



King's Health Partners Neurosciences



King's Health Partners

King's Health Partners brings together:

- three of the UK's leading NHS Foundation Trusts
- a world-leading university for health research and education
- nearly 4.8 million patient contacts each year
- 40,000 staff
- nearly 30,000 students
- a combined annual turnover of more than £3.7 billion
- services provided across central and south London and beyond, including nine mental health and physical healthcare hospitals and many community sites
- a comprehensive portfolio of high-quality clinical services with international recognition in cancer, diabetes, mental health, regenerative medicine, transplantation, cardiac and clinical neurosciences
- a major trauma centre and two hyper-acute stroke units

About King's Health Partners

King's Health Partners Academic Health Sciences Centre brings together one of the world's top research-led universities, King's College London, and three NHS Foundation Trusts – Guy's and St Thomas', King's College Hospital and South London and Maudsley.

We are an Academic Health Sciences Centre where world-class research, education and clinical practice are brought together to benefit our patients.

To support our mission, we are delivering programmes of work to:

- Join up mental and physical healthcare so that we treat the whole person, through our Mind and Body Programme.
- Increase the value of the care we provide, and the outcomes we achieve for our patients and service users through a Value Based Healthcare approach.

- Bring together our partnership's collective strength in a range of specialist services to deliver world-class patient care and research through our institutes programme.
- Developing education, research and capacity building programmes in global health including partnerships with healthcare teams and organisations in Sierra Leone, Somaliland and Zambia.

We are uniquely structured to deliver our mission for excellence. Our 22 Clinical Academic Groups (CAGs) bring together all the clinical services and staff from the three trusts with the relevant academic departments of King's College London.

Foreword



King's Health Partners mission as an Academic Health Sciences Centre is to combine the collective strengths of our partners to bring world-class research, education and clinical practice together for the benefit of patients.

The vision of King's Health Partners Neurosciences is ambitious, to become a world-leading centre for neurological recovery and experimental medicine research in neurological conditions, and the most highly rated UK centre for education and training in clinical and basic neuroscience.

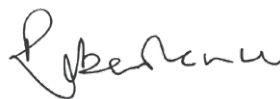
King's Health Partners Neurosciences is building on a distinctive set of strengths to achieve this, consolidating our expertise to tackle the complexity of the nervous system and the vast array of conditions and disorders that can affect it.

We collectively provide one of the largest, most comprehensive clinical neurosciences services in the country to a population of nearly four million people in south east London and Kent. Many of these services are recognised to be of the highest standards. Combined with the world-leading clinical research, a large commercial research portfolio, advanced therapies and the outstanding facilities

described in this book, this means we have the ability to improve outcomes for people with neurological conditions over the entire lifespan, from earliest embryonic development to late life neurodegeneration.

This is all underpinned by excellent education programmes, integrating Mind, Body & Brain Care for patients and service users, value based healthcare approaches and reducing inequalities by ensuring excellent of care across all our pathways.

This book highlights some of the strong foundations we are building on to achieve this goal. Working in partnership and sharing our clinical academic expertise across organisational boundaries provides a real opportunity for us to transform care for neurological conditions benefitting our local communities and having a global impact as a leading neurosciences centre.

A handwritten signature in black ink, appearing to read 'Robert Lechler', written in a cursive style.

Professor Sir Robert Lechler

Executive Director of King's Health Partners,
May 2019

Foreword



At King's Health Partners we are committed to improving outcomes for our patients and service users and achieving maximum value for money in everything we do. We believe that being open and transparent about the care and outcomes we deliver results in a culture of improvement across our partnership.

This is why we are publishing a series of outcomes books that will help patients, service users, carers, referring clinicians and commissioners to make better informed decisions, and our staff to drive up the quality of the care we provide. The books report key outcomes for treatments provided by our 22 Clinical Academic Groups. Clinical Academic Groups form the building blocks of our Academic Health Sciences Centre. By bringing together our clinical and academic staff across teaching, training and research, we can use their combined expertise to achieve better outcomes for our patients and service users.

Our books are designed for a clinical and lay audience and contain a summary of patient volumes and measures (e.g. length of stay, re-admissions, patient experience), clinical outcomes, educational activities, technological and research innovations and publications.

They also focus on other important measures, such as staff satisfaction and wellbeing. The primary purpose of King's Health Partners is to improve health and wellbeing locally and globally. We must deliver this goal in a challenging economic environment with rising demand for, and costs of, healthcare. We will only achieve sustainable health improvement if we strive always to increase value. We define value in terms of outcomes that matter to patients, over the full cycle of care, divided by the cost of producing those outcomes. By publishing outcomes books, we have more information to support us measuring the value of the healthcare we provide.

We hope you find these data valuable. Please send comments and suggestions to us at kingshealthpartners@kcl.ac.uk.

For more information please visit our website at www.kingshealthpartners.org.

A handwritten signature in black ink, which appears to read 'John Moxham'.

Professor John Moxham

Director of Value Based Healthcare, May 2019

Neurosciences foreword



Dr Jozef Jarosz
Joint Director
King's Health Partners
Neurosciences

The brain and nervous system is sometimes seen as the 'final frontier' of science, because of its enormous complexity. Neuroscience has become one of the major areas of scientific research in the 21st century, leading to many important discoveries. The complexity of the nervous system is reflected in the vast array of conditions and disorders that can affect it – about 600 different disorders have been identified, some of which are very common but many of which are rare. It is currently estimated that in England there are around 14.7 million cases of neurological conditions.



Professor Mark Richardson
Joint Director
King's Health Partners
Neurosciences

King's Health Partners is playing a major role in the management of neurological and neurosurgical disorders, and in scientific research applied to the nervous system. Neuroscience is a prominent part of all four of our partner organisations including a regional Neurosciences Centre in King's College Hospital and a large Division of Neuroscience in King's College London. We undertake world-leading scientific research in many areas, including: development of the brain and nervous system; later life neurodegeneration and dementia; and common disorders such as headache, epilepsy and Parkinson's disease. We provide clinical services recognised to be of the highest standard across

a broad-spectrum including brain trauma, stroke, brain tumour, neurofibromatosis, motor neuron disease, neuromuscular disorders and Parkinson's disease.

There is much more we can do to build on the excellence we have already achieved. We have new research opportunities in our state of the art basic research facilities in the Maurice Wohl Clinical Neuroscience Institute, in the National Institute for Health Research (NIHR)-Wellcome King's Clinical Research Facility, and through our new UK Dementia Research Institute, all of which are based at Denmark Hill. We have recently expanded facilities for neurorehabilitation in south east London and will see ever greater need for this.

King's Health Partners Neurosciences has major ambitions to improve the care and outcomes of people with conditions affecting the nervous system, through innovation in clinical services, research and education. This book sets out a snapshot of our current position. This is just the beginning of an important journey, and we hope you will travel with us, and see our visions for the future realised.

Highlights

Our clinical services and outcomes page 23

- Regional Neurosciences Centre providing comprehensive services to four million people in south east London and Kent, with fully integrated diagnostic services
- Two accredited international Centres of Excellence – one for Parkinson's disease and one for neuromuscular disease, a nationally commissioned neurofibromatosis service, a multi-award-winning motor neuron disease clinic and neurosurgery services rated as the national exemplar by the Getting It Right First Time (GIRFT) review
- Established and effective focus on recovery and on mental health in neurological conditions.

Research and innovation page 39

- World leading research, ranked 16th in the world and fourth outside the USA
- Ranked second in UK for research power by the Research Excellence Framework 2014

■ Exceptional research infrastructure, including:

1. National Institute for Health Research Biomedical Research Centre focused on mental health and neuroscience
2. National Institute for Health Research-Wellcome Trust King's Clinical Research Facility
3. One of six centres within the UK Dementia Research Institute
4. Medical Research Council (MRC) Centre for Neurodevelopmental Disorders
5. National Institute for Health Research BioResource for Mental and Neurological Health
6. Maurice Wohl Clinical Neuroscience Institute.

Education and training page 52

We have a comprehensive education and training portfolio to develop tomorrow's researchers and clinicians. This includes:

- Developing the next generation of scientists through a BSc in Neuroscience, MScs in neuroscience disciplines, a PhD programme and nurturing of post-doctoral researchers
- Training the next generation of clinicians through the full range of neuroscience clinical sub-specialties
- Continuing to develop our staff through a wide range of continuing professional development (CPD) opportunities.

Clinical pathways

In this section of the book we showcase the contribution we are making to driving improved clinical outcomes and linked research for each of our major patient pathways.

Epilepsy page 61

We offer the widest range of treatments for epilepsy in the UK, including the first out-of-hospital video electroencephalography (EEG) diagnostic service in the UK, and the largest programme of remote monitoring of epilepsy symptoms in the UK.

Headache page 69

We have the leading headache clinical and research team in the world, taking pioneering research from the laboratory through to the successful development of novel treatments for headache disorders.

Nerve and muscle page 74

Our service in nerve and muscle is the largest UK centre for skin biopsy in small fibre neuropathy, and is linked to a world-leading programme of research into the mechanisms of nerve function, pain and childhood muscle disorders.

Neuro inflammation page 78

We provide a comprehensive service in neuroinflammation, offering the full range of disease-modifying therapies for multiple sclerosis, driven by a large and successful track-record of clinical trials.

Neuro-oncology page 84

Led by the Brain Tumour Charity's Clinician of the Year 2018, our neuro-oncology service pioneered the adoption of new techniques and service models, including being the first UK centre to use BrainPath for keyhole brain surgery.

**Neurodegeneration – motor neuron disease
page 91**

We have the first Motor Neuron Disease Care and Research Centre in the UK, which led pivotal treatment trials of Riluzole, now the standard treatment, and developed a clinical staging system used in patient management worldwide.

**Neurodegeneration – Parkinson's disease
page 97**

In Parkinson's disease we have pioneered outcome measurement, including identifying and addressing the importance of non-motor symptoms, and have a large research programme supported by a highly active patients and carers group.

Neurofibromatosis page 106

Our neurofibromatosis service is one of only two in the UK for Neurofibromatosis 1, and one of only four in the UK for Neurofibromatosis 2, and has developed a specific quality of life outcomes measurement tool.

Neuropsychiatry page 112

Neuropsychiatry is linked to the world's leading psychiatry research centre in King's College London, and is embedded in all our care pathways, providing innovative Mind, Body and Brain care.

Neurorehabilitation page 120

We have an expanding service in neurorehabilitation, recently adding 20 beds and a neuronavigation service that covers south east London. Our outcomes show year on year improvements in functional gains, and we are pioneering the introduction of new outcomes measures.

Spinal surgery page 131

Our spinal surgery team, with King's Health Partners Orthopaedics, is leading the South East London and Kent Regional Spinal Network, and pioneering the collection of outcomes data for spinal surgery, using the British Spine Registry.

Stroke (cerebrovascular disease) page 139

We provide two of London's eight Hyper Acute Stroke Units, linked to an accredited National Institute for Health Research Hyper Acute Stroke Research Centre, undertaking a wide range of clinical trials.

Trauma page 153

Survival from traumatic brain injury is amongst the best of any of the London Trauma Systems, and we continue to innovate to provide support and self-management tools for people following brain injury and their carers.

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The value of partnership at King's Health Partners

King's Health Partners aims to create a centre where world-class research, education and clinical practice (the 'tripartite mission') are brought together for the benefit of patients.

We want to make sure that the lessons from research and innovation are used swiftly, effectively and systematically to achieve better patient outcomes, improve public health and join up health and care services for people with physical and mental health problems.

By working together in this way, integrating care across different organisations and sectors, we can not only improve the health of the people we care for, but we can also achieve better value for money.

Integrating mental and physical health

The mind and body are inseparable, and mental and physical health conditions are often connected. Mental health illness can have a significant negative impact on physical health. Likewise, many people with long-term physical health conditions and progressive illnesses suffer from depression or other mental health conditions. Despite this, many health services separate care into physical and mental and often fail to share patient information. At King's Health Partners we are working to overcome these barriers by treating the whole person, through our Mind & Body Programme and across all of our CAGs.



**Nearly
half**

of people with mental illness also have at least one long-term physical condition



30%

of people with long-term physical health conditions also have a mental illness



**15-20
years**

shorter life expectancy for someone with a severe mental illness or learning disability than for those without



£8bn

a year is spent by the NHS treating the effect of poor mental health on physical illnesses

Across all King's Health Partners, we will treat the whole person by:

- Screening all patients with chronic physical diseases for mental health conditions, and using the learning from this to improve the care we provide;
- Improving our understanding of the physical health needs of people with severe mental ill health;
- Addressing the traditional distinctions between the mind and body in research and education allowing us to train students and staff to deliver more integrated care;
- Better organising and expanding current training provision for physical and psychiatric comorbidity;
- Working with our local commissioners to find new ways of paying for integrated services;
- Linking IT systems across our partner trusts so that clinicians have access to a person's physical and mental care records;
- Investing in innovative programmes such as IMPARTS (Integrated Mental and Physical Healthcare: Research, Training and Services) and 3DLC (3 Dimensions of care for Long Term Conditions);
- Recognising the importance of employee mental and physical health and wellbeing.

Public health

Public health is one of our biggest challenges. At the root of much of the ill health in south London is a high incidence of smoking, alcohol abuse and obesity. With our health and social care partners, we are developing strategies to tackle these public health priorities. We are also developing plans for a new Institute for Population Health, a collaboration with local partners to bring about transformational change to health in local communities. We want to achieve a measurable improvement and impact on health gain and local management of physical and mental health problems through new evidence-based interventions.

Alcohol strategy – key aims

- Developing appropriate resources for clinical staff and patients;
- Developing and implementing training for all staff on harmful drinking supporting early identification and intervention;
- Establishing ourselves as a centre of excellence for integrated research, training and practice in the management and prevention of alcohol misuse;
- Attracting funding for future alcohol clinical, training and research initiatives;

- Monitoring the impact of the strategy on indicators of alcohol related harm;
- Embed in-reach alcohol teams in our hospitals to identify and support patients who misuse alcohol.
- Co-producing clinical care pathway for nicotine dependence treatment;
- Developing and implementing training packages for smoking cessation interventions for all our healthcare professionals;

Tobacco strategy – key aims

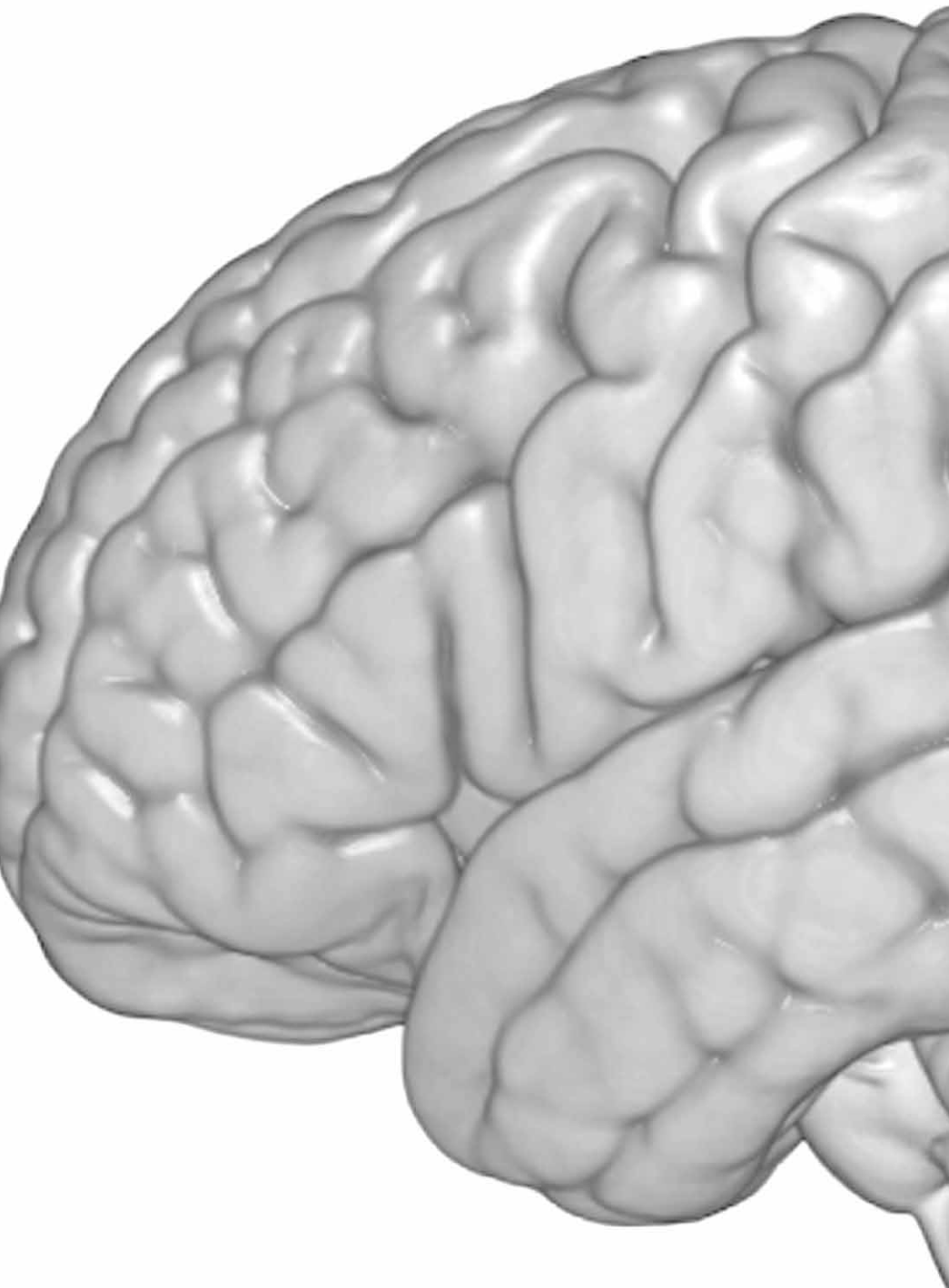
- Supporting all clinical sites to be smoke-free;
- Developing an informatics structure for routinely and systematically recording smoking status;
- Support, referrals and treatment uptake for smoking cessation across the partnership;
- Monitoring the impact of our smoking cessation strategy in relation to knowledge and uptake of skills by staff, uptake of smoking interventions, outcomes of interventions, user satisfaction, prevalence of smoking, cost-effectiveness of interventions;
- Implement the Ottawa model of smoking cessation across our trusts.

The Vital 5

Addressing the front end of the complete pathway of care

Vital 5	Aim
Blood pressure	To reduce stroke and heart attack, and improve wellbeing.
Obesity	To reduce diabetes, renal dialysis, liver transplants, amputations and other comorbidities, and improve wellbeing.
Mental health score	To reduce the burden of mental illness, improve physical health, recovery and wellbeing.
Alcohol intake	To reduce liver transplants and malignant disease, and to improve wellbeing.
Smoking habits	To reduce respiratory and malignant disease, and improve wellbeing.

Standardised, routine recording and clinical management of these five measures for all our patients should be a vital component to delivering consistent, high quality care to all our patients.



Overview of King's Health Partners
Neurosciences



Overview of King's Health Partners Neurosciences

We are at the vanguard of developments in neurosciences care and research. We bring together neuroscience clinical and academic expertise across three leading NHS Foundation Trusts: Guy's and St Thomas'; King's College Hospital and South London and Maudsley; together with our university partner King's College London.

Collectively we provide a comprehensive clinical neurosciences service, which is one of the largest in the country.

- At the heart of this is a large regional **Neurosciences Centre at King's College Hospital** which serves a population of 3.5 to 4 million across south east London and Kent. King's College Hospital NHS Foundation Trust also provides neurology services at the Princess Royal University Hospital and neurorehabilitation services at Orpington Hospital.
- **Guy's and St Thomas' NHS Foundation Trust** provide neurology and neurophysiology services to the south central London population as well as a national neurofibromatosis service. Alongside this, the Trust also provides neurorehabilitation services including community neurorehabilitation.
- Renowned neuropsychiatry services are provided by **South London and Maudsley NHS Foundation Trust** which provides specialist treatment and accepts referrals from across the UK.

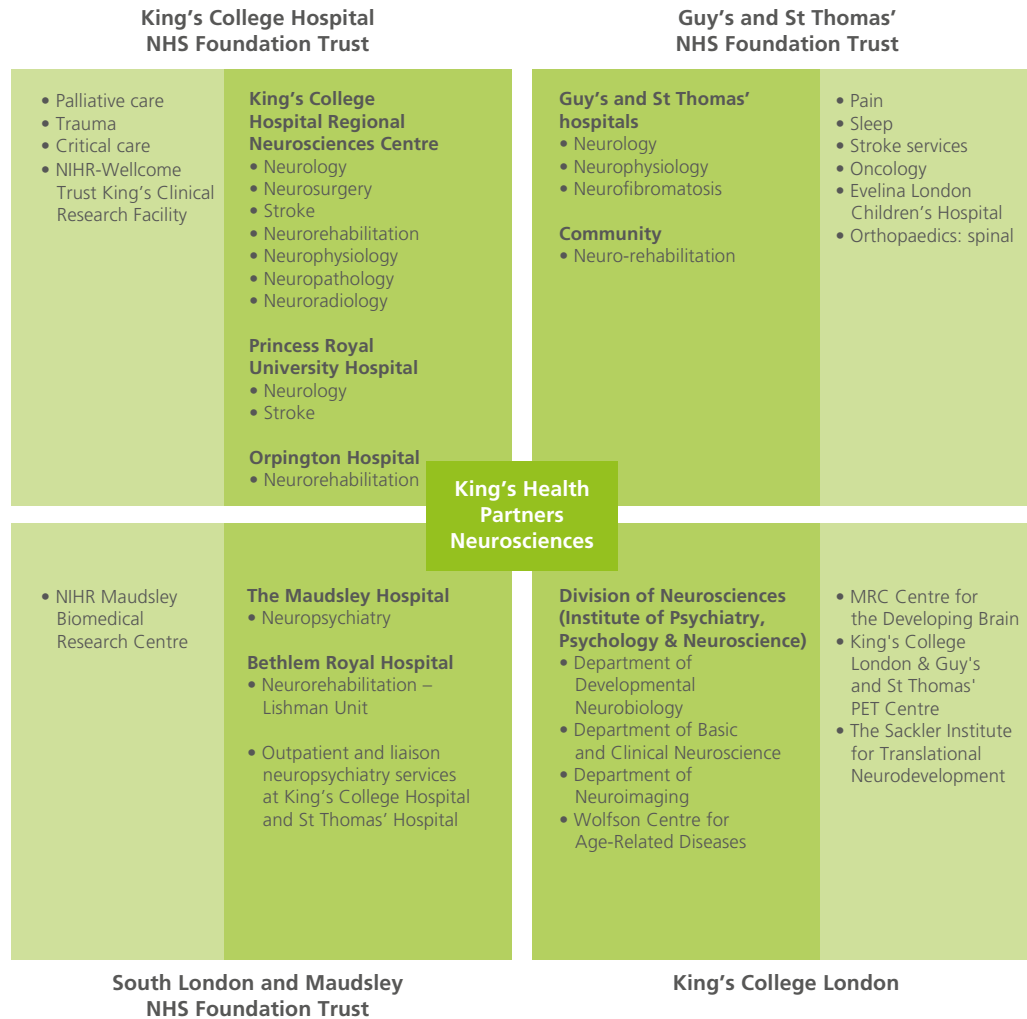
King's Health Partners Neurosciences has the second largest academic neuroscience department in the UK. Academic strengths include neurodegeneration (with particular expertise in motor neuron disease and Parkinson's disease) and we conduct world-leading clinical research in epilepsy, headache and stroke, as well as an extensive programme of preclinical research in neurodevelopment, neurodegeneration and neuroregeneration after injury. We also have a large portfolio of commercial research. We have outstanding facilities including:

- The Maurice Wohl Clinical Neuroscience Institute – a state-of-the-art facility with 250 clinicians and research scientists from neurology, psychiatry, neuroimaging, genetics, molecular biology, cellular biology and drug discovery;
- The NIHR-Wellcome King's Clinical Research Facility;
- King's Dementia Research Institute Centre.

Our collective strengths include:

- a wide range of specialist services, many with excellent outcomes (see 'our clinical services' chapter on page 23 and each of the clinical pathways chapters from pages 59 to 157);
- a wide range of national and international centres of excellence;
- a very large neuroscience research community, based alongside a world-leading psychiatry and psychology environment, with extensive collaborations between these areas;
- excellent research activity related to the entire lifespan, from earliest embryonic development to late life neurodegeneration;
- immediate access to very large and well-characterised patient populations in all areas of neurological and psychiatric disease, and access to very large collections of patient samples (such as DNA, living cell lines and post-mortem brains) to facilitate research;
- extremely close collaboration between basic scientists, clinical scientists and clinical staff working in our hospitals which provides an exceptionally clear line of sight between basic science and improving outcomes for people with neurological conditions;
- our excellence in neuroscience research is reflected in our outstanding education, so that discoveries made in King's Health Partners laboratories today are taught in the classrooms of tomorrow.

Figure 1 | The components of King's Health Partners Neurosciences



■ King's Health Partners Neurosciences ■ Other clinical services or research infrastructure with strong links

The significance of neurological conditions

Neurological conditions matter, as it is estimated that one in six people have a neurological condition and that there are approximately 14.7 million cases in England (Figure 2). Neurological conditions are

disorders of the brain, spinal cord, nerves and muscles. There are more than 600 types of neurological conditions, some of which are very common whilst others are rare (Figure 2 shows numbers by broad category).

Figure 2 | The estimated number of neurological conditions in England



Source: Neuro Numbers, A report by the Neurological Alliance, March 2019.

The cause of each neurological condition varies, and for many it is still unknown. Our researchers are working to further the understanding of disease mechanisms and to develop ground breaking treatments. Examples of our work are shown throughout this book.

The impact that a particular disease has on people can vary. Using stroke as an example:

- It is the second leading cause of death globally, and the leading cause of disability in the UK.

- Almost two thirds of stroke survivors in England, Wales and Northern Ireland leave hospital with a disability (Stroke Association, State of the Nation, February 2018).

- As well as coping with the physical symptoms and their impact, people who have had a stroke may also experience cognitive, emotional and behavioural problems.

It is therefore of paramount importance that our care, education and research address the holistic needs of patients.

Aims and ambitions

Quality of life can be significantly impaired by having a neurological condition. We want to ensure we provide the best possible care for patients, whilst finding new treatments and ultimately cures.

Our vision is to deliver outstanding outcomes for people with neurological conditions through world-class clinical services, supported by innovative training and pioneering research.

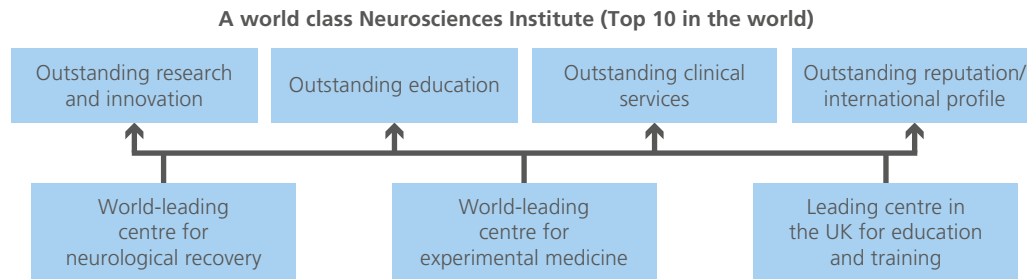
We aim that King's Health Partners Neurosciences will become:

- A globally leading neurosciences centre, focused on driving improved outcomes for patients with neurological conditions, through integrating clinical services with research, education and training.
- The leading centre in the world for experimental medicine research in neurological conditions, building on our research achievements, internationally-leading expertise and outstanding facilities.

- A system leader in driving excellence of care across all pathways for patients with neurological conditions in south east London and Kent.
- The most highly-rated UK centre for training in clinical and basic neuroscience.
- A distinctive neurosciences centre driving the integration of mental and physical health.

This book highlights some of the outstanding work already taking place across our partnership in neurosciences. However, we want to go further faster, and have selected three key themes where we will put focused effort into making a step change. These themes are set out in Figure 3.

Figure 3 | King's Health Partners Neurosciences programme themes



A world-leading centre for neurological recovery

Our centre will build neurological recovery knowledge, skills and ethos to drive improved outcomes and quality of life for patients. This will include:

- Empowering patients to live as well as possible with their condition.
- Enhancing therapy across patient pathways to maximise recovery.
- Harnessing the potential of emerging non-invasive techniques to assess the efficacy of intervention and to further tailor and personalise the therapeutic input.
- Using novel technology to drive and augment recovery e.g. transcranial magnetic stimulation, gaming consoles, robots, virtual wards.

- Extending the application of wearable technology to monitor patients at home/in community and prolong therapeutic impetus.
- Measuring holistic outcomes across patient pathways beyond hospital-based care including social and vocational outcomes.

A world-leading centre for experimental medicine

We have the opportunity to lead the world in experimental studies carried out in patients as we have: exceptional research effectiveness; a large basic science enterprise; an exceptional clinical research infrastructure and world-leading bioengineering in King's College London.

This includes:

- Experimental research in advanced therapies: small molecules (especially where King's Health Partners has discovered the target and/or developed the drug), gene therapy, viral vectors, cell therapy, neuromodulation.
- Biomarker discovery: imaging, -omics, electrophysiological markers – EEG (Electroencephalography), EMG (Electromyography), and NCS (Nerve conduction studies); especially linked to experimental studies, to stratify patients.
- Neuroengineering: novel devices, novel control systems in devices, surgical robotics, artificial intelligence (AI) in real-time therapeutic decision-making.
- Develop a pipeline of clinical research talent, to include a clinical PhD programme for medical and allied health professionals.
- Continually strengthen clinical training programmes.
- Maximise opportunities for continuing professional development, both for our staff and others.
- Develop underpinning education required to support new models of care, including patient self-care.

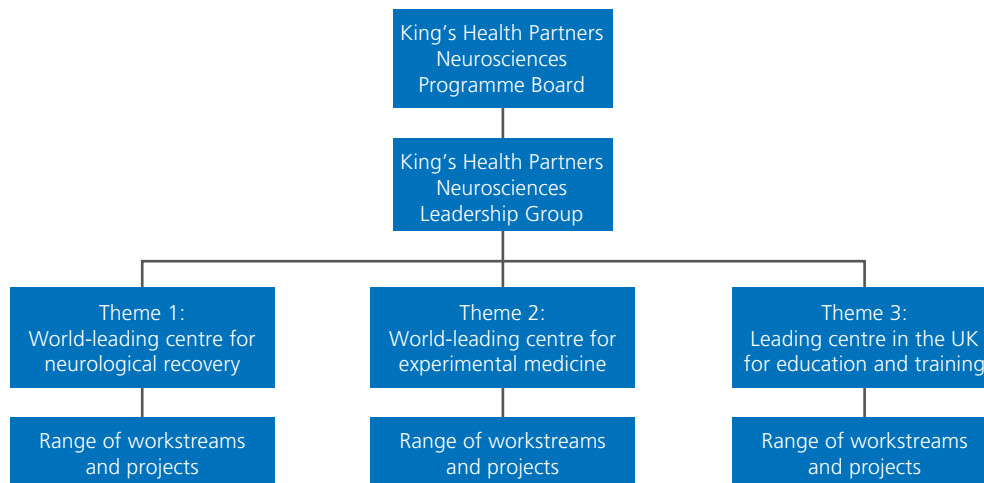
A leading centre in the UK for education and training

We will bring together our education and training activity across neurosciences into an Education Academy. This will enable us to:

- Mutually support, share and learn between university-based programmes.
- Develop more education for professionals using materials developed for our (on-line) university courses.

King's Health Partners Neurosciences leadership

In order to drive our ambitions, and maximise our impact, we have developed a governance structure as set out below. There is wide representation from each of the partners and members of the multidisciplinary team.





Our clinical services

Our clinical services

King's Health Partners Neurosciences incorporates a comprehensive range of clinical services that work together to meet the complex needs of people with any of the wide range of neurological conditions. Collectively we offer one of the largest neurology, neurosurgery, neurophysiology and neuropsychiatry services in the country.

We offer a complete range of sub-specialty services including adult and paediatric neurosurgery, acute neurology, stroke, epilepsy, spinal surgery, neurodegeneration (including Parkinson's disease and motor neuron disease), neuro-inflammation (including multiple sclerosis), neuromuscular disease, neuro-oncology, neurofibromatosis, neuro-ophthalmology, neuro-otology, headache and neurorehabilitation. Paediatric neurology services are provided by specialist children's services at the Variety Children's Hospital (part of King's College Hospital NHS Foundation Trust) and the Evelina London Children's Hospital (part of Guy's and St Thomas' NHS Foundation Trust). These are not part of the King's Health Partners Neurosciences organisational structure, but we have strong links with them, particularly when transitioning from paediatric to adult services.

We have diagnostic services fully integrated into clinical pathways, including neuroradiology, neurophysiology, neuropathology and neuropsychology. Given that many conditions we treat involve protracted recovery, or are chronic or incurable, we have a strong emphasis on restorative, rehabilitation and therapy services.

We have internationally recognised clinical centres of excellence for stroke, motor neuron disease, Parkinson's disease, neuropsychiatry and neurofibromatosis (the latter is commissioned nationally as a highly specialised service). Our paediatric epilepsy surgery service has been commissioned in partnership with Great Ormond Street Hospital for Children NHS Foundation Trust as one of four national centres, and we are a national leader in adult and paediatric functional neurosurgery. We are national leaders in delivering immune modifying therapy to patients with multiple sclerosis and in moving delivery of their care into the community.

To give context, Table 1 shows clinical activity for neurosurgery, stroke and neurology noting that the regional neurosciences centre is based at King's College Hospital.

Table 1 | King's Health Partners Neurosciences inpatient and out-patient Clinical Activity Audit for Neurosurgery, Stroke and Neurology (April 2016–March 2018)

Service	2016/17				2017/18			
	King's College Hospital NHS Foundation Trust		Guy's and St Thomas' NHS Foundation Trust		King's College Hospital NHS Foundation Trust		Guy's and St Thomas' NHS Foundation Trust	
	Inpatient admissions	Out-patient attendances	Inpatient admissions	Out-patient attendances	Inpatient admissions	Out-patient attendances	Inpatient admissions	Out-patient attendances
Neurosurgery	4,367	21,509	Service not provided		4,529	22,755	Service not provided	
Stroke Medicine	4,077	1,637	Not part of King's Health Partners Neurosciences		5,811	1,798	Not part of King's Health Partners Neurosciences	
Neurology	4,683	24,783	994	16,166	4,701	26,147	1,552	18,364

Source: Activity collected from Healthcare Evaluation Data (HED) – attended appointments used to calculate out-patient activity and Finished Consultant Episode (FCE) to calculate inpatient activity.

Our services operate from several sites across south east London (as shown in Figure 6).

Figure 4 | The main sites where King's Health Partners Neurosciences provide clinical services



Description of each of our clinical services

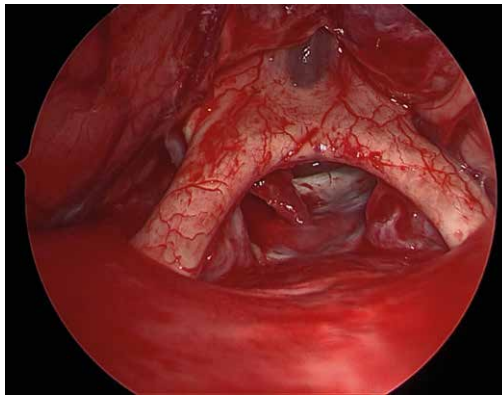
Neurology

Neurology deals with the diagnosis and treatment of all conditions and diseases involving the brain, spinal cord, peripheral nerves and muscles. We care for patients with a wide variety of symptoms, including headache, dizziness, seizures, difficulty moving, limb weakness and problems with speech and swallowing. Neurological inpatient services are provided at King's College Hospital and out-patient services at King's College Hospital, Guy's Hospital, St Thomas' Hospital and Princess Royal University Hospital.

Neurosurgery

Neurosurgery is concerned with the surgical (and non-surgical) treatment of injury to and diseases of the brain, spinal cord and nerves. Our neurosurgery services include well developed subspecialty services in brain trauma, skull base surgery, neurovascular (surgical treatment of the blood supply to the brain), neuro-oncology (brain tumours) and spinal surgery. Neurosurgical inpatient services are provided at King's College Hospital.

Figure 5 | Magnified neuroendoscopic view (1cm across) of the optic nerves and chiasm behind the orbits at the base of the brain. A tumour compressing the chiasm and threatening vision was completely removed. We have pioneered endoscopic treatment of brain tumours in adults and children.



© Mr B Zebian

Stroke

A person suffering a stroke will be immediately treated in one of our two Hyper Acute Stroke Units, either at King's College Hospital or at Princess Royal University Hospital. Subsequently, rehabilitation will take place either in dedicated Stroke Rehabilitation wards based at a range of hospitals across south east London, or in the community. We also provide out-patient services for patients who have had stroke-like symptoms, but which have improved by the time they are seen (transient ischaemic attacks).

Neurorehabilitation

We provide intensive inpatient neurorehabilitation for patients recovering from a severe neurological illness or injury requiring specialist care. Inpatient services are based at Orpington Hospital and the Pulross Centre in Brixton. Patients are cared for by multi-disciplinary teams to support the transition from hospital to home, with Guy's and St Thomas' NHS Foundation Trust providing community neurorehabilitation. We also care for patients requiring cognitive rehabilitation in the Lishman Unit, run by South London and Maudsley NHS Foundation Trust.

Neuroradiology

Our department provides specialist brain and spine imaging to the regional Neurosciences Centre at King's College Hospital, clinical psychiatric imaging at South London and Maudsley NHS Foundation Trust and reporting of specialist imaging at both Guy's and St Thomas' hospitals.

Techniques include:

- Magnetic Resonance Imaging (MRI) scanning, which uses powerful magnet and radio waves to produce cross-sectional and 3D images. We offer clinical perfusion, functional MRI, tractography and spectroscopy services.

- Computerised Tomography (CT) scanning, which uses x-rays to produce detailed cross-sectional and 3D images.
- Angiography, which uses x-ray images to look at blood vessels.
- Interventional neuroradiology, treating conditions such as brain aneurysms (a bulge in the blood vessel) and thrombectomy for some strokes.
- Evoked potentials, which includes a range of techniques to stimulate the nervous system and record the response, allowing many aspects of nervous system function to be revealed.

We provide clinical neurophysiology services from King's College Hospital, Guy's Hospital and St Thomas' Hospital.

Neurophysiology

Clinical neurophysiology uses specialised techniques to record and analyse the electrical signals that are the basis of nervous system function, including:

- Electroencephalography (EEG), which records electrical "brain waves" to detect conditions such as epilepsy and sleep disorders.
- Electromyography (EMG), which studies electrical signals from muscles, to provide information about conditions affecting muscle, peripheral nerves, spinal cord and brain.
- Nerve conduction studies, which provide information about electrical activity in peripheral nerves, supporting diagnosis of a wide range of nerve injuries and diseases (neuropathy).

Neuropathology

Neuropathology is a diagnostic service which is concerned with the precise identification and diagnosis of disease processes in tissue samples analysed in the laboratory. In the investigation of neurological and neurosurgical conditions tissue samples may be obtained during surgical operations or by various minimally invasive methods such as needle biopsies. Based at King's College Hospital, we have one of the busiest departments of its type in the country. The department provides a high quality, wide-ranging diagnostic service and carries out research into the diseases of the nervous system. We also provide clinical diagnoses for the MRC London Brain Bank for Neurodegenerative Diseases. The department has connections with many hospitals and scientific institutions across the UK and abroad.

Neuropsychology

The clinical neuropsychology service aims to improve the diagnosis and rehabilitation of people with neurological and neurosurgical conditions using psychological skills. Our neuropsychology diagnostic service plays a key role in determining the extent of neuropsychological disability in a variety of conditions, including dementia, epilepsy, multiple sclerosis, movement disorders, acquired brain injury through accident or stroke and brain tumours. The work of the neuropsychology rehabilitation service is embedded both within specialist neurorehabilitation services and also inpatient services for neurology, neurosurgery and stroke. It focuses on improving the psychological understanding and management of people with neurological conditions causing disability as well as the family and social context.

Neuropsychiatry

Our neuropsychiatry service manages the psychological complications of neurological disorders. This includes psychiatric complications of epilepsy, Tourette's syndrome, movement disorders and other neurological disorders, including: early onset dementias and other memory disorders; depersonalisation; and conversion and dissociative disorders such as non-epileptic seizures and other somatoform disorders.

Therapies

Dietitians, occupational therapists, physiotherapists and speech and language therapists work across acute care, specialist inpatient rehabilitation, out-patients and community services within the disciplines of neurorehabilitation, stroke, neurosurgery and neurology, and have key roles in rehabilitation and disability management.

Nursing

Our nurses work in a wide range of services including the acute inpatient wards at King's College Hospital, rehabilitation wards at Orpington Hospital, Bethlem Royal Hospital and the Pulross Centre, and out-patient services across King's Health Partners. We have a wide range of disease specific clinical nurse specialists.

Figure 6 | Members of the nursing team at the Pulross Centre, where we provide inpatient and community neurorehabilitation



Clinical outcomes

Overview

Historically, at a national level, there has been a limited focus on clinical outcomes reporting in relation to neurosciences. Stroke and epilepsy are the only named conditions with associated indicators in the latest NHS Outcomes Framework 2018/19 and the Clinical Commissioning Group Outcomes Indicator Set for 2018/19. There are indicators in relation to dementia, stroke and epilepsy in the National Institute for Health and Care Excellence (NICE) Quality and Outcomes Framework (QOF).

We participate in national audits and registries, use outcome measures in research studies and have also developed and validated a number of outcome measures. As a consequence of the above, our services collect, collate and review outcomes data to varying degrees of maturity.

Patient experience is shared through the Friends and Family Test, as well as national condition-specific surveys and local feedback tools. In this section we summarise high level outcomes and experience measures whereas the pathways section of this book, from page 59 to 157, includes examples of outcomes and patient experience surveys from across our portfolio.

Survival and mortality data

Using national audit data and organisation-level data analysis, all clinical services hold regular meetings to review mortality data.

Neurosurgical mortality

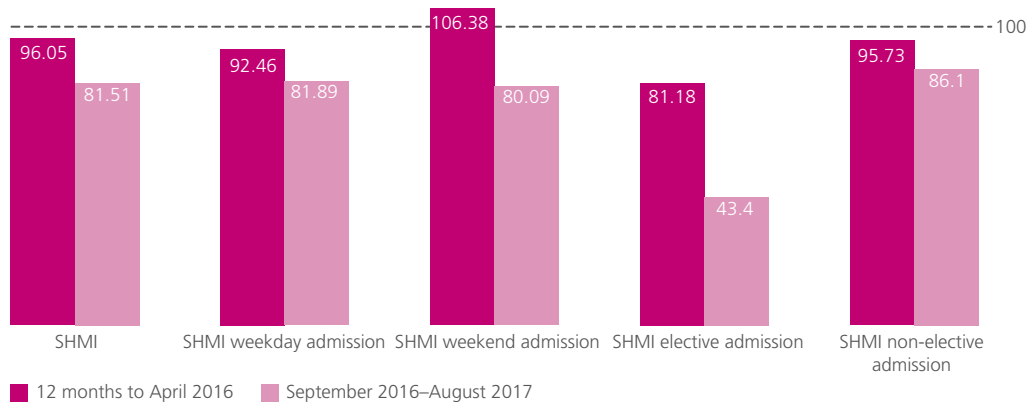
Figure 7 shows that King's College Hospital had the lowest 30-day standardised mortality rate of any neurosurgical centre at 1.63%.

Figure 7 | National comparison of 30-day standardised mortality rate for neurosurgical procedures for King's College Hospital April 2014–March 2017



Source: Society of British Neurological Surgeons, Neurosurgery National Audit Programme reports, accessed November 2018.

Figure 8 | Neurosurgery Summary Hospital-level Mortality Indicator (SHMI) – King's College Hospital



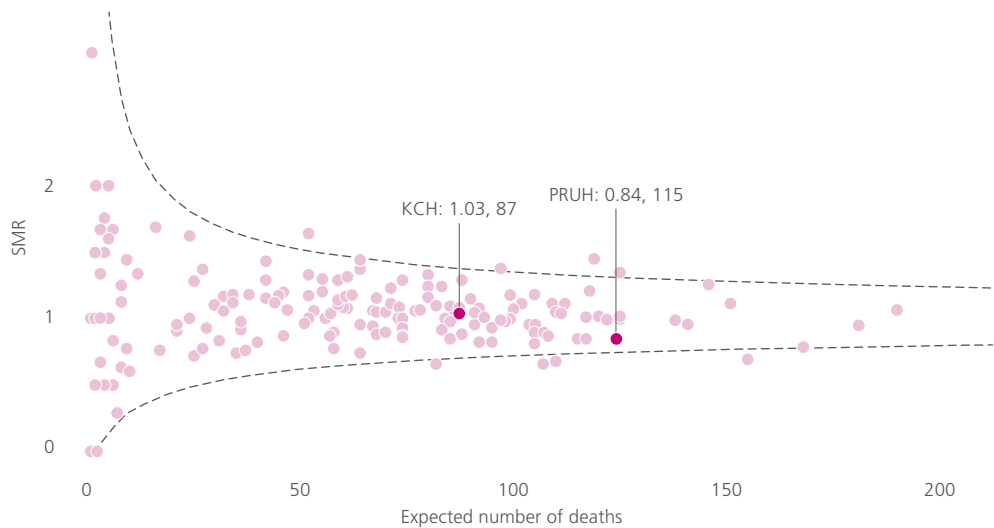
Note: Summary Hospital-level Mortality Index (SHMI) reports on mortality at trust-level. SHMI is the ratio between actual number of patients who die following hospitalisation at the trust and the number that would be expected to die on the basis of average England figures, given the characteristics of the patients treated there.

A large part of the reduction in mortality is attributed to the increasing super-specialisation in neurosurgical services at King's College Hospital. This strong performance is also reflected in the Getting It Right First Time (GIRFT) programme which recognises King's College Hospital neurosurgery as exemplary.

Stroke mortality

A national comparison from 2016–17, using the Sentinel Stroke National Audit Programme (SSNAP) data, shows that mortality lies within the main 95% confidence interval for both of our Hyper Acute Stroke Units. This means that the actual number of deaths have remained within the confidence interval for expected number of deaths based on number of admissions (Figure 9).

Figure 9 | Stroke standardised mortality ratio for King's College Hospital (KCH) and Princess Royal University Hospital (PRUH) compared nationally



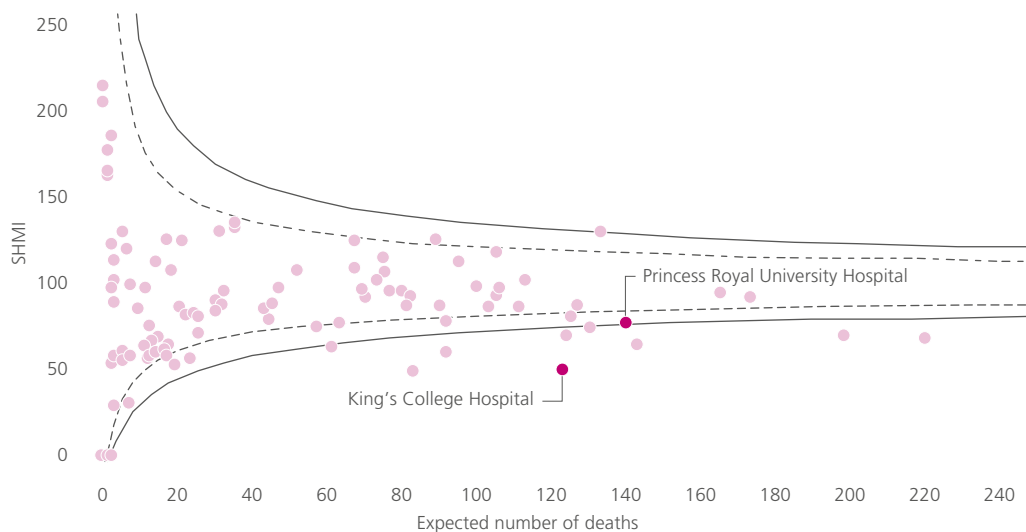
Source: Sentinel Stroke National Audit Programme, 2016–2017 Reports.

Note: An SMR score of 1 indicates that actual number of deaths is equal to expected number of deaths.

Mortality data from the more comprehensive NHS Hospital Episode Statistics (HES) which incorporates additional comorbidities (not captured in SSNAP) shows a slightly different

picture, with statistically significant lower number of expected deaths at King's College Hospital and Princess Royal University Hospital at the threshold of statistical significance (Figure 10).

Figure 10 | Hyper acute stroke Summary Hospital-level Mortality Indicator (SHMI) for King's College Hospital and Princess Royal University Hospital – Poisson Distribution compared nationally 2017–2018



Source: Hospital Episode Statistics, Healthcare Evaluation data, 2017–18.

Note: An SHMI score of 100 indicates that actual number of deaths is equal to expected number of deaths.

Patient experience

The Neurological Alliance's Survey 2016 revealed that nationally people with neurological conditions do not feel well served (Neurological Alliance, *Falling short: how has neurology patient experience changed since 2014*, March 2017). Furthermore, only 19% of patients described services to meet their mental health needs as good or excellent (Neurological Alliance, *Parity of Esteem for People affected by Neurological Conditions*, July 2017). Whilst a review of our patient experience data shows a more positive position, King's Health Partners Neurosciences must play its part in helping to raise the current poor national perceptions and challenges facing neurological services. This will involve working with partners across the whole patient pathway.

Friends and Family Test

The NHS Friends and Family Test was created to help service providers and commissioners understand whether their patients are satisfied with the service provided, or where improvements are needed. The 2017/18 results across King's Health Partners Neurosciences' main sites show that around 90% of patients were likely or extremely likely to recommend the service.

"Felt as if my mother is getting proper help from a team of people who understand her complex medical issues and who were able to provide excellent advice, care and support with a great deal of empathy and patience. Could not fault them. Only say how grateful we are for their time and help and in giving us hope as a family."

Source: Friends and Family Test 2017.

Figure 11 | Friends and Family Test results for Neurosciences services provided by King's College Hospital NHS Foundation Trust

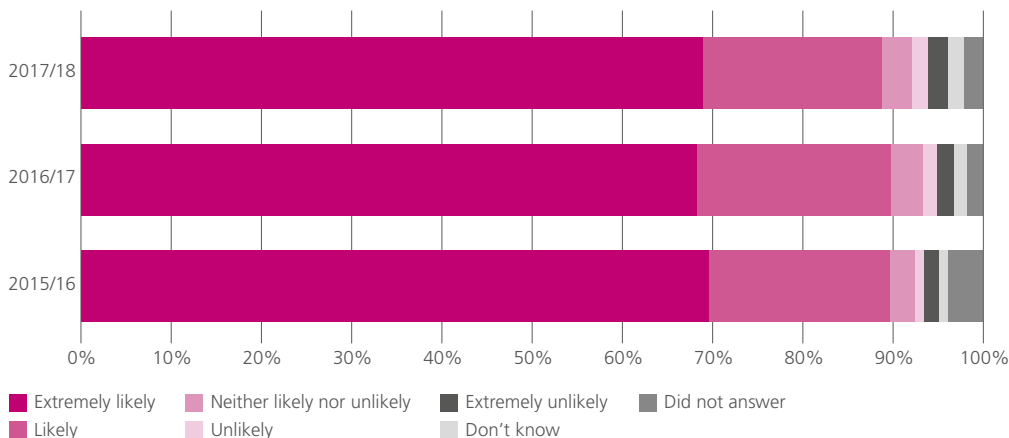


Figure 12 | Friends and Family Test results for Neurology, Neurophysiology and Neurofibromatosis services provided by Guy's and St Thomas' NHS Foundation Trust

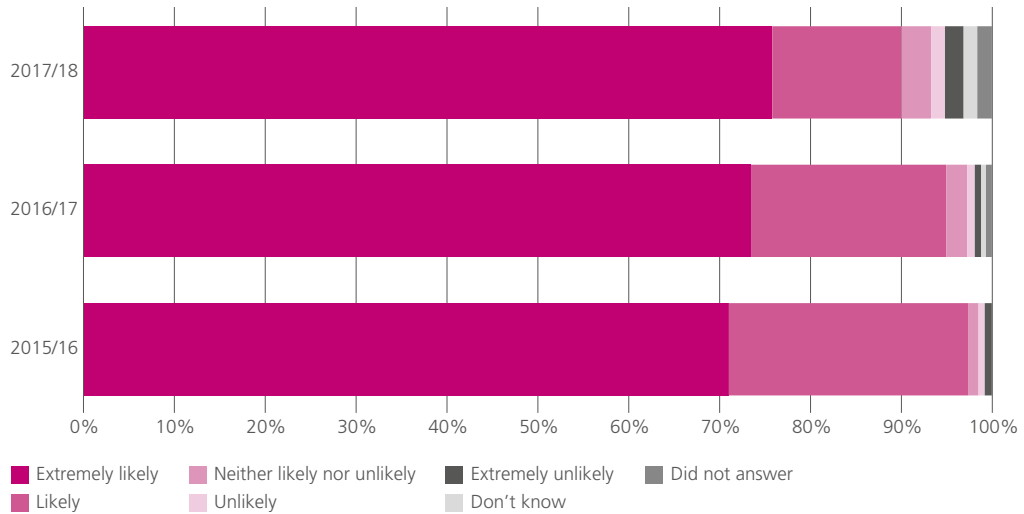
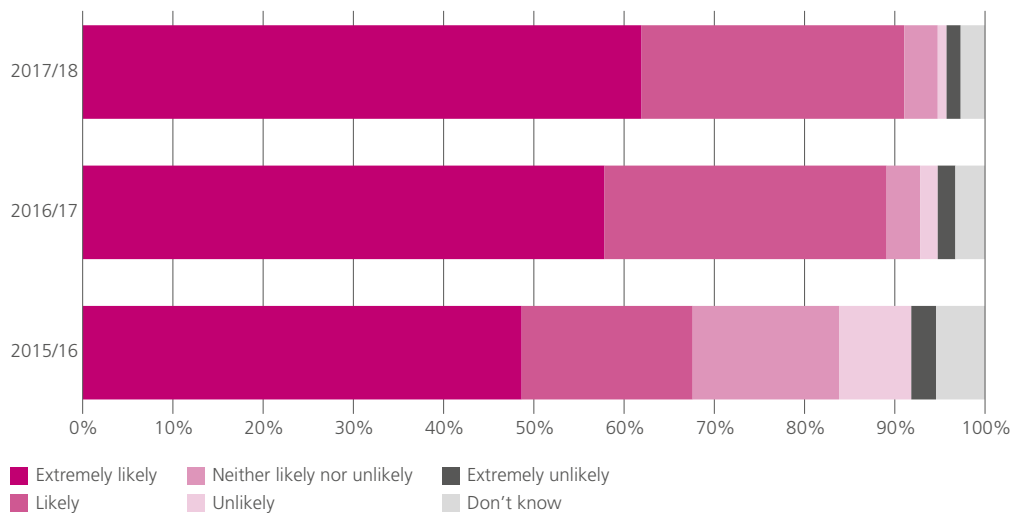


Figure 13 | Friends and Family Test results for Neuropsychiatry services provided by South London and Maudsley NHS Foundation Trust
















Monitoring patient experience – King's College Hospital Speech and Language Therapy Services

Our Speech and Language Therapy Services collect outcomes in relation to patient satisfaction at key points within a patient's management. They use a variety of feedback methods with patients and carers – all immediately after a therapy

session – in order to facilitate communication with patients who may have communication and/or cognitive impairment.

Staff select or create, depending on patient ability, an appropriate feedback sheet. Figure 16 is an example of a satisfaction measure sheet showing how alternative approaches to gathering patient feedback can be used where verbal communication may be limited.

Figure 14 | Example of a patient satisfaction sheet used by the Speech and Language Therapy Services at King's College Hospital

0	1	2	3	4
Yes a lot	Yes sometimes	Not very much	No	Last option offered
YES			NO	?/not sure/not relevant
				
				
				
				

Case study: Improving patient experience through redesign – the Rapid Access Neurology Clinic at Guy's and St Thomas' NHS Foundation Trust

Avoiding unnecessary hospital stays benefits patients and also reduces costs. A useful strategy to prevent unnecessary neurological admissions is to refer suitable patients to a Rapid Access Neurology Clinic (RANC), allowing discharge from the Accident and Emergency Department with an appointment in place to see a Neurologist within a few days. The RANC at Guy's and St Thomas' NHS Foundation Trust was set up in 2014 as a single consultant-led service providing four appointments per week. Audit data from the first two years of the RANCs operation showed that patients were seen within 14 days in 89% of cases, and that their neurological diagnosis was clarified or changed in 86%. Using the Health and Social Care Information Centre (HSCIC) and National Audit Office (NAO) data for Migraine length of stay (2.4 bed days per emergency admission), and average cost per neurology admission (£1,067) as a conservative benchmark, the (estimated) 210 admissions prevented by the RANC in its first two years has saved approximately 500 bed days and £224,000 in expenditure. Figures 15 and 16 show the impact of the Rapid Access Neurology Clinic (RANC) at Guy's and St Thomas' NHS Foundation Trust 2014–2016.

Figure 15 | Impact on presentations to Accident and Emergency Department

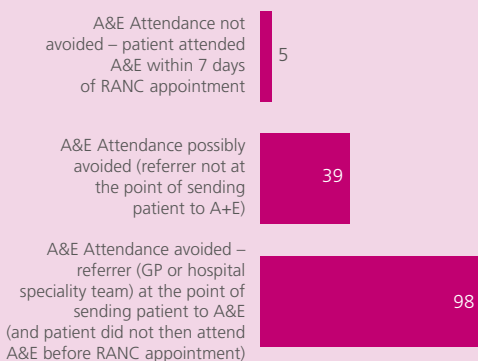
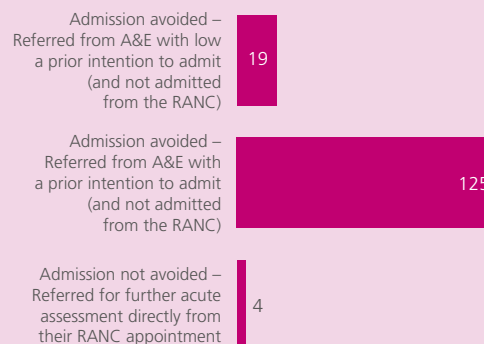


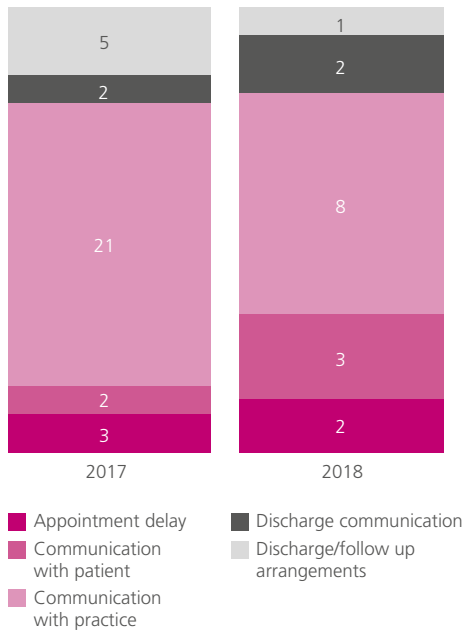
Figure 16 | Known impact on hospital admissions (excludes estimated impact)



GP Quality Alerts

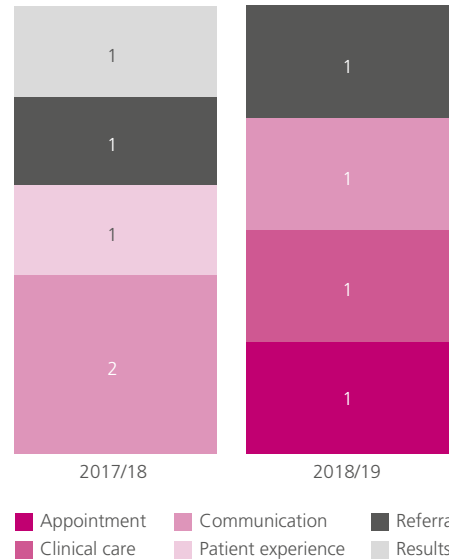
Another useful perspective is to consider the views of GPs, who are able to raise quality alerts with trusts when they have concerns. A review of GP Quality Alert data, outlined in Figures 17 and 18 below, shows that there were very few alerts regarding quality of care, and the majority of concerns related to communication.

Figure 17 | The reason for neuroscience related GP Quality Alerts for King's College Hospital NHS Foundation Trust (January 2017–December 2018)

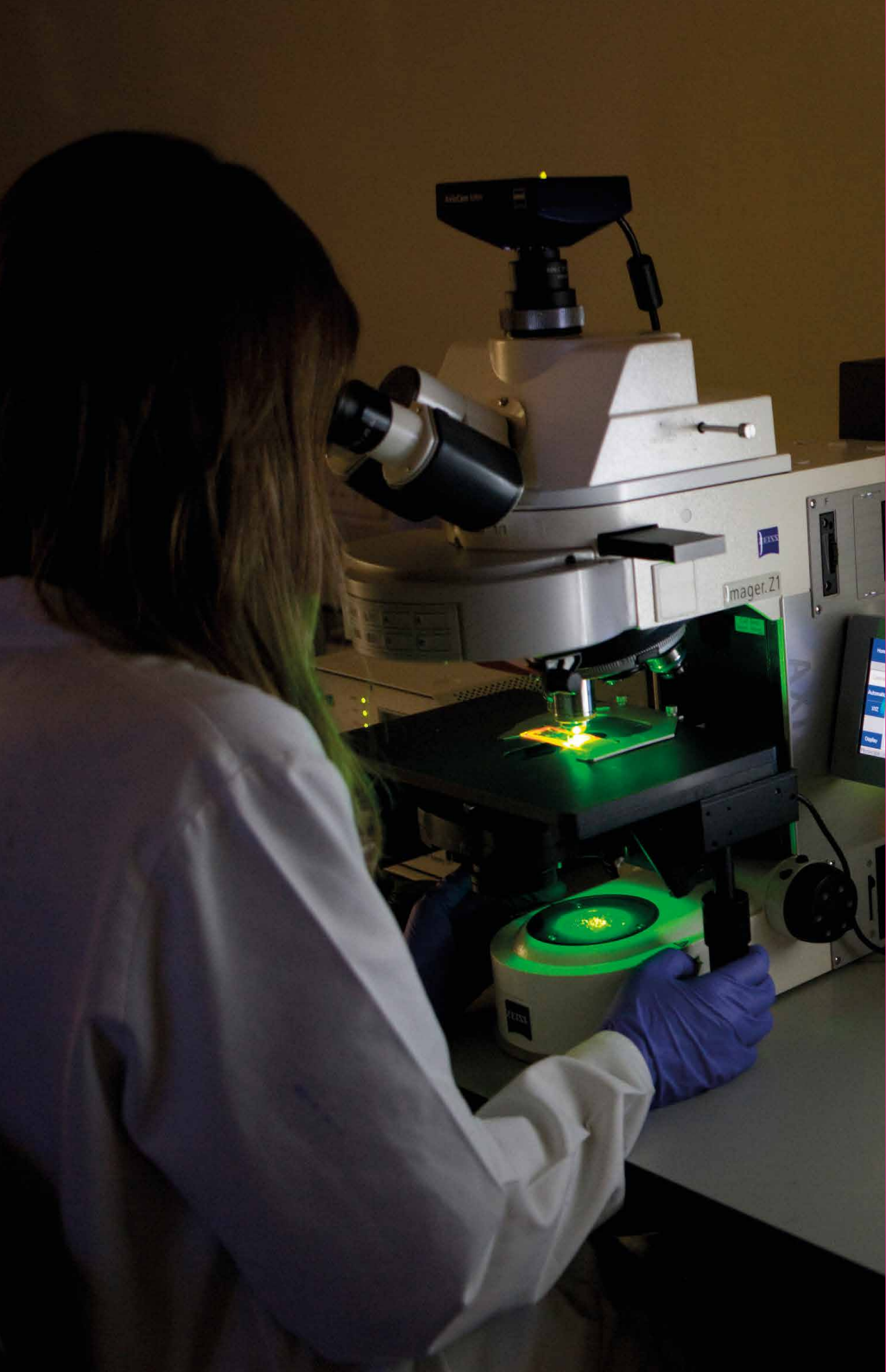


Note: Activity for 2017/18 – 15,041 inpatient admissions and 50,700 out-patient attendances.

Figure 18 | The reason for neuroscience related GP Quality Alerts for Guy's and St Thomas' NHS Foundation Trust (April 2017–February 2019)



Note: Activity for 2017/18 – 1,552 inpatient admissions and 18,364 out-patient attendances.



Research and innovation

Research and innovation

Figure 19 | Lab research at the Department of Developmental Neurobiology, King's College London



© John Wildgoose Photography

Our vision is to undertake world-leading research in neuroscience, spanning from molecules to mind, which will provide vital new knowledge and bring significant impact to people with conditions and diseases affecting the brain. We are well placed to do this with:

- 100 faculty-level research team leaders (lecturer to professor)
- State-of-the-art facilities spread across four departments (see Table 2)

- An outstanding translational research infrastructure
- Access to very large and well characterised patient populations in all areas of neurological and psychiatric disease, and access to large collections of patient samples.

Current performance

In the 2014 Research Excellence Framework (REF) – the nationwide review and benchmarking of university research performance in the UK – neuroscience was included in a larger category of psychiatry, psychology and neuroscience (known as Unit of Assessment 4, UoA4). King's College London performed exceptionally well in UoA4, achieving greater research power in this area than either Oxford or Cambridge, and higher overall quality ("grade point average") in this area than University College London (Times Higher Education, December 2014).

Using the US News rankings for the world's top universities for neurosciences, which separates neurosciences from mental health, we were ranked 16th globally in 2019 (compared to 17th in 2017) and remain fourth of the non-North American universities. The ranking is based on reputation and research in this field.

Figure 20 | The Maurice Wohl Clinical Neuroscience Institute



© Ståle Eriksen
The Maurice Wohl Clinical Neuroscience Institute, a purpose-built 6,500m² laboratory building, opened in June 2015 by the Princess Royal HRH Princess Anne has been exceptionally equipped through a £10 million grant from the UK Research Partnership Infrastructure Fund.

Table 2 | An overview of the departments within the King's College London Division of Neuroscience

Neurosciences department	Location	Primary aims
Department of Developmental Neurobiology	Guy's Campus	To decipher how neural circuits assemble during development, from neural patterning to synapse formation and plasticity, and how disruption of this process leads to disease.
Department of Basic and Clinical Neuroscience	Denmark Hill Campus	To change the therapeutic options for people affected by neurological and psychiatric disorders. Our main themes are: Neurodegeneration; Neurological Disorders; and the Cellular Basis of Behaviour. Our work makes extensive use of human samples and observations.
Wolfson Centre for Age-Related Diseases	Guy's Campus	To develop strategies aimed at restoring function to the aging or damaged nervous system. The Centre is organised into five research areas: <ul style="list-style-type: none"> ■ Neurobiology and pharmacology of pain ■ The genetics of age related hearing loss ■ Neurodegeneration and ageing ■ Neural regeneration and adult neurogenesis ■ Drug discovery unit
Department of Neuroimaging	Denmark Hill Campus	Focused on the research and development of imaging methods to improve our understanding of brain disorders. This is achieved using a battery of neuroimaging techniques which include perfusion, diffusion, functional, molecular and structural imaging. Our longer-term objective is to translate validated imaging biomarkers to the clinic in order to improve diagnosis and treatment.

Funding and research grants

The staff of the Division of Neuroscience have won more than £19 million annually in new research grants based on the strength and excellence of the group. In total the active research grants attributed to the division amount to more than £250 million (December 2018).

Table 3 | Snapshot of current funding awards attributed to the Division of Neuroscience, December 2018

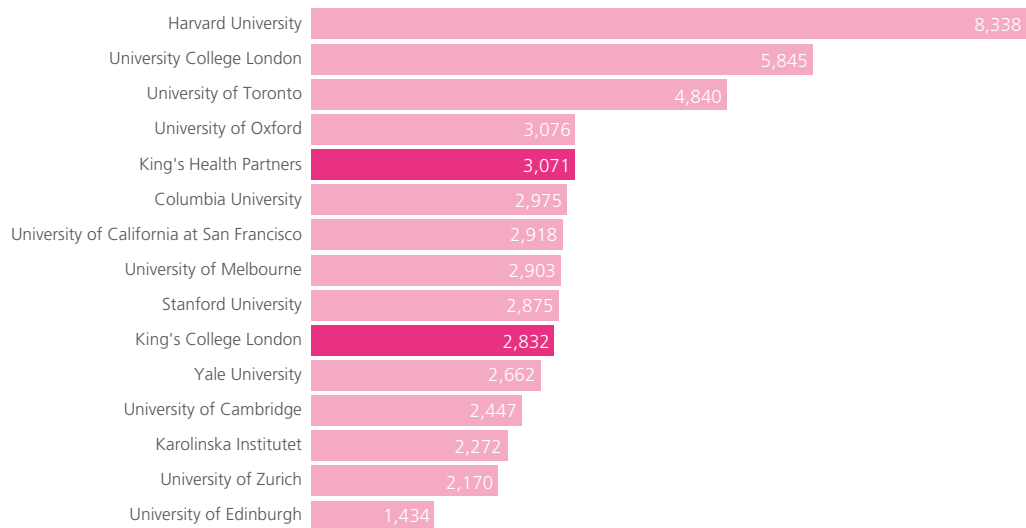
Category	Number of current awards	Total value	%
Research councils, including Royal Society and British Academy	69	£40,261,886	15.16
UK charities	120	£114,512,118	43.12
UK Government and local, health and hospital authorities, excluding NIHR	2	£16,700	0.01
NIHR	10	£26,766,957	10.08
Industry – UK	23	£8,843,286	3.33
Industry – overseas	20	£2,049,213	0.77
European Commission and EU Government	25	£70,661,855	26.61
Other sources – UK	6	£717,818	0.27
Other sources – overseas	11	£1,762,195	0.66
Total	286	£265,592,029	100

Source: King's College London Research Portal, accessed 6th December 2018.

Research quantity and quality

Our publication volume is similar to the University of Oxford and greater than the University of Cambridge (see figure 21 below). Compared to other world-leading neuroscience research centres, our science is highly influential: 21.9% of our publications are in the top 10% of the most cited worldwide, which compares very favourably with Cambridge, Harvard, Stanford, Oxford and University College London as shown in Figure 22.

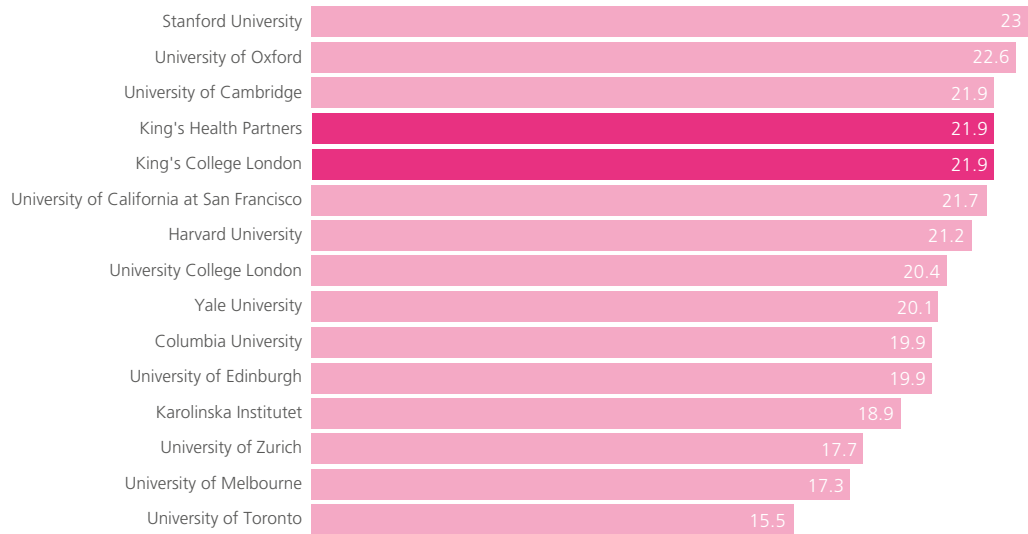
Figure 21 | Scholarly output for a selection of universities well-known for neuroscience – number of publications 2013–2017



Source: Scopus, bespoke report, September 2017.

Note: King's Health Partners includes King's College London as well as papers published by research-active clinicians whose primary affiliation is either Guy's and St Thomas', King's College Hospital or South London and Maudsley NHS Foundation Trusts. King's College London is also shown separately.

Figure 22 | Percentage outputs in the top 10 citation percentile for a range of universities well-known for neuroscience



Source: Scopus, bespoke report, September 2017.

Research impact

We collected a set of examples of the impact of our research, which were very highly rated in the Research Excellence Framework 2014. These are summarised in Table 4.

Table 4 | Examples of the impact of our research (collected for Research Excellence Framework 2014)

Theme	Summary	Reference
Stroke Units: Driving excellence in stroke care	Pioneering research that showed that patients admitted to dedicated specialist units had better outcomes than those admitted to general wards.	www.kcl.ac.uk/ioppn/about/difference/13-Driving-excellence-in-stroke-care.aspx
Stem cell therapy to repair stroke damage	Our stem cell research underpinned the UK's first ever clinical trial to treat stroke patients with manufactured neural stem cells.	www.kcl.ac.uk/ioppn/about/difference/15-Stem-cell-therapy-to-repair-stroke-damage.aspx
Treating non-motor symptoms of Parkinson's disease	Our researchers developed questionnaires that are now used by doctors to help ensure patients with Parkinson's disease get treatment for debilitating non-motor symptoms.	www.kcl.ac.uk/ioppn/about/difference/18-Treating-non-motor-symptoms-of-Parkinsons.aspx
Cognitive Behavioural Therapy (CBT) for chronic fatigue syndrome (CFS)	Our researchers developed CBT for CFS, using therapy where people were able to engage in exercise that helped to reduce and manage symptoms.	www.kcl.ac.uk/ioppn/about/difference/22-CBT-for-chronic-fatigue-syndrome.aspx
Genetic testing for motor neurone disease (MND)	Our research has led to the development of genetic tests that can reveal whether someone carries a mutated version of several MND risk genes and therefore has an increased risk of developing MND.	www.kcl.ac.uk/ioppn/about/difference/24-Genetic-testing-for-motor-neurone-disease.aspx
Drugs to prolong the lives of people with MND	Our researchers helped demonstrate that 100mg of riluzole a day, now available on the NHS, can prolong the lives of people with motor neuron disease.	www.kcl.ac.uk/ioppn/about/difference/28-Drugs-to-prolong-the-lives-of-people-with-MND.aspx

Translational research

King's Health Partners has the world's largest cohorts of well-characterised patients with common neurological and psychiatric disorders making it the ideal place to translate research findings into new therapies for patients. Our infrastructure includes:

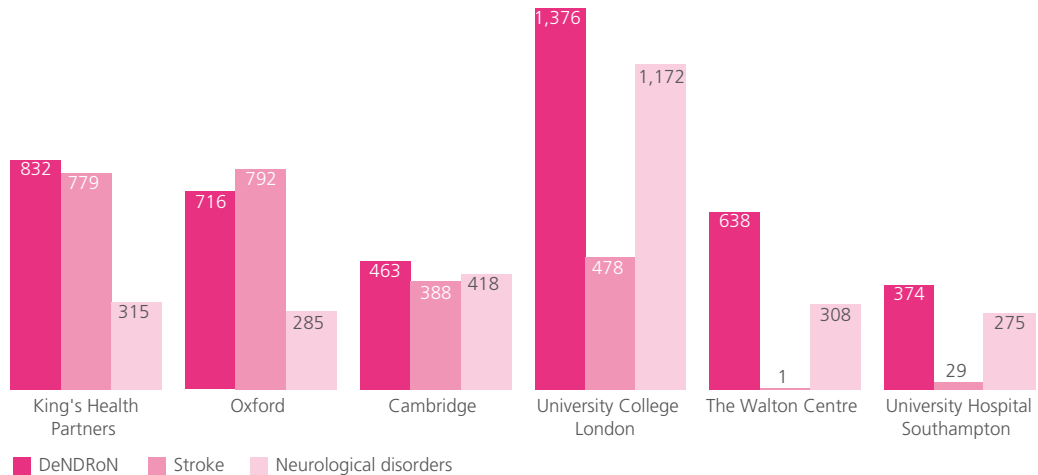
- an NIHR Biomedical Research Centre focused on mental health and neurosciences (£66 million), now incorporating the work of the previously designated NIHR Biomedical Research Unit focused on dementia.
- an NIHR-Wellcome Trust funded Clinical Research Facility on the Denmark Hill campus to support academic-led and industry-funded experimental medicine studies and drug trials. With renewed funding in 2017, this provides ideal opportunities for us to lead Phase I first-in-human drug trials for neurological disorders, completing four such trials in 2017–18.
- NIHR Bio Resource for Mental and Neurological Health, which is increasing our sample collection by more than 5,000 patients per year.

- an unrivalled collection of patient samples: blood (greater than 20,000), DNA (greater than 60,000), brains (greater than 2,000) and living cell lines (greater than 4,000).
- Patients can be enrolled into clinical trials on the basis of their biomarker or genetic profiles advancing the prospect of personalised medicine for neuropsychiatric disorders.

NIHR Clinical Research Network activity

Figures 23, 24 and 25 below show the strong contribution that our staff make across the range of neuroscience categories in recruitment to NIHR Clinical Research Network adopted research studies.

Figure 23 | A comparison of Clinical Research Network study recruitment for a selection of clinical centres known for neurosciences (1st April 2017 to 31st March 2018)



Note: DeNDRoN is the Dementias & Neurodegenerative Diseases Research Network.

Figure 24 | Participants recruited to South London Clinical Research Network studies – stroke (2013/14 to 2017/18)

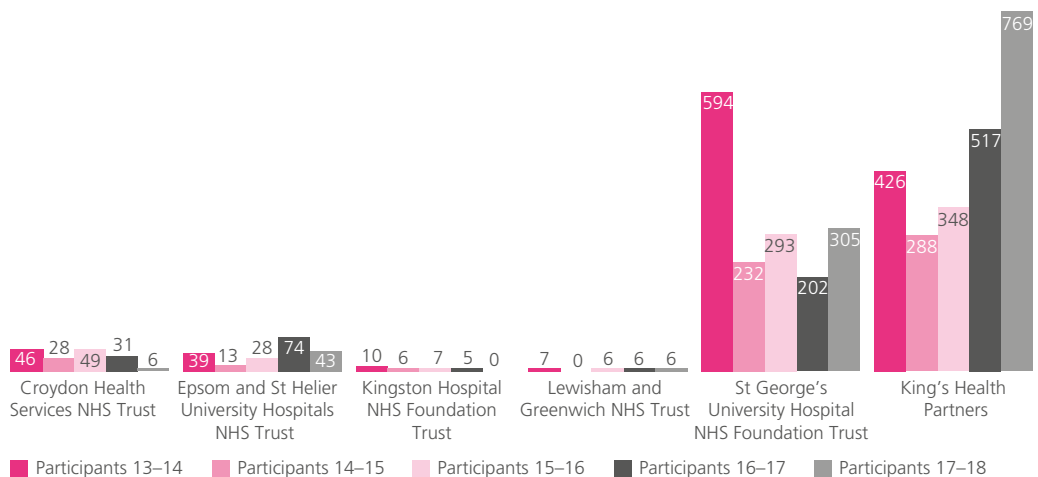
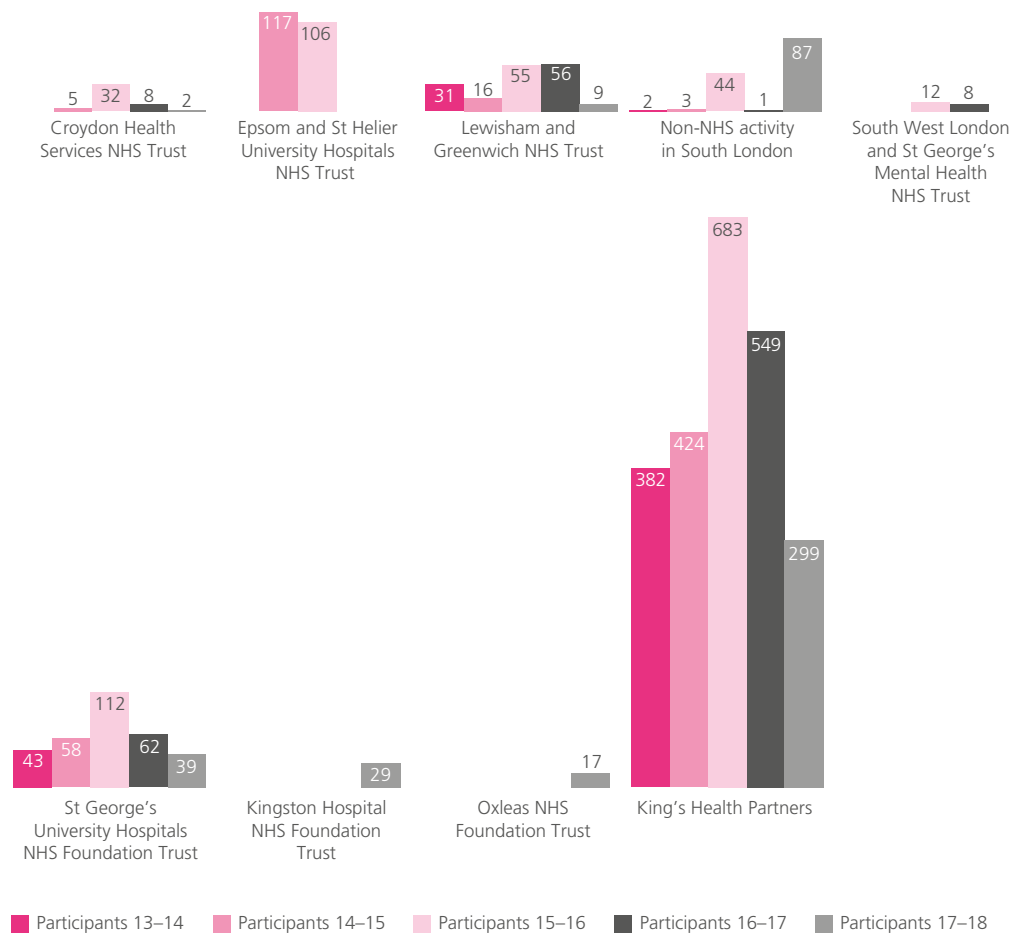


Figure 25 | Participants recruited to South London Clinical Research Network studies – neurological disorders (2013/14 to 2017/18)



Innovation

E-health

We are successful innovators in e-health. For example, supported by charity funding, an application has been developed for motor neuron disease (MND) patients, which alerts clinical professionals at King's College Hospital to the fact that a patient with MND has been admitted to an A&E department anywhere in the country. This enables proactive advice to be given by our MND team to non-expert professionals in other centres, particularly aiming to prevent inappropriate interventions or lack of intervention and to reduce premature deaths.

Further examples of e-health innovations are illustrated in the pathways section of this book (see pages 59 to 157).

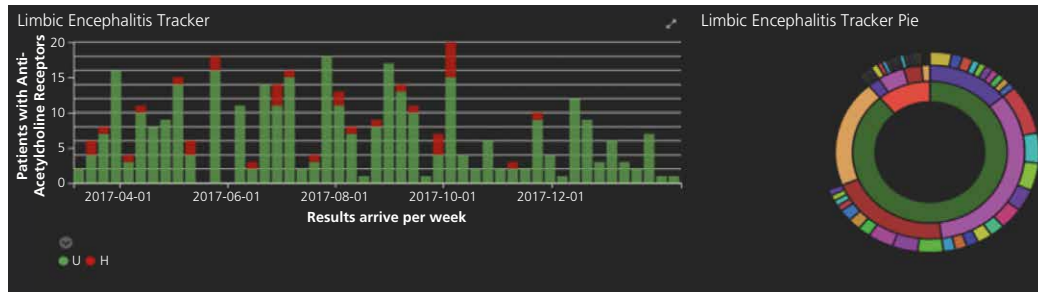
Big data – developing the use of analytical platforms for data analysis

Building on innovation led from our NIHR Biomedical Research Centre, CogStack, a clinical analytics platform, has been implemented at King's College Hospital. This will allow large scale research utilising the anonymised health records of more than three million patients.

We are using CogStack to link rich sources of patient data held in multiple information systems at King's College Hospital, to assist with real time patient management, predictive modelling, audit and research. Some examples of early use cases include: dashboards alerting systems; assistance with depth of clinical coding/improved cost recovery; supporting service improvement by providing complex baseline data and supporting audits e.g. review of anticoagulation prescription for atrial fibrillation (see the stroke pathway section on page 139).

Custom dashboards are easily set up and run in real time pulling data from the electronic patient record. An example is shown in Figure 26.

Figure 26 | A partial screenshot of a custom dashboard tracking patients with limbic encephalitis with responsible antibodies, generated by CogStack

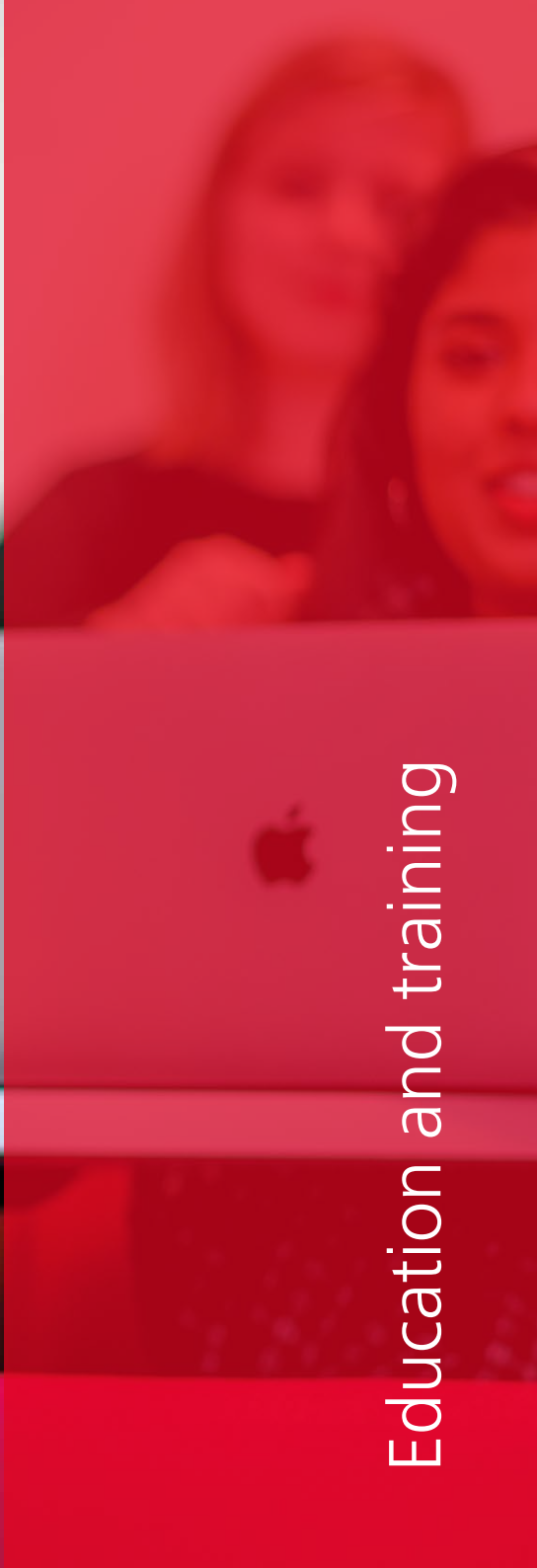


Novel drug treatments and therapies

Our neuroscientists lead on three of the most important Innovative Medicines Initiative academic-industry consortia: EUROPAIN (pain, €18M), RADAR-CNS (depression, epilepsy, multiple sclerosis, €22M) and AIMS-2-TRIALS (autism and epilepsy, €100m). We lead more commercial and academic-led drug trials in neuroscience than any other European centre and have €11m of currently-active research grants from industry. Our research has directly contributed to the identification of novel drug targets and testing of new therapies in Alzheimer's disease, Parkinson's disease, motor neuron disease and several psychiatric disorders. We are currently chief investigators in three ongoing first-in-human studies of novel drugs and compounds in neurological disorders.

New developments – UK Dementia Research Institute

The UK Dementia Research Institute (DRI) at King's College London builds on the university's world-class basic and clinical neuroscience research that drives a strong translational mission for neurodegenerative disorders. Our initial focus is on a form of dementia called Frontotemporal dementia, making use of our strongest and most promising research. We will then expand the Institute to explore the contributions of synucleinopathies and neuroinflammation to dementia, exploiting our strengths in immunology and developmental neuroscience and extending our collaborations with researchers in the MRC Centre for Neurodevelopmental Disorders and the Wolfson Centre for Age-Related Diseases.



Education and training

Education and training

Figure 27 | Research seminar at the Maurice Wohl Clinical Neuroscience Institute, King's College London



© John Wildgoose Photography

Across King's Health Partners Neurosciences we offer an extensive portfolio of training and education opportunities for students and staff. This ranges from undergraduate courses through to PhDs as well as postgraduate training, preparing people for roles in research or clinical practice.

Education in the King's College London Division of Neuroscience

We provide the following taught neurosciences courses, as well as teaching on the undergraduate Medicine (MBBS) programme:

- BSc in Neuroscience
- MSc Neuroscience
- MSc Clinical Neuroscience
- MSc Neuroimaging
- MSc Neuropsychiatry – new course launched in 2017
- MSci Neuroscience (an integrated Bachelors and Masters course)

We have continued to innovate and now run the following on-line courses:

- MSc Psychology and Neuroscience of Mental Health – launched in June 2016, and now has 450 students (March 2019).
- MSc Applied Neuroscience – launched in June 2017, and has 200 students (March 2019).

At PhD level we offer:

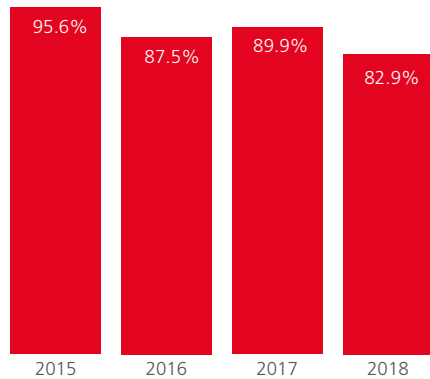
- A large range of four-year and three-year PhD training opportunities, including a one-year MRes in the MRC Centre for Neurodevelopment Disorders, which can be teamed with a three-year research project.
- Four-year PhD studentships under the Medical Research Council Doctoral Training Partnership in Biomedical Sciences.

Post-PhD level:

- We actively support the career development of promising post-doctoral researchers, inspiring them to become successful independent scientists and future research leaders. We provide mentorship, grant writing workshops, mock interview panels and schemes to establish independent careers and to apply for competitive external fellowship funding. We host numerous externally funded prestigious Fellowships, including MRC, Wellcome Trust, Royal Society and Research Councils UK Career Development Awards and Senior Fellowship Awards. Many previous Fellows have secured senior positions at King's College London and have progressed to being leaders in their field.

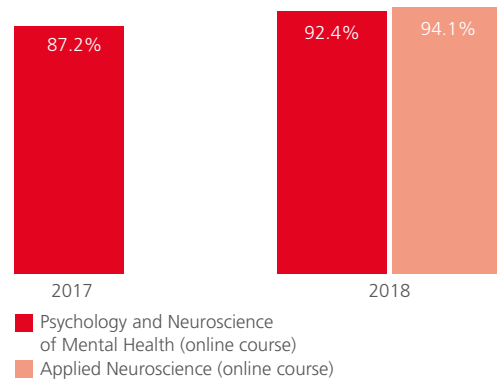
Our undergraduate and postgraduate taught and on-line courses continue to be well regarded by students, as measured by national student satisfaction surveys. Results from the National Student Survey (NSS) (undergraduate) and Postgraduate Taught Experience Survey (PTES) are shown in Figures 28, 29 and 30.

Figure 28 | Overall student satisfaction levels for BSc in Neuroscience



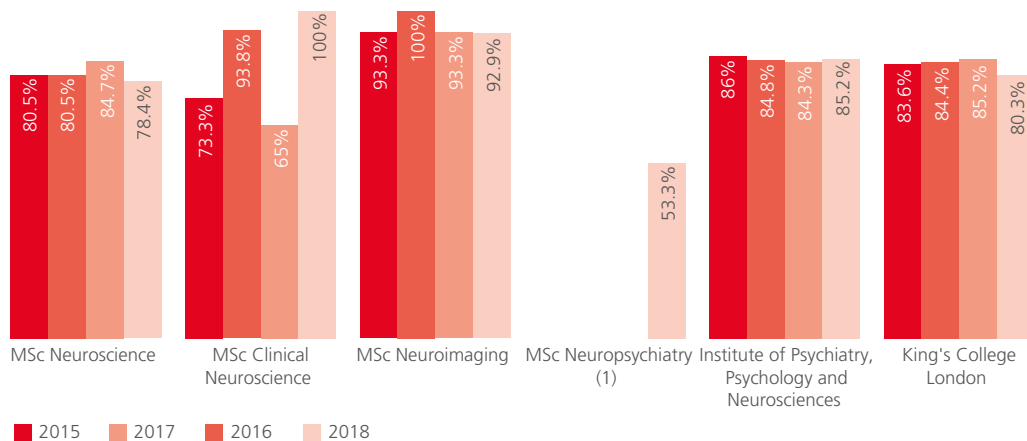
Source: King's College London Business Analytics, September 2018.

Figure 29 | Overall student satisfaction levels for on-line neuroscience courses



Source: King's College London Business Analytics, September 2018.

Figure 30 | Post-Graduate Taught Experience Survey (PTES) results for Neuroscience MScs



Source: King's College London Business Analytics, September 2018.

Note: (1) New course launched in 2017. Feedback is being used to drive improvement in satisfaction levels.

Postgraduate clinical training in neuroscience specialties

We offer a range of clinical and clinical-academic training opportunities for medical staff. We:

- are the lead providers of postgraduate education in south London for all neuroscience clinical specialties.
- provide a full run-through of posts in the clinical-academic training pathway from Foundation Year 2 (F2) to Academic Clinical Fellow (ACF) to Academic Clinical Lecturer (ACL) in neurology, with posts also in neurophysiology and neurosurgery.
- provide specialist Fellowship training posts to holders of a Certificate of Completion of Training in both neurology and neurosurgery (available in skull, neurovascular and neuro-oncology).

A number of our recent trainees have held competitive research fellowship posts, such as MRC Clinical Research Training Fellowships. Looking to the future, we are keen to develop a clinical PhD programme to complement our wide range of non-clinical PhDs.

Trainee satisfaction levels, as measured by the General Medical Council survey are set out in Table 5.

Table 5 | Trainee satisfaction levels over time

Post specialty	Trust	Indicator	2012	2013	2014	2015	2016	2017	2018
Neurology	Guy's and St Thomas' NHS Foundation Trust	Overall satisfaction %	–	91	89.6	88	92	90.2	86.6
Neurology	King's College Hospital NHS Foundation Trust	Overall satisfaction %	74.86	59.5	73.33	77.45	73.14	60.4	81.8
Neurosurgery	King's College Hospital NHS Foundation Trust	Overall satisfaction %	77.33	88.44	90.91	86	85.78	83.71	77.88

Source: General Medical Council Survey, accessed September 2018.

Neurology and neurosurgery continuing professional development (CPD) training

Our team of neurosurgeons deliver a wide range of training events/courses, which includes the following:

- Neuro endoscopy course – annual
- Neuro monitoring course – twice per year
- Red flags in neurosurgery – targeted at GPs – annual
- Paediatric neurosurgery – annual
- Spinal training days – twice per year
- Glioma training days – three times per year
- Paediatric movement disorders – annual
- In June 2019 we will host the prestigious European Low Grade Glioma meeting
- Later in 2019 we will also host the UK Skull Base meeting.

Our neurologists also offer a wide range of training events/courses, which include the following:

- Stroke Masterclass
- Neuromuscular Disease Symposium

Further examples of training provided by King's Health Partners neurologists are listed in the pathways section of this book.

Training of nurses and allied health professionals

Given the importance of the multidisciplinary team approach to care, we have a strong focus on developing our non-medical workforce and examples include:

- **Practice Education Team at King's College Hospital** – providing a progressive learning environment for all grades of nursing staff. Also, through links with the National Neuroscience Benchmarking Centre, Practice Development Nurses ensure that care is audited and delivered to the latest evidence-based practice standards.
- **Neuroscience Foundation Course for nurses** – introduced in January 2018. Over 12 months this offers nurses an exciting opportunity to rotate around King's College Hospital's Regional Neurosciences Centre, incorporating neurology, neurosurgery, acute stroke and neuro-rehabilitation.
- Hosting the first ever **King's Health Partners neurosciences nursing conference** in 2018 – with presentations and roundtable discussions by 20 speakers, this was an opportunity for nursing colleagues to come together to learn about latest practice and network together. Around 60 nurses attended, and feedback showed that 88% of participants rated the conference as excellent or very good.
- **Therapy staff** – strong focus on continuing professional development and the development of research interest and skills, including a Consultant Therapist post in Neurosciences.
- **Neuropsychology** – our neuropsychologists run a range of internal teaching sessions for staff across the multidisciplinary team. We are looking to develop this material into a series of bite size training presentations and sharing these on the King's Health Partners Learning Hub to widen access to such invaluable training. King's College London offers a highly-regarded Doctorate of Clinical Psychology training programme.

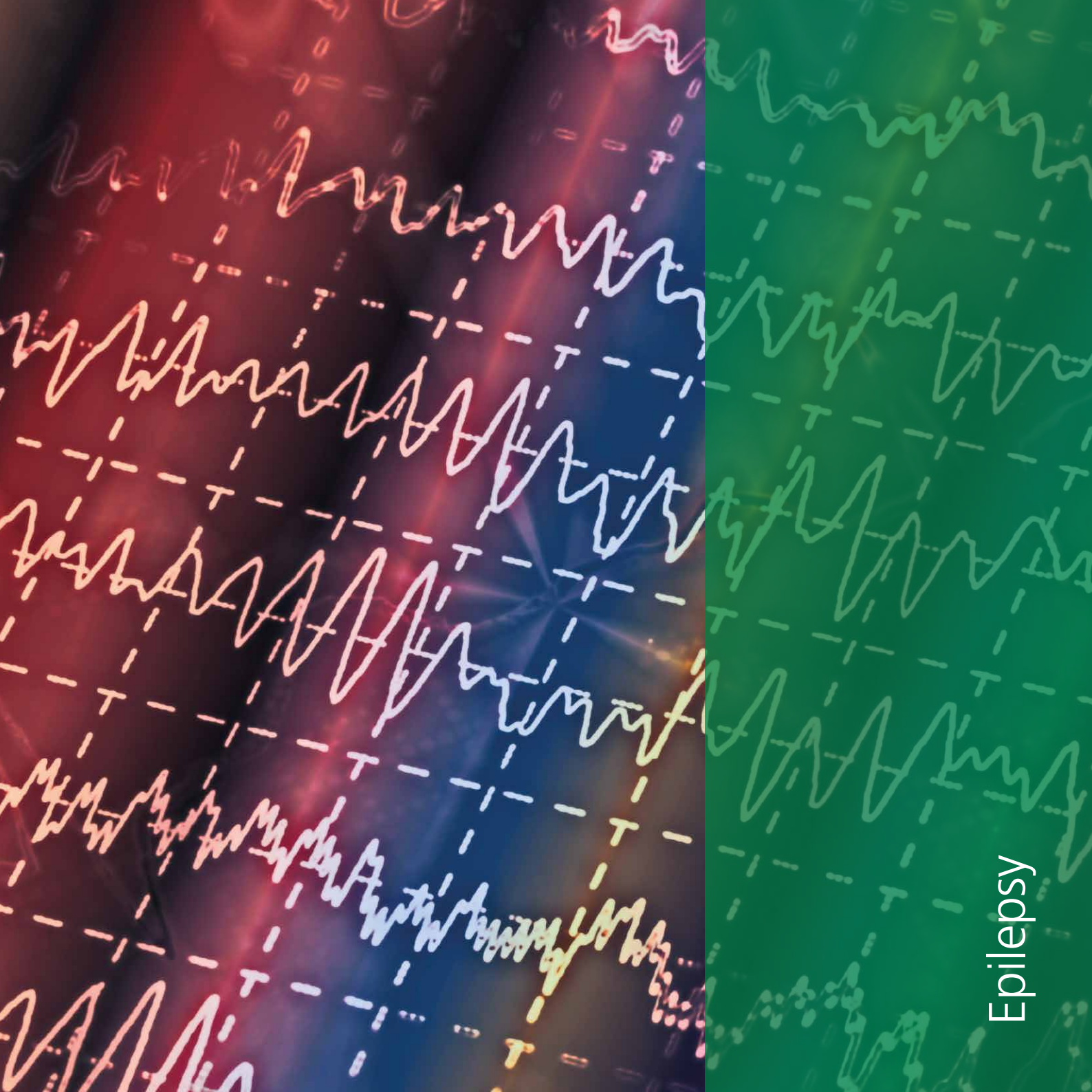


Clinical pathways in focus

Clinical pathways in focus

King's Health Partners Neurosciences plays a major role in the management of neurological and neurosurgical disorders, and in scientific research applied to the nervous system. Our aim is to drive closer integration to maximise patient outcomes.

We believe that a focus around patient pathways is the best way to achieve greatest impact. In the sections that follow, we showcase the contribution we are making to driving improved clinical outcomes and linked research through major patient pathways.



Epilepsy

Epilepsy

Introduction

Epilepsy is a common neurological condition. Approximately 30,000 new cases of epilepsy (50 per 100,000 population) are seen every year in the UK. At any one time 0.7–1.0% of the UK population or 400,000–600,000 individuals have epilepsy.

Our service

Our epilepsy services are nationally and internationally renowned. We provide care, support and information for people with epilepsy, from new onset seizures to managing complex epilepsy syndromes. Many patients with complex epilepsy are referred to us from other centres to benefit from our expertise, which includes treatment-resistant focal and primary generalised epilepsies, and sleep disorders in epilepsy.

We see people with epilepsy in our general neurology and specialist epilepsy clinics at King's College Hospital, St Thomas' Hospital and Princess Royal University Hospital. In addition, some people with epilepsy and psychological or behavioural difficulties will be seen by our

neuropsychiatry and neuropsychology experts. We liaise with other specialties and GPs to provide all-round care including investigations, diagnoses and the latest treatments, plus information and support.

Collectively, King's Health Partners offers the widest range of treatment options of any epilepsy centre in the UK. At first diagnosis we provide drug treatment where indicated, extensive information about epilepsy through our Epilepsy Specialist Nurses and Advanced Nurse Practitioners, and counselling if needed. We were an early adopter of Vagus Nerve Stimulation (VNS) treatment and have one of the largest groups of people benefitting from this treatment of any centre in the world. Epilepsy sometimes fails to respond to any drug and neurosurgical treatment is needed and effective. We carry out presurgical assessment, including invasive intracranial EEG monitoring, and many epilepsy surgical procedures for patients whose medication is unsuccessful and who still have frequent seizures. We are a centre in the UK for intracranial EEG, using the latest robotic technology.

Our team consists of neurologists, neurophysiologists, neurosurgeons, epilepsy nurses, EEG technicians, epilepsy counsellors, neuropsychologists and neuropathologists. Our teams at Guy's and St Thomas' and King's College Hospital NHS Foundation Trusts work closely with paediatric epilepsy specialists, including transition clinics. We also work with specialist midwives and consultant obstetricians for the management of complex epilepsy in pregnancy. We collaborate with cardiac physiology to assess undiagnosed blackouts, and with neuropsychiatry to evaluate and

manage dissociative seizures resulting from psychological causes. Other areas of specialist interest include learning disabilities.

Patient experience and outcomes

The following case studies show how we strive to improve patient experience by redesigning our services and ensuring we meet the holistic needs of our patients.

Case study: Taking a holistic approach to patient care – epilepsy counselling

A patient with a history of epilepsy first diagnosed in childhood was referred for specialist epilepsy counselling. Married with two young children, the patient had a history of poor anger management dating back to childhood which he attributed to his epilepsy. Several years previously he had also made a serious suicide attempt. He reported that his main and most immediate stressors resulted from his work situation where he found his manager dismissive when he approached her to discuss his seizure management. At the time of first attending counselling, his relationships at work had deteriorated culminating in a period of sickness and suspension when his seizures had increased. The patient was initially reluctant to engage in counselling; however eventually he was able to explore several issues including his anger, its origins, past consequences and the fear of losing his temper around his children. He also explored the impact of his work situation on home life and family concerns about the impact of his seizures on his children. At the end of the course of counselling sessions the patient was assessed, using a range of screening tools, the result of which showed a positive outcome with a reduction in the patient's levels of anxiety and depression.

Case study: Redesigning epilepsy clinics at Guy's and St Thomas' NHS Foundation Trust

In 2016, Guy's and St Thomas' NHS Foundation Trust carried out an audit of its first seizure clinic to review performance against standards one and two of The National Institute for Health and Care Excellence (NICE) Guidelines for Epilepsy (2013). The audit revealed areas for improvement from the booking process through to follow-up arrangements. The aim of the redesigned service is to ensure all patients with a suspected seizure receive appropriate safety advice and support within seven days of admission to A&E or attending their GP, through a dedicated first seizure telephone clinic. A member of our team takes a detailed history and witness account. All patients are discussed with a consultant colleague and appropriate tests such as MRI and EEG will be arranged prior to consultant review. We aim to ensure all patients are seen by a consultant neurologist within two weeks as per NICE guidance.

We also developed open review – a process allowing patients who are clinically stable to be discharged to their GP with a quick route back into the epilepsy specialist service if required during the next two years (without the need for a full referral). The process is simple: prior to the patient's follow-up appointment the epilepsy consultant and Advanced Nurse Practitioner decide whether the patient is suitable to be discharged under open review. During the face-to-face consultation this is explained and agreed with the patient, who receives a leaflet with all the necessary information that allows them to monitor the progress of their condition and how to contact the department should any of their symptoms change. A routine clinic letter that explains the above management plan is sent to the patient and their GP. If the patient contacts the department to discuss the change of their symptoms an experienced Advanced Nurse Practitioner will contact the patient to discuss the change in their condition and if appropriate arrange a further appointment with the service.

This has been very successful in allowing patients to self-manage their long-term condition without the need to visit the hospital in order to maintain contact with their consultant. Since this process was introduced in November 2017, the service has discharged 63 patients of whom only two have since contacted the service to request further review.

Case study: Innovation in practice

Making a diagnosis of epilepsy can sometimes be difficult and require prolonged video-EEG monitoring. It is expensive to do this in hospital and taking the person out of their usual environment may alter the pattern of attacks. We have piloted, assessed and implemented a new approach, which is to undertake video-EEG telemetry in the patient's home, which we call King's@Home. This innovation won an NHS Innovations Challenge Prize in 2013. Currently, we have undertaken more than 1,000 video-EEG assessments at home and have extended the service to include polysomnography (the study of sleep and its disorders) in the patient's home. We have continued to innovate and now data can be transferred securely via a cloud service, avoiding the need for EEG technicians to visit patients' homes to collect such data. Our service at Guy's and St Thomas' NHS Foundation Trust also uses home video telemetry.

Figure 31 | Certificate award – NHS Innovations Challenge Prize 2013



National Audit of Seizure Management in Hospitals (NASH Audit)

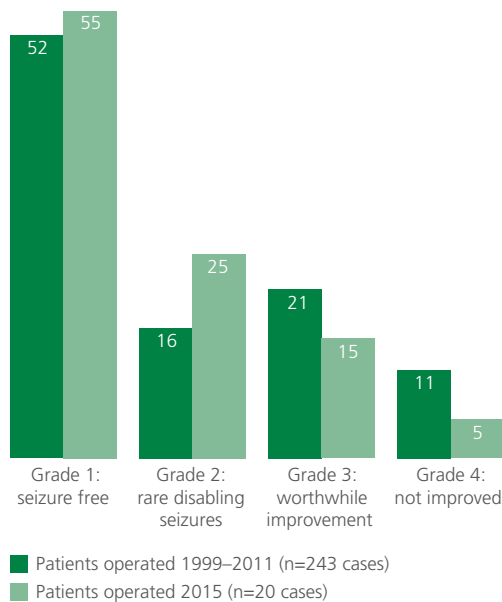
The NASH audit included A&E departments throughout the country, in our case A&Es at King's College Hospital, Princess Royal University Hospital and St Thomas' Hospital. Data were collected in 2011 and again in 2013 to describe and understand the organisation of care available for people presenting to emergency departments with seizures, with the aim of improving pathways. The audit included 30 consecutive people attending each A&E department. Of the 39 measures evaluated in 2013, King's College Hospital met or exceeded the expected standard in 32; Princess Royal University Hospital met or exceeded the standard in 29. The audit results were used to drive improvements.

Epilepsy surgery outcomes

For patients whose seizures are severe and cannot be controlled by epilepsy medications, epilepsy surgery is an option. Pre-operative investigations seek to identify the region of the brain that generates seizures; if safe and feasible, surgery may then be carried out to remove this region of brain. The intention is to cure seizures completely, although in some cases seizures are only partially improved, and in a few there is no improvement. We have reviewed and published

the outcomes of 243 patients operated on between 1999 and 2011.¹ We use these data as a reference for more recent outcomes.

Figure 32 | Epilepsy surgery (Engel Score) outcomes – (adult and paediatric) assessed at least one year later



Data show that at least 50% of patients are seizure free post-surgery. Although the number of cases is small, the data suggest an improvement in outcomes in the more recent cohort.

¹ Preoperative estimation of seizure control after resective surgery for the treatment of epilepsy. *Seizure*, 2013. Kumar A., Valentin A., Humayon D., Longbottom A.L., Jimenez-Jimenez D., Mullatti N.

Research and innovation

Our research portfolio includes a number of clinical trials which we lead, including:

- a trial of self-management education funded by NIHR: *Self-management education for adults with poorly controlled epilepsy (SMILE)*
- a trial of cognitive behavioural therapy for dissociative convulsions funded by NIHR: *Cognitive behavioural therapy versus standardised medical care for adults with Dissociative non-Epileptic Seizures (CODES)*
- trials of thalamic stimulation and direct cortical stimulation for drug-resistant severe epilepsy
- a trial of monitoring devices for epilepsy funded by the EU Innovative Medicines. This aims to investigate whether wearable sensor technology in smartwatches and smartphones can be used to monitor and detect important clinical events in people with epilepsy.

A large programme of research work comprises a team of researchers from several different disciplines, including neurology, psychology, engineering and physics. We study the brain as an entire functioning system, rather than studying small components of the brain. Most of our work involves the direct study of people with epilepsy, their relatives, and people unaffected by epilepsy. Current work, funded by an MRC programme grant, aims to understand the brain networks underlying epilepsy, how these network abnormalities affect cognition, and whether interventions targeting specific components of the network can improve epilepsy.

The Childhood Epilepsy group is comprised of clinical and basic science researchers from a variety of disciplines dedicated to finding the causes of childhood epilepsies. Research in the Childhood Epilepsy Group is aimed at both the basic level of cause and mechanism as well as the clinical level of symptom management. A variety of methods are used, including genetics and neuroimaging, neuropsychological assessment and clinical investigation. We have made some fundamental discoveries of new genetic mutations causing epilepsy as well as experimental work to understand their mechanisms. We have also identified that some non-seizure aspects of epilepsy syndromes (such as cognitive and behavioural problems) are inherited and have specific genetic causes. We are currently leading an NIHR programme grant to develop and implement a new approach to ameliorating the reading and language difficulties associated with a common childhood epilepsy, rolandic epilepsy.

A very exciting new development is the award to King's College London by the MRC of a Centre for Neurodevelopmental Disorders. This Centre will specifically study autism, schizophrenia and epilepsy, and will bring together basic laboratory scientists studying how the brain develops with clinicians studying these diseases.

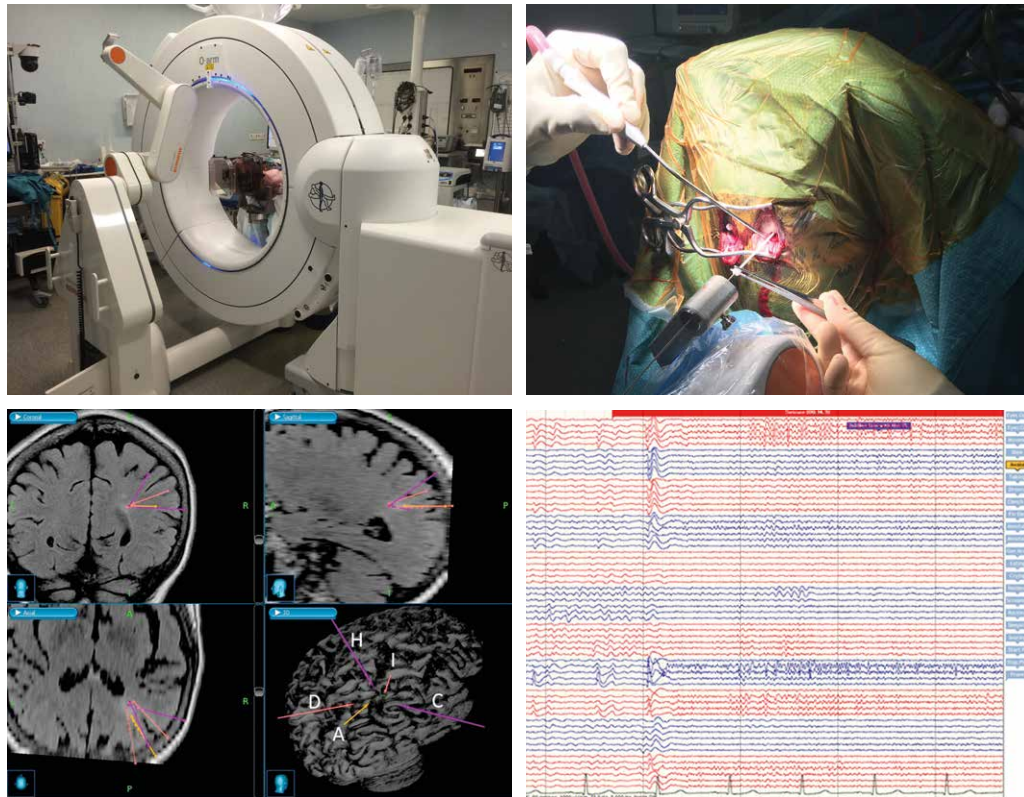
Involving patients in research

As part of our Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy (CASTLE study), our teams are working in partnership with children and young people, as well as parents and carers, through Advisory Panels. These panels help the researchers by using their experience to directly inform how the research should be designed, carried out and shared with others.

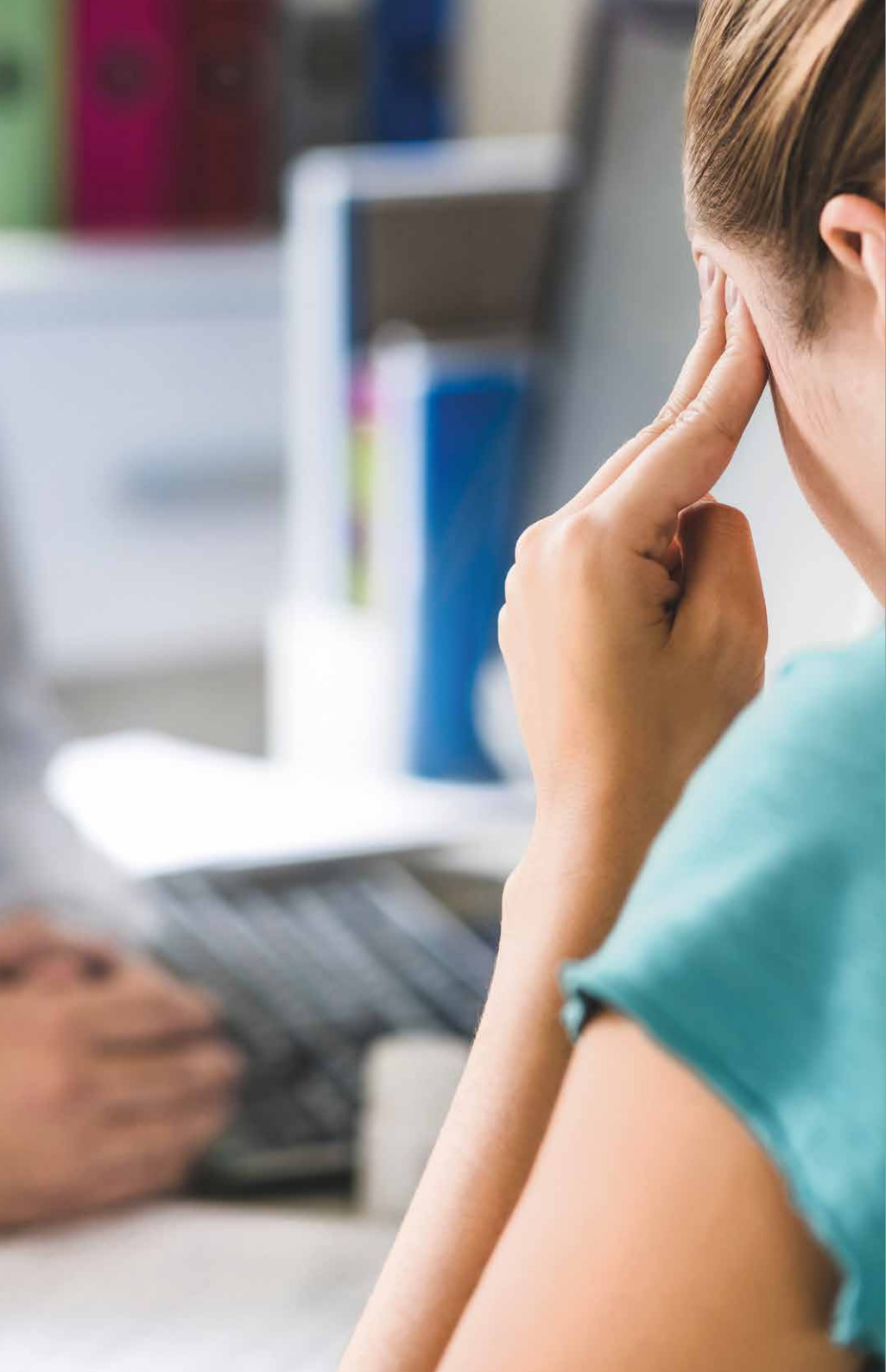
"Working with the researchers can be a bit frightening at first as they sometimes talked in ways that I don't understand, however, being on the panel is not only helpful but rewarding. You may mention something that helps another family – that's a great feeling. Then someone else says something and you think, I never knew that! So while you are helping others you are always learning at the same time."

Debbie, whose daughter has rolandic epilepsy and is involved in the CASTLE study.

Figure 33 | Robot guided insertion of multiple very closely packed depth electrodes into the brain of a patient with intractable seizures to localise and map the seizure focus. The patient was cured of epilepsy after resection of the focus identified.



© Mr R Selway



Headache

Headache

Introduction

Headache disorders are a group of extremely common, severe and disabling disorders such as migraine, tension-type headache (TTH), cluster headache (CH), and other trigeminal autonomic cephalalgias (TACS). Headache disorders are the most common neurological disorders. Migraine alone affects over a billion sufferers globally and is the neurological disorder with the most years of life lost to disability. There are estimated to be around eight million migraine sufferers in England.

Our service

Across King's Health Partners we provide a complete portfolio of services to meet the needs of people with headache from general neurology to specialist headache services. Our specialised headache teams comprise consultants, clinical research fellows, GPs with a special interest in headache and specialist nurses. Our teams provide a range of treatment options including acute and preventive medication (such as the administration of monoclonal antibodies, onabotulinumtoxin A and therapeutic nerve

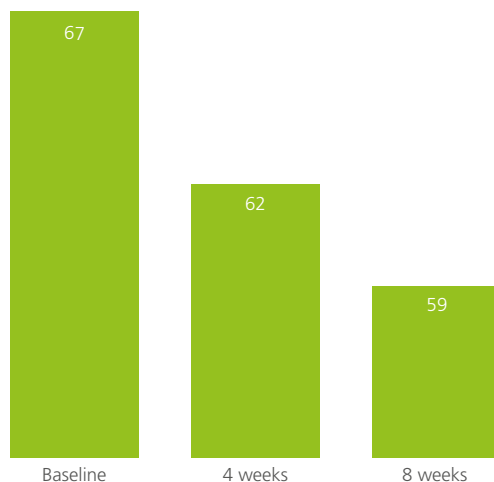
blocks). Non-pharmacological approaches include neuromodulation techniques such as transcranial magnetic stimulation (TMS), noninvasive vagal nerve stimulation (VNS) and sphenopalatine ganglion (SPG) stimulation.

Patient experience and outcomes

As part of individual patient management in our specialist clinics at King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts, scales such as Headache Impact Test (HIT-6), Migraine Disability Assessment (MIDAS) and Hospital Anxiety and Depression Scale (HADS), along with patient diaries, are used to measure changes in headache and migraine severity, frequency and impact on quality of life. Results from these tools help clinicians assess the most appropriate treatment for patients and track changes over time. HIT-6 is a validated tool used to assess headache-related disability in migraine patients.

In order to review the impact of a new treatment for chronic migraine we looked at the HIT-6 scores for patients attending our most recent clinic, the calcitonin gene-related peptide (erenumab) clinic at Guy's Hospital. The mean HIT-6 score dropped by eight points after two months of treatment compared with baseline reflecting a significant improvement from the patient's perspective, as shown in Figure 34.

Figure 34 | Changes in Headache Impact Test (HIT-6) scores after administration of Erenumab at Guy's Hospital



Innovation – community-led service for Bromley Patients

A recent innovation has been the change in service at the Princess Royal University Hospital from a hospital-based service to a community-led service. The purpose of this pilot service is to offer a more appropriate alternative to hospital care for patients suffering from headaches within Bromley. It aims to reduce unnecessary out-patient appointments and improve capacity within hospital neurology services, enabling the specialist team to focus on more urgent or complex cases. New evidence based guidelines for GPs, which were developed with input from neurologists at King's Health Partners, are underpinning a borough-wide GP training and education programme around headache management. The service will aim to improve service quality and patient experience for individuals with a range of headache types, including: migraine, episodic tension type headache, cluster headaches, medication overuse headache.

Research and innovation

Case study: Bench to bedside innovation

Amongst many advances made in this area is the discovery of a specific mechanism underlying the pain experienced by migraine sufferers, and the development and successful trialling of an entirely novel treatment based on this mechanism. Starting more than 30 years ago, an internationally leading team, now based at King's College London reported that specific small molecules were a key component of migraine mechanisms. Over the next decade, they demonstrated that these peptides could be detected in human migraine sufferers during their attacks. Laboratory experiments demonstrated that interfering with the action of calcitonin gene-related peptide (CGRP) could ameliorate neuronal activity in trigeminal pain pathways that are essential in the pathophysiology of migraine suggesting clinical efficacy. These findings were then confirmed in several clinical trials including recent Phase 3 trials that proved the efficacy of monoclonal antibodies against CGRP or its receptor in the preventive treatment of episodic and chronic migraine. The recent work completes a journey from bench through experimental medicine, proof-of-principle and phase II.

Several monoclonal antibodies have now been approved by the European Medicines Agency (EMA) and the Food and Drug Administration (FDA) and the CGRP receptor antibody erenumab is now available at King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts.

The King's Health Partners headache research programme extends from animal models to experimental medicine and clinical trials. An overview is set out below.

Preclinical research

The underlying pathophysiology of primary headache disorders is complex and not completely understood. We specialise in the development and use of preclinical models of primary headaches to explore the underlying

neural mechanisms which predispose individuals to attacks. Our translational approaches include a wide range of techniques including electrophysiological, brain imaging, behavioural and molecular approaches. Our primary focus aims to advance our understanding of the pathophysiology and pharmacology of headache disorders to gain an increased understanding of disease mechanisms, comorbidities and novel translational therapeutic approaches.

Clinical research

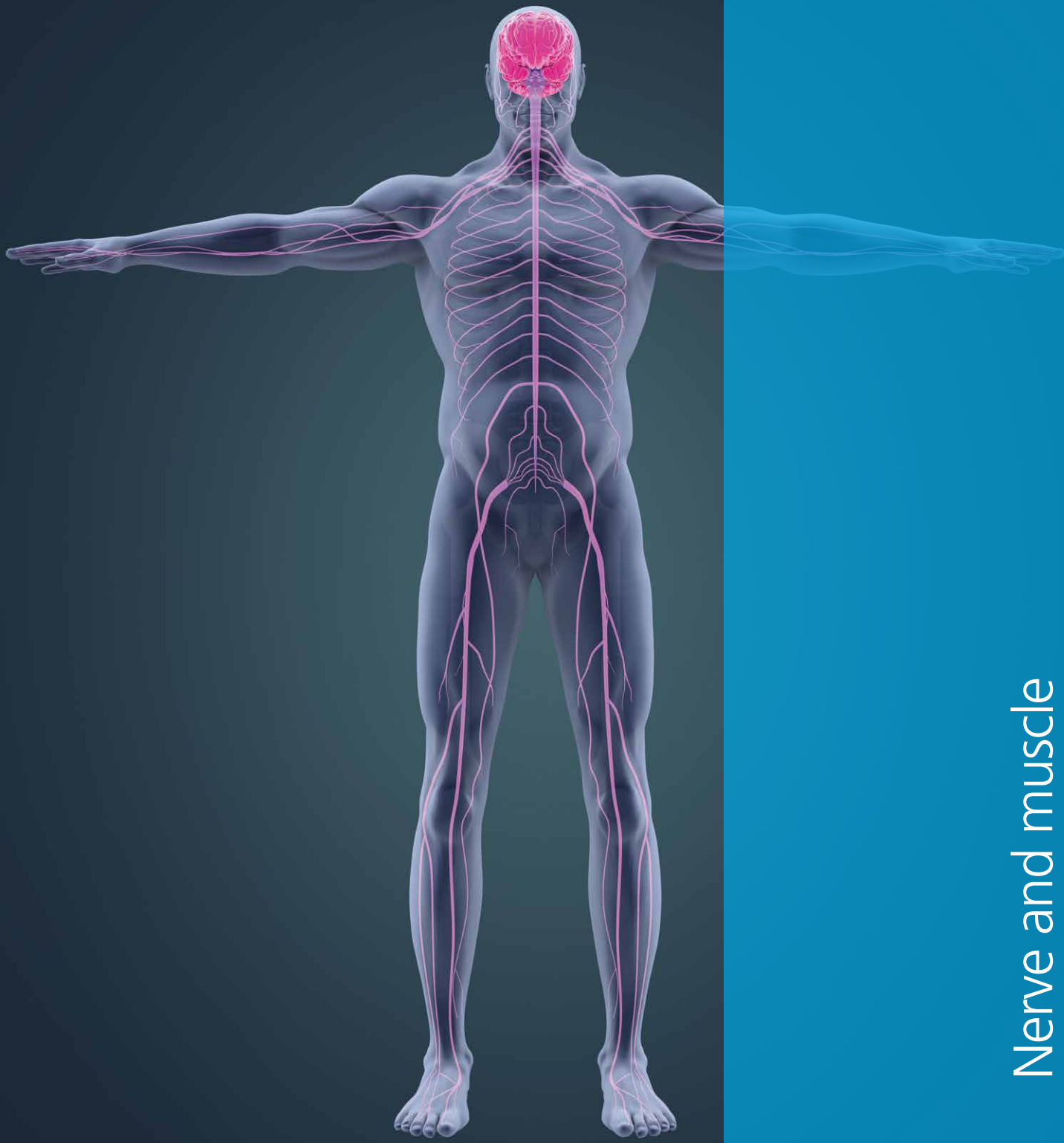
Primary headache disorders are common and often have a significant inherited component. We specialise in the diagnosis, treatment and understanding of primary headache, with a special interest in migraine and cluster headache. Our research focuses on the mechanisms and management of head pain, with the intention of developing an increased understanding of the brain regions involved in headache and the development of novel treatment strategies.

We also lead the *Transforming outcomes and health economics through imaging* (TOHETI) Headache study: This is a prospective observational study of the management of chronic headache patients comparing direct access to MRI for GPs with the existing pathway of management in the neurology service. The results are currently being analysed and should provide us with information to enable us to update our current headache pathway.

We are also interested in the functional and clinical links between primary headache disorders, such as migraine, cluster headache and hypnic headache, with sleep and circadian physiology and primary sleep disorders. This includes study of unusual migraine phenotypes such as migraine with brainstem aura causing hypersomnolence, as well as common co-occurrences such as headache in sleep apnoea, chronic migraine, restless legs syndrome and circadian rhythm sleep-wake disorders.

Applied health services research

Our portfolio of research in headache disorders has also included a focus on applied health services research. Our research on the use of GPs with Special Interest (GPwSI) found that patients seen by the GP with Special Interest Service were more satisfied than patients who saw hospital-based general neurologists, and cost to the commissioners was less for the GP with Special Interest service than for hospital care. The Royal College of Physicians and Association of British Neurologists have used this evidence in a report (2011) to recommend this as a service model for implementation more widely.



Nerve and muscle

Nerve and muscle

Introduction

Neuromuscular disorders affect the peripheral nerves (neuropathy), muscles (myopathy) and neuromuscular junctions (myasthenia). It is estimated that there are about 10,000 people with myasthenia in England (Neurological Alliance, 2019).

Our service

The peripheral nerve and muscle services at King's College Hospital are the leading clinical services for the region of south London, Kent and Sussex. The service offers a full out-patient and inpatient diagnostic and treatment service across a wide range of neuromuscular disorders.

The regional specialist peripheral nerve service at King's College Hospital is recognised as a Centre of Excellence by the Guillain Barre/Chronic Inflammatory Demyelinating Polyneuropathy (GBS/CIDP) Foundation International and is the largest UK centre for skin biopsy for small fibre neuropathy.

Peripheral nerve diseases

We run several innovative and notable specialist clinical services. Painful small fibre neuropathy is a distressing condition which can be difficult to diagnose. King's College Hospital has the most comprehensive clinical diagnostic service for painful small fibre neuropathy in the UK – the only department to offer microneurography and the only NHS service offering nerve fibre density by skin biopsy, respectively for functional and structural assessment of small fibres. More than 500 skin biopsies have been reported, including referrals from at least 12 centres around the UK.

Inflammatory neuropathy covers a range of disorders including some that cause devastating paralysis. King's College Hospital is recognised as a Centre of Excellence by the GBS/CIDP Foundation International, one of only three such centres in the UK. We were one of the first UK neurology services to offer subcutaneous immunoglobulin treatment at home as an alternative to in-hospital intravenous immunoglobulin (IVIG).

Within our team we have a national leader in peripheral nerve ultrasound of mononeuropathies. We also carry out large fibre nerve excitability studies in toxic/metabolic neuropathies and channelopathies. We provide an electromyography (EMG) outreach service to district hospitals.

Research

We have several internationally leading basic science groups investigating topics relating to peripheral neuropathy, based at the Wolfson Centre for Age-Related Diseases. Major research interests include neuropathic pain, injury and repair of peripheral nerves, sensory receptors, ion channels and signalling, and pharmaceutical blockers of mechanisms important in neuropathic pain.

We have an active clinical research programme. One of our leading experts has an international reputation for research in electrophysiology of painful small fibre neuropathies, particularly recording abnormal activity in nerve fibres and studying the excitability of unmyelinated axons. Another expert within King's Health Partners has co-authored three international clinical guidelines on the diagnosis and treatment of inflammatory neuropathy and recently co-led a randomised control trial (RCT) of exercise therapy in chronic inflammatory neuropathy. We participate in many multicentre research studies in inflammatory neuropathy. We lead

international research on clinical outcome measures in vasculitic peripheral neuropathy and recently co-authored new diagnostic criteria.

Muscle diseases and myasthenia

King's College Hospital has a number of innovative and notable clinical specialist services in this area. We analyse more than 300 muscle biopsies per year. We provide a highly experienced multidisciplinary team for long term care of muscle disease, with a specialist muscle physiotherapist and the involvement of a patient advocate. We undertake thymectomy, plasma exchange and intravenous immunoglobulin (IVIG) therapy for myasthenia.

Research

We have a prominent programme of work in genetic, molecular and cellular mechanisms of childhood onset muscle disorders, which has strong links with the Muscle Signalling Group of the King's College London Randall Division of Cell & Molecular Biophysics. This group studies the genetic regulation of the development of the musculoskeletal system, the proteins responsible for signalling and the structural integrity of muscle, the fundamental mechanisms of contraction and regulation in skeletal and cardiac muscle, and mutations that underlie the pathology of striated muscle.

Members of the team have many other research roles, including co-editor of the Cochrane Neuromuscular Diseases Collaborative Review Group, developing and cataloguing clinical trial outcome measures, membership of the Research Committee, European Neuromuscular Centre 2008–2013, establishing international standards of care for people with inclusion body myositis and development of national guidelines for the management of myasthenia during pregnancy.

Education and training

The highly-regarded and long-established annual one-day King's Neuromuscular Symposium attracts a national audience of around 100 clinicians. We have a large specialty registrar training programme in neurology and EMG and offer post-completion of training (CCT) clinical training fellowships in neuromuscular diseases.



Neuro inflammation

Neuro inflammation

Introduction

Neuro inflammation includes a wide range of conditions: multiple sclerosis; sarcoid; neuromyelitis optica (NMO) and transverse myelitis. In this section we focus only on multiple sclerosis pathways.

Multiple sclerosis is a chronic inflammatory disorder that affects the body's central nervous system. The symptoms vary between patients, but the most common signs of the condition include loss of balance, numbness in the limbs, blurred vision and a lack of co-ordination. More than 100,000 people in the UK have multiple sclerosis, which is equivalent to around one in every 600 people.

Our service

The service across King's Health Partners has grown since it was first set up in 2000. We run out-patient adult multiple sclerosis clinics (doctor, nurse and pharmacist led) at King's College Hospital, Princess Royal University Hospital, Guy's Hospital and St Thomas' Hospital. Paediatric clinics are held at the Evelina London Children's Hospital (part of Guy's and St Thomas' NHS Foundation Trust). Ongoing support is also provided for patients and their families by community clinics (in GP surgeries and intermediate care in some London boroughs) run by the community nursing teams, who may provide home visits, including nursing homes.

In our clinics across King's Health Partners, we see local multiple sclerosis patients as well as patients with more complex needs mainly from south east London and Kent. The latter group are usually at the request of other consultant neurologists. We provide second opinions on diagnosis, initiate and monitor disease-modifying therapies, manage relapse and complex symptoms. We also see patients with multiple sclerosis who have been

admitted to hospital for other reasons and require specialist advice. We may admit patients ourselves for investigation or treatment.

Given the wide range of symptoms people with multiple sclerosis experience, close working with other specialties is important and includes: neuroradiology; spasticity; pain; (neuro-) ophthalmology; neuropsychology; pharmacy; continence service (joint clinics); urology; urogynaecology; chemotherapy/haematology; palliative care; mental health services and neuropsychiatry as well as movement disorders (tremor/Deep Brain Stimulation (DBS)).

Treatment

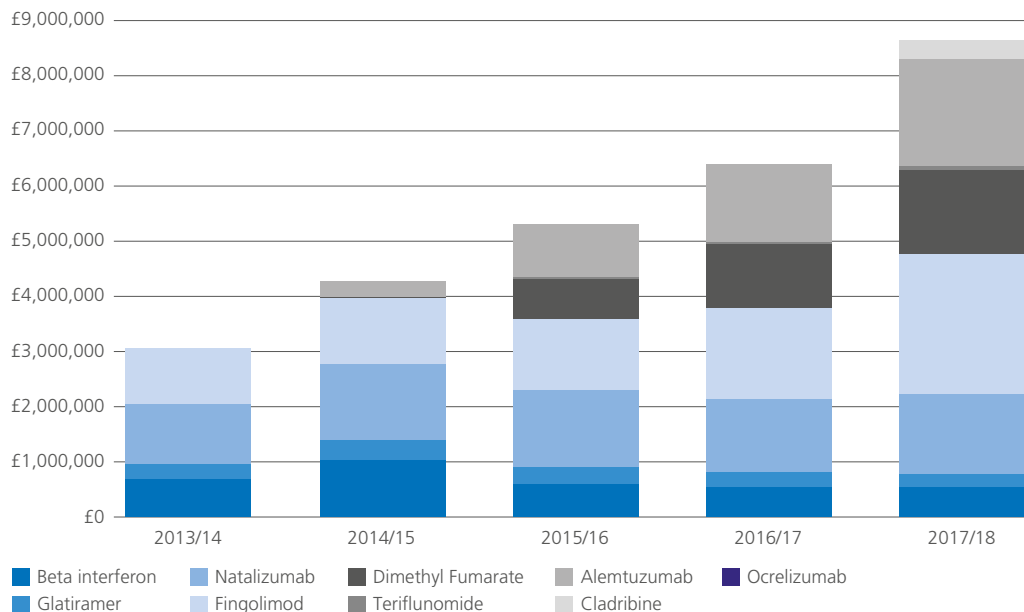
There is no cure for multiple sclerosis, but over recent years there has been a significant growth in the number and effectiveness of disease modifying therapies to reduce disease activity in patients with relapsing multiple sclerosis. Many of these therapies require very close monitoring due to their potential side effects. We have recently developed comprehensive guidelines for each of these therapies to ensure appropriate screening and monitoring. These guidelines are used across south east London and Kent to ensure safe and consistent treatment.

We recognise the importance of managing symptoms in everyone with multiple sclerosis, whether or not they are eligible for disease modifying therapy. We work closely with therapy colleagues in the hospital and community to provide treatments such as physiotherapy to help with walking and stiffness, Cognitive Behavioural Therapy for anxiety and depression, fatigue management advice as well as equipment and adaptations at home.

We maintain databases of people on disease-modifying treatments for multiple sclerosis so that we can safely monitor their treatment. Measures such as the Expanded Disability Status Scale (EDSS) and 25-foot walking time are recorded to monitor patients' progress.

Figure 35 shows the expenditure on disease modifying therapies to illustrate the growth in their use.

Figure 35 | Expenditure on disease modifying therapies for patients with multiple sclerosis at King's College Hospital by type of therapy (2013/14 to 2017/18)



Note: There was no expenditure on the disease modifying therapy Ocrelizumab during these years.

Patient experience and outcomes

In 2015 an audit was undertaken looking at patient satisfaction and compliance with the NICE guidelines. This audit showed a very high level of overall satisfaction with the services across King's Health Partners, with an average score of 9.1/10. The audit identified some areas for improvement, including provision of more written information, which were acted upon.

Also in 2015, the multiple sclerosis service at the Princess Royal University Hospital carried out a patient survey using a survey tool developed by the Multiple Sclerosis Trust as part of 'Generating Evidence in multiple sclerosis Services', a UK wide programme to evaluate and improve multiple sclerosis specialist services. The survey consisted of 30 questions to assess patients' use and experience of multiple sclerosis specialist nurses and the impact this had on their ability to manage their condition.

Key findings from the survey are set out below.

Figure 36 | Measures of patient experience – involvement in decision making

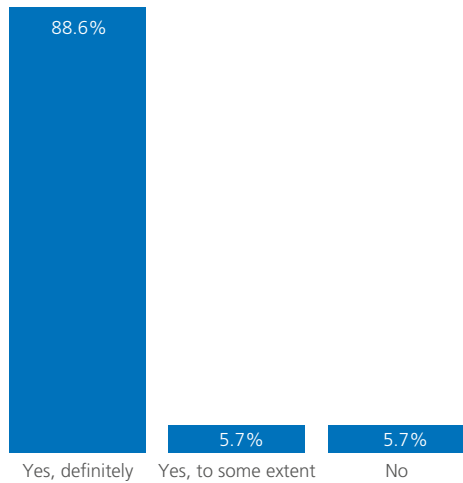


Figure 38 | Measures of patient experience – degree of trust and confidence

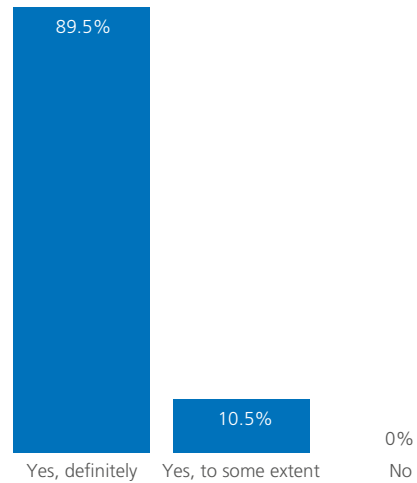
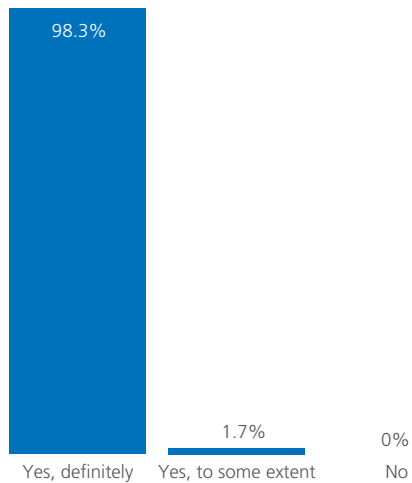


Figure 37 | Measures of patient experience – dignity and respect



Research and innovation

Our team have run many clinical trials, including commercial trials. A snapshot of active commercial trials in Neurosciences (including stroke) at King's College Hospital in March 2018 showed that 30% were multiple sclerosis related.

Staff have contributed to research papers on palliative care (we were the best recruiting site for OPTCARE: neuro, a study looking at the impact of short term palliative care intervention), investigating anxiety surrounding illness uncertainty in multiple sclerosis, behavioural and psychological risk factors for fatigue in patients with multiple sclerosis, pain experiences in people with multiple sclerosis, pregnancy and multiple sclerosis, multiple sclerosis in the Caribbean population and diagnosing multiple sclerosis.

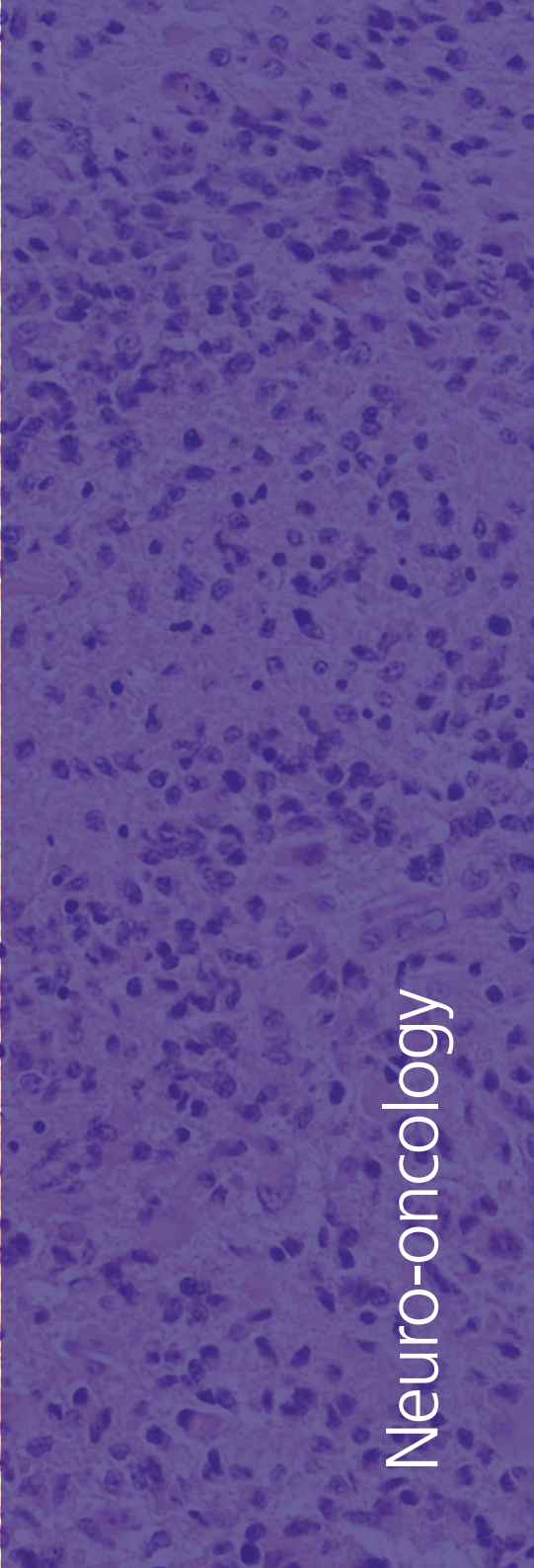
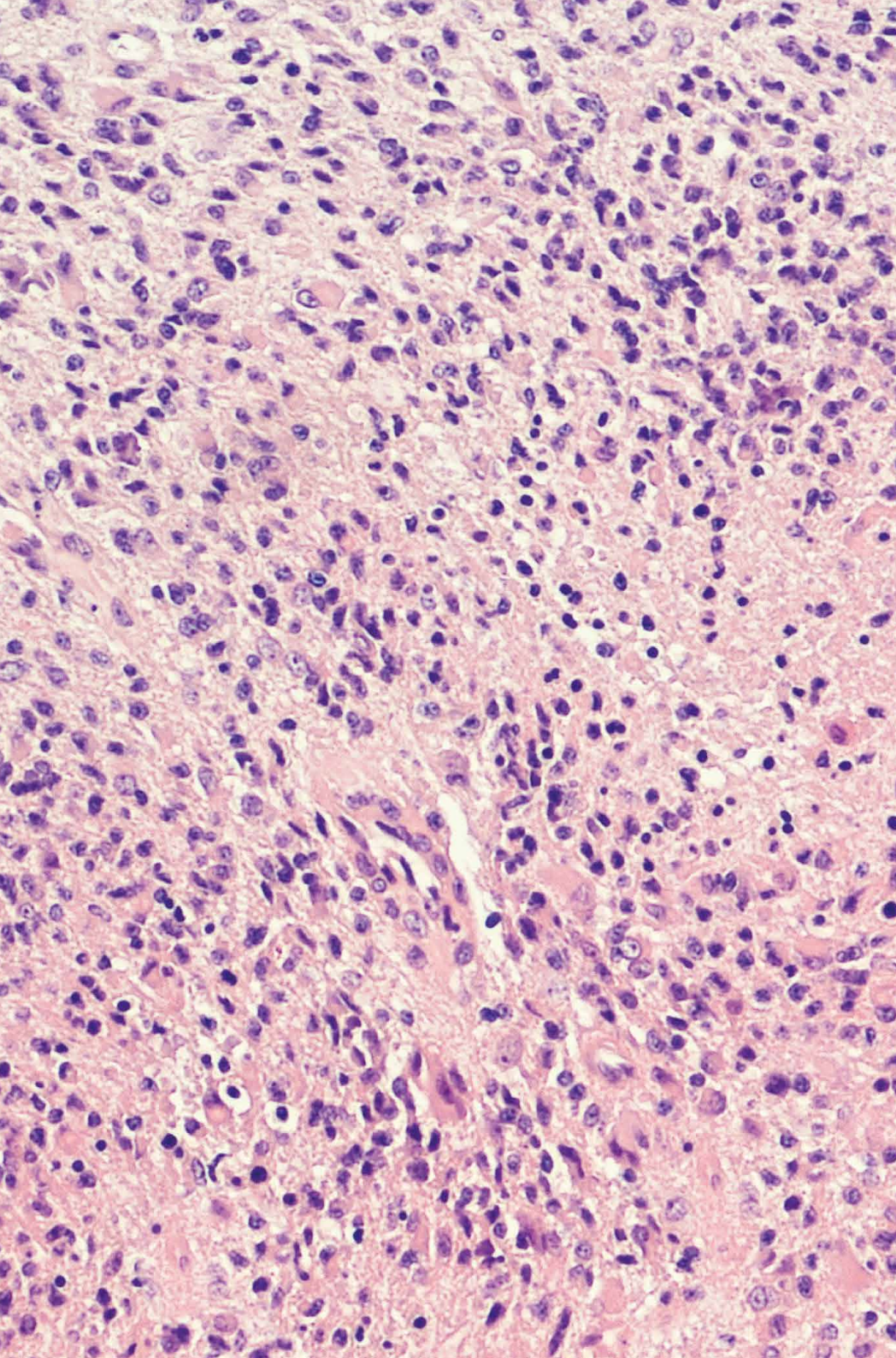
Members of our specialism are influential in the multiple sclerosis world and are members of:

- the multiple sclerosis group within the Association of British Neurologists (ABN)
- the Guidelines Development Group (GDG) for the Royal College of Physicians (RCP) NICE multiple sclerosis guidelines and recently with colleagues, has produced nationally adopted guidelines for the management of multiple sclerosis during pregnancy
- the MS Society, including a medical advisor role.

Education and training

We hold a wide range of educational activities relating to multiple sclerosis including:

- monthly regional meeting to discuss multiple sclerosis services and complex cases
- regional multiple sclerosis nurse meetings
- annual 'A to Z of multiple sclerosis' meeting held at the Royal College of Physicians
- annual South East London, Kent and Medway (SELKaM) multi-disciplinary multiple sclerosis meeting to highlight and share good practice
- biannual regional multiple sclerosis audit meetings.



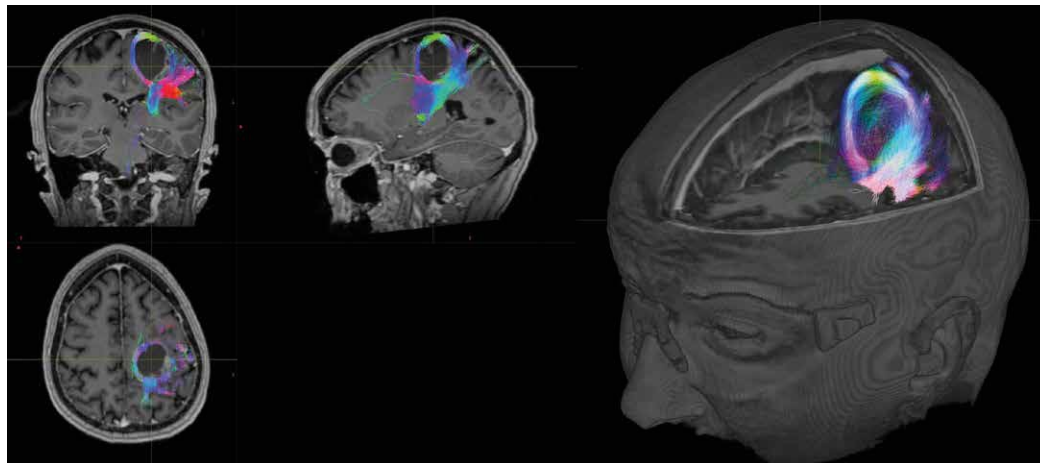
Neuro-oncology

Neuro-oncology

Neuro-oncology is the management and treatment of tumours which occur in the brain and spinal cord (the central nervous system). There are more than 150 different types of brain tumours, usually named after the type of cell they develop from or the area of the brain where they are growing. Primary tumours start in the brain or related structures. Secondary

brain tumours have spread from another part of the body. Tumours are categorised according to how quickly they are likely to grow; graded from one to four (fastest growing) and are also now partly categorised by the underlying genetic abnormalities. There were 11,432 newly identified cases of brain tumours in 2015 in the UK (Cancer Research UK).

Figure 39 | Magnetic resonance scan and tractography of a patient with a brain tumour lying in the middle of the pathways controlling movement of the arm and leg. This allowed safe resection of most of the tumour with no deficit after surgery.



© Dr M Borri

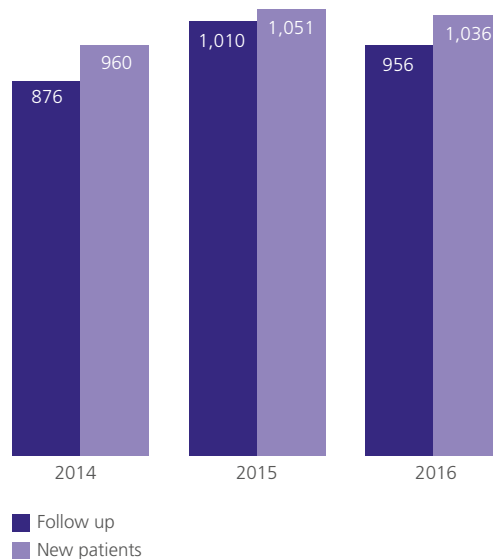
Our service

The neuro-oncology service at King's Health Partners is a large centre in the UK, serving a catchment population of around 4.5 million.

In line with the NICE Improvement Outcome Guidance (2006), our neuro-oncology service is structured around the multidisciplinary team (MDT), comprising of three dedicated neuro-oncology neurosurgeons, with a fourth concentrating on paediatric and teenage patients, four neuro-oncologists, neuro-pathologists, neuro-radiologists, neurologists, palliative care specialists, clinical nurse specialist, therapists, MDT coordinator and data analyst. There are separate MDTs for the skull base tumours, pituitary tumours and patients with malignant spinal cord compression. The team meets weekly to discuss all new referrals and also post-operative patients. The team was commended on its achievements in the 2012 national neuro-oncology external peer-review and in subsequent internal peer-reviews.

The number of patients seen in the weekly team meeting is shown in Figure 40. 764 operations for primary and secondary tumours were carried out in 2013/14.

Figure 40 | Number of patients seen in the weekly neuro-oncology multidisciplinary team meeting by year

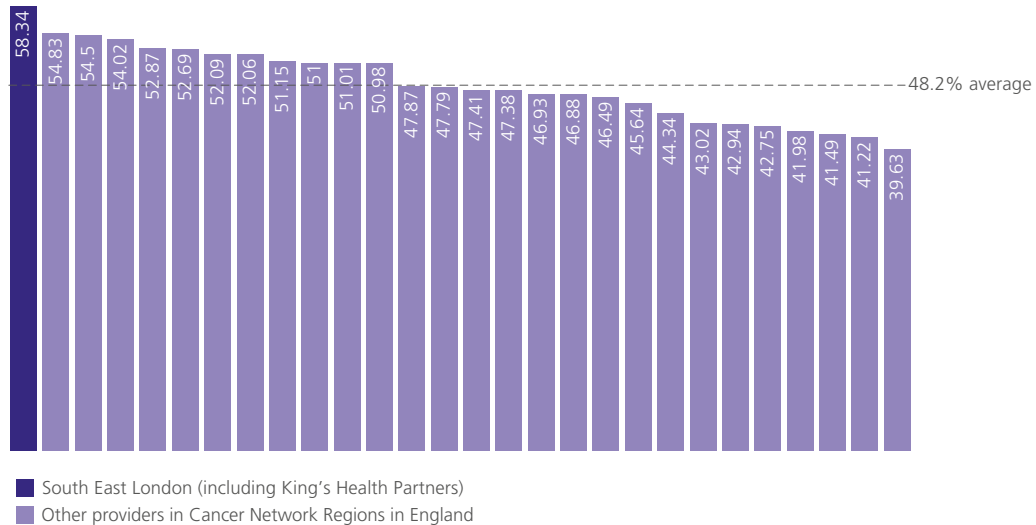


Patient experience and outcomes

Using the most recent national comparative data available, the King's Health Partners neuro-oncology service had the highest one-year survival in the UK (London Cancer Alliance), 10 percentage points higher than the national average (58.34% compared to 48.2%). This data is no longer collected nationally and our aim is to restart its collection for our patients.

In spite of the large volume of the work, there has never been a target breach with any of the neuro-oncology patients. In our in-house patient satisfaction audits, designed specifically with the needs of neuro-oncology patients in mind, we have consistently achieved high scores.

Figure 41 | Comparison of one year relative survival by Cancer Network Regions in England, population based, for patients diagnosed with brain/CNS cancers 2007–2009



Case study: Speech and language therapy in neuro-oncology

Speech and language therapists are playing an increasingly important role in the neuro-oncology service at King's College Hospital. Our input is extremely important for patients who are being considered for "awake craniotomy" when the lesion is in an area of the brain important for speech and language. We see patients pre, intra and post operatively. We play a vital role in explaining the surgical process, helping the patient feel as at ease as possible with awake surgery, assessing for language difficulties before surgery, testing and monitoring for language difficulties during the surgery and reviewing patients on the ward post-surgery, using the Sheffield Aphasia Screen.

We collect patient feedback on our speech and language therapy input and this has been very positive. Patients have reported that they especially value the time taken to explain the procedure and the support of the therapist during the procedure.

In conjunction with the rest of the neuro-oncology therapy team (occupational therapists and physiotherapists) we review both the asleep and awake craniotomy patients post-surgery on the ward. The therapy team is an integral part of the discharge process and we handover to local hospital therapy staff or refer to inpatient or community teams as appropriate.

Innovation to improve patient experience and outcomes

We continually strive to improve our service and examples of recent innovations include:

- BrainPath (a revolutionary device that allows surgeons to perform keyhole surgery on the brain) was used at King's College Hospital as a UK first. With BrainPath, neurosurgeons use the folds in the brain (which are like deep crevasses) combined with new knowledge of the fibre pathways to get to the brain tumour without causing any damage to vital connections in the brain
- UK's first Low Grade Glioma Clinical Nurse Specialist to focus on the quality of life for brain tumour patients, funded by the Brain Tumour Charity. This post has been established in response to the charity's findings that only 53% of patients with low-grade tumour had access to a single point of contact compared to 76% of those diagnosed with a high-grade brain tumour. Those without a specialist nurse or single point of contact were more likely to report a high symptom burden, say their brain tumour had severely affected their emotional or mental health, to disagree that they had good access to information

on managing symptoms, and to disagree that the healthcare professionals they dealt with understood brain tumours

- the first fluorescent guided tumour resection in London (2010). King's Health Partners is now a national training centre for this technique. Even now this technique is only used in about 50% of Neurosurgery Units in the UK (the Brain Tumour Charity, August 2018)
- UK's first dedicated Teenage and Young Adult neuro-oncology clinic to cater for the specific needs of this patient group
- a Neuro-oncology Pre-assessment Clinic which allows optimisation of patients' medical condition before surgery, comprehensive consent for surgery, minimise cancellations/length of stay and improve patient satisfaction (confirmed by an in-house audit, presented at the British Neuro-Oncology Society meeting, 2012)
- a dedicated results clinic, run in the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation to allow ample time for discussion with patients during this most difficult time, in calm surroundings, and where immediate access to the support services is available (our experience presented at the British Neuro-Oncology Society meeting, 2014)
- nurse led telephone-clinic to improve patient access and avoid unnecessary journeys to the hospital (high patient satisfaction confirmed by an in-house audit, presented at the British Neuro-Oncology Society meeting, 2014)
- UK's first drama therapy group for brain tumour patients to enhance holistic care, now being accessed by other centres across London (high patient satisfaction confirmed by an in-house audit, presented at the British neuro-Oncology Society meeting, 2011).

Research and innovation

Examples of research led by our experts include:

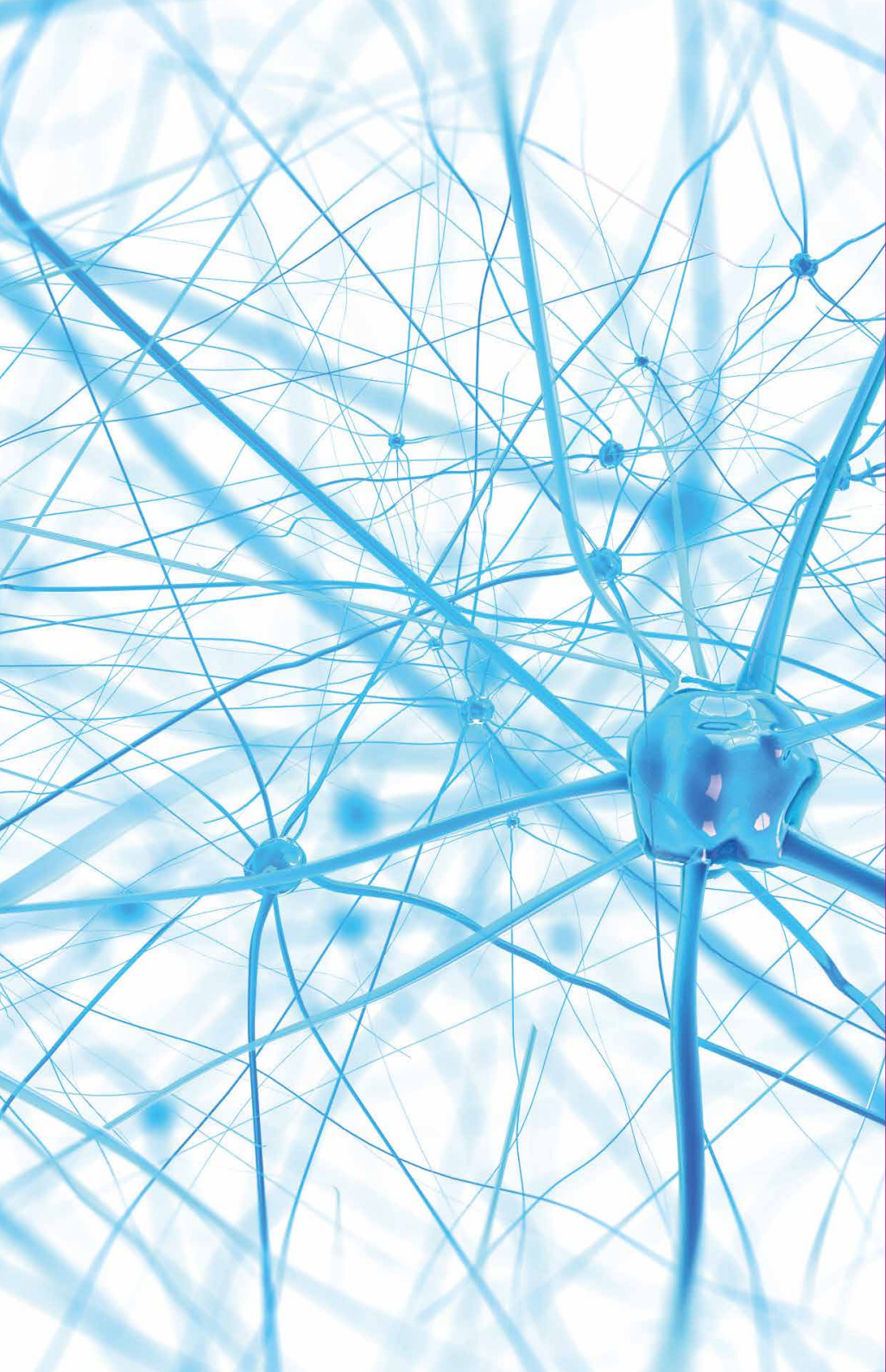
- immunotherapy for brain tumours: chief investigator for a phase III trial of DCVax for glioblastomas in the UK and the highest recruiter worldwide for the study. The early findings were published in May 2018 in the Journal of Translational Medicine. Patients who took part in the trial – the largest so far of an immunotherapy vaccine – survived for more than 23 months on average following surgery
- GALA 5 trial of combined fluorescent guided resection and intra-operative chemotherapy: Our team provides the second highest recruitment in the UK with one of our experts as principle investigator

- National Brain Tumour Study: This high recruiting study has principal investigators from both King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts
- our oncologists with an interest in brain tumours are research active. For example, one of them is a principal investigator on the ACT IV trial
- an active research group in neuro-pathology with multiple innovative publications
- several of the King's Health Partners neuro-oncology MDT members have served as national external peer-reviewers for neuro-oncology
- most recently in April 2018, a leading senior member of our team was named as UK Clinician of the Year by The Brain Tumour Charity. The award recognised his contribution to improving patients' quality of life and his research in finding new therapies.

Driving improvement through national roles

Members of our clinical team have held several influential roles, including:

- neuro-oncology opinion on the Health Care for London's Cancer Services Review Board contributing to the Brain and Central Nervous System (CNS) Cancer section of the three documents (Case for Change, Model of Care and Cancer Co-dependencies) published in 2010 to define the strategy of cancer care in London
- chair of the Brain and CNS Pathway Group for the London Cancer Alliance
- acting President of the British Skull Base Society



Neurodegeneration – motor neuron disease

Neurodegeneration – motor neuron disease

Introduction

Motor neuron disease (MND), sometimes called amyotrophic lateral sclerosis (ALS), describes a group of diseases that affect the messaging from the nerve cells (motor neurons) in the brain and spinal cord to the muscles, which over time causes muscles to weaken, stiffen and waste. MND affects up to 5,000 adults in the UK at any one time, six people are diagnosed every day and six people die every day. One in every 300 people will develop MND. Around 35% experience mild cognitive change causing difficulties with planning, decision-making and language.² A further 15% of people show signs of a form of dementia resulting in more pronounced behavioural change (MND Association) and the risk of these changes in thinking and behaviour increase as the disease progresses.

Our service

The King's Motor Neuron Disease Care and Research Centre was the first specialist centre for MND/ALS to have been established in the UK and is a partnership between King's College Hospital NHS Foundation Trust and King's College London. The Centre is part-funded by the Motor Neurone Disease Association (MNDA), which is a patient group. A prize-winning, highly specialised multidisciplinary clinical team oversees care for patients and their families in close communication with local and community teams. Its services have been recognised for high standards and the research team has won many awards for important new discoveries.

² Motor Neurone Disease Association, 2017.

Patient experience and outcomes

The service at King's College Hospital is externally peer-reviewed by the Motor Neurone Disease Association every four years, during the process of application for renewal of grant funding and is also peer-reviewed against agreed milestones every six months by the MNDA.

Our team use these survey results to drive improvements in care and they are addressing access times to ensure that all patients see a consultant neurologist within four weeks of diagnosis (recognition and referral), all patients are now given the MNDA booklet 'Introduction to MND' and an information sheet on MNDA's Benefits and Advice Service (organisation of care) and we are looking at ways to meet patients' and families'/carers' psychological needs.

Results from the Motor Neurone Disease Association's Transforming MND Care Audit – 2017

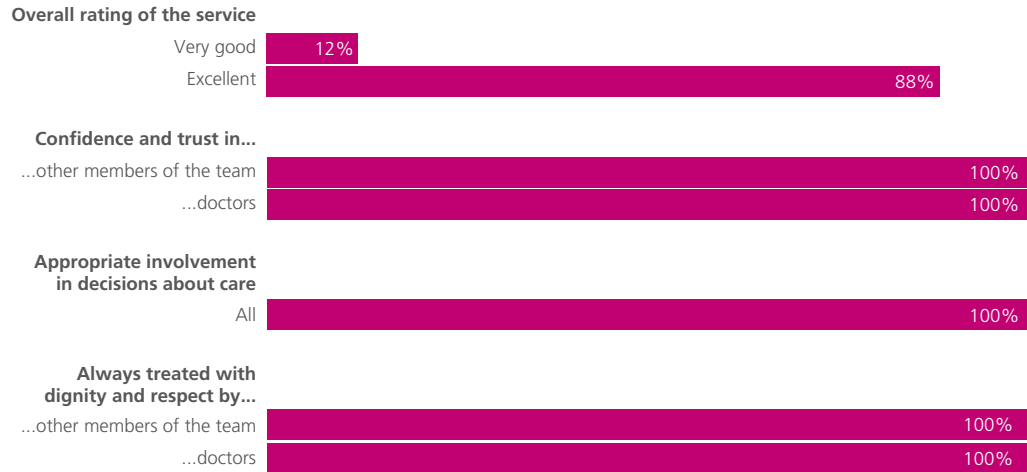
This audit tool has been designed by the MNDA to determine whether services are implementing and complying with the NICE guideline (NG42 – Motor neuron disease: assessment and management, 2016) in a standardised way. In total 109 indicators are assessed, grouped into categories, and our performance is shown in Figure 42. On average we have a 90% compliance rate, although performance does vary by category.

Figure 42 | Compliance results from the Motor Neurone Disease Association's Transforming Care Audit 2017



Results from an in-house survey

Figure 43 | Results of the Patient Satisfaction Survey (2015) showed that patients rated the service highly



Note: Sample size = 17, Survey data collected March – June 2015.

Research and innovation

Our research is focused on ALS and other motor neuron diseases and has been recognised with national and international awards and prizes. Our aim is to find a cure for ALS. Two of our team members, have been recognised by the American Association of Neurology and ALS Association Sheila Essey prize, given annually to outstanding researchers in motor neuron disease.

King's Health Partners' research work in MND has led the world for several decades. Our genetic research has had significant impact on the current and future care of people with MND and revealed the relationship between genes and risk in people with and without a family history. Our researchers discovered several MND-causing genes, which have been taken up by diagnostic and research laboratories throughout the world. This has improved early diagnosis and predictive gene testing in high-

risk families and enabled children to be born free of MND by pre-implantation genetic diagnosis. Research laboratories in academia and industry have used mutant genes in cellular and animal models to identify fundamental disease mechanisms and disease-critical pathways to advance drug discovery for this fatal disease.

In addition to research into the fundamental genetic causes of MND, we have a very active programme of research aiming to improve treatment and management of MND. Riluzole is the only drug shown to improve survival in any neurodegenerative disease. Following pivotal trials led by King's Health Partners scientists, Riluzole is now the standard treatment for MND worldwide and is recognised by NICE as indicated for MND.

A tool we developed to predict the survival rate of people with MND in different circumstances has allowed us to discuss prognosis and the factors that influence it more effectively with patients³ and was selected as "Patients' Choice" for the journal by patients, confirming the value of the tool. Further work on this has led to an international tool for prediction of survival, available for neurologists, and for clinical trials: the ENCALS Survival Prediction Tool.⁴

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- 3 A clinical tool for predicting survival in ALS. *Journal of Neurology, Neurosurgery and Psychiatry*, 2016. Knibb, J.A., Noa, K., Kulka, A., Leigh, N., Shaw, C.E., Tsuda, M., Al-Chalabi, A., Martin, S.
 - 4 Prognosis for patients with amyotrophic lateral sclerosis: development and validation of a personalised prediction model. *Lancet Neurology*, 2018. Westeneng, H-J. et al.

MND is usually regarded as a painless condition. Our study investigating pain in our patients (2015) found that pain is frequent and under-reported, because the focus of care is on motor symptoms.⁵ As a result, we now ask all our patients about pain, proactively manage it, and have translated the findings into an information leaflet.

We have developed a clinical staging system for ALS which is used worldwide in clinics, in clinical trials, in clinical research and for health economics analysis.⁶ It forms part of the international consensus on clinical trials in ALS. Using staging, we and others have shown that Riluzole works best in very early and very late stage disease, allowing patients and physicians to make informed decisions about its use.

Our research has also shown that our clinical multidisciplinary team has improved the survival of people with MND independently of other treatments (519 people studied, 20% improvement in survival, $p = 0.03$).

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- 5 The evaluation of pain in amyotrophic lateral sclerosis: A case controlled observational study. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 2014. Victoria C. J. Wallace, Cathy M. Ellis, Rachel Burman, Catherine Knights, Christopher E. Shaw & Ammar Al-Chalabi.
 - 6 A proposed staging system for amyotrophic lateral sclerosis. *Brain*, 2012. Roche J.C., Rojas-Garcia R., Scott K.M., Scotton W., Ellis, C.E., Burman, R., Wijesekera, L., Turner, M.R., Leigh P.N., Shaw C.E., Al-Chalabi, A.



Neurodegeneration – Parkinson's disease

Neurodegeneration – Parkinson's disease

Introduction

Parkinson's disease develops when cells in the brain that produce the chemical dopamine stop working properly and are lost over time. Symptoms are varied and consist of "motor" which are – tremor (shaking when the hand is resting for instance), slowness of movement and rigidity (muscle stiffness), along with many other non-motor symptoms. There are approximately 145,000 people diagnosed with Parkinson's in the UK, which equates to one adult in every 350 (Parkinson's UK).

Our service

We provide full specialist services for Parkinson's disease, caring for a wide range of patients, with a catchment of about 4,000 cases – one of the largest in the UK. We are one of only two centres in the UK, four in Europe and 11 internationally, to receive the status of Parkinson Foundation (a prestigious

US patient charity) Centre of Excellence for the care, treatment and research of Parkinson's disease. The centre, which spans King's College Hospital and King's College London, integrates clinical services with research and education. The team spans across neurosciences, nursing and therapies, and provides a full spectrum of services under one roof.

We are the hub of the European Network for Parkinson's disease (euroPA) research organisation, and are an accredited European Federation of Neurological Societies (EFNS), International Movement Disorders Society and Parkinson's Disease Non-Motor Group (PDNMG) centre for teaching and research. This is led by our team at King's College Hospital NHS Foundation Trust which is also the lead organisation for the London South Local Parkinson's Excellence Network, developing care and research standards which have been influential in a nationally adopted signposting initiative.

Our service is neuroscience led, rather than elderly care led, in common with only 50% of services nationally. The centre sees around four to five new referrals and over 30–40 follow-up patients a week, across various clinics. Notable aspects of our service include:

- we are one of the few centres in the UK able to provide advanced therapies for advanced Parkinson's disease such as duodopa, apomorphine and deep brain stimulation (DBS)
- a transition clinic within the neurology service providing specialist care for older people with Parkinson's disease and the only service that has a nurse consultant able to provide home based care for palliative stages of care
- a quarterly Parkinson's expert patient group
- a NICE-approved patient empowerment clinic held every three months
- a regional service for patients with dystonia, restless leg syndrome (RLS) and Huntington's disease
- our team works closely with King's College Hospital paediatrics service and runs a transitional clinic for young adults with Deep Brain Stimulation entering adulthood
- we work closely with neuropsychiatry and neuropsychology for patients with more complex cognitive, emotional or behavioural needs

Patient experience and outcomes

Our services participate in the mandatory national Parkinson's UK audit, and our results show that services provided by our Neurologists at both trusts were above the national average in all three measured domains for both 2015 and 2017.

Figure 44 | Parkinson's UK Audit results for King's College Hospital NHS Foundation Trust (KCH) and Guy's and St Thomas' NHS Foundation Trust (GSTT)

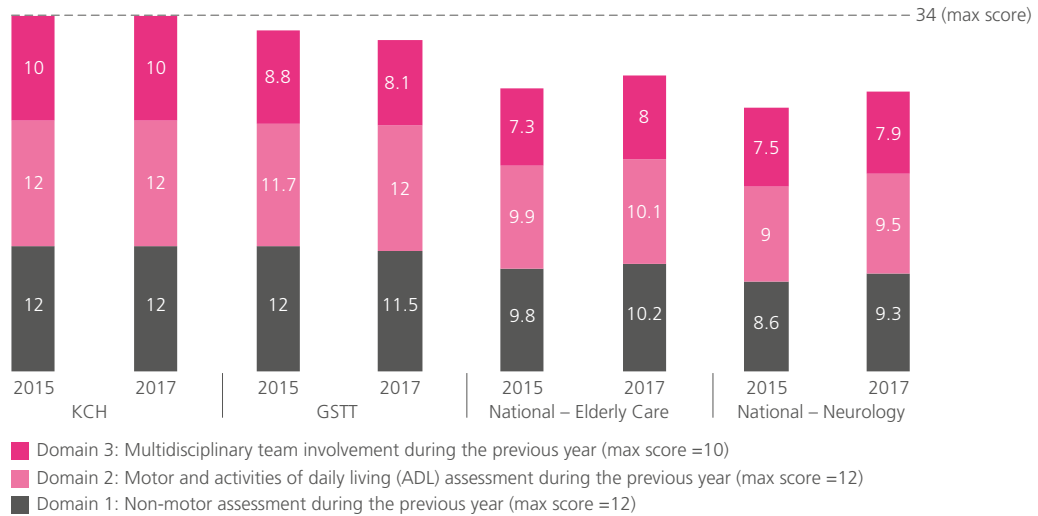
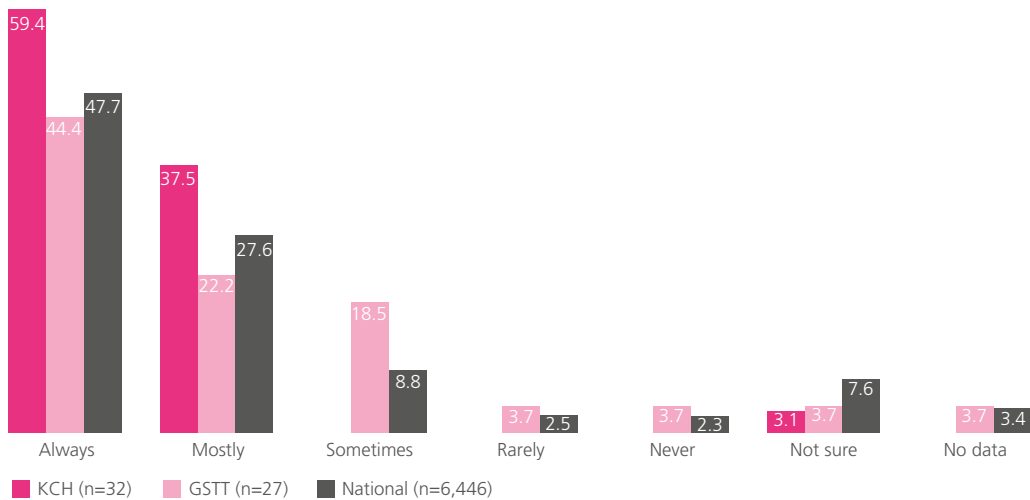


Figure 45 | Patient reported experience measure from the Parkinson's UK 2017 Audit – responses on degree of involvement in decision making (percentage of respondents)



Case study: Developing outcomes measurement tools that are now used internationally

Practically everyone who has Parkinson's disease also has significant 'non-motor' symptoms that often have a greater impact on their quality of life than the movement difficulties caused by Parkinson's. These include memory loss, sleep problems, mood changes, dribbling, apathy, concentration difficulties, fatigue and constipation.

Our researchers established that most people who have Parkinson's experience at least six non-motor symptoms, but some people can have up to 30. All non-motor symptoms are treatable but doctors need to be made aware of them. Our research showed that despite this, doctors and nurses across Europe did not discuss non-motor symptoms with their patients, and patients themselves did not mention them, either because they were embarrassed or because they did not think the symptoms were related to the disease.

Our researchers developed and validated the Non-Motor Symptoms Questionnaire, a simple questionnaire now used in clinics around the world to help ensure patients get the treatment they need for non-motor symptoms caused by Parkinson's disease. We have developed further outcomes tools for assessing sleep including Parkinson's Disease Sleep Scale (PDSS), King's Parkinson's Pain Scale (KPPS) as well as Parkinson's Fatigue Scale (PFS 16).

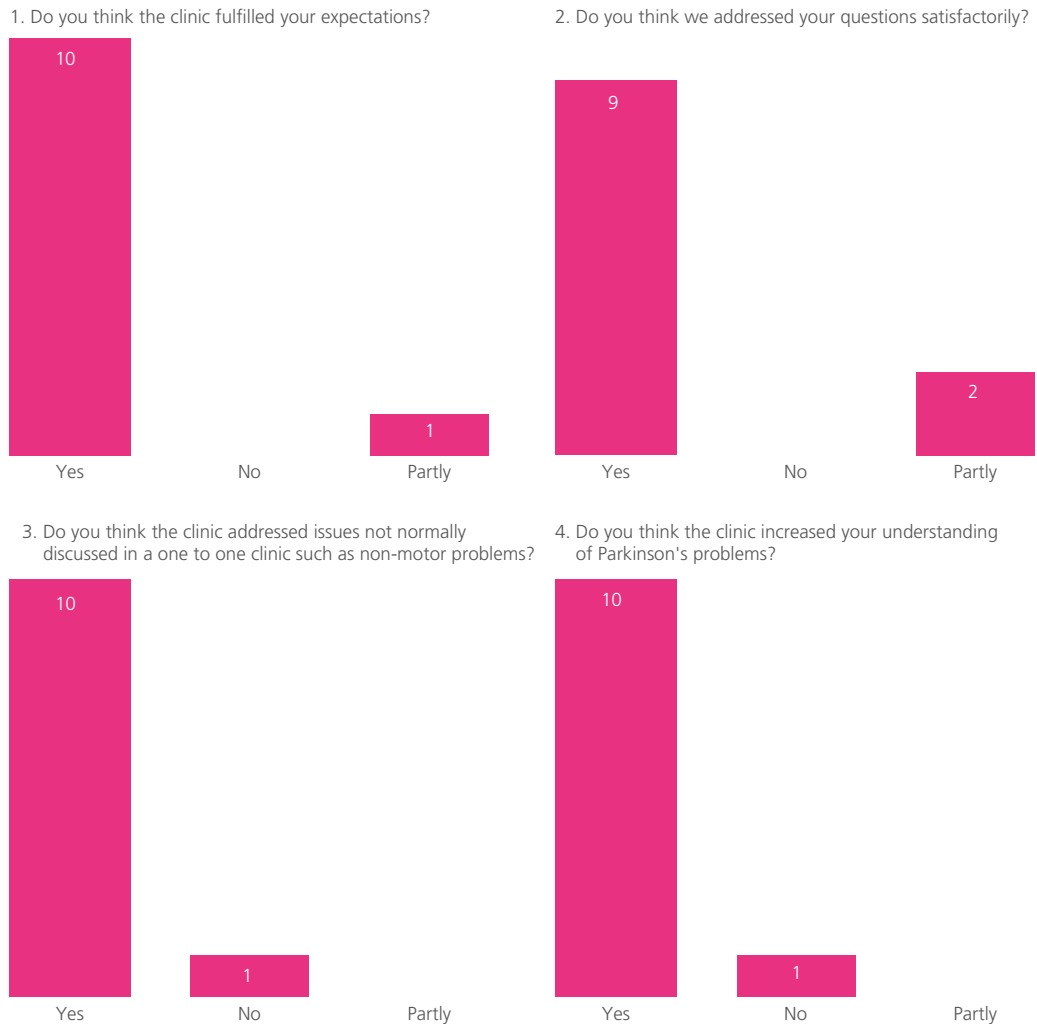
Innovation driving improvements in patient experience and outcomes

Parkinson's Education and Therapy Clinic

Feedback has shown us that one thing which all Parkinson's patients could have more of is education around their understanding of the condition. To meet this need, we established a NICE approved Parkinson's Education and Therapy Clinic (PETC) which provides teaching, education and support on Parkinson's disease

to patients and their families. Thus far, feedback from patients and their family members show that the PETC is an informative, useful and valuable experience, as shown in Figure 46.

Figure 46 | Patient feedback from the Parkinson's Education and Therapy Clinic



Case study: Skylarks – a choir for people with Parkinson's disease

Speech and language therapists at King's College Hospital have set up a choir for patients with Parkinson's disease to help them manage their condition. The Camberwell Skylarks – as they are named – meet weekly for five weeks each term and provide an opportunity for patients to exercise their voices.

"Singing has proven benefits for patients with Parkinson's, as well as improving their emotional wellbeing" explains the Clinical Lead Speech and Language Therapist for Neurology at King's College Hospital NHS Foundation Trust.

King's College Hospital patient Catherine, 47, from Camberwell was diagnosed with Parkinson's in 2016 and attends Skylarks rehearsals. She said "Singing is fantastic speech therapy but it's also great for dual tasking – in particular singing and moving at the same time."

"It feels like a support group without actually being one – it's important to do something I love with people going through the same thing. I can't express how valuable it is."

Advanced therapies

Our Centre of Excellence provides advanced therapies such as apomorphine infusion and has the largest collection of patients treated by intrajejunal levodopa infusion (IJLI) in the UK. Longitudinal outcome data is collected (motor, non motor and quality of life) and has been published.

Our work showed sustained and significant improvements in the IJLI treatment group on all parameters; particularly Unified Parkinson's Disease Rating Scale (UPDRS III and UPDRS IV), Non-Motor Symptom Scale (NMSS) total score and quality of life scores.⁷

Similar data is also captured with patients on apomorphine infusion.

We have published the only head to head comparison of advanced therapies, apomorphine versus levodopa infusion (Euroinf) and subsequently a comparison of Deep Brain Stimulation versus apomorphine versus levodopa infusion (Euroinf 2).

7 Intrajejunal levodopa versus conventional therapy in Parkinson disease: motor and nonmotor effects. *Clinical Neuropharmacology*, 2012. Reddy, P., Martinez-Martin, P., Rizos, A., Martin, A., Faye, G.C., Forgacs, I., Odin, P., Antonini, A., Chaudhuri, K.R.

Research and innovation

Our research mainly focuses on high quality clinical and translational work addressing non motor aspects of Parkinson's disease regarded and listed as a key unmet need by NICE.

We have led a number of initiatives, examples of which include setting up an international network of research centres for a combined non-motor data registry tracking natural history. This is mediated through two main networks:

1) European Parkinson's Group (EUROPAR)

A multidisciplinary group that was formed to perform "real life" non-motor based clinical studies across a wide range of people with Parkinson's throughout Europe with the aim of pursuing studies as they happen in real life and focuses on translational "bench to bedside" research (for example, looking at what impact 'real life' treatments such as skin patches, injections and infusions may have on the non-motor aspects of Parkinson's) and the development of better patient and public involvement in the treatment of Parkinson's disease.

EUROPAR involves 14 centres across Europe while the international non-motor research group led from King's College Hospital involves 34 centres worldwide.

2) International Parkinson's and Movement Disorders Society (IPMDS) Non-Motor Study Group (NM-PD-SG)

In 2012, as part of International Parkinson's and Movement disorders society, a new study group was set up. The non motor PD Study Group is developing international collaborative research in the field of non-motor symptoms in Parkinson's disease. Its goals are:

- to collect new and novel patient and carer reported information on non-motor symptoms (NMS) of Parkinson's disease from around the world
- to develop an MDS version of a new Parkinson's disease non-motor symptoms scale
- to ensure that comprehensive and unified NMS assessments in clinical trials and scientific studies are increasingly used to increase the "real life" value of clinical trials and clinical studies
- to develop new and novel NMS instruments for use in clinics – Parkinson's disease pain scale (currently in development and validation); Vision scale
- to set up and start international cross cultural studies, to improve existing tools for NMS (e.g. non-motor symptoms questionnaire)

- to develop animal models addressing non-motor phenotypes of Parkinson's disease
- to refine, validate and establish non-motor subtypes of Parkinson's disease and related biomarkers.

Involving patients in shaping research

CRISP (Community for Research Involvement and Support for People with Parkinson's) is a group comprised of patients, carers and health professionals who are directly involved with Parkinson's disease in some way. The group helps to shape and feedback on research within the field of Parkinson's and nervous systems disorders in south London. CRISP members have developed a video which can be found on the King's College London website, sharing their good experience with getting involved in research to encourage other Parkinson's disease patients to get involved too.

Recognition of the team

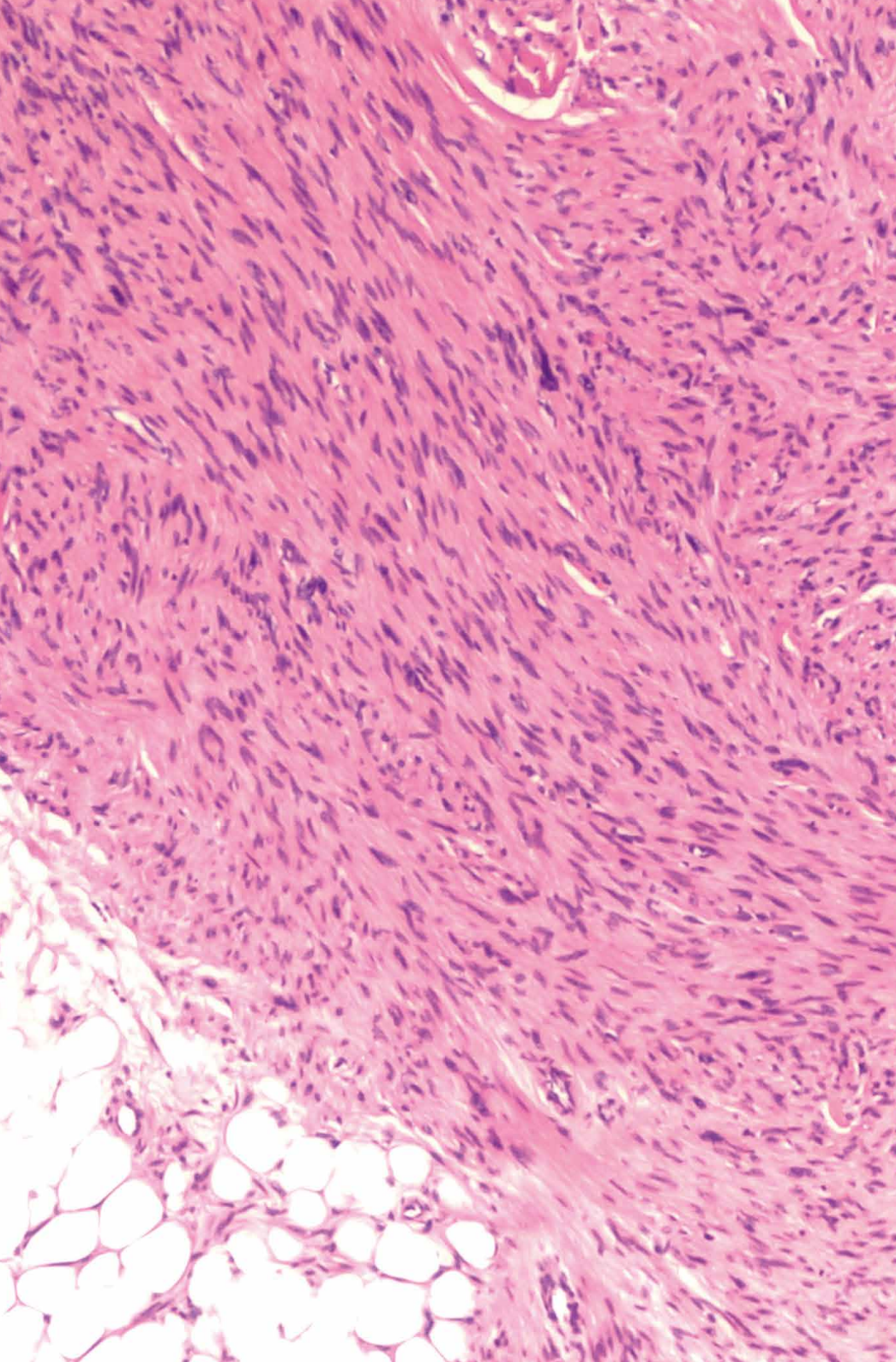
King's Health Partners has a number of key opinion leaders in this field. One of our Parkinson's experts has led people based research and established the non-motor aspects of Parkinson's disease as a key priority and was recognised by the Van Andel award (Chicago, USA) in 2018 for outstanding services to the care of people with Parkinson's disease. He was also recognised by The Royal College

of Physicians and the National Institute of Health Research for innovations in clinical research in 2018.

Case study: National recognition for contribution to the field – Restless Leg Syndrome

A senior member of our team was awarded the 2015 Andrew Wilson National award for services to people suffering from Restless Legs Syndrome (RLS) by RLS:UK. He was nominated by the Trustees of RLS for his contribution to care and research in the field.

RLS, now known as Willis-Ekbom disease, is one of the most common causes of sleep issues for patients and can be disabling, but it is still widely under recognised. Our team has been responsible for a broad range of initiatives supporting the cause and care of RLS in the UK. This has included setting up the educational academic group RLS:UK in 2000, which became the first and only patient charity for RLS in the UK in 2010 and leading several trials, as well as managed the only dedicated RLS clinic at King's College Hospital where a monthly telephone clinic has been set up to offer a specific RLS remote advice service.



Neurofibromatosis

Neurofibromatosis

Introduction

Neurofibromatosis 1 (NF1), Neurofibromatosis 2 (NF2) and schwannomatosis are inherited conditions that have a major impact on the nervous system and can result in tumour growth. NF1 is characterised by benign nerve sheath tumours called neurofibromas that can grow on peripheral nerves and spinal nerve roots and can impinge on the spinal cord. The manifestations of NF1 vary even within families and range from learning and behavioural problems, cardiovascular abnormalities, disfigurement and bone dysplasia to epilepsy and malignancy including central nervous system tumours. There are approximately 25,000 people in the UK diagnosed with NF1, and it occurs in 1 in 2,500 of the population.

NF2 occurs in one in 35,000 of the population and at any one time in England there are around 860 people living with NF2. The hallmark of NF2 is benign tumours that occur on hearing and balance nerves called vestibular schwannomas. Schwannomas are benign tumours occurring on cranial, spinal and peripheral nerves. Tumours including meningiomas occur on the lining of the brain and spine and ependymomas are found in the brain and spinal cord. Visual

impairment may occur but skin signs are less prominent. Currently treatment of NF1 and NF2 involves regular monitoring and treating any problems as they occur, including the use of novel drugs to reduce the size of schwannomas and diffuse neurofibromas.

Our service

Guy's and St Thomas' NHS Foundation Trust is one of the few organisations providing care for children and adults with complex and non complex NF1, NF2 and schwannomatosis. We are the UK's leading centre for complex NF1 along with Manchester University NHS Foundation Trust. Individuals with complex NF1 have rare or potentially life threatening complications that often do not receive appropriate management by non-specialist services. We are one of four national centres for NF2 (along with Manchester, Cambridge and Oxford). We are an internationally recognised centre for the diagnosis of malignant peripheral nerve sheath tumours (MPNST) in NF1.

Our neurofibromatosis team includes consultants who are specialists in a range of disciplines to meet the complex needs of our patients. We have built a psychiatry and psychology support service to improve patient's quality of life and to work closely with clinicians, physiotherapists and clinical nurse specialists to provide lifelong holistic care for our patients. Our clinical nurse specialists support patients when they come to clinic and are also available to give advice via telephone and email.

Patient experience and outcomes

Our service was commissioned in 2009 and is continually audited and evaluated, including the production of an annual report which is produced jointly with colleagues from Manchester and reviewed by NHS England (who commission this service). Results from the 2017–18 review show the following number of patient attendances:

Table 6 | New and follow up activity data for patients with NF1

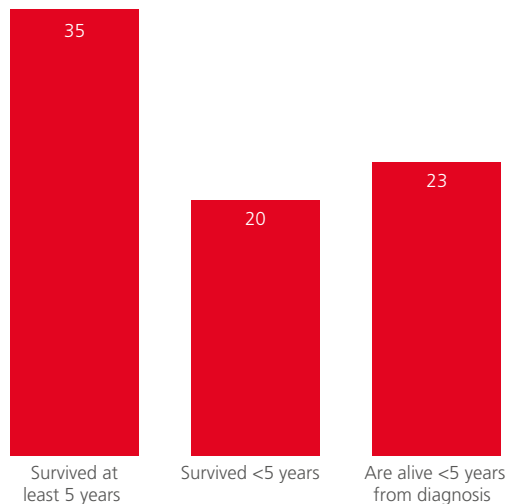
		Number of patients	Number of visits
Complex NF1 patients	All patients new	79	79
	All patients follow up	363	486
Complex NF1 patients	All patients new adults >18	25	25
	All patients follow up adults >18	231	345
Non-complex NF1 patients	All patients new	277	277
	All patients follow up	877	1,058

The predominant cause of death since 2009 has been cancer including malignant peripheral nerve sheath tumours and this reflects the fact that NF1 is a tumour suppressor disease.

Figure 47 | Cause of death of 55 complex NF1 patients between 2009 and 2018



Figure 48 | Survival rates for Malignant Peripheral Nerve Sheath Tumours (MPNST) between 2009 and 2016



These survival rates are higher than the early published figures of ~20%. This has been accomplished by increased education and awareness amongst people with NF1, and increased recognition of these tumours in the medical population. The judicious use of 18 fluorodeoxyglucose (FDG) PET CT allows the identification of potentially malignant lesions. We still cannot influence the outcome of some patients presenting with high grade lesions. To support the appropriate management of MPNST, Guy's and St Thomas' NHS Foundation Trust have helped develop international treatment guidelines.

Involvement with patients and patient groups

Our team have built extensive links with patients and patient groups to improve the quality of care in NF1. Patient involvement increases knowledge of NF1, promotes independence and self-esteem and fosters links with people coping with similar problems and adjusting to chronic illness.

Examples include:

- one to one educational session for all new patients
- educational days/workshops for teenagers, adults, older adults
- focus sessions – mindfulness; pain; changing faces; headaches
- informal meeting and mutual support during clinics
- patient educator to teach medical students and administration team
- focus group of patients to develop our service
- carers groups
- leaflets on headache, pain toolkit, needle phobia and suicide

- national education sessions/webinars for patients with limited access to specialist clinics
- links with Nerve Tumours UK (the charity offering support to people with neurofibromatosis).

Case study: Developing outcomes tools to drive improvement

We have developed a disease specific patient focused quality of life questionnaire to evaluate therapy – the Impact of NF1 on Quality of Life (INF1-QOL) questionnaire.

INF1-QOL is a validated, reliable disease specific questionnaire that is quick and easy to complete. It reflects the patient perception of disease related quality of life and correlates moderately well with clinician rated disease severity. Patient focused outcomes are essential in the context of evaluating novel therapy. A drug will be of limited benefit, if for instance, it reduces tumour size, but the patient perceives no improvement of quality of life. For patients it is helpful in monitoring quality of life in the clinic setting as well as a disease outcome measure in clinical trials and therapeutic intervention.

Research and innovation

Our teams are committed to the research of neurofibromatosis types 1 and 2, in collaboration with other national and international neurofibromatosis specialists. We are participating in an international study of the natural history of NF1 associated optic pathway glioma (which impairs vision), which will evaluate the best way to diagnose and treat this tumour.

We are involved in producing outcome measures to evaluate novel therapy, see case study. This includes motor outcomes and quality of life in neurofibromatosis – we are assessing the impact of complex inherited diseases on quality of life.

We are evaluating current diagnosis, treatment and outcome of NF1 related malignant peripheral nerve sheath tumours.

The influence of our staff

Our clinical team has been recognised for its expertise. The team includes a recipient of the European Theodor Schwann award for contributions to Neurofibromatosis who was also the London lead for NF2 from 2010–2014 and is the national lead for the multidisciplinary Complex Neurofibromatosis 1 service. Our clinicians also hold positions with national bodies such as the medical advisory board for Nerve Tumours UK and the British Association for the Study of Headache (BASH).



Neuropsychiatry

Neuropsychiatry

Introduction

Neuropsychiatry sits at the interface of psychiatry and neurology. It is the only mental health service that sits within a non-psychiatric Clinical Academic Group within King's Health Partners and serves as an example of how mind and body is embedded in all of our pathways.

Our services

Our neuropsychiatry service manages the psychological complications of neurological disorders. This includes psychiatric complications of epilepsy, Tourette's syndrome, movement disorders and other neurological disorders, including: early onset dementias and other memory disorders; depersonalisation; conversion and dissociative disorders, including non-epileptic seizures and other somatoform disorders. Our services are provided on an out-patient, day case or inpatient basis:

- inpatient services at the Lishman Unit for the treatment of patients with Functional Neurological Disorders and brain injury
- day hospital programme: Functional integrated Neurological Disorders (FiND) out-patient day programme.
- out-patient clinics:
 - King's College Hospital
 - Maudsley Hospital
 - Specialist clinics
 1. Neuropsychiatry and memory disorders clinic at St Thomas' Hospital
 2. Depersonalisation disorder clinic
 3. Complex functional disorders clinic
 4. Deep Brain Stimulation (DBS) multidisciplinary team (MDT) clinic – using DBS innovatively
- out-patient cognitive behavioural therapy treatment
- liaison services at King's College Hospital and St Thomas' Hospital.

Figure 49 | Occupational therapy at the Lishman Unit



Patient experience and outcomes

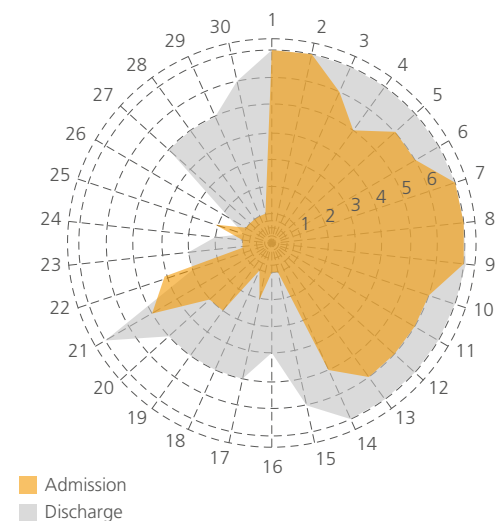
Outcomes for the inpatient Lishman Unit

The Lishman Unit participates in the UK Rehabilitation Outcomes Collaborative (UK ROC).

Data collected includes functional gain (FIM+FAM) scores. The Functional Independence Measure (FIM) is an 18 item measure of disability with each item being scored between one and seven. The Functional Assessment Measure (FAM) enhances FIM with an additional 12 items also scored between one and seven largely looking at cognitive and psychosocial function. Higher scores indicate greater independence/less disability. See figure 57, page 122 for a full description of each indicator.

Outcomes show significant reductions in dependency between admission and discharge on all measures.

Figure 50 | FIM-FAM results 2018/19 for the Lishman Unit (based on 11/01/19 data submission)



Note: 2018/19 number of admissions = 6, number of discharges = 5.

Table 7 | FIM-FAM results for the Lishman Unit

Functional gain (FIM+FAM scores)	2016/17	2017/18	2018/19	Total
% reported	100%	89%	100%	94%
Motor score on admission (mean)	84	86.9	87	86
Motor score on discharge (mean)	94.9	90.7	100.4	93.5
Motor gain during episode (mean)	10.9	3.8	13.4	7.5
Cognitive score on admission (mean)	38.4	43.7	35.6	40.8
Cognitive score on discharge (mean)	57.4	55.5	54.6	56
Cognitive gain during episode (mean)	19	11.8	19	15.2
FIM+FAM efficiency (median)	0.2	0.1	0.2	0.1
FIM+FAM efficiency (pop.mean)	0.2	0.1	0.2	0.1

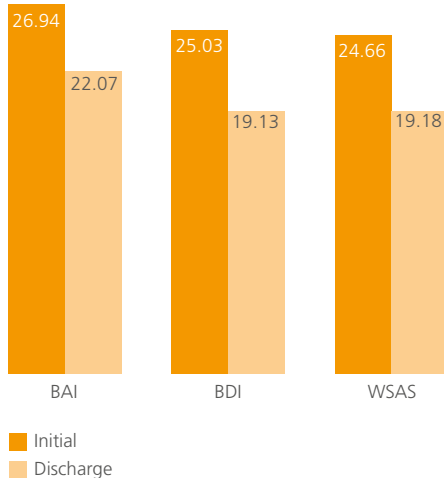
Studies have shown that often the level of cognitive function of patients at admission will affect their rehabilitation outcomes. The scores on admission are also a good predictor of expected gains or improvements. FIM + FAM efficiencies measure the time taken to offset the cost of rehabilitation by savings in ongoing care.

Outcomes from the Functional integrated Neurological Disorders out-patient day programme

The following charts show improved results for the previous cohorts of patients entering and completing the FiND programme (approximately eight patients per cohort, noting completion rate is less than 100%).

Psychology outcome measures were averaged for patients in Cohorts 1–13, as shown in Figure 51.

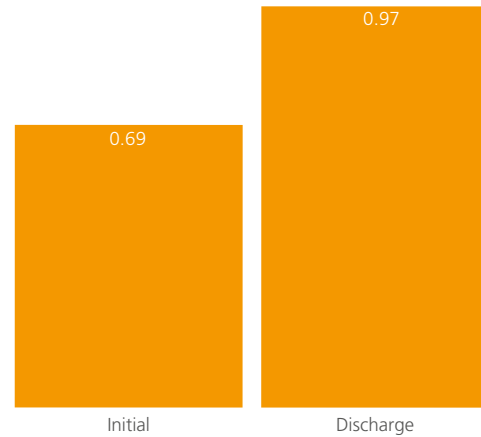
Figure 51 | Psychology outcomes



BAI = Beck Anxiety Inventory. Maximum score is 63 and lowest is 0. Lower scores indicate lower levels of anxiety.
 BDI = Beck Depression Inventory. Maximum score is 63 and the lowest is 0. Lower scores indicate lower levels of depression.
 WSAS = Work and Social Adjustment Scale. Maximum score is 40 and lower scores are better.
 N = 50 patients
 BAI Max 56. Min 0. Range = 56.
 BDI Max 60. Min 0. Range = 60.
 WSAS Max 38. Min 0. Range = 38.

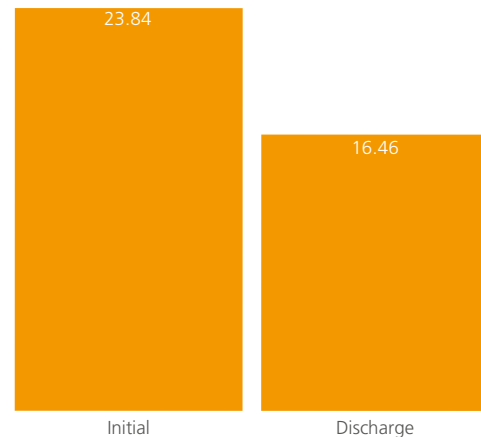
Physiotherapy outcome measures were averaged for Cohorts 6–13 only, due to a change in the way outcome measures were collected. Results for a range of outcome measures are shown in Figures 52 to 56.

Figure 52 | 10 metre walk test (average walking speed shown in metres per second)



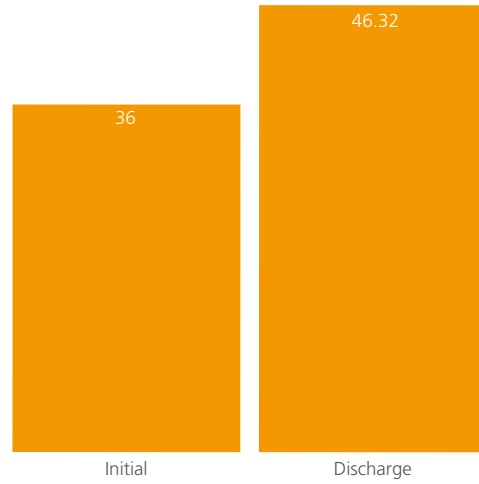
N = 23 patients
 Max 1.37m/s. Min 0.00m/s. Range = 1.37m/s.

Figure 53 | Timed up and go test (average time taken to complete task)



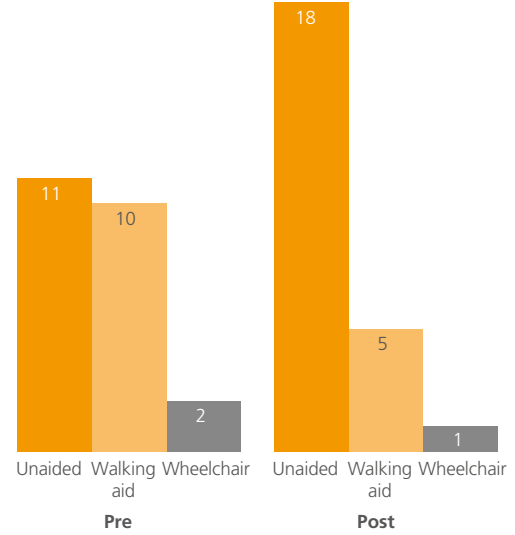
N = 23 patients
 Max. 165s. Min 0s. Range = 165second.

Figure 54 | Berg balance scale



N = 23 patients
Max 56. Min 9. Range = 47.

Figure 55 | Mobility aids – level of need



N = 23 patients

Case study: Patient story from the Functional integrated Neurological Disorders out-patient programme

I had suffered for 18 years with Dystonia and Nonepileptic symptoms (NES) which impacted mine and my family's life immensely and it affected my day to day living. I felt that I was defined by the condition as it had so much control over my every decision each day. The choices I made about what I could or couldn't do were not because I wanted them but because it governed each aspect of my life. From the simplest task of washing up, to walking the dog, to eating out with my friends or family, every moment was like walking on egg shells. The pain as well would be exhausting and then the seizures would be debilitating and embarrassing if I was out. I felt too vulnerable to be out on my own and so became a prisoner of my house. My confidence shattered and so depression then became my new friend.

When I was recommended to try the FiND programme I knew that after so many years I had nothing to lose. Finally, there were people who didn't judge but had the 'know how' to help. The programme was hard work, intense but so fulfilling. From the physical exercise to the psychological teachings...I began to get stronger in mind and body and therefore the tools I gained in dealing with and controlling my symptoms unlocked the real me and I began to feel whole again.

Nothing prepared me for the turn around in my life. I am able to do pretty much all the things I couldn't do before with the confidence and independence I had lost over the years.

I continue with exercise, I can now drive plus most importantly I am able to go out on my own without feeling so vulnerable.

Research and innovation

Our neuropsychiatrists are research active, and a couple of examples of research are set out in the Research in Focus section (page 166).

Case study: Development of a novel treatment for motor Functional Neurological Disorder (FND), using Transcranial Magnetic Stimulation

There has been steadily accumulating evidence for the potential therapeutic application of Transcranial Magnetic Stimulation (TMS) for motor FND – patients with limb weakness that is not due to organic disease and previously labelled psychogenic weakness or ‘conversion’ disorder. Such patients are common and there are few evidence-based treatments and consequently outcomes are poor. Through the ‘TONICS’ trial we have completed the feasibility study and are starting the larger pilot study. The trial compares ‘active’ TMS that stimulates movement of the affected limb to ‘inactive’ TMS that does not induce movement of the limb. The feasibility study indicates that the transcranial magnetic stimulation seems to be acceptable to patients in that it is safe and well tolerated. The upcoming pilot study will assess efficacy in more detail. It is hoped that early interventions such as this can significantly improve recovery for this patient group.

Education and training

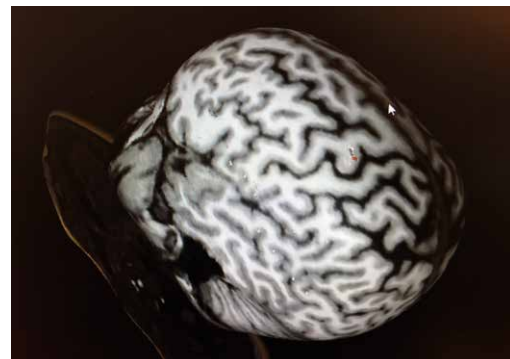
As recognised national field leaders in a number of areas including Parkinson’s disease/Deep Brain Stimulation, Non Epileptic Attack Disorder (NEAD), depersonalisation, memory and Tourette’s we contribute to lectures and conferences, in addition to designing and delivering graduate education, providing training placements and supervision.

Recently we held a masterclass on Functional Neurological Disorders (FND) to give staff across King’s Health Partners greater confidence in diagnosing and managing patients with FND. Evaluation showed the following:

- Overall rating – 90% rated the masterclass as excellent or very good

- Met training needs – 88% rated the masterclass as excellent or very good.

Figure 56 | Transcranial magnetic stimulation shows the area of the brain responsible for hand movement (red dot) mapped on to an MRI scan. This allows completely non invasive stimulation and mapping of the brain.



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Neurorehabilitation

Neurorehabilitation

Introduction

Rehabilitation focuses on the impact that the health condition, developmental difficulty or disability has on the person's life, rather than focusing just on their diagnosis. It involves working in partnership with the person and those important to them so that they can maximise their potential and independence and have choice and control over their own lives. It is a philosophy of care that helps to ensure people are included in their communities, employment and education rather than being isolated from the mainstream (Commissioning Guide for Neurorehabilitation, March 2016).

Although it is often attributed to the end of a treatment pathway, rehabilitation intervention can have significant impact as a preventative measure. For example:

- exercise post-stroke has been shown to reduce the risk of a further vascular event.

- advice and support directed towards smoking cessation, physical activity, obesity management, and maternal and child nutrition reduces the risk of adult cardiovascular disease.
- if accessed at an earlier stage in the pathway, prehabilitation intervention (such as prior to surgery) can improve functional outcomes, reduce length of hospital stay and enable timely return to work or occupation.
- both prevention and prehabilitation are powerful tools for achieving a good outcome for individuals.

In the rehabilitation service we focus on health and wellbeing as a core aspect of the rehabilitation programme. We use an adaptive approach to maximise participation in physical activity using specialist equipment where required.

Our service

We provide a portfolio of neurorehabilitation services, including: intensive inpatient neuro-rehabilitation, community based services and a neuro-navigation service, which are delivering improved outcomes.

Specialist inpatient rehabilitation is provided at Orpington Hospital (15 level 1b beds on the Frank Cooksey Rehabilitation Unit and 14 level 2b beds on Ontario Ward) and at the Pulross Centre, Brixton (six level 2b beds). Intensive rehabilitation includes help with learning how to regain as much personal independence and confidence as possible improving mobility, self-care and supporting return to work or valued activity. Our large multi-disciplinary team includes neurorehabilitation doctors, specialist nurses, physiotherapists, speech and language therapists, occupational therapists, specialist social workers, psychologists and dieticians. They work together to help patients make the transition from hospital to home and onward to community reintegration and return to work where possible. Our aim is to maximise the impact of rehabilitation.

We also provide spasticity services for south east London and Kent, including the Regional Intrathecal Baclofen Service and Specialist Multidisciplinary Rehabilitation Clinic.

We are also commissioned to provide community neurorehabilitation services for the boroughs of Lambeth and Southwark, as well as the South East London Neuro navigation service, which covers six boroughs.

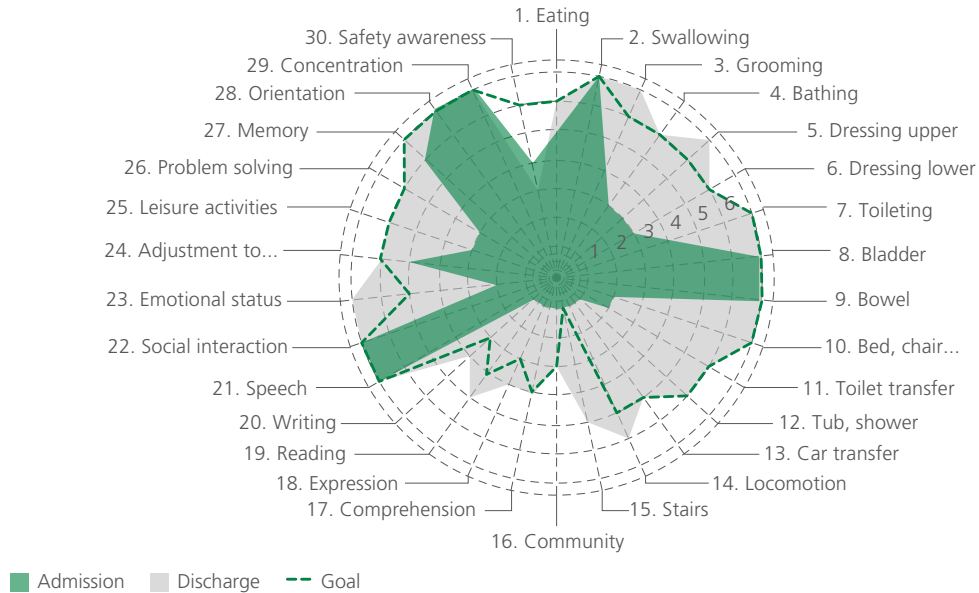
These services have strong links with the Lishman Unit, run by South London and Maudsley NHS Foundation Trust, which cares for patients with neuropsychiatric manifestations of acquired brain injury – see the Neuropsychiatry section (pages 112 to 118) for further details.

Patient experience and outcomes

UK Rehabilitation Outcomes Collaborative (UK ROC) outcomes

Data collected as part of the UK Rehabilitation Outcomes Collaborative is a key source of outcomes data, using the Functional Independence Measure (FIM) and Functional Assessment Measure (FAM). A description of these measures is given on page 113.

Figure 57 | An example of admission, goal and discharge scores for an individual



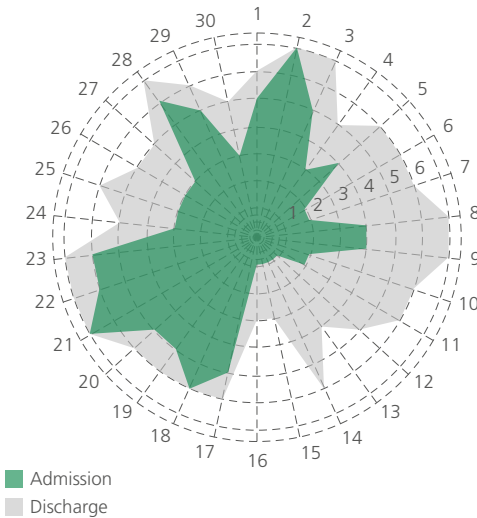
Service FIM-FAM results

Alongside reviewing progress for individual patient outcomes, our teams review overall outcomes monthly and critically reflect on the results for patient care and service development. These scores show a year on year improvement in patients’ motor and cognitive gains.

FIM-FAM results for the level 1b beds in the Frank Cooksey Rehabilitation Unit (FCRU), Orpington Hospital

The UK ROC outcomes data show that patients admitted to the unit achieve significant improvement, in both physical and motor gains.

Figure 58 | FIM-FAM results for Frank Cooksey Rehabilitation Unit 2018/19



Note: 2018/19 number of admissions = 33, number of discharges = 35.

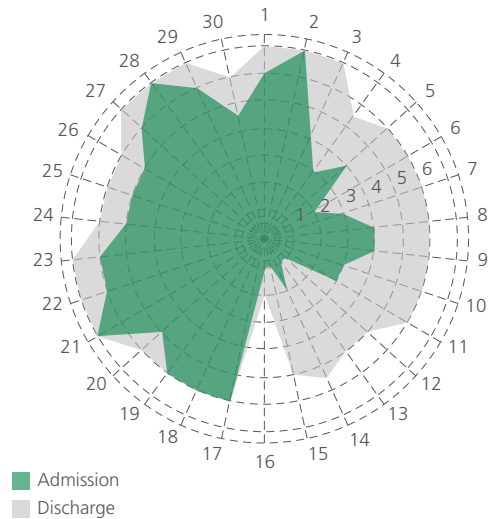
Table 8 | FIM-FAM results for Frank Cooksey Rehabilitation Unit (based on 14/01/19 submission)

Functional gain (FIM+FAM scores)	2016/17	2017/18	2018/19	Total
% reported	96%	89%	100%	95%
Motor score on admission (mean)	45.7	45.5	46.8	45.9
Motor score on discharge (mean)	67.5	75.1	78.5	73
Motor gain during episode (mean)	21.8	29.6	31.7	27.1
Cognitive score on admission (mean)	60.8	63.4	63.7	62.5
Cognitive score on discharge (mean)	71.6	75.6	77.1	74.4
Cognitive gain during episode (mean)	10.8	12.2	13.3	12
FIM+FAM efficiency (median)	0.4	0.3	0.4	0.4
FIM+FAM efficiency (pop.mean)	0.4	0.4	0.4	0.4

FIM-FAM results for the level 2b beds (Ontario Ward and Pulross neurorehabilitation beds)

Data show that patients admitted to the 2b inpatient service achieve a significant measurable gain in physical and cognitive function, as shown in the FIM/FAM scores for Ontario Ward (Orpington Hospital) and the Pulross Centre (Brixton), since they became operational in 2016/17.

Figure 59 | FIM-FAM results 2018/19 for Ontario Ward (based on 14/01/19 data submission)

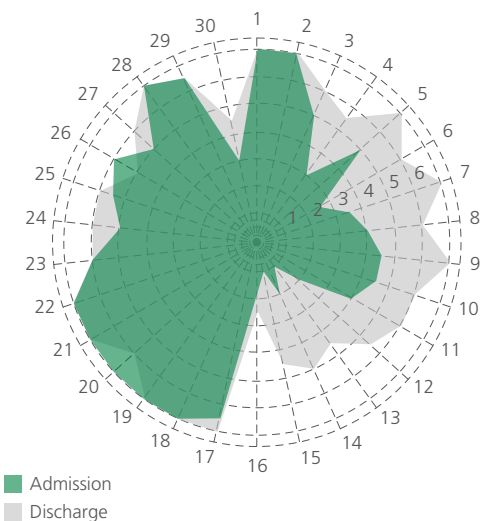


Note: 2018/19 number of admissions = 47, number of discharges = 51.

Table 9 | FIM-FAM results for Ontario Ward

Functional gain (FIM+FAM scores)	2016/17	2017/18	2018/19	Total
% reported	86%	95%	94%	92%
Motor score on admission (mean)	68.5	61.1	55.1	61
Motor score on discharge (mean)	94.4	83.7	80.7	85.3
Motor gain during episode (mean)	25.9	22.7	25.5	24.3
Cognitive score on admission (mean)	74.1	75.7	73.3	74.6
Cognitive score on discharge (mean)	87.8	84.3	81.7	84.3
Cognitive gain during episode (mean)	13.7	8.6	8.4	9.7
FIM+FAM efficiency (median)	0.7	0.4	0.5	0.5
FIM+FAM efficiency (pop.mean)	0.6	0.5	0.5	0.5

Figure 60 | FIM-FAM results for Pulross neurorehabilitation beds



Note: 2018/19 number of admissions = 13, number of discharges = 8.

Table 10 | FIM-FAM results for Pulross neurorehabilitation beds

Functional gain (FIM+FAM scores)	2016/17	2017/18	2018/19	Total
% reported	92%	92%	100%	93%
Motor score on admission (mean)	62.9	56.3	57.4	57.8
Motor score on discharge (mean)	84.9	74.2	82.4	77.6
Motor gain during episode (mean)	22	17.8	25	19.7
Cognitive score on admission (mean)	69.5	64.7	78.2	67.7
Cognitive score on discharge (mean)	80.4	75	84.8	77.5
Cognitive gain during episode (mean)	10.9	10.3	6.5	9.8
FIM+FAM efficiency (median)	0.6	0.6	0.8	0.6
FIM+FAM efficiency (pop.mean)	0.7	0.5	0.6	0.6

Patient experience

Alongside King's College Hospital NHS Foundation Trust's standard patient experience questionnaire the team at Orpington Hospital collect experience data from patients at the point of discharge, using the Neurorehabilitation Patient Experience Questionnaire (NREQ).

Figure 61 | Neurorehabilitation Patient Experience Questionnaire (NREQ) results



Figure 62 | Neurorehabilitation Patient Experience Questionnaire (NREQ) – patient satisfaction with levels of therapy

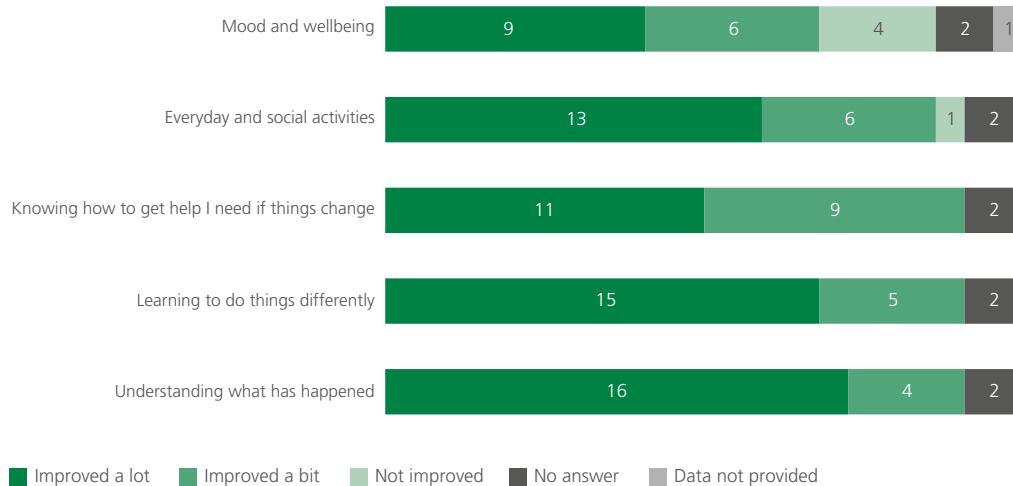


Evaluating our recently established level 2b beds

14 beds in Ontario Ward at Orpington Hospital opened in July 2016 and a further six beds at the Pulross Centre opened in October 2016. Feedback from patients across the service has been collated and reflects a positive patient experience. The services have analysed the data to highlight good practice as well as identifying any areas for improvement.

From July 2016 to July 2017, 100 patients provided feedback about Ontario Ward – of these, 96% would be extremely likely or likely to recommend Ontario Ward to their friends and family. Of the 90 comments received, 81 were entirely positive, eight were mixed and there was only one negative comment. All three of the patients who took part in the in-depth interview felt they had made significant progress since being on Ontario Ward and their comments reinforced the positive feedback from the surveys about staff attitude and professionalism.

Figure 63 | Patient Satisfaction Questionnaire results for the Pulross neurorehabilitation beds



Neuronavigation service

Our recently established Neuronavigation service is already demonstrating an impact. Our neuronavigators are specially trained therapists who work closely with ward staff, specialist centres and social care providers to get patients the right rehabilitation service at the right time. In 2017 the service helped 360 patients move smoothly through the different levels of care, saving an estimated 4,800 bed days across several hospital and specialist rehabilitation centres in south east London.

Figure 64 | Home visit by one of our neuronavigators from Guy's and St Thomas' NHS Foundation Trust



Implementing new outcome measures

Case study: Measuring functional outcome for acquired brain injury across the rehabilitation pathway from inpatient to community

We have introduced and piloted the Mayo-Portland Adaptability Inventory (MPAI-4) and the Mayo-Portland Participation Index (M2PI) which measures the recovery pathway from improvement in specific impairments to functional restoration. It is a measure which encourages partnership with patients and their families focussing on outcomes such as independence, return to work and improved interpersonal relationships. Data collection is at the early stages across our range of rehabilitation services, and the data will be analysed and used to identify service priorities and unmet need.



Spinal surgery

Spinal surgery

Introduction

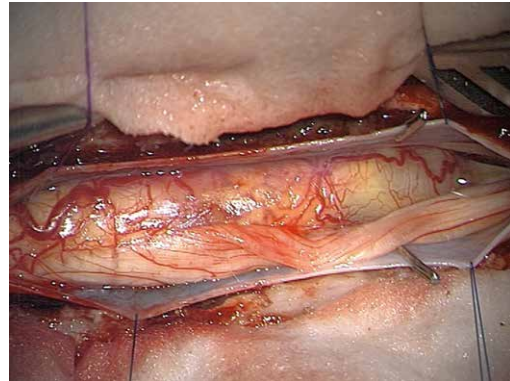
Disease of the spine may cause axial back or neck pain, or symptoms of nerve or spinal cord irritation, such as pain, numbness or weakness radiating down the leg or arm. Spinal disorders are very common and are largely treated non-operatively. Pain or neurological symptoms may be caused by degenerative conditions, deformity, infection, trauma and tumours. Back pain affects around 80% of people in the UK at some point in their lives and £48 billion is spent each year on medical treatment, medication, benefits and lost productivity (British Spine Registry website, January 2018).

Our service

The Regional Neurosurgical Unit at King's College Hospital provides a specialist spinal service for people living in south east London and Kent. Our team includes neurosurgeons, physiotherapists, pain specialists, neuroradiologists and spinal clinical nurse specialists, enabling us to offer a wide range of treatments and provide the best possible patient care.

We have five neurosurgeons who specialise in complex spinal surgery and the treatment of spinal injuries. We also have a joint complex spine clinic which enables the team to discuss the best treatment options for each patient.

Figure 65 | Intraoperative image of a spinal cord tumour (the pale area on the right of the image). The spinal canal has been opened from behind to expose the spinal cord.



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Patient experience and outcomes

In recent years we have focused on improving our patient experience, by tackling long waits for planned spinal surgery and redesigning patient pathways through the establishment of a Regional Spinal Network that covers south east London and Kent. This network is led jointly by a spinal neurosurgeon and an orthopaedic spine surgeon from King's Health Partners.

The main aims of the network are to:

- implement the 'National Back Pain Pathway' by transforming patient pathways so that patients are triaged, and treated where appropriate, by local musculoskeletal or pain services, prior to onward referral for surgery, rather than direct GP referral to a spinal surgeon as in many cases surgery is not the appropriate course of action for the patient
- new pathways will contribute to reduced waiting times for treatment, as patients will be referred to the most appropriate service earlier
- agree common policies and procedures for spinal services across the region
- build relationships across the region; clinicians and commissioners to enhance collaboration and partnership
- improve training opportunities for staff across the spinal pathway

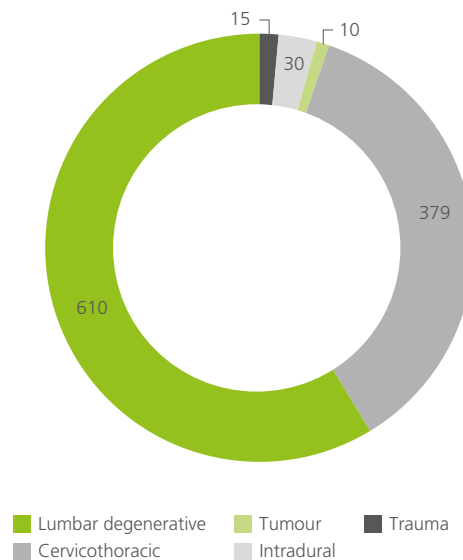
- more effective use of resources across the network.

Spinal surgery outcomes data

King's College Hospital is pioneering the way in the collection of outcomes data for spinal surgery, using the British Spine Registry (BSR), and in 2016/17 was one of only 20% of hospitals doing so.

We present here outcomes from the 1,040 cases registered at King's College Hospital during the year 01/04/2017–31/03/2018.

Figure 66 | Number of cases in each of the seven spinal pathways (2017/18)



1,040 patients have been registered by King's College Hospital since April 2017 with 176 patients to date having completed both pre and post-operative questionnaires about their health and symptoms. Patients in all pathways completed the EQ5D questionnaire, which measures multiple aspects of their general health and symptoms. Two summary measures can be extracted, called EQ5D index and EQ5D VAS; for both measures, with a range from 0 to 100, higher scores mean better health and fewer symptoms. King's College Hospital patients improved on both measures. National average benchmarks from 2016–17 data showed, on average registered patients from around the UK, an improvement of EQ5D Index from 0.4 to 0.62, and EQ5D VAS from 57.61 to 68.21. The charts below show comparable measures for King's College Hospital. King's College Hospital patients showed a similar level of improvement to the national average, but their overall health status before their operation was poorer than the national average. Comparisons to national performance should be made with caution given that only 20% of hospitals have submitted data to the BSR, and the data relate to different years.

Figure 67 | Changes in EQ5D Index for patients receiving spinal surgery at King's College Hospital

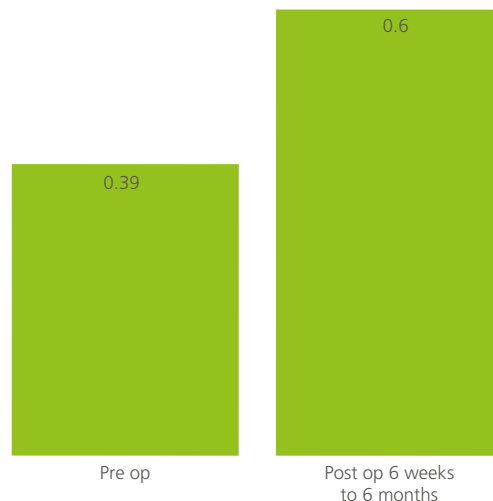
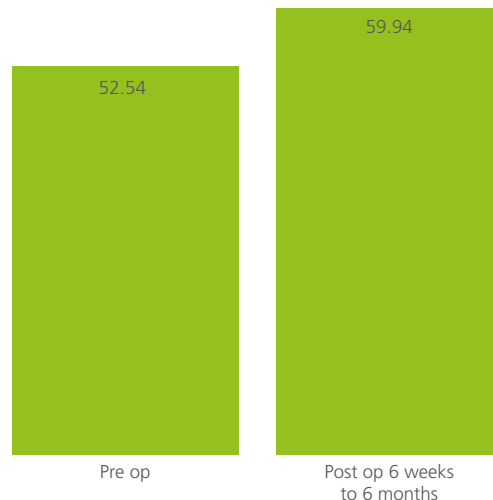


Figure 68 | Changes in EQ5D VAS for patients receiving spinal surgery at King's College Hospital



Outcomes of lumbar spine surgery

110 patients completed a set of questionnaires before and after lumbar spine surgery: Visual Analogue Scales (VAS) for Back Pain and Leg Pain (0 = no pain and 10 = extreme pain) and the Oswestry Disability Index (ODI) (percentage scale where 0–20% = minimal disability and 100% = extreme disability/bed dependent). National average benchmarks in 2016–17 showed an improvement in Back Pain VAS from 6.14 to 3.45; an improvement in Leg Pain VAS from 6.32 to 2.92; and an improvement on the ODI from 46.97 to 31. King’s College Hospital patients showed a similar level of improvement to the national average, but their overall health status before their operation was poorer than the national average.

It should be noted that the national data includes the combined outcomes of all lumbar operations ie degenerative, tumour, deformity and trauma whereas the King’s College Hospital data only includes operations for degenerative lumbar spine conditions.

Figure 69 | Changes in VAS – Back Pain for patients receiving lumbar spine surgery at King’s College Hospital

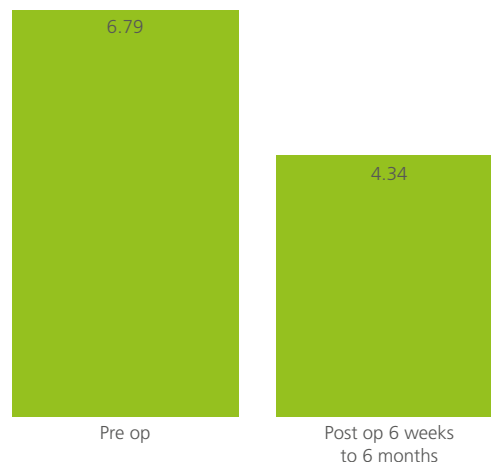


Figure 70 | Changes in VAS – Leg Pain for patients receiving lumbar spine surgery at King’s College Hospital

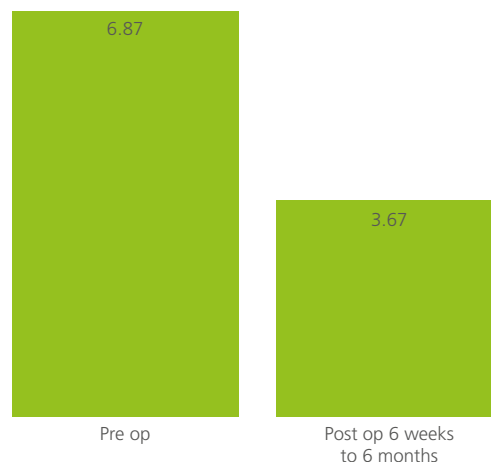
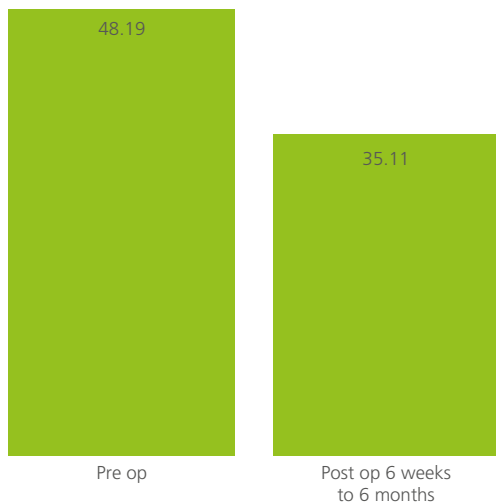


Figure 71 | Changes in Oswestry Disability Index (ODI) for patients receiving lumbar spine surgery at King's College Hospital



Oswestry disability scoring range	
0%–20%	Minimal disability
21%–40%	Moderate disability
41%–60%	Severe disability
61%–80%	Crippled
81%–100%	Bedbound or symptoms are exaggerated

Outcomes of cervical/thoracic spine surgery

A total of 58 patients completed a set of questionnaires before and after cervical or thoracic spine surgery: Visual Analogue Scales (VAS) for Neck Pain and Arm Pain (0 = no pain and 10 = extreme pain) and the Neck Disability Index – a functional disability index (0% = little or no disability and 100% = severe/extreme disability). The British Spine Registry report from 2016–17 does not provide specific benchmarking data for cervical or thoracic spine surgery. Nonetheless, King's College Hospital data demonstrates an improvement in all domains.

Figure 72 | Changes in VAS – Neck Pain for patients receiving cervical/thoracic spine surgery at King's College Hospital

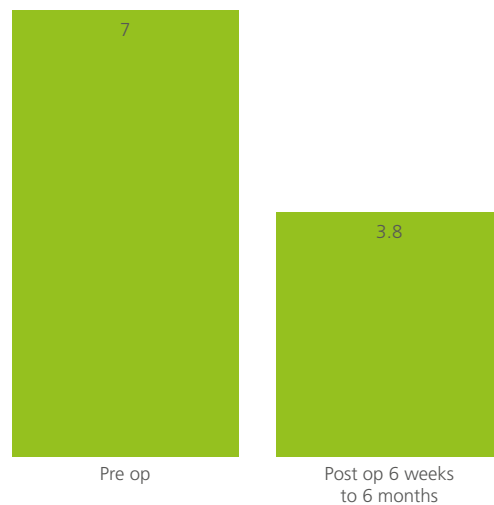


Figure 73 | Changes in VAS – Worst Arm Pain for patients receiving cervical/thoracic spine surgery at King's College Hospital

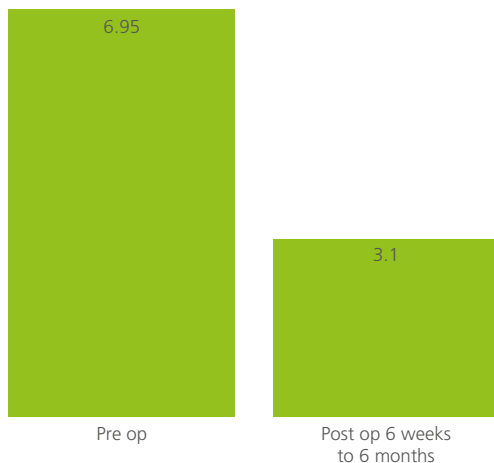
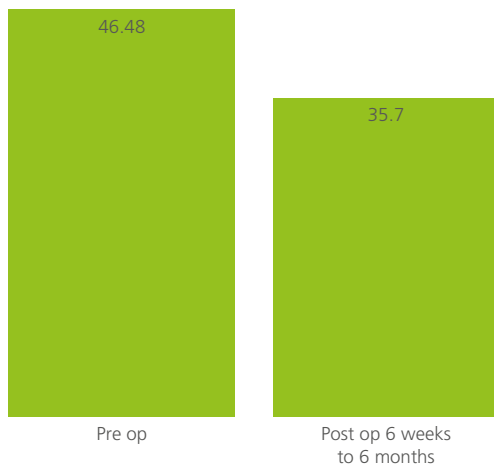


Figure 74 | Changes in Neck Disability Index (NDI) for patients receiving cervical/thoracic spine surgery at King's College Hospital



Research and innovation

We have particular strength in translationally-relevant experimental science in spinal cord injury. We highlight here two recent studies:

Largescale chondroitin sulfate proteoglycan digestion with chondroitinase gene therapy leads to reduced pathology and modulates macrophage phenotype following spinal cord contusion injury

Journal of Neuroscience, 2014. Bartus, K., James, N.D., Didangelos, A., Bosch, K.D., Verhaagen, J., Yáñez-Muñoz, R.J., Rogers, J.H., Schneider, B.L., Muir, E.M., Bradbury, E.J.

Spinal cord injury can be devastating. Following the initial injury, structural molecules of the normal spinal cord, chondroitin sulfate proteoglycans, inhibit repair mechanisms and allow additional injury through inflammation. In this study in rats with spinal cord injury, recovery was enhanced by a viral vector-delivered enzyme, chondroitinase ABC, which breaks down chondroitin sulfate proteoglycans. Secondary damage to spinal cord was significantly reduced and there was long-term improved functional outcome.

Immune-evasive gene switch enables regulated delivery of chondroitinase after spinal cord injury

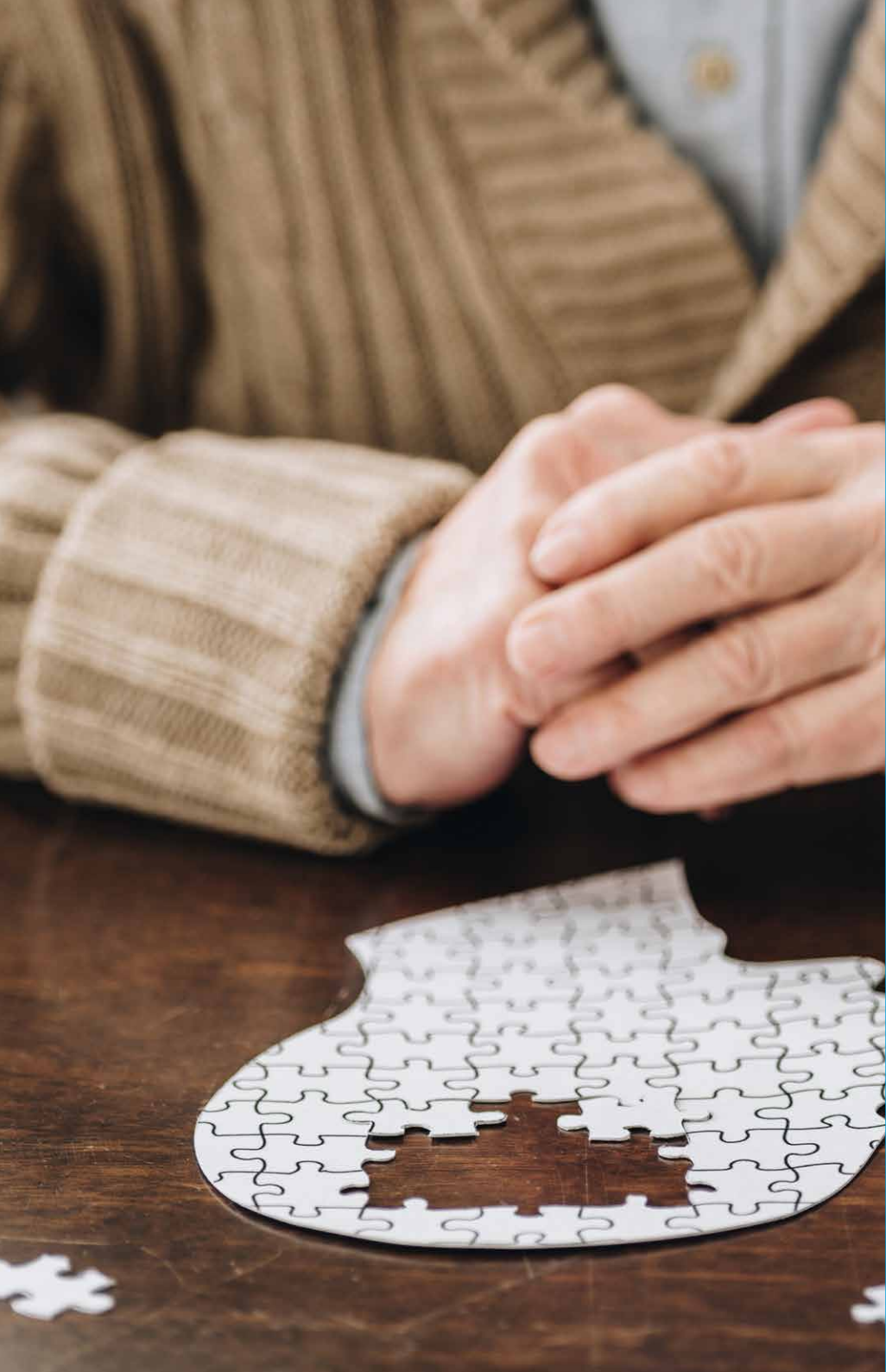
Brain, 2018. Burnside E.R., De Winter F., Didangelos A., James N.D., Andreica E.C., Layard-Horsfall H., Muir E.M., Verhaagen J., Bradbury E.J.

Following on from the above study, the same team led work to develop a viral-delivered gene therapy treatment for rats with spinal cord injury. Using a novel immune-evasive delivery system, the researchers found that the gene therapy significantly enhanced recovery of function. Future studies in humans are needed.

Education and training

Redesigning care pathways as part of the Regional Spinal Network required a wide range of educational activity, including:

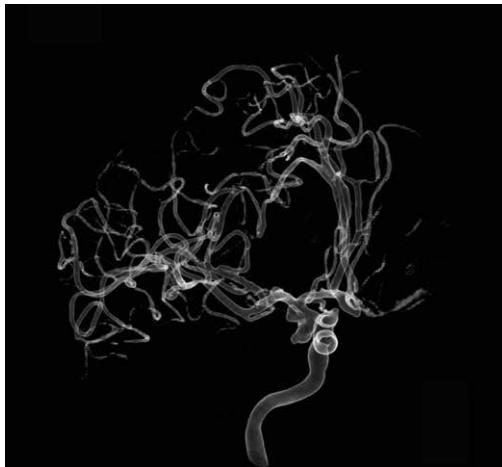
- GP education events throughout south east London and Kent
- secondary care educational events to inform rheumatology, neurology and pain consultants of the planned changes to referral patterns
- a full training needs analysis of front-line MSK advanced practitioners (n=52) working across south east London and Kent was undertaken. In response to the findings, a 'Spinal Triage' course is being developed to meet these needs (currently in the process of accreditation through King's College London, 30 credits at level 7).



Stroke (cerebrovascular disease)

Stroke (cerebrovascular disease)

Figure 75 | Digital subtraction angiogram showing the internal carotid and anterior and middle cerebral arteries supplying the brain. An aneurysm is seen at the bottom of the image to the left of the main vessel. The transparent display is used to plan the placement of coils in the aneurysm.



© Dr J Hart

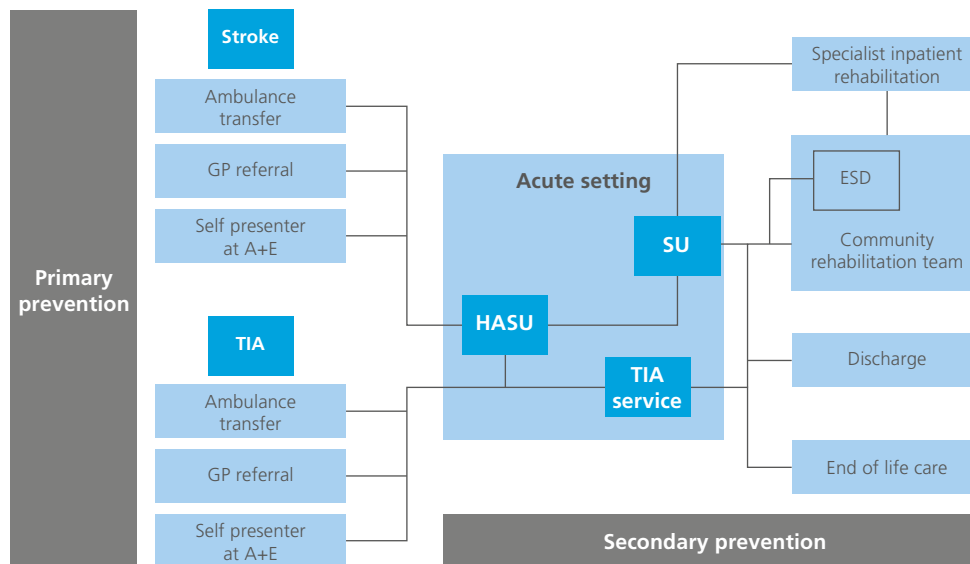
Introduction

There are more than 100,000 strokes in the UK each year; which equates to one stroke every five minutes. There are over 1.2 million stroke survivors in the UK. Stroke is the fourth single leading cause of death in the UK (Stroke Association, State of the Nation Stroke Statistics, January 2017).

Our service

Since late 2009 stroke services across London have been reorganised to ensure optimum care, and we have been instrumental in delivering such change. Figure 76 shows the current pathway, and we deliver care in the acute and post-acute phase.

Figure 76 | The pan-London stroke pathway



We have two of London’s eight Hyper Acute Stroke Units (HASUs): one at King’s College Hospital and one at Princess Royal University Hospital. Both sites also have Stroke Units (SUs), which are part of a network of 20 sites across London offering acute rehabilitation for stroke patients. Our services are highly multidisciplinary and involve doctors, nurses and a wide range of therapists to support patients on their journey to recovery. We continue to evolve our services as new drugs and techniques are developed and we are currently offering thrombectomy from 9am – 5pm, Monday to Friday. Out of hours we have an excellent transfer service to St George’s University Hospitals NHS Foundation Trust.

Guy’s and St Thomas’ NHS Foundation Trust provides specialist community stroke rehabilitation services in Lambeth and Southwark for up to 12 weeks offering a seamless transfer of care from acute to community setting. Offering a multi-disciplinary team approach to care, the teams consist of rehabilitation support workers who can provide rehabilitation seven days per week (for up to six weeks), and includes Occupational Therapists, Physiotherapists and Speech and Language Therapists. The service delivers reviews of stroke patients six months after a stroke and in Lambeth has a stroke specific information and advice service.

The Stroke Unit at Guy's and St Thomas' NHS Foundation Trust is part of the Medicine and Integrated Care CAG and therefore outcomes and research for this service have not been reported here.

Patient experience and outcomes

Mortality data for our stroke services is shown earlier, on page 31.

Sentinel Stroke National Audit Programme (SSNAP)

Stroke services are well audited at a national level through the Sentinel Stroke National Audit Programme (SSNAP) which is the single source of stroke data in England, Wales and Northern Ireland. The clinical audit collects a minimum dataset for stroke patients in every acute hospital, and follows the pathway through recovery, rehabilitation, and outcomes at the six month assessment. Overall results for our HASUs and SUs are shown in Table 11, based on scores across 44 indicators, adjusted for case ascertainment and audit compliance.

Table 11 | Overall SSNAP ratings for King's Health Partners Neurosciences' Hyper Acute Stroke Units (HASUs) and Stroke Units (SUs)

Timeframe	King's College Hospital – overall		Princess Royal University Hospital – overall	
	HASU	SU	HASU	SU
July–Sept 2018	A	A	B	B
April–June 2018	A	B	B	B
Dec–Mar 2018	C	B	B	C
Aug–Nov 2017	B	B	B	C
April–July 2017	A	B	A	C
Dec–Mar 2017	B	B	A	C
Aug–Nov 2016	A	C	A	B
Apr–July 2016	A	B	A	B
Jan–Mar 2016	A	B	A	B
Oct–Dec 2015	A	A	A	B
July–Sept 2015	A	A	A	A
April–June 2015	B	B	A	C
Jan–Mar 2015	B	B	B	B

Source: The Sentinel Stroke National Audit Programme, Summary Performance Reports, 2015–2018.

A = First class service

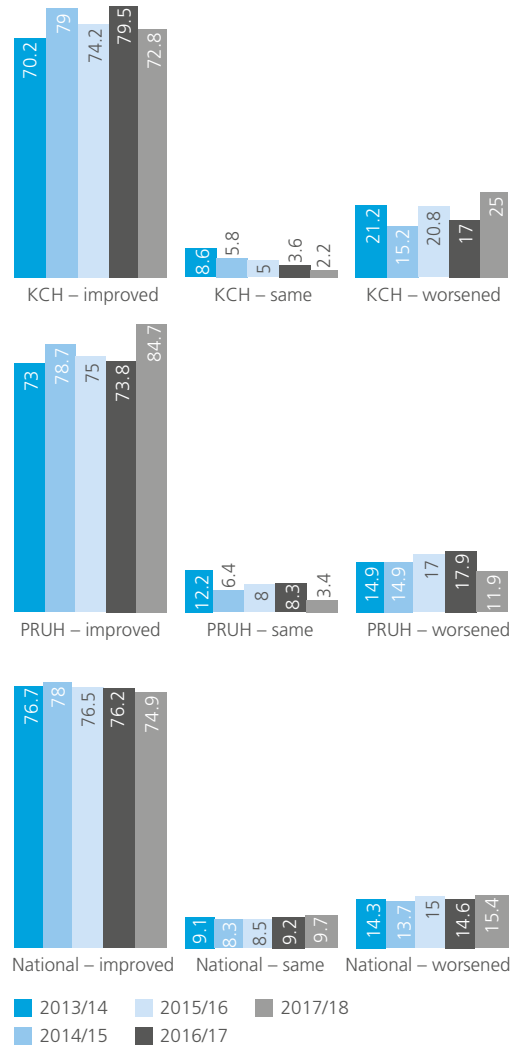
B = Good or excellent in many parts

C = Reasonable overall – some areas require improvement

D = Several areas require improvement

E = Substantial improvement required

Figure 77 | Changes in NIHSS from arrival to 24 hours after thrombolysis (shown as a percentage of all patients)



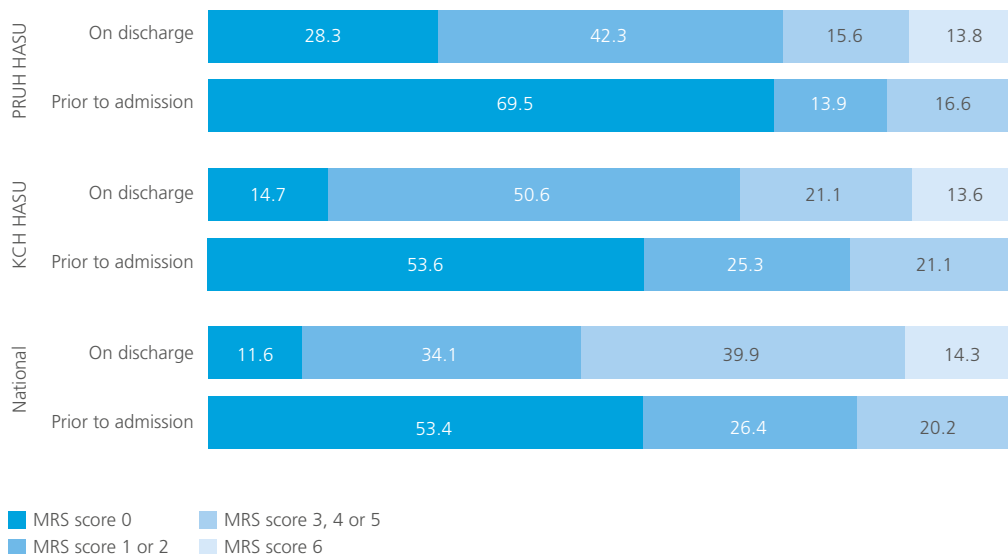
The National Institutes of Health Stroke Scale (NIHSS) is a systematic assessment tool that provides a quantitative measure of stroke-related neurologic deficit.

Figure 77 shows the performance attributed to the teams at our two HASUs, compared to national results.

A measure collected across the pathway is the Modified Rankin Scale (mRS) score. This measures the degree of disability or dependence in the daily activities of people who have suffered a stroke or other causes of neurological

disability. We would like to be able to join the data up and understand performance across a patient's whole pathway, rather than the measures at an organisational level.

Figure 78 | Comparison of Modified Rankin Scores prior to admission compared to on discharge from the HASUs 2017/18



Source: The Sentinel Stroke National Audit Programme, Summary Performance Reports, 2017–2018.

Note: mRS scores of 6 are interpreted from the data.

0 – No symptoms.

1 – No significant disability. Able to carry out all usual activities, despite some symptoms.

2 – Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities.

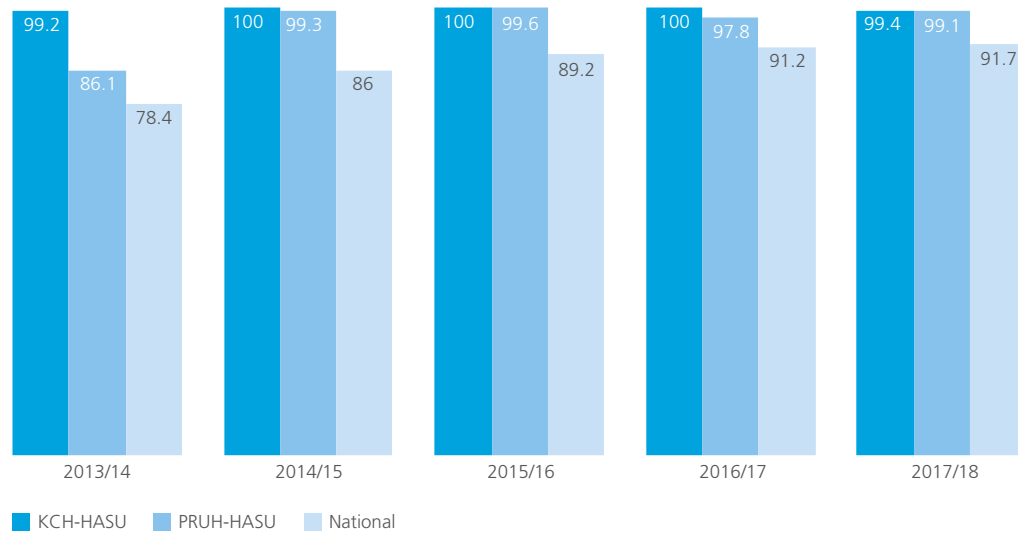
3 – Moderate disability. Requires some help, but able to walk unassisted.

4 – Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted.

5 – Severe disability. Requires constant nursing care and attention, bedridden, incontinent.

6 – Dead.

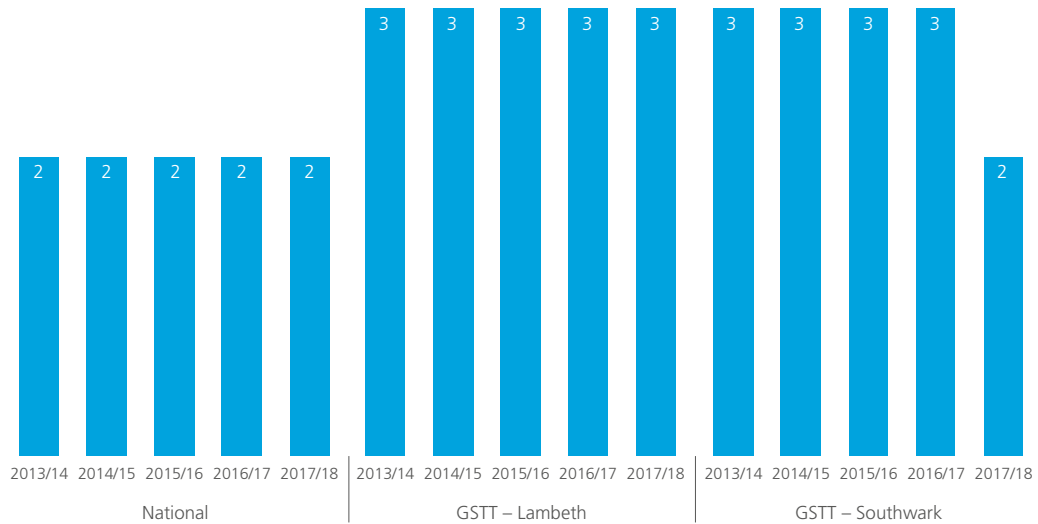
Figure 79 | Percentage of applicable patients who have mood and cognition screening by discharge from the HASUs



Source: The Sentinel Stroke National Audit Programme, 2013–2018.

The SSNAP audit captures the contributions different professionals make, as well measures which capture holistic needs of patients, such as mood and cognition screening, as shown above in figure 79.

Figure 80 | Median Modified Rankin Score on discharge from Community Stroke Services



Source: The Sentinel Stroke Audit Programme, 2013–2018.

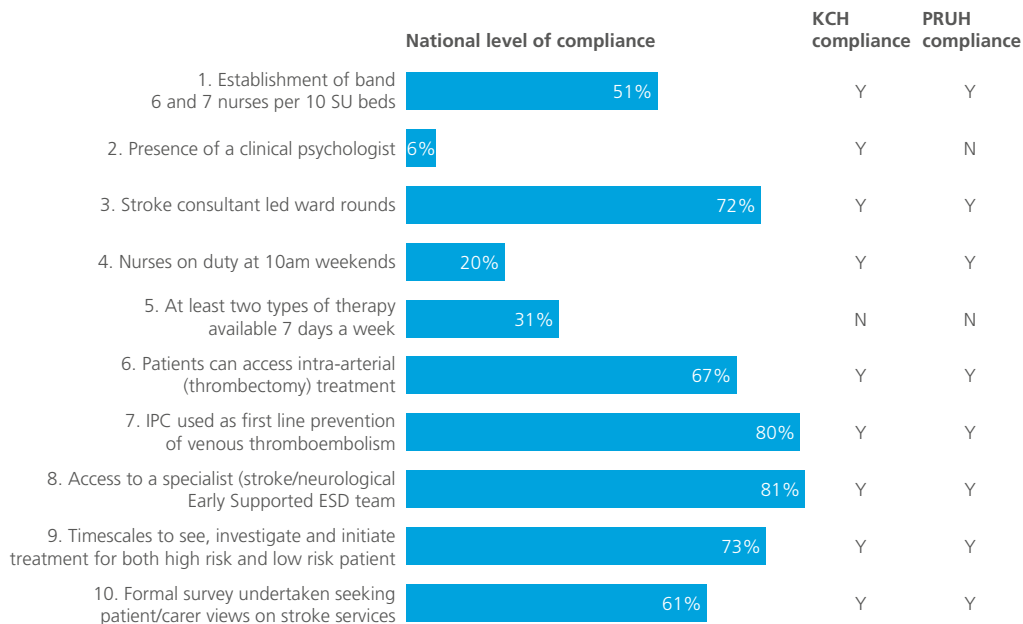
Figure 80 shows the mRS scores for patients on discharge from our community stroke services. Our patients in general leave with a higher mRS score than compared to national performance for all community stroke services as we accept patients with higher complexity and a greater level of disability than the national average.

The Acute Organisational Audit – 2016

The SSNAP acute organisational audit provides a biennial ‘snap-shot’ of the quality of stroke service organisation in acute settings, mapped against ten indicators. Figure 81 below shows national performance and our compliance, based on data from the 2016 audit.

Only 16% of organisations were compliant with eight or more indicators, and 5% with nine or more. We perform well in terms of national performance with both services achieving compliance with eight or more indicators.

Figure 81 | Performance against the SSNAP National Organisational Audit 2016



Source: The Sentinel Stroke National Audit Programme, Acute Organisational Audit, November 2016.

Patient experience and expert patients

Whilst patients are on the Stroke Units they, and family members, are offered group psychosocial education sessions run by our neuropsychologists to prepare them for any long term effects of living with a stroke. These sessions are audited to ensure that they meet the needs of patients and their families. An audit of the sessions run in 2017 at King's College Hospital shows that 90% of attendees found the session very helpful and 10% found it quite helpful.

We are always striving to improve care for our patients, and we have three Expert Patients who work very closely with the clinical team and have been involved in a variety of ways including:

- membership of interview panels
eg Matron post
- attendance at Stroke Governance meetings (ongoing)
- advising on patient information leaflets eg The Stroke Handbook, discharge information
- advising on issues important to patients and their families eg visiting times, eating and drinking regimes
- regular attendance at the South East London Operational Stroke Network.

Research and innovation

Our clinical staff are actively involved in a range of hyper-acute, acute and sub-acute trials. King's College Hospital is one of the nine Hyperacute Stroke Research Centres (HSRC) in the UK. The HSRC status is awarded to sites that are able to consistently support a portfolio of stroke studies requiring advanced neuro-imaging, specialist interventional skills and rapid enrolment of patients. With this status comes an expectation to deliver hyperacute stroke research studies on the Clinical Research Network (CRN) stroke portfolio including recruitment times and targets, as well as achieving CRN speciality objectives relating to HSRCs. The renewal of the HSRC status is subject to an annual review of performance. Data on CRN recruitment in stroke is shown on page 47 earlier in the book.

Case study: An innovative audit of stroke prevention in atrial fibrillation, using automated analysis of electronic health records

Atrial fibrillation (AF) is the most common abnormal heart rhythm (arrhythmia), affecting 2% of the UK population. It is estimated that 25–30% of all strokes are due to AF. Strokes occur in people with AF because blood clots can form in the heart as a result of its impaired pumping function. Anticoagulation (drugs to reduce the likelihood of blood clotting) has proven effectiveness in preventing stroke in people with AF. Despite its proven effectiveness, anticoagulation is underused in AF patients in UK. We set out to audit the use of anticoagulation in all patients with AF attending King's College Hospital between 2011 and 2017. We were particularly interested to examine whether NICE guidelines introduced in 2014 had an impact on our use of newer oral anticoagulants rather than older injected anticoagulants, and whether the use of anticoagulation reflected the individual patient's risk for developing a stroke (based on an established risk scoring method).

King's College Hospital has the largest continuously-used Electronic Health Record (EHR) in the UK; these electronic records open up the possibility to use computer-assisted methods to audit the data.

We identified 10,030 patients with atrial fibrillation from King's College Hospital NHS Foundation Trust and 464,958 relevant text documents in the electronic health records. It would be prohibitively time-consuming for researchers to calculate a risk score for every patient, so we developed an automated risk scoring pipeline using highly sophisticated methods to extract information from text in the electronic records. We were then able to extract information automatically from the electronic health records about each patient's stroke risk score, whether they were prescribed an anticoagulant, and if so which anticoagulant they were prescribed. A stroke neurologist and a cardiologist checked "by hand" in a subset of patients whether the automated pipeline had correctly identified medical concepts and drug prescriptions, and found that the automated process was correct in 94%–100% of instances.

We believe this is a highly convincing proof of concept that automated analysis of electronic health records can be used for large-scale audit of our clinical practice.

Figure 82 shows that since 2014 there is a steady decrease in the proportion of AF patients prescribed warfarin, coupled with an increase in newer anticoagulants.

Figure 82 | Oral anticoagulant prescribing

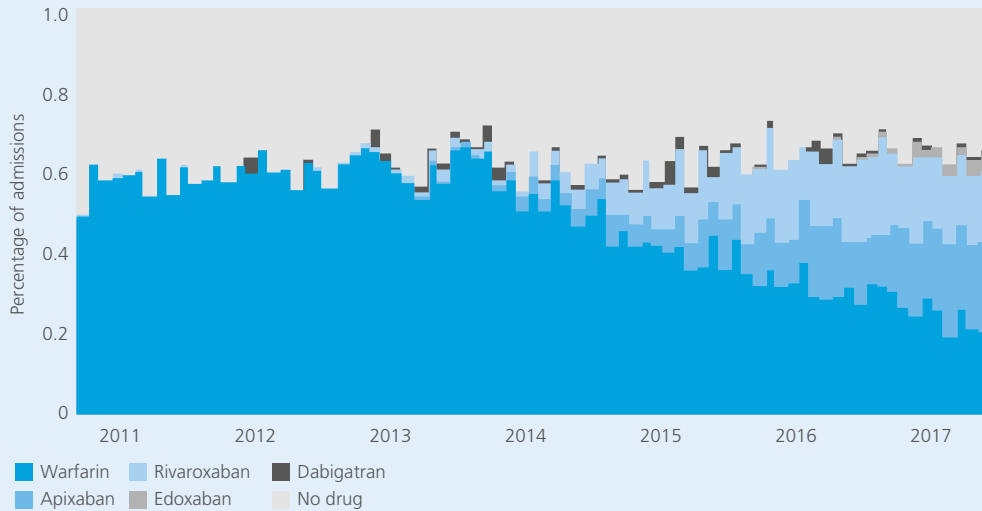
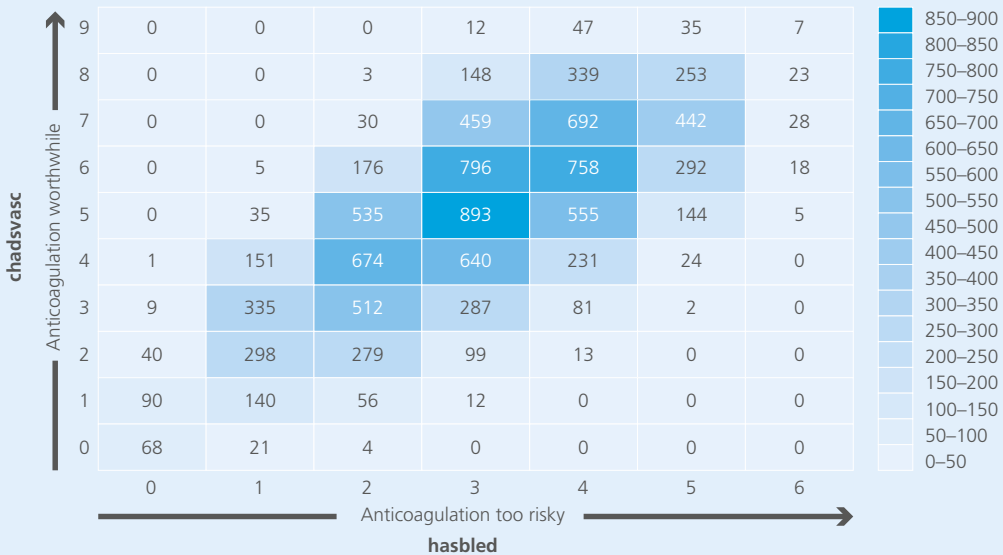


Figure 83 | Multidimensional scoring of stroke risk and bleeding risk



In figure 83, we used automated analysis of text in the electronic health records to estimate the multidimensional risk scoring of stroke risk and bleeding risk (as a side-effect of anticoagulation) in individual patients. In each cell is the number of patients with a particular stroke risk score ("chadsvasc") and a particular bleeding risk ("hasbled"). Modelling in this way will enable us to gain a more nuanced understanding of prescribing patterns to estimate the population where anticoagulation is too risky.

As well as research in patients, we have a basic science programme in stroke. An example of work from this group is below:

Stroke recovery in rats after 24h-delayed, intramuscular neurotrophin-3 infusion

Annals of Neurology, 2019. Duricki, D. A., Drndarski, S., Bernanos, M., Wood, T., Bosch, K., Chen, Q., Shine, H. D., Simmons, C., Williams, S. C. R., McMahon, S. B., Begley, D. J., Cash, D., Moon, L. D. F.

It is often assumed that regions of brain injury caused by stroke cannot recover. In this study in rats following experimental stroke, Neurotrophin-3, which plays a key role in the development of brain areas involved in movement, was injected into the blood. The study showed that it moved into the brain and that after 4 weeks of treatment, movement function was significantly improved. Future studies of Neurotrophin-3 as a treatment for stroke in humans are needed.



Trauma

Trauma

Introduction

Traumatic brain injury (TBI) is an injury to the brain caused by trauma to the head. There are many possible causes including: road traffic accidents; assaults; falls and accidents at home or at work. TBI is one of the commonest causes of death and disability in young people in the UK.⁸ Headway, the UK national brain injury charity, have estimated that there were 162,544 head injuries in the UK during 2013/14, which equates to 254 per 100,000 population. It is estimated that 1.3 million people in the UK live with a disability related to a TBI with an estimated cost of £15 billion a year to the UK economy (Parsonage, 2016).

Outcomes from TBI can be wide ranging. The most severely injured patients may survive but in a permanent disorder of consciousness. For survivors who do regain consciousness, TBI is often associated with physical, cognitive, mental health and behavioural impairments, which impact on quality of life.

Figure 84 | Helicopter landing on the helipad of Ruskin Wing, King's College Hospital, with a major trauma patient on board



© Dr J Jarosz

⁸ Early management of head injury: summary of updated NICE guidance. *BMJ*, 2014. Hodgkinson. S., Pollit, V., Sharpin, C., Lecky., F.

Our service

King's College Hospital is the Major Trauma Centre for the South East London, Kent and Medway Trauma Network. We have extensive experience in managing patients with traumatic brain injuries of all severities. Our team includes: nursing; speech and language, physiotherapy and occupational therapies; neurosurgery; neurology; neurophysiology; neuroradiology; neuro-critical care; neurorehabilitation; neuropsychology; neuropsychiatry; paediatric neurology, including a Traumatic Brain Injury (TBI) service; elderly care (PROKARE) and neuropathology. Our patients are managed via common pathways with detailed information collected as part of the Major Trauma Centre, via the Trauma Audit and Research Network (TARN).

Once patients' immediate, acute needs have been met, they may be 'repatriated' to our partner Trauma Units nearer to where they live for ongoing care; referred to an inpatient rehabilitation unit or discharged home. We have close links with community rehabilitation services across south east London and Kent.

A dedicated brain injury team of clinical nurse specialists, a clinical psychologist and a link worker from the local Headway group provide support to patients and families affected by acquired brain injuries. In addition to TBI, there are a significant number of patients with non-stroke, acquired brain injury (ABI) such as subarachnoid haemorrhage or hypoxic injury due to out of hospital cardiac arrest, who are also admitted to King's College Hospital each year. Numbers are shown in Table 12.

Table 12 | Numbers of brain injury patients admitted to King's College Hospital NHS Foundation Trust

	2017	2018
Traumatic brain injury	306	389
Neurovascular (including subarachnoid haemorrhage (SAH), ruptured arteriovenous malformations (AVMs))	245	244
Hypoxic brain injury	32	52

At any one time, there are between 35–50 inpatients at King's College Hospital that the Brain Injury Team have some involvement in, including organisation of their follow up.

The team has developed processes to manage this clinical caseload, including:

- a multi-disciplinary inpatient ward round with a Consultant Neurologist and a Consultant in Neurorehabilitation
- weekly nurse-led clinics (face to face and telephone)
- monthly multi-disciplinary out-patient clinic (neurology, nursing, psychology)
- clinical neuropsychology assessment and treatment
- a patient and family helpline
- family support-work clinics.

Patient experience and outcomes

Trauma Audit and Research Network (TARN)

National guidelines state that patients with severe head injuries should be transferred to the care of neurosurgery units regardless of whether they need surgical intervention. As there are several different types of head injury, each of

which require different types of treatment, a prompt diagnosis from a CT scan is critical so that the correct treatment can be administered. In Table 13, data from the TARN website has been collated to show comparative performance for neurosurgical units in relation to injury to the brain and skull.

Table 13 | Trauma Audit and Research Network – summary performance based on data from 1st January 2016–30th November 2018

Trauma network	Neurosurgical unit	Number of patients with severe head injury admitted	Number of these patients transferred to this hospital from another hospital	Number of patients treated at this neurosurgical unit who survived up to 30 days or until discharge from hospital	Time taken from arrival to CT scan (hours)
South East London, Kent and Medway	King's College Hospital	441	71 (16%)	202 (65%)	0.52
South West London and Surrey	St George's Hospital	410	52 (13%)	229 (63%)	0.43
North East London and Essex	The Royal London	630	113 (18%)	318 (66%)	0.42
North West London	St Mary's Hospital	501	99 (20%)	236 (62%)	0.43

Note: NICE Head Injury Guidelines state that CT Imaging should be performed within one hour of arrival for patients with a head injury and a Glasgow Coma Scale (GCS) score of less than 13. The national average performance is 0.53 hours.

Service innovation to improve patient experience

Continuity of care for patients with brain injuries is important and we continue to innovate by developing our services and resources to address the needs of these patients, including continuity between acute and social care provision across local statutory and voluntary sectors, considering brain injury across the lifespan and its impact upon the family. Some examples of our innovations are set out below.

Co-producing supported self-management resources with people affected by TBI

With funding support from the Health Foundation and King's College Hospital Charity, we collaborated with a social enterprise, Bridges Self-Management⁹ to develop resources and staff training to support self-management of the common problems that people live with after brain injury.

People with brain injuries and their families may only have episodic and limited input from clinical teams, yet many find ways without professional support to understand, overcome or live with the challenges of a brain injury.

Through a series of focus groups and in-depth interviews with King's College Hospital brain injury patients and their families we learned about the problems they faced and

the strategies they used to guide their own recovery. These insights were used to develop an interactive book for patients, as well as a companion book for family and friends. The books are tools to help people set their own personal goals and then work out how they're going to reach them – and chart their progress – in a positive, step-by-step way.

These resources were also used to develop a programme of training for staff in the King's College Hospital acute and rehabilitation units and the Headway centre. The training embeds a more person-centred, strengths-based approach to working with people with brain injuries; supporting them to feel more confident to self-manage and less reliant on services, making our care more effective and impactful.

Headway Early Intervention Co-ordinators

We've worked in collaboration with the local branch of Headway, a brain injury charity. A dedicated worker attends King's College Hospital to identify new patients with a brain injury. Practical advice and support is given to the family in the early stages. The worker then follows-up the patient until they are discharged home, at that point assessing the person's needs and applying for social care funding so they can have a support worker or attend the Headway day centre. A monthly carers support group is also available. The Headway Co-ordinators can act as a useful link back to clinical services if new problems arise. For example:

9 www.bridgesselfmanagement.org.uk

Case study: Sally's story

Sally was living at home with her husband and three children, nearly three years after her brain injury. She was no longer receiving community rehabilitation or any other clinical input. Her husband needed to care for her as she had significant cognitive and behavioural impairments. Unfortunately her behavioural problems became worse and her husband had to stop working to care for her. Their housing was also over-crowded and poorly accessible. The Headway worker was able to support him to maximise his benefits; apply for rehousing and request an urgent clinical review from the King's College Hospital Brain Injury team. A multi-disciplinary assessment identified a new rehabilitation need and an admission was arranged for neuropsychiatric treatment.

Improving psychological and family support along the care pathway

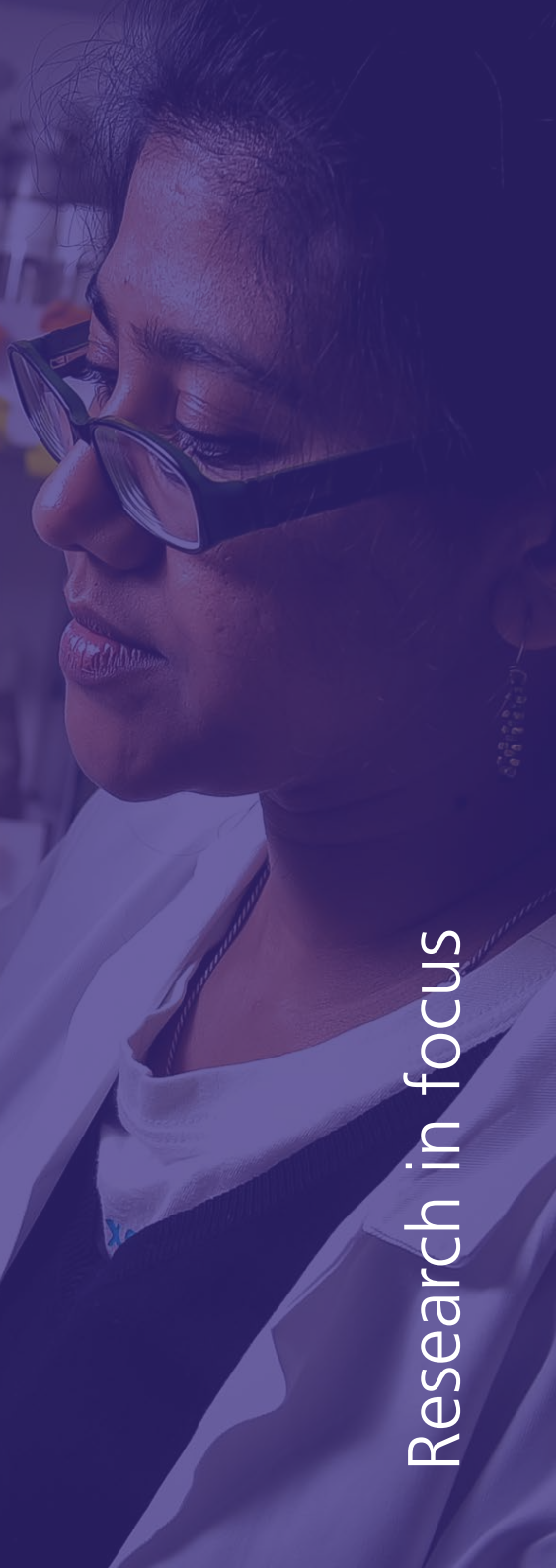
The effects of a brain injury on the individual and their family can be very challenging in both the early stages of an injury and longer term. We aim to improve the psychosocial care of people with brain injuries and their families. With the support of King's College Hospital Charity, we have been developing an innovative clinical psychology post that works in both the very acute setting – providing expert assessment

and intervention, advice and support to clinical teams, families and patients and also in the out-patient setting, following up patients who have been treated at King's College Hospital.

One of the team has also received training in systemic family therapy approaches to enable them to work more effectively with families in the acute and long-term, out-patient settings. For example:

Case study: Steven's story

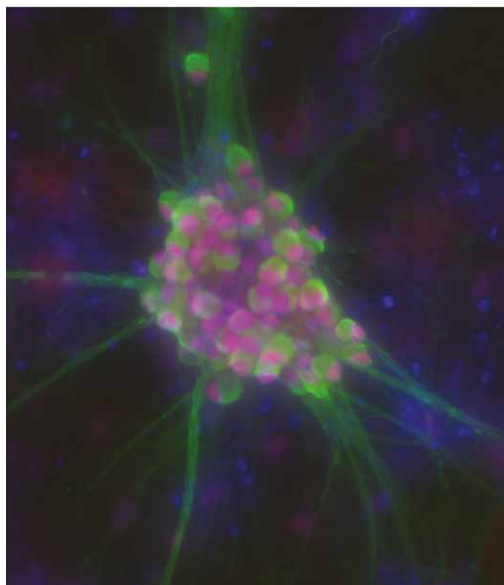
Steven had suffered a frontal brain injury four years ago, that had significantly changed his cognition, physical abilities and behaviour at home. His wife contacted the team as she was worried their children were becoming distressed by his behaviour. A series of family meetings were held with the specialist nurse and clinical psychologist to help the family understand how the brain injury had changed family dynamics. Steven needed some individual work with the clinical psychologist around his mood and adjustment, whilst the nurse worked with Steven's wife and children, supporting them to find more effective ways of dealing with the difficult situations at home.



Research in focus

Research in focus

Figure 85 | In ALS/MDN motor neurones, like the one in the image, degenerate causing the muscles they control to weaken and waste away



© Institute of Psychiatry, Psychology & Neuroscience

In the five years 2012–2017, King's Health Partners Neurosciences researchers published more than 2,600 peer-reviewed scientific papers. During the same period, our publications were cited almost 50,000 times by researchers in other institutions. Almost 6% of our publications were in the top 1% of "most-cited" papers worldwide in our field, reflecting that our work has a very significant impact on the scientific community. Here we list a selection of our publications from the last six years, each with a short explanatory commentary, which reflect the range and excellence of our work.

Neurodegeneration – basic and clinical

Pimavanserin for patients with Parkinson's disease psychosis: a randomised, placebo-controlled phase 3 trial

The Lancet, 2014. Cummings, J., Isaacson, S., Mills, R., Williams, H., Chi-Burris, K., Corbett, A., Dhall, R., Ballard, C.

Some people with Parkinson's disease suffer debilitating psychotic symptoms, such as hallucinations and delusions. In this study, 199 people with Parkinson's disease and psychotic symptoms were randomised to receive a new treatment, pimavanserin, compared with a placebo. The study found that pimavanserin was significantly more effective than placebo and was safe and well-tolerated. This is an important step forward because few other treatments are available.

Regional multiple pathology scores are associated with cognitive decline in Lewy body dementias

Brain Pathology, 2015. Howlett, D.R., Whitfield, D., Johnson, M., Attems, J., O'Brien, J.T., Aarsland, D., Lai, M.K.P., Lee, J.H., Chen, C., Ballard, C., Hortobágyi, T., Francis, P.T.

Dementia with Lewy bodies and Parkinson's disease dementia are important causes of dementia. In this study, detailed examination of postmortem brain specimens revealed that cognitive decline and dementia in these disorders involves a complicated interaction between pathology caused by dementia with Lewy bodies and Parkinson's disease (α -synuclein-containing Lewy bodies) and pathology typically caused by Alzheimer's disease ($A\beta$ plaque and phosphotau). Future treatment may need to target both types of pathology.

Nucleus basalis of Meynert degeneration precedes and predicts cognitive impairment in Parkinson's disease

Brain, 2018. Schulz, J., Pagano, G., Fernández Bonfante, J. A., Wilson, H., Politis, M.

Cognitive impairment is an important and disabling later-stage consequence of Parkinson's disease. At the current time, we cannot predict who will develop it or when it will emerge. In a large study of MRI brain scans in people with Parkinson's disease, it was found that there was reduced size and altered appearance of a part of the brain called nucleus basalis of Meynert in patients who had cognitive impairment compared to those who did not. In a second study in which patients with Parkinson's disease and no cognitive decline at baseline were followed for 36 months, reduced size and altered appearance of nucleus basalis of Meynert at baseline predicted future cognitive impairment. This finding might be useful in a clinical setting to identify patients at higher risk of cognitive decline.

Stage at which riluzole treatment prolongs survival in patients with amyotrophic lateral sclerosis: a retrospective analysis of data from a dose-ranging study

Lancet Neurology, 2018. Fang, T., Al Khleifat, A., Meurgey, J-H., Jones, A., Leigh, P. N., Bensimon, G., Al-Chalabi, A.

Riluzole is known to prolong survival in motor neuron disease (also called amyotrophic lateral sclerosis). It is not known whether the prolongation of survival occurs in early stages of the disease or later in the disease. It would be important to know whether prolonged survival allows more time in early, less affected disease state, or prolongs a later severely affected state. In this study of 959 people who had been enrolled in the riluzole treatment trial in the mid-1990s, detailed statistical examination of the data showed that prolongation of survival occurred in the late stage of the disease. The stage at which benefit occurs is important for counselling of patients before starting treatment.

Novel mutations support a role for Profilin 1 in the pathogenesis of ALS

Neurobiology of Aging, 2015. Smith, B.N., Vance, C., Scotter, E.L., Troakes, C., Wong, C.H., Topp, S., Maekawa, S., King, A., Mitchell, J.C., Lund, K., Al-Chalabi, A., Ticozzi, N., Silani, V., Sapp, P., Brown, R.H., Landers, J.E., Al-Sarraj, S., Shaw, C.E.

King's College London researchers have discovered several of the most important genes that cause motor neuron disease (also called amyotrophic lateral sclerosis). In this study, the causal nature of a new gene mutation was investigated, showing it to be a rare cause of motor neuron disease, but that it produces aggregations of proteins in cells, similar to other gene mutations. This study adds more detail to the complex picture of motor neuron disease genetics.

Analysis of amyotrophic lateral sclerosis as a multistep process: a population-based modelling study

The Lancet Neurology, 2014. Al-Chalabi, A., Calvo, A., Chio, A., Colville, S., Ellis, C.M., Hardiman, O., Heverin, M., Howard, R.S., Huisman, M.H.B., Keren, N., Leigh, P.N., Mazzini, L., Mora, G., Orrell, R.W., Rooney, J., Scott, K.M., Scotton, W.J., Seelen, M., Shaw, C.E., Sidle, K.S., Swingler, R., Tsuda, M., Veldink, J.H., Visser, A.E., van den Berg, L.H., Pearce, N.

In this study, sophisticated statistical modelling was applied to data on the age at which motor neuron disease (also called amyotrophic lateral sclerosis) starts in patients, and data on how common motor neuron disease is at each age. Similar studies in cancer have revealed that cancers often result from several sequential changes or steps over a period of time. In this study, motor neuron disease was found to occur following six steps. Future work will be needed to elucidate the nature of each of these steps, in order to prevent and treat the condition.

Understanding brain development and brain anatomy

King's College London is a world-leading centre for research into the mechanisms of normal brain development and into the ways in which brain development can go wrong, leading to a number of important developmental conditions and disorders, such as autism and some forms of epilepsy. Here, we focus on a selection of outstanding work on the development of the normal brain.

Pyramidal cell regulation of interneuron survival sculpts cortical networks

Nature, 2018. Wong, F. K., Bercsenyi, K., Sreenivasan, V., Portalés, A., Fernández-Otero, M., Marín, O.

Neurons in the brain are connected in microscopic circuits consisting of excitatory and inhibitory neurons. Balanced populations of both types of neuron are essential to normal brain function. This study showed that in a specific period of brain development, this balance is dictated by the activity of the excitatory cells. This discovery may in future help to explain and treat developmental brain disorders where the balance between excitatory and inhibitory neurons is altered.

Early emergence of cortical interneuron diversity in the mouse embryo

Science, 2018. Mi, D., Li, Z., Lim, L., Li, M., Moissidis, M., Yang, Y., Gao, T., Hu, T. X., Pratt, T., Price, D. J., Sestan, N., Marín, O.

Brain activity is controlled in important ways by a class of neurons called inhibitory interneurons, which are very diverse in structure and function. This study reveals that this diversity is determined very early in embryonic development. This discovery may help to find new ways to understand and treat disorders in which specific interneuron classes are abnormal.

A distance-dependent distribution of presynaptic boutons tunes frequency-dependent dendritic integration

Neuron, 2018. Grillo, F. W., Neves, G., Walker, A., Vizcay, G., Fleck, R., Branco, T., Burrone, J.

Neurons receive inputs from many other neurons, and use these inputs to determine whether or not to fire an output. Exactly how the neuron makes this subtle computation is not well understood. This study reveals how the neuron “manages” inputs from other neurons.

The anatomy of fronto-occipital connections from early blunt dissections to contemporary tractography

Cortex, 2014. Forkel, S.J., Thiebaut de Schotten, M., Kawadler, J.M., Dell'Acqua, F., Danek, A., Catani, M.

The brain contains very short connections between neurons that are close together, as well as long connections between neurons that are far apart – such as neurons in the occipital (visual) areas and neurons in the frontal lobes. These long-range fronto-occipital connections are well described in animals but not in humans. Here, an MRI scanning technique called diffusions tensor imaging was used to examine the detailed anatomy of long-range fronto-occipital connections in humans. Better understanding of human brain connections is likely to cast important light on normal cognition as well as disease processes.

A distinct subtype of dopaminergic interneuron displays inverted structural plasticity at the axon initial segment

Journal of Neuroscience, 2015. Chand, A.N., Galliano, E., Chesters, R.A., Grubb, M.S.

Neurons alter their function in response to changing inputs, a process called plasticity, which allows the brain to learn and alter its function in the light of experience. A specific part of the output pathway of the neuron, the axon initial segment, is altered structurally as part of the process of plasticity in excitatory neurons. For this first time, this study reveals the details of axon initial segment plasticity in inhibitory neurons, adding further to our knowledge of how the brain learns and adapts.

Neurological disorders – basic and clinical

A Controlled Trial of Erenumab for Episodic Migraine

New England Journal of Medicine, 2017. Goadsby P.J., Reuter U, Hallström Y., Broessner G., Bonner J.H., Zhang F., Sapa S., Picard H., Mikol D.D., Lenz R.A.

Migraine is a very common disorder with few specific treatments. Basic science carried out by a King's College London researcher discovered a key mechanism responsible for pain in migraine, involving the calcitonin gene-related peptide. This pivotal phase three study of 955 people with migraine compared erenumab, a novel monoclonal antibody that inhibits the calcitonin gene-related peptide receptor, with placebo. Erenumab significantly reduced migraine frequency, the effects of migraines, and the use of other migraine-specific medication.

Nitroglycerin triggers triptan-responsive cranial allodynia and trigeminal neuronal hypersensitivity: triptan-responsive cranial allodynia

Brain, 2019. Simon, A., Karsan, N., Bose, P.R., Hoffmann, J. R., Holland, P., Romero-Reyes, M., Goadsby, P. J.

In this study, researchers sought to develop a pre-clinical model of a particular type of migraine, in which head pain can be provoked by stimuli that are not usually painful. In both normal rats and people with migraine, nitroglycerin provoked sensitisation to usually non-painful stimuli, and this sensitisation (called allodynia) responded to treatment with triptan drugs, a mainstay of migraine treatment. The nitroglycerin-induced changes are one of several mechanisms that can produce migraine, and the discovery of similar mechanisms in the rat model opens the possibility of a new platform for treatment development.

Dynamic brain network states in human generalised spike-wave discharges

Brain, 2018. Tangwiriyasakul, C., Perani, S., Centeno, M., Yaakub, S.N., Abela, E.C., Carmichael, D.W., Richardson, M.P.

Epileptic seizures usually start suddenly and with no warning. In this study, electrical brain wave activity (EEG) was studied simultaneously with functional MRI (fMRI), a technique that identifies the brain regions involved in brain function. Out of 43 people with epilepsy studied, 20 had brief electrical discharges seen on EEG, which are associated with seizures. The study revealed that these discharges did not occur without warning, but emerged during a long (at least one minute) pre-seizure brain state identified with fMRI. This study opens the possibility to predict and prevent seizure onset.

Changes in neurocognitive architecture in patients with obstructive sleep apnea treated with continuous positive airway pressure

EBioMedicine, 2016. Rosenzweig, I., Glasser, M., Crum, W.R., Kempton, M.J., Milosevic, M., McMillan, A., Leschziner, G.D., Kumari, V., Goadsby, P., Simonds, A.K., Williams, S.C.R., Morrell, M.J.

Obstructive sleep apnea is a common disorder in which breathing is transiently and frequently blocked during sleep by tissues of the throat. It may be a risk factor for major disorders including Alzheimer's disease. Using brain scans and cognitive testing in people with obstructive sleep apnea, it was found that a breathing mask treatment called Continuous Positive Airway Pressure resulted in improved sleep, better memory, and some change in the structure of the brain. Future studies should examine whether obstructive sleep apnea is an important cause of Alzheimer's, and whether Continuous Positive Airway Pressure is helpful.

The analgesic effect of oxytocin in humans: a double-blind, placebo-controlled cross-over study using laser-evoked potentials

Journal of Neuroendocrinology, 2016. Paloyelis, Y., Krahé, C., Maltezos, S., Williams, S.C., Howard M.A., Fotopoulou, A.

Oxytocin, sometimes referred to as the “love hormone”, is released in humans and animals when they are in social situations and nurturing their young. In this study, the effect of oxytocin on pain perception is examined. The study revealed that oxytocin in humans results in reduced perception of pain and modulation of the brain wave response to pain (evoked potentials). This study provides new insights into pain mechanisms and how pain can be modulated.

The expression of inflammatory mediators in bladder pain syndrome

European Urology, 2016. Offiah, I., Didangelos, A., Dawes, J., Cartwright, R., Khullar, V., Bradbury, E.J., O’Sullivan, S., Williams, D., Chessell, I.P., Pallas, K., Graham, G., O’Reilly, B.A., McMahon, S.B.

In this study, researchers compared gene expression in bladder biopsies of patients with bladder pain syndrome (BPS) and controls without pain and identified two genes that were increased in BPS patients and correlated with clinical profiles. The study tested the effect of these genes in laboratory animals, confirming their role in bladder pain. Manipulating these genes in BPS is a potential treatment strategy.

Thalamotemporal impairment in temporal lobe epilepsy: a combined MRI analysis of structure, integrity and connectivity

Epilepsia, 2014. Keller, S.S., O’Muirheartaigh, J., Traynor, C., Towgood, K., Barker, G.J., Richardson, M.P.

Focal-onset epilepsy, such as temporal lobe epilepsy, has been regarded as a condition in which a focal region of brain is abnormal, causing seizures, whereas the rest of the brain is unaffected. In this study using MRI brain scans, researchers found that a key part of the central area of the brain, the thalamus, which is remote from the temporal lobe, was abnormal in people with temporal lobe epilepsy. Specifically, the part of the thalamus that is connected to the temporal lobe was smaller and had an abnormal appearance in patients compared to healthy control subjects. This study provides evidence that focal epilepsy may be caused by a widespread set of abnormalities in the brain, not just focal abnormality.

Neuropsychiatry

Failures of metacognition and lack of insight in neuropsychiatric disorders

Journal of Neuroscience, 2012. David, A.S., Bedford, N., Wiffen, B., Gilleen, J.

Lack of insight or unawareness of illness are the hallmarks of many psychiatric disorders, especially schizophrenia and other psychoses and could be conceived of as a failure in metacognition (awareness and understanding of one's own thought processes). This study explored cognitive models based on self-reflectiveness and their possible social and neurological bases, including data from structural and functional MRI. The medial frontal cortex appears to play an important role in self-appraisal in health and disease.

Modelling psychiatric and cultural possession phenomena with suggestion and fMRI

Cortex, 2014. Deeley, Q., Oakley, D.A., Walsh, E., Bell, V., Mehta, M.A., Halligan, P.W.

Involuntary movements occur in a variety of neuropsychiatric disorders and culturally influenced dissociative states (for example, delusions of alien control and attributions of spirit possession). This study used functional MRI to investigate the brain systems involved in the control of movement in different situations where suggestible people experienced apparent loss of movement control due to suggestions of external or internal alien control. The brain scans revealed differences between the different situations, with abnormal connects between motor control regions of the brain and other areas involved in attribution of mental states and representing the self.

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