19 pandemic and possibly Brexit (Figure 5).

Figure 4: Annual growth of the research partnership network

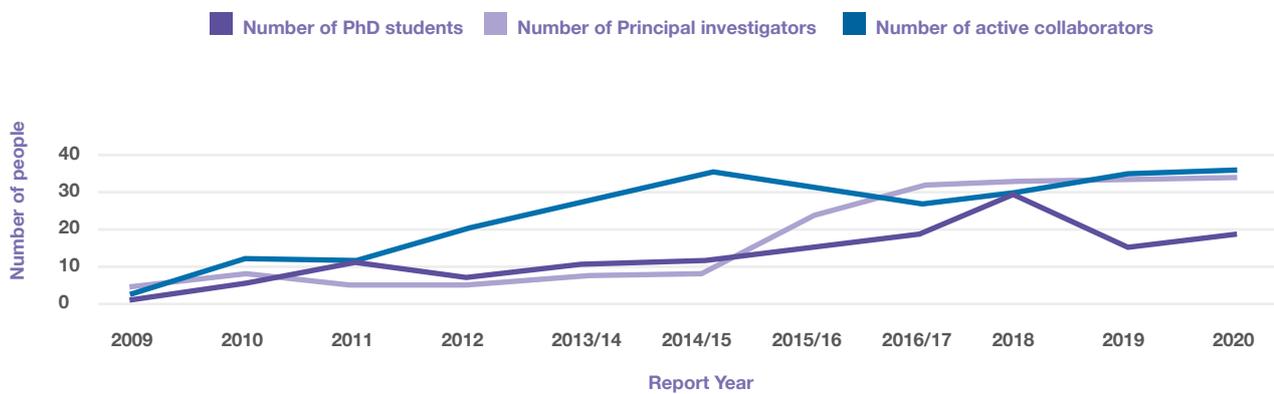
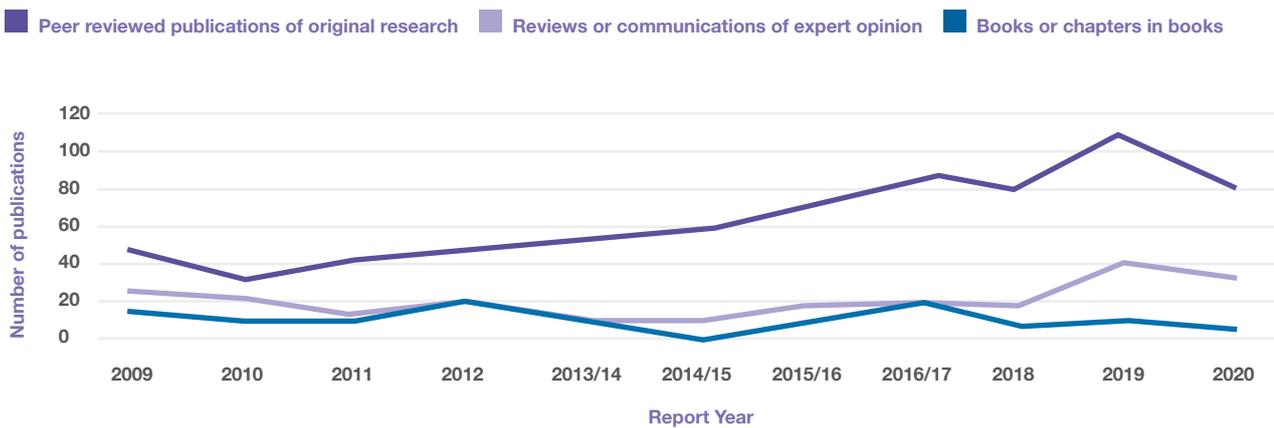
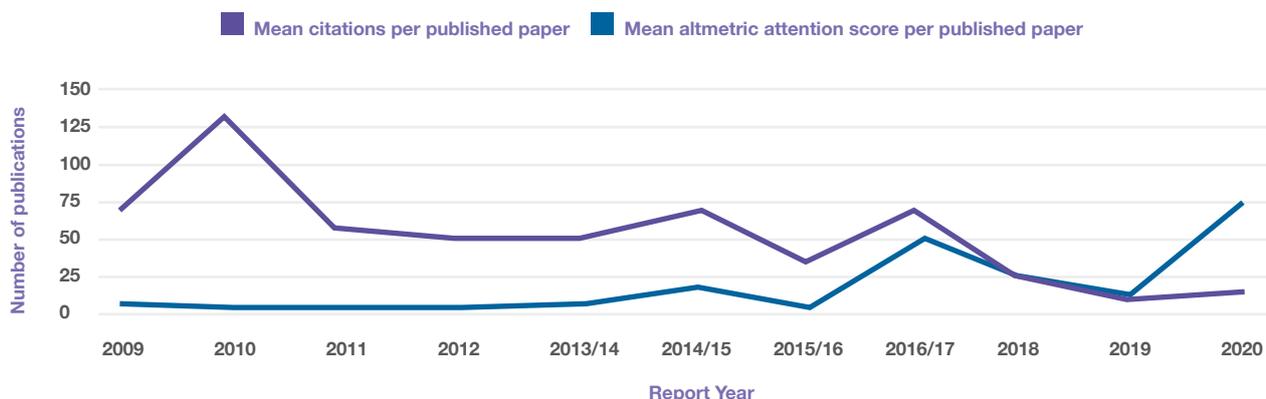


Figure 5: Number of research publications produced per year



We track the progress and influence of these research publications over time using two metrics – citations and an altmetric attention score (Figure 6). A citation is counted when an individual research paper is referred to in a later research publication as a source of evidence. The altmetric attention score that we use is produced by an independent bibliographic data organisation, **Dimensions.ai**, and is calculated based on the public attention that an individual publication has received across news articles, social platforms, and policy documents.

Figure 6: Impact of research publications -The mean number of citations and mean altmetric attention score per paper published in each year (correct at November 2020)



These data reveal to us that although last year we produced more publications (160), this year's 95 publications have made more immediate impact. Despite having less time to be cited by subsequent work, this year's papers have a mean of 11 citations each, versus a mean of 8 citations per paper published last year (Figure 6). Usually, the longer a publication is available, the more citations you can expect it to accrue, however older papers eventually become less relevant and are cited less.

The difference in mean altmetric attention score is profound, with a score of 11.45 for last year and 79.26 for this year (Figure 6). To put this in context, last year, three papers had an altmetric attention score of >100, meaning that they were in the top 5% of all the research papers tracked by Dimensions.ai. This year there are nine, with three scoring over 1000. This difference is likely due to the increasing access to research and increasing ability to track this access, but in these extreme cases, it is due to their being linked to current global affairs, such as COVID-19 and Genomics.

Topics of the 2019/20 high impact papers cover:

- the risks of prescribing certain antibiotics during pregnancy and their relationship to birth defects including neurological problems
- the application of whole genome sequencing to better understand and treat rare diseases in the NHS
- the psychological, social, and neuroscientific effects of COVID-19 and set out the immediate priorities and longer-term strategies for mental health science research
- agreed advice from international clinical experts for the continued clinical management of epilepsy during the COVID-19 pandemic
- the efficacy of a new anti-seizure medicine for Dravet Syndrome
- evidence which challenges the common understanding of mitochondrial DNA inheritance in humans. A critical step in the progression of the treatment of mitochondrial diseases (2 papers)
- how loneliness and disease containment measures impact on the mental health in children and adolescents
- categorisation of the major functional groupings of epilepsy-associated genes in light of currently available genetic testing approaches, and the known genetic landscape of the epilepsies.

Ensuring our research reflects the real needs of patients

Our research collaboration with GOSH and ICH naturally ensures that research themes are developed from clinical needs. However, to strengthen the voice of children and young people with epilepsy in our research, Young Epilepsy and doctors from ICH launched the first research network for both young people with epilepsy, and parents of people with epilepsy. Their sole purpose is to consult on the development of research projects across the unit. So far this year this group, the E-CURE (Epilepsy Carers Uniting with Researchers) has:

- held a launch event to showcase projects seeking support from patients and the public on research design and importance of research themes,
- co-designed the research design of the biggest trial of cannabis as a medicinal product,
- consulted on and improved the design of the Young Epilepsy Coronavirus and Epilepsy Experience Survey,
- recruited a parent representative for the Ketogenic diet in Infants with Epilepsy (KIWE) Trial Steering Group,
- recruited a parent clinician board member for the British Paediatric Neurology Association (BPNA) and Advanced Life Support Group (ASLG) Status Epilepticus Working Group to update the management guidelines for convulsive status epilepticus,
- presented the parent view of participating in research at the Young Epilepsy Annual Paediatric Epilepsy Research Retreat 2020,
- engaged in the award process of the Young Epilepsy and Epilepsy Research UK Joint Fellowship.

The practice of involving patients in research is called Patient and Public Involvement (PPI) and it is crucial in the development of practical, relevant research.

“ I attend meetings where we discuss our experiences as young people with epilepsy. We help to adapt the wording of documents to make them more accessible and discuss what children would struggle with if they were participants from our experiences. As well as being able to give [something] back through helping research, a lot of services that I didn't know were available have been mentioned and in general, [being part of the PPI group] has helped my understanding of the condition. If anything was to improve, it would be attending more!”

Young E-CURE Member

“I helped to secure the project funding and joined the research team as a co-applicant, gave me a much better understanding of how the whole research process works. My main role is co-ordinating the research advisory group and co-chairing our quarterly meetings – the content of which varies depending on the phase of the project.

Outside of the organised sessions, we have an active WhatsApp group which is a place where we can find information or support from each other, which can be so difficult to find elsewhere.”

Parent E-CURE Member

How does our research impact ultimately benefit children and young people with epilepsy?

This is the toughest question to answer. In the future Young Epilepsy is looking to work with an independent research impact assessor to further explore the true impact of research under our research partnership. Currently we record the translation of research to benefit children and young people with epilepsy through our completed projects featured in the 2020 Paediatric Epilepsy Research Report (available online and in print from Young Epilepsy).

Projects under Workstream 1 and 2 filter immediately into further research, updated guidance or into clinical practice. Projects under Workstream 3 are further translated by Young Epilepsy into programs such as our **Guide for Schools** (youngepilepsy.org.uk/guide-for-schools) and information on the newly launched information hub for young people with epilepsy, **The Channel** (thechannel.org.uk), and we plan to expand this area of activity over the coming years.



What's Next?

Looking to the future of childhood epilepsy research three key themes emerge which are strongly aligned to our Workstreams:

Genetic Revolution

Advances in genetics over the past decade have brought us closer than ever to understanding the causes of almost every epilepsy. 40% of people with epilepsy never know what causes their epilepsy and this can mean identifying the right treatment is a challenge. This number is even higher in early-onset and childhood epilepsies. Almost all the unknown causes of epilepsies are likely to be genetic in origin. The better we understand the origin, the better we can positively impact the pace and effectiveness of treatment. It is important to understand that a genetic cause of epilepsy very rarely means that it was inherited from a parent. The great majority of genetic epilepsies are caused by changes in a person's genetic make-up which happened within that individual and was not inherited.

Targeted Treatment

Apart from surgery and ketogenic diet therapies, all epilepsy treatment is symptomatic. This means it does not treat the cause or alter the condition, it relieves symptoms such as seizures. With the recent advances in imaging and genomics we have started to develop treatments which target the cause of the epilepsy such as more advanced surgery and gene therapy.

Expertise Without Borders

As the understanding and treatment for epilepsy advances, so must the support networks to deliver new learning to patients. Not all hospitals, regions and countries have the same opportunities to support the epilepsies, and so borderless collaboration is vital to maximise the outcomes for all children, and young people with epilepsy. The European Reference Network for Rare Epilepsies - EpiCARE, initially led in the UK by Professor Cross and now by Professor Arzimanoglou in Lyon, brings together experts from 43 highly specialised health centres across 24 European countries and they can each contribute to the care of individual cases.

A World First

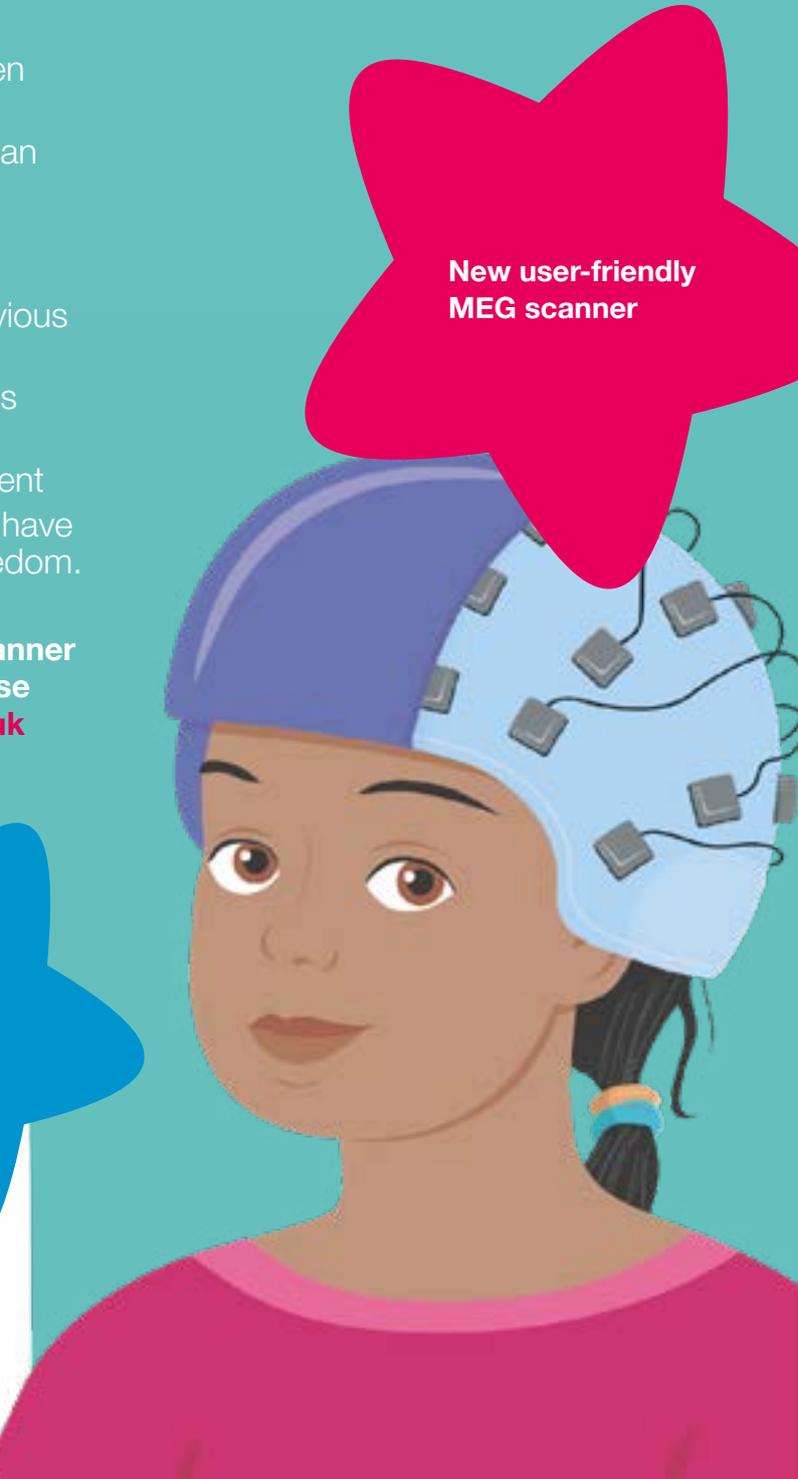
Young Epilepsy is working with UCL Institute of Neurology, University of Nottingham, Magnetic Shields Ltd, Wellcome Centre for Human Neuroimaging, and UCL GOS-ICH to design and build the world's first wearable MEG scanner.

This new type of brain scanner will transform the lives of young people with epilepsy by giving more young people the chance of seizure freedom through epilepsy surgery.

The Young Epilepsy MEG scanner will:

- Be the first MEG scanner which children can use unsedated
- Provide greater clarity and accuracy than current MEG systems
- Provide an easier and less stressful experience for patients
- Be less expensive to operate than previous MEG systems
- Pioneer the technology for UK hospitals
- Increase the opportunity for early intervention and more accurate treatment
- Give more young people the option to have surgery which can result in seizure freedom.

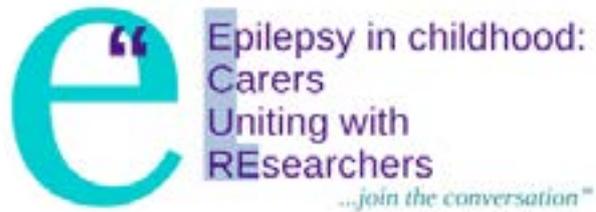
If you can help us build the new MEG scanner by donating or helping to fundraise, please contact fundraising@youngepilepsy.org.uk



**New user-friendly
MEG scanner**



**Old MEG
scanner**



We Need You

to help us strengthen the voice of children and young people with epilepsy and their families in research.

We have launched the first network of young people with epilepsy, and parents of people with epilepsy, whose sole purpose is to consult on the development of research projects across our partnership.

If you would like your experiences to ensure epilepsy research is answering the right questions in the right way, please get in contact and sign up to the E-CURe network.

Thanks To...

Central to the research programme is the ability to apply for and manage research grants and charitable donations. Our collaborative funding strategy has enabled us to build the world's largest paediatric epilepsy research partnership and network of multidisciplinary practitioners.

We remain ever grateful for the generosity and dedication of the organisations and individuals who support our work

Thank you!

Action Medical Research

Autistica

Brain Tumour Charity

Cancer Research UK

Child Health Research Trust

Children with Cancer UK

Epilepsy Research UK

Ethypharm

European Association of Neurosurgical Societies

European Commission

Freya Foundation

Google Cloud Platform Research Credit Award

GOSH NIHR BRC

Great Ormond Hospital Children's Charity Research Leadership grant

Great Ormond Street Children's Charity

GW Pharmaceuticals

Innovate UK

James Lewis Foundation

Medical Research Council Clinician Scientist Fellowship

National Institute of Health Research (NIHR)

NIHR GOSH Biomedical Research Centre

NIHR GOSH BRC PPIE Small Grants

Novartis

Nutricia

Oakgrove Foundation

Rosetree's Trust

Sir Henry Wellcome Fellowship

UCB BioPharma

UCL Child Health Research CIO Strategic Initiatives Pump-Priming Fund

Veriton Pharma

Vitaflo

Waterloo Foundation

Wellcome Research Enrichment - Public Engagement

Wyfold Charity Trust

Young Epilepsy

If you can help us continue to provide better outcomes for children with epilepsy by fundraising, or joining the E-CURE Network, please contact us at:

Research@youngepilepsy.org.uk

Young Epilepsy is the children and young people's epilepsy charity

We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

Let's work together.

For more information on our research or if you want to get involved please contact:

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Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy. Registered Charity No: 311877 (England and Wales).