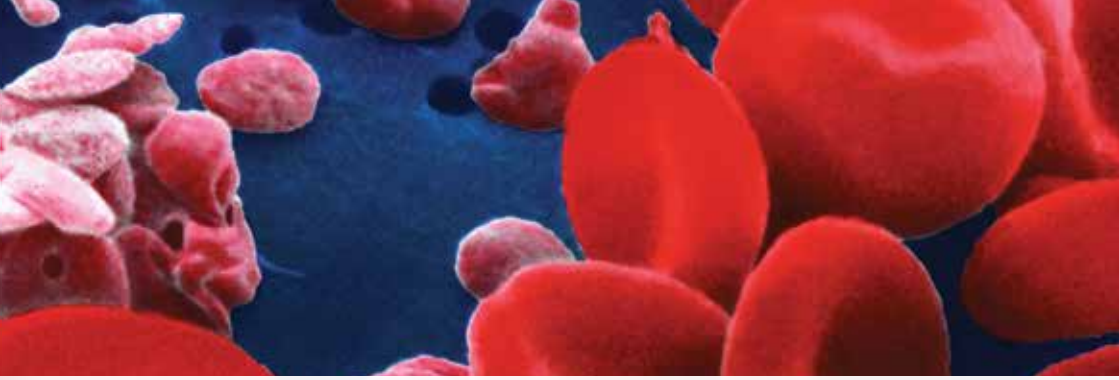
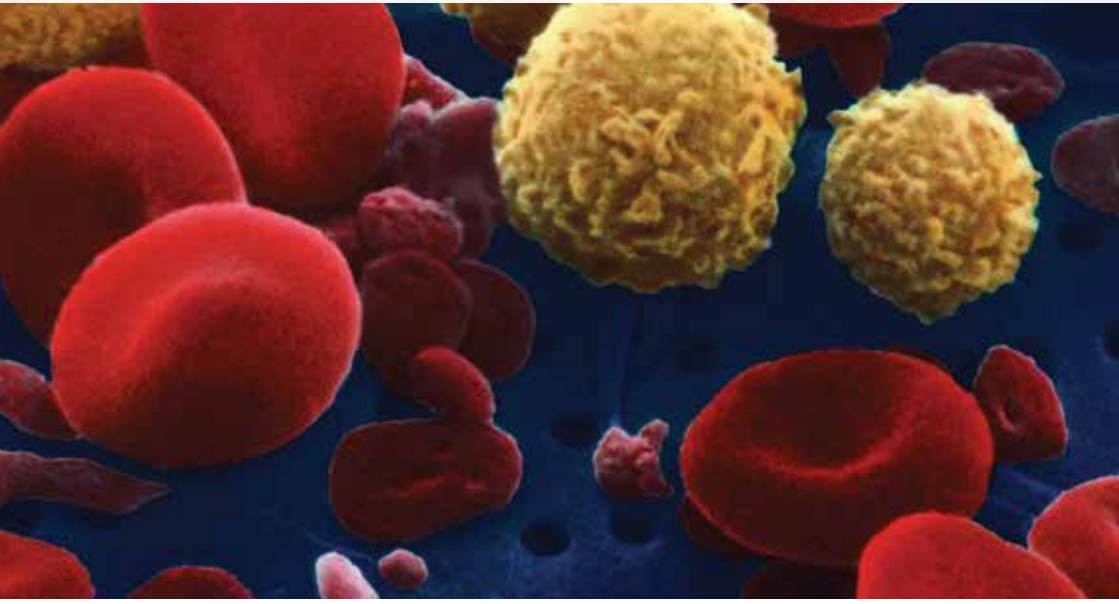


A Healthy Future for UK Medical Research

All-Party Parliamentary Group on Medical Research



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Foreword

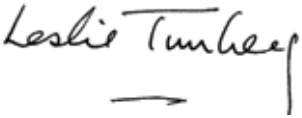
Advances in medical research have brought great benefit to the UK's health and economic prosperity.

In this booklet we showcase some recent examples that clearly demonstrate the continuing excellence of the UK's cutting edge and high impact research. We show how this research, funded by government, charities and industry, often in collaboration, can help people live longer, healthier lives. It leads to new diagnostic tests that make personalised medicines a reality for patients; it leads to the development of blockbuster drugs that are key UK exports; it helps raise awareness of important health issues and it informs health policy. The UK life sciences sector is indeed a jewel in the crown.

We are blessed with a vibrant research ecosystem made possible by public, private and charitable funders, each making a unique contribution to the research base. Strong links between research, innovation, education and clinical care have been established. The combination of highly skilled researchers in our universities, the NHS with its universal coverage of the patient population, and research infrastructure provided by, amongst others, the National Institute of Health Research (NIHR) funded by the Department of Health, gives us a unique advantage. No other country provides this sort of opportunity for engaging in research for the benefit of patients.

Medical research is the UK's most popular charitable cause but we need a long-term commitment to research from this and future governments if we are to maintain our leading position. Stable, long term support will provide the confidence that global investors need and the leverage for further funds from industry and charities. Furthermore, economic analysis reveals that for each pound invested in cancer research, we receive a return in health benefits equivalent to about 40 pence per annum thereafter.

Medical research makes a huge difference to people's lives and remains a key national strength. Collectively, we must do everything we can to ensure that it has a healthy future.



Leslie Turnberg

Chair of the All-Party Parliamentary Group on Medical Research

Awareness and prevention

Research provides evidence that allows us all to make better decisions. It can help raise public awareness of the steps we can take to live longer, healthier and happier lives. With the right information, people can choose for themselves how to live their lives to avoid poor health. Research also informs policy makers and healthcare commissioners, helping them make decisions that can affect the nation's health and economic prosperity.

1. Preventing brain injury in newborn babies

Sparks

Every year in the UK more than 1000 babies experience oxygen starvation at the time of their birth. Until fairly recently, around a third of these babies died and another third were left with a permanent disability due to brain injury. The impact on families can be enormous and the lifetime cost of looking after a significantly disabled child can be up to £7 million.

Marianne Thoresen pioneered the investigation of hypothermia to prevent brain damage by cooling babies who have been starved of oxygen. Sparks supported an early pilot study led by Professor Thoresen to investigate the changes taking place in newborns during cooling.

Following this research, two multi-centre, multi-investigator clinical trials took place with one of these, the TOBY trial, funded by the Medical Research Council. They showed that cooling babies to 33.5°C for 72 hours was a viable way of preventing brain damage in babies starved of oxygen at birth. The proportion of babies who suffered a poor outcome was reduced from 70% to around 50%. Cooling therapy for newborn babies was incorporated into NICE guidelines in 2010 and is estimated to save the NHS around £200 million a year.

Professor Thoresen is now focusing her efforts on the 50% of babies who are not helped by cooling. With funding from Sparks, she is investigating whether xenon gas alongside cooling will improve these babies' outcomes too.

Medical research is the UK's most popular charitable cause, with 11.2 million people donating each month.[1]

2. Reducing antipsychotic use: Putting research into practice

Alzheimer's Society

People with dementia can be inappropriately prescribed antipsychotic drugs to treat complex or challenging behaviours. The practice is particularly common in care homes, but the drugs can be harmful, causing severe side-effects and increasing the risk of avoidable death.

In 2002, Alzheimer's Society funded a study called FITS (Focussed Intervention for Training of Staff) to develop and test a programme of person-centred care as an alternative to antipsychotic drugs. The FITS programme comprised a 10-day training course for care home staff, followed by nine months of supervision and monitoring. Delivered in 12 care homes, the programme reduced the use of antipsychotic drugs in people with dementia by 40%, bringing clear benefits to patients and staff.

Putting evidence into practice is a huge challenge in the health and social care sectors. In 2012, Alzheimer's Society took the lead to implement FITS in a large number of care homes. With funding from the Department of Health and a major care-home provider, the FITS programme has been scaled up and delivered to 67 UK care homes by the University of Worcester. With supportive management, time to undertake the additional work and stability within staff teams, FITS training empowers teams to work in a person-centred way, reduces the prescription of inappropriate antipsychotics in care homes and enables residents to enjoy a better quality of life.

3. Examining the effectiveness of standardised tobacco packaging

University of Bristol and Action on Smoking and Health (UK)

Qualitative studies have suggested that standardising the way tobacco products are packaged, by putting the brand name in a standard font and location, might be effective in stopping young people from smoking. New research from the University of Bristol, using novel experimental measures never before used to investigate smoking prevention, supports these findings.

Researchers used eye-tracking technology to measure the eye movements of adults and adolescents looking at branded and standardised cigarette packs. Standardised packaging directed the attention of people who were not regular smokers away from branding and towards health warnings. The first brain imaging study to investigate standardised packaging then showed that looking at standardised and branded packaging resulted in different patterns of activation in brain regions related to processing threatening information, supporting the idea that more attention was directed towards the health warnings on standardised packs. Finally, in the first randomised controlled trial of standardised packaging, using standardised packs diminished smokers' experience of smoking and smokers reported the health warnings as being more prominent.

This adds to the evidence that standardised packaging is an effective tobacco control measure. Action on Smoking and Health (UK) and the UK Centre for Tobacco and Alcohol Studies helped to disseminate these findings, which have been used by the UK, Australian and Irish governments and the European Commission to inform decisions about standardised packaging of tobacco products.

Charity and government funders provide UK researchers with a broad choice of grants, making the UK an attractive funding environment for leading scientists.[2]

4. Increasing organ donor registration

Kidney Research UK

People from black, Asian and minority ethnic (BAME) groups are at greater risk of organ failure but are less likely to be organ donors and wait longer for transplants. A Kidney Research UK study revealed that people from BAME communities felt they did not have the resources to discuss and come to a decision about organ donation; it recommended Peer Educators be used to address this issue.

Recruited from BAME communities in London, ordinary people were trained and deployed at social, community and faith events. In the first year, almost 500 registrations were achieved on the NHS Organ Donor Register. Seven Peer Educators held over 100 events and NHS Blood & Transplant reported 867 new registrations. Independent evaluation showed that 9% of people not already on the Register signed up, increasing the proportion of registered donors from 13.7% to 20.9%. "It is critical that Peer Educators continue to attend these types of local and national events, and do so in greater numbers," the evaluation concluded.

The cost of keeping one kidney patient alive on dialysis is around £35,000 a year, while every new donor can potentially save the lives of up to nine patients. Kidney Research UK's work continues in Birmingham and Scotland, engaging communities about donation and bringing important economic, social and health benefits.

Medical research charities invested over £1.3 billion in UK medical research in 2013.[3]

5. A FAST test to save lives

Stroke Association

In 2004, a Stroke Association-funded study found that paramedics using the Face, Arm, Speech, Time-to-call 999 (FAST) test could identify a stroke as accurately as specially trained doctors. Over 85% of suspected stroke patients brought to A&E by paramedics trained to use the FAST test had actually had a stroke, and they received quicker medical treatment due to their early diagnosis. This prompted the Stroke Association's 'FAST' public awareness campaign.

The Department of Health adopted the campaign in 2009. They spent £8.5 million over three years informing emergency paramedics and the wider public about the signs of stroke. In four months, emergency 999 calls for stroke increased by 55%, bringing life-saving medical attention to thousands more stroke patients in the UK. Sir Roger Boyle, the former National Clinical Director for Heart Disease and Stroke, said: "FAST is one of the most successful government public awareness campaigns ever, that has undoubtedly contributed to saving lives and reducing consequent disability from stroke for many people."

In March 2014, Public Health England brought the campaign back with updated TV adverts and additional activity aimed towards black and minority ethnic communities – people of African and South Asian origins are twice as likely to suffer a stroke as people of European origin.

The FAST campaign shows how researchers, health services, the third sector and government working together can change public understanding of a major health problem.

Diagnosis

Research and development of better diagnostic tools means we can catch disease earlier, making cure and recovery more likely. Good diagnostics can also save the NHS money by helping doctors decide on the most appropriate treatment. Diagnostics and treatments are increasingly being developed together in parallel – this is especially true in the emerging field of stratified medicine, where treatments are tailored to fit patients' specific medical history and biological makeup.

6. Personalising treatments for blood cancer patients

Leukaemia & Lymphoma Research

Acute lymphoblastic leukaemia (ALL) is the most common cancer in children. It was previously a death sentence, but the last 30 years have seen progressive improvements in survival through more intensive treatment and minimal residual disease (MRD) testing. The MRD test detects leukaemia cells to an accuracy of 1 in 10,000 cells, which enables doctors to adjust the intensity of treatment to each patient's needs, minimising side-effects while delivering a cure.

The key challenge for MRD testing was ensuring its reproducibility in a clinical setting. In 2002, Leukaemia & Lymphoma Research created a UK MRD laboratory network to develop a standard for the MRD test so it could be conducted consistently across the NHS.

The network led to Leukaemia & Lymphoma Research working with the Medical Research Council on the first MRD-based clinical protocol for childhood ALL in the UK. The UKALL 2003 trial increased overall survival to over 90% and reduced relapses and treatment-related deaths. Using MRD saved money as well as lives: fewer patients required stem cell transplants and drug and nursing costs were lower. As a result, MRD testing in ALL has been adopted as standard of care by the NHS.

Leukaemia & Lymphoma Research are now funding the UKALL 2011 trial to further refine MRD-based personalised treatments. The aim is to continue increasing survival while improving quality of life for children suffering from ALL.

7. Transforming diagnosis and care for dementia patients

Medical Research Council and GE Healthcare

In 2012, three years after the UK's first National Dementia Strategy was published, Prime Minister David Cameron launched the dementia challenge. A key part of it was to improve health and care for patients, starting with diagnosis. Dementia with Lewy bodies (DLB) is the second most common type of dementia after Alzheimer's disease, affecting about 120,000 people in the UK each year. But DLB is difficult to diagnose in its early stages, when it may be confused with other neurological disorders, particularly Alzheimer's, leading to incorrect treatment with potentially severe, sometimes fatal, consequences.

In the early 2000s, University of Newcastle researchers, led by Professor Ian McKeith and funded by the Medical Research Council, showed that patients with DLB had lower dopamine levels than healthy patients or people with Alzheimer's. The team worked with GE Healthcare, which is headquartered in Buckinghamshire, to create a test based on a brain imaging technique called dopamine transporter imaging. GE then funded clinical trials that showed the test accurately distinguished DLB from Alzheimer's. It was approved by the European Medicines Agency in 2006.

The initial public investment has led to a technique that allows DLB patients in the UK and Europe to receive an accurate diagnosis and the specific treatment and care they need. The NHS also saves when patients avoid repeated inconclusive diagnostic assessments or inappropriate treatments.

For every £1 spent by the Government on R&D, private sector R&D output rises by 20p per year in perpetuity by raising the level of the UK knowledge base.[4]

Between 2006 and 2013, government research investment through MRC of £3.5 billion leveraged a further £1.5 billion commitment from charitable organisations.[5]

8. Peek: A smarter way to diagnose eye disease

Medical Research Council and Fight For Sight

Around 80% of blindness is curable or preventable, but most of the world's 285 million people with visual impairment do not have access to suitable healthcare. To help solve this problem, Dr Andrew Bastawrous' team developed a portable eye examination kit – Peek – that can be used without access to specialist equipment or training.

In 2011, Dr Bastawrous, based at the London School of Hygiene & Tropical Medicine, was leading a large study of eye disease in Kenya as part of his three-year clinical research training fellowship funded by the Medical Research Council and Fight for Sight[6]. The study was a "logistical nightmare": his team had to carry fragile, expensive equipment around 100 remote villages. So, working with mobile app and medical instrument experts, Dr Bastawrous developed a set of small, portable gadgets and applications to be used with a standard smartphone to easily and cheaply diagnose sight loss, including diseases such as diabetic retinopathy and macular degeneration. Data can be sent from the phone to specialists for expert advice; Google Maps pinpoints patients' location so follow-ups can be arranged.

The team[7] is now confirming the app's accuracy and exploring other uses for the technology, including a pilot in 30 Kenyan schools testing whether teachers can identify visual impairment in children. This innovative product demonstrates how public investment in basic science can leverage charitable funding – and benefit patients globally.

9. Improving diagnosis of rare childhood diseases

Rosetrees Trust

One in 17 people suffer from rare diseases. Next-generation genetic sequencing, a UK strength and government priority, has the potential to improve their diagnosis and treatment, but it is not yet widely available.

In 2012, two siblings were admitted to Great Ormond Street Hospital (GOSH) with CANDLE syndrome, one of a group of genetic periodic fever syndromes. They had severe rashes, fevers, arthritis and inflammation of their muscles, eyes and lungs. All conventional treatments failed and they spent the first two years of their life in hospital. They were dying. Only six genes that cause these syndromes can be tested in the NHS at the moment, and theirs was not one of them. Doctors thought the only hope was bone marrow transplantation, which itself carries up to a 20% risk of death.

In November 2012, however, following a significant grant from Rosetrees Trust, the doctors tried next-generation sequencing and discovered the genetic mutations causing the siblings' illness. This information transformed their lives, enabling a new treatment that has stabilised their condition and allowed them a home life outside of hospital.

Advances in genetic sequencing technologies have brought personalised medicine closer to reality – how to translate these technologies into the NHS so that patients can benefit from the power of genomics will be a major challenge over the next few years.

14 of the global top 100 medicines were developed in the UK.[8]

The 100,000 Genomes Project

Genomics England, with the consent of participants and the support of the public, is creating a lasting legacy for patients, the NHS and the UK economy through the sequencing of 100,000 genomes. The 100,000 Genomes Project will build on Britain's long and successful history in genetic sequencing technology, preparing the NHS for genomic medicine and supporting UK medical research.

Currently in its pilot phase, the project will sequence whole genomes from 10,000 NHS patients with rare diseases or cancer in 2014. Genomic data generated through the project will be linked with clinical and other data in secure safe havens which will be accessed under strictly controlled and monitored conditions. This will allow researchers from academia and industry to develop new insights and understanding, leading in time to better treatments and diagnostics for patients. Access to Genomics England's data service will also seed a vibrant ecosystem of genomics-based SMEs, creating jobs and ensuring the UK leads this new global industry.

The scale of the project has already dramatically driven down the cost of sequencing and will drive up the quality of interpretation and analysis of genetic data. These advances will enable the development of a genomic medicine service for the NHS providing routine genetic testing for patients by the time the project finishes in 2017.

There will be immediate clinical benefit for some participants. More will know that use of their data will benefit others like them. And all of them will have played a part in developing an NHS genomic medicine service for anyone who needs it.

www.genomicsengland.co.uk

Genomics
england

Treatment

Research is helping us treat and cure more conditions than ever before. It leads to new treatments and the improvement of existing ones. Public and charitable research funders, small and medium-sized biotechnology firms, and large pharmaceutical companies in the UK work together to develop treatments that save and improve lives.

10. Diarrhoeal disease: In search of a life-saving treatment

BioFocus

Cholera-induced acute secretory diarrhoea is responsible for the deaths of approximately 600,000 children under the age of five in the developing world each year. The current standard treatment is oral rehydration therapy using a solution of salt and glucose. Although effective, the regime is labour-intensive with little symptomatic relief. Because diarrhoea continues even though the child is being hydrated, mothers often stop giving the life-saving therapy too early. A drug that works in association with oral rehydration therapy, and helps speed up the relief of diarrhoea symptoms, would have a profound effect on world health.

One possibility to complement oral rehydration would be a drug that blocks an ion channel called CFTR, which is involved with the rapid fluid loss associated with acute secretory diarrhoea. To search for a small molecule able to do this, BioFocus undertook a drug discovery programme in collaboration with OneWorld Health, supported by a grant from the Bill & Melinda Gates Foundation. The programme started in 2006, with medicinal chemistry design and biological assays conducted at BioFocus facilities near Cambridge.

After four years, several CFTR inhibitors discovered at BioFocus were shown to be effective in animal models of cholera infection. This led to the first small molecule inhibitor of CFTR to enter clinical trials, with phase II clinical trials currently underway in Bangladesh.

11. Collaborating to develop new cancer drugs

Cancer Research UK

The development of blockbuster cancer drugs can take years of collaboration between scientists, the health service, and public, private and charity research funders.

In the 1990s, scientists at The Institute of Cancer Research (ICR) in London, supported by Cancer Research UK, discovered that abiraterone acetate blocked production of male sex hormones and so had the potential to treat prostate cancer. Cancer Research Technology, the business arm of Cancer Research UK, brought in BTG International Ltd to finance further development: the Cancer Research UK Formulation Unit in Strathclyde made the drug suitable for people and the charity's Drug Development Office oversaw the first human trials at the ICR.

Having shown that it successfully blocked testosterone production, larger clinical trials were conducted by the ICR with Cougar Biotechnology and Janssen Pharmaceuticals, the subsequently licensed partners. Safety and effectiveness were established, and the drug significantly increased survival in men with prostate cancer. Approval for abiraterone acetate (Zytiga) was granted in the US and Europe in 2011.

Sales of the drug, approximately $1.7 billion in 2013, provide royalties to Cancer Research UK, contributing to the discovery and development of more cancer treatments. But abiraterone acetate itself has more potential because it blocks the production of other sex hormones. In 2008, Cancer Research UK's Drug Development Office began a new trial to test its effectiveness in breast cancer, with encouraging initial results.

The average time lag between investment in cancer research and eventual impact to patients is around 15 years.[9]

12. Improving access to mental health therapies

The University of Manchester

With high rates of common mental health problems like anxiety and depression in the UK, there is an urgent need for people to have better access to psychological therapies. Researchers at the University of Manchester have developed and evaluated 'low intensity' interventions such as guided self-help based on cognitive behavioural therapy (CBT), and offering CBT by telephone, an approach that has been implemented nationally by the Improving Access to Psychological Therapies (IAPT) initiative.

Using the telephone overcomes many social, physical and economic barriers that can prevent access to mental health services. The researchers showed that the therapy remained effective and they established the clinical efficacy and acceptability of telephone-delivered CBT for obsessive–compulsive disorder, anxiety, depression and chronic pain.

A telephone CBT service was established in partnership with Anxiety UK, a charity which has supported more than a million people, while a self-help manual written by the researchers is published by Rethink, a national mental health charity. Around 12,000 copies are sold through a not-for-profit scheme each year, and the manual is also used in IAPT services. Between 2009 and 2012, more than a million people used IAPT. Recovery rates were in excess of 45% and 45,000 people moved off benefits as a result.

More than one in 30 people in the UK are currently participating in a cohort study.[10]

13. Refining treatment for rheumatoid arthritis

The British Society for Rheumatology and the University of Manchester

Rheumatoid arthritis affects one in every hundred adults, causing chronic pain, disability, job loss and lower life expectancy. Standard treatments such as methotrexate are not effective in all patients and have undesirable side-effects. In 2002, anti-TNF therapy was approved to treat rheumatoid arthritis in the NHS. At the time, however, very few people had received this new class of drugs – known as biologics – and their effectiveness and safety in the 'real world' were unproved.

In 2001, the University of Manchester launched the British Society for Rheumatology Biologics Register. Funded by the British Society for Rheumatology, it is the world's largest prospective study of biologic drugs in rheumatoid arthritis, having recruited and followed over 22,000 NHS patients being treated with biologics. It showed better control of disease among patients who also continued with methotrexate therapy, a finding now incorporated in prescribing guidelines. A previously unknown increased risk of salmonella and listeria infections was identified – rates of infection dropped dramatically when drug information leaflets were updated to advise patients to avoid high-risk foods. The study also provided strong evidence that women do not need to stop anti-TNF treatment before pregnancy.

Millions of patients worldwide have now received biologics. The systematic observation of treatment and outcomes among NHS patients has led directly to more effective prescribing and better outcomes for patients with this chronic disabling condition.

14. CAPS: From a rare diagnosis to a national treatment service

University College London

Cryopyrin-associated periodic syndrome (CAPS) causes recurrent attacks of fever, pain and rash from birth, with serious long-term risks to the child's growth and development. Genetic and clinical studies at University College London, funded by the NHS with support from pharmaceutical company Novartis, showed that patients with CAPS had certain genetic mutations. From these results, the researchers, still in collaboration with Novartis, developed a drug called canakinumab.

Canakinumab alleviates symptoms in virtually all CAPS patients. It clears the inflammation that causes serious flu-like symptoms and fevers and affects the skin, eyes, joints and brain. This ends the overwhelming fatigue that impedes employment and social activities. It allows normal quality of life, as well as catch-up growth and sexual maturation in adolescents. Early treatment is expected to prevent the skeletal deformities, blindness, deafness and kidney failure that can otherwise occur. Canakinumab has also been shown to be effective in treating other autoinflammatory disorders.

As a result, the Department of Health now funds the NHS CAPS Treatment Service: this is the national service for patients with autoinflammatory diseases, offering a diagnostic service as well as treatment. In the UK centre, 57 patients with CAPS are currently receiving canakinumab and worldwide 846 CAPS patients are now being treated.

The pharmaceutical industry employs around 73,000 people directly in the UK.[8]

15. Deep brain stimulation: A new lease of life for people with Parkinson's

Parkinson's UK

As Parkinson's disease progresses, it becomes increasingly difficult to balance a patient's medication and manage their symptoms without side-effects. For some, oral medication fails to work properly, leaving them frozen to the spot, while others develop uncontrollable movements. A pioneering surgical therapy called deep brain stimulation (DBS) can help some patients when increasing oral medication is no longer an option.

In 2002, the Medical Research Council, the Department of Health and Parkinson's UK funded the world's largest trial of DBS for Parkinson's. 366 patients with advanced Parkinson's were randomly assigned to either receive DBS or continue using the best medical therapy alone. After 12 months, results showed that DBS improved quality of life and mobility compared to medication alone, and those who had DBS needed less medication.

Bob Taylor, who recently had DBS, said: "Undergoing surgery has given me hope for the future. I have so far reduced my medication by 25%. It is not a cure, but I do feel more in control of my life again."

However, he said access to DBS is patchy: "Out of two hospitals I visited, only one answered my questions and offered me adequate information to make me feel comfortable." Parkinson's UK wants everyone with Parkinson's to have equal access to the care and support they need, including DBS when appropriate.

16. Translating basic research into cancer treatment

The Institute of Cancer Research, London

Mutations in the BRCA1 and BRCA2 genes increase the risk of breast and ovarian cancer. BRCA2 was identified at The Institute of Cancer Research (ICR) in the 1990s; more recently, a team of ICR researchers discovered that BRCA2 has a key role in repairing damaged DNA. While losing this repair function makes cells more likely to become cancerous, it should also leave them vulnerable to drugs that switch off alternative DNA repair pathways.

In 2005 the research team targeted PARP, a key enzyme in another DNA repair pathway. They found that cells with BRCA1 or BRCA2 mutations were up to 1000 times more sensitive to PARP inhibitors than normal cells. Clinical trials at the ICR's partner hospital, The Royal Marsden, followed in which cancer patients received olaparib, a PARP inhibitor developed by British company KuDOS (later acquired by AstraZeneca). Many of the patients on these trials showed a remarkable response to olaparib and had significant tumour shrinkage without showing many of the side-effects that are normally found with other cancer drugs.

Olaparib has moved into phase III studies and been tested in over 3000 patients. It is effective in treating breast, ovarian and prostate cancer patients with mutant BRCA genes. The drug has been put forward to the regulatory authorities for approval and registration in Europe, and is being assessed by NICE for use in the NHS. The rapid translation of laboratory work into patient benefit exemplifies how UK research can have a real impact on cancer patients' lives.

Each pound invested in cancer-related research by the taxpayer and charities returns around 40p to the UK every year in perpetuity.[9]

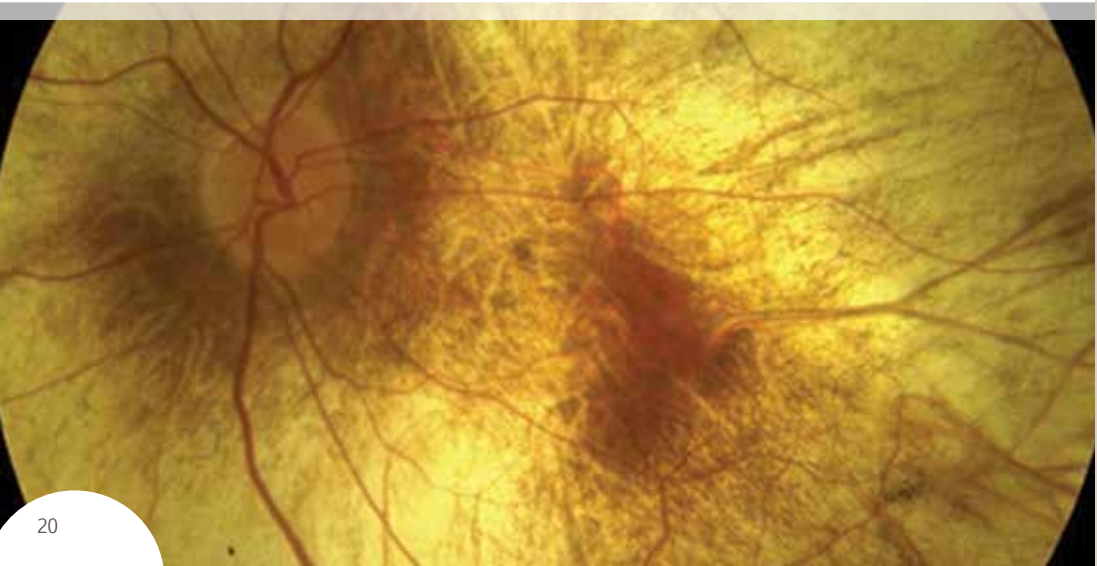
17. A new gene therapy for blindness

Department of Health, University of Oxford, Wellcome Trust

Choroideremia is an incurable degenerative disease that causes progressive loss of vision, eventually ending in blindness. The disease is found almost exclusively in men, affecting at least 500 people in the UK, with a worldwide prevalence of 1 in 50,000. A multicentre programme to develop and test the safety of a gene therapy treatment for the condition is underway at the University of Oxford, funded through the Health Innovation Challenge Fund — a joint partnership between the Wellcome Trust and the Department of Health which aims to accelerate the clinical application of innovative R&D.

Choroideremia is caused by deficiency of a protein encoded by the choroideremia gene (CHM), which leads to a progressive deterioration in sight over about 40 years. The group in Oxford, led by Professor Robert MacLaren, has developed a procedure to replace the faulty copies of CHM in cells in the eye. Specially engineered virus particles carrying a functional CHM gene are injected beneath the retina. To make the procedure easier, the team has developed a safe way to detach the fovea, a small but essential part of the eye.

Early results of Phase I trials with 12 patients were promising in terms of safety and produced encouraging data on improved vision. If the degeneration can be slowed, this procedure would represent the first ever treatment for choroideremia. A recent £12 million deal with investment company Syncona has created a spin-out company called NightstaRx to develop this technology into a licensed treatment.



The Francis Crick Institute

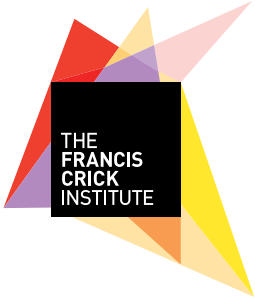
The Francis Crick Institute (the Crick) will be a new and distinctive biomedical research institute. It will be located in London, but its vision is UK-wide, and relevant worldwide.

The Crick is a consortium of six of the UK's most successful scientific and academic organisations: the Medical Research Council, Cancer Research UK, the Wellcome Trust, UCL (University College London), Imperial College London and King's College London. Its work will help to understand why disease develops and find new ways to treat, diagnose and prevent a wide range of illnesses such as cancer, heart disease and stroke, infections, and neurodegenerative diseases. Rather than focusing on particular research disciplines or disease areas, the Crick will develop a highly collaborative approach that draws on broad expertise, including from disciplines such as mathematics, physics and engineering.

The Crick will be a large institute (over 1200 scientific staff) with access to an even larger pool of knowledge and expertise from its three university partners. It is also developing partnerships with industry to promote cross-fertilisation of ideas and accelerate translation of research into health and economic outcomes.

The Crick will place a strong focus on attracting and developing young and emerging scientists. A majority of group leaders will remain at the Crick for no more than 12 years before being supported to find scientific leadership positions elsewhere, with a strong emphasis on UK institutions. This innovative approach means the Crick will play a national role in expanding the talent pool for biomedical science across the UK.

www.crick.ac.uk



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The Academy of Medical Sciences is the independent body in the UK representing the diversity of medical science. Our mission is to promote medical science and its translation into benefits for society. The Academy's elected Fellows are the United Kingdom's leading medical scientists from hospitals, academia, industry and the public service. We work with them to promote excellence, influence policy to improve health and wealth, nurture the next generation of medical researchers, link academia, industry and the NHS, seize international opportunities and encourage dialogue about the medical sciences. • www.acmedsci.ac.uk

Arthritis Research UK

Arthritis Research UK is the charity dedicated to stopping the devastating impact that arthritis has on people's lives. Everything that we do is focused on taking the pain away and keeping people active. Our remit covers all conditions which affect the joints, bones and muscles including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis. We fund research into the cause, treatment and cure of arthritis, provide information on how to maintain healthy joints and bones and to live well with arthritis. We also champion the cause, influence policy change and work in partnership with others to achieve our aims. We depend on public support and the generosity of our donors to keep doing this vital work.

• www.arthritisresearchuk.org

Association of Medical Research Charities

The Association of Medical Research Charities (AMRC) is the national membership organisation of leading medical and health research charities. We help our members to meet their charitable objects by interpreting and influencing the regulatory, policy and research environments, and connecting members to encourage collaboration and share learning. Our vision is charities delivering high quality research to improve health and wellbeing for all.

AMRC members support over one third of all publicly-funded medical research in the UK. Our members invested over £1.3 billion in health research in 2013. Many of these charities exist because the public choose to donate money to support research to develop new treatments and cures. • www.amrc.org.uk

Cancer Research UK

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. We receive no government funding for our research and rely on the generosity of the public. In 2012/13, we spent more than £330 million on research into all aspects of cancer, from exploratory biology to clinical trials as well as epidemiological studies and prevention research. This is achieved through the work of over 4,000 scientists, doctors and nurses.

Cancer Research UK's vision is to bring forward the day when all cancers are cured. In the 1970s, less than a quarter of people with cancer survived. But over the last 40 years, survival has doubled – today half will survive. Our ambition is to accelerate progress and see three-quarters of people surviving the disease within the next 20 years.

- www.cancerresearchuk.org

The Medical Research Council

The Medical Research Council has been at the forefront of scientific discovery to improve human health. Founded in 1913 to tackle tuberculosis, the MRC now invests taxpayers' money in some of the best medical research in the world across every area of health. Twenty-nine MRC-funded researchers have won Nobel prizes in a wide range of disciplines, and MRC scientists have been behind such diverse discoveries as vitamins, the structure of DNA and the link between smoking and cancer, as well as achievements such as pioneering the use of randomised controlled trials, the invention of MRI scanning, and the development of a group of antibodies used in the making of some of the most successful drugs ever developed. Today, MRC-funded scientists tackle some of the greatest health problems facing humanity in the 21st century, from the rising tide of chronic diseases associated with ageing to the threats posed by rapidly mutating micro-organisms. • www.mrc.ac.uk

The Wellcome Trust

The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests. • www.wellcome.ac.uk

References and further information

This booklet was produced by the All-Party Parliamentary Group on Medical Research, June 2014.

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The image on page 4 and 9 is courtesy of the Wellcome Library, with thanks to the Disconnected Mind project funded by Age UK at the University of Edinburgh Centre for CognitiveAgeing and Cognitive Epidemiology, www.ccace.ed.ac.uk

The image on page 19 is courtesy of Understanding Animal Research