annual review
2017
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INTRODUCTION

Introduction from the chair and chief executive

It has been another successful year for the Trust. Within these pages you will get some sense of the impressive contribution made by teams at our hospitals to patient care now and in the future.

You will read about one young girl’s life-saving surgery that reflects the very best our Trust has to offer: seamless collaboration between clinical teams on both sites, another specialist Trust and a device manufacturer; the availability of highly specialist expertise across a number of disciplines; and a desire to innovate that not only saved a life, but also paved the way for a new treatment to be made available to children – in this case total artificial heart implantation.

You will read about our cystic fibrosis ‘virtual clinics’ – introduced to cut the number of hospital visits patients need to make, saving them time and money and crucially, eliminating any risk of cross-infection. Skype clinics have allowed our experts to establish proof of principle. The next phase of their programme will involve working with technology companies to develop equipment and apps to be used at home to measure lung function, oxygen levels and other key diagnostics. The benefit for patients will be significant.

You will also read about the continuing success of our research teams who, during 2016/17, had 790 papers published, raised over £11 million in external funding and recruited 2,700 patients to 200 research programmes, including global studies sponsored by industry, trials involving new devices and medicines and international registry studies.

These examples have a common theme, one that is present in much of the delivery of 21st Century healthcare, the theme of collaboration.

To deliver the best patient care, healthcare is becoming less and less about single institutions and far more about collaboration and creating networks and systems of care. Organisations working alone are increasingly finding it difficult to deliver what patients need.

For a heart and lung specialist Trust such as ours, the need to look ahead and consider new models of working has also never been more important.

Cardiovascular diseases are the most prominent cause of death globally; year on year, more people die from these diseases than from any other cause. In the UK, there are an estimated seven million people living with
To deliver the best patient care – healthcare is becoming less and less about single institutions and far more about collaboration and creating networks and systems of care. Organisations working alone are increasingly finding it difficult to deliver what patients need.

Cardiovascular disease, with an average of one death every three minutes. Respiratory illnesses account for around 25 per cent of all deaths worldwide, and there are an estimated 12.7 million people living with a longstanding respiratory illness in the UK today.

Cardiovascular and respiratory diseases are often congenital or inherited – meaning that life-long care is central to a way of working for healthcare providers. Those conditions that are acquired are more prevalent in later life, and obesity and other lifestyle factors mean that there will be a continued and increasing demand for services to treat these diseases.

Collaboration across our clinical and academic programmes is a key component of their success. We value our proud and rich history with the National Heart and Lung Institute of Imperial College London, a partnership which spans over 20 years. Our joint Institute of Cardiovascular Medicine, a partnership with Liverpool Heart and Chest Hospital supported by Imperial College, combines the resources of two leading cardiothoracic centres to deliver clinical research programmes that translate directly into clinical practice. Our membership of the South London Genomic Medicine Centre, along with partner hospital trusts such as Guy’s and St Thomas’ and St George’s, will enable clinical genetics to be applied as a mainstream diagnostic tool for a population of 10 million. And our life-saving primary angioplasty service based at Harefield’s heart attack centre, is the culmination of over ten years’ seamless working with the London, East of England and South Central ambulance services.

It is this willingness to adapt to the changing needs of patients, by forming new alliances and developing existing ones, that lies at the heart of our planned collaboration with King’s Health Partners (the Academic Health Sciences Centre comprising Guy’s and St Thomas’, King’s College Hospital and South London and Maudsley NHS Foundation Trusts and King’s College London). We believe the collaboration has the potential to revolutionise cardiovascular and respiratory services for patients, creating a global powerhouse for heart and lung medicine and research in London, providing the best possible patient care and experience. The partnership will:

- deliver world-class clinical services from before birth through to old age for common and rare conditions on a local, regional, national and international level, offering new treatments;
- the organisations involved to deliver best practice care in modern facilities, making the best use of NHS estates;
- provide a large-scale service for adults and children with heart and lung conditions, offering outstanding outcomes and sustainable care within a collaborative network;
- allow the organisations to cement their place at the forefront of UK health research and build strong industry and commercial partnerships; and
- train the next generation of clinicians and researchers, through extensive education including national and international training.

We look forward to updating you on our progress.

Mr Robert Bell
Chief Executive
Royal Brompton & Harefield NHS Foundation Trust is the largest specialist heart and lung centre in the UK and among the largest in Europe.

The Trust is a partnership of two specialist hospitals – Royal Brompton in Chelsea, West London, and Harefield, near Uxbridge – which are known throughout the world for their expertise, standard of care and research success.

We are a specialist trust, providing treatment for people with heart and lung disease only. This means our doctors, nurses and other healthcare staff are experts in their chosen field, and many move to our hospitals from other parts of the UK and abroad so that they can develop their skills even further.

We carry out some of the most complicated surgery, and offer some of the most sophisticated treatment that is available anywhere in the world. We treat patients from all over the UK and other countries.

Our fetal cardiologists can perform scans at just 12 weeks, when a baby’s heart valve is just over a millimetre in size, and our clinical teams regularly treat patients well into their 90s.

Over the years our experts have been responsible for several major medical breakthroughs – performing the first successful heart and lung transplant in Britain, implanting the first coronary stent, founding the largest centre for cystic fibrosis in the UK, and pioneering intricate heart surgery for newborn infants.

We are the leading UK provider of respiratory care and a national leader in the specialist areas of paediatric cardiorespiratory care, congenital heart disease and cystic fibrosis.

Our patients are supported by adult intensive care units at both hospitals and a dedicated paediatric intensive care unit at Royal Brompton.

Our research

Research programmes play a vital role at both our hospitals. Our clinicians work on numerous research projects that bring benefits to patients in the form of new, more effective and efficient treatments for heart and lung disease. Many medical advances made at the Trust have been taken up across the NHS and beyond. Each year between 600 and 700 papers by researchers associated with the Trust are published in peer-reviewed scientific journals such as The Lancet and The New England Journal of Medicine.

Our main partner is the National Heart and Lung Institute at Imperial College, London, and we run additional research projects with other hospitals and universities in the UK and abroad.

Collaboration

Our proximity to the specialist cancer hospital, The Royal Marsden, enables the two trusts to jointly run one of the largest lung cancer programmes in the UK.

Close collaboration with neighbouring Chelsea and Westminster Hospital allows both trusts to provide significantly enhanced services to patients with heart or lung disease. Harefield teams are supported across a range of specialist disciplines by Hillingdon Hospital NHS Foundation Trust.

During 2016/17 we cared for more than 200,000 patients in our outpatient clinics and nearly 40,000 patients of all ages on our wards.
Our vision and values

Our vision is to be the UK’s leading specialist centre for heart and lung disease, developing services through research and clinical practice to improve the health of people across the world.

The Trust will achieve this vision by:

- improving patient safety and satisfaction
- providing world class specialist treatments that others cannot offer
- bringing innovation to clinical practice through our research partnerships
- attracting, developing and retaining world class clinical leaders
- investing in services, technologies and facilities to support new service models at both sites.

We are supported in this by active patient and community groups who enthusiastically encourage and challenge us to deliver our goals.

Our values

At the heart of any organisation are its values: belief systems that are reflected in thought and behaviour. When values are successfully integrated throughout an organisation, the result is a shared outlook and consequent strength, from performance through the style of communications to the behaviour of employees.

Our values were developed by staff for staff. We have three core patient-facing values and four others which support them.

Our three core values are:

We care

We believe our patients deserve the best possible specialist treatment for their heart and lung condition in a clean, safe place.

We respect

We believe that patients should be treated with respect, dignity and courtesy and that they should be well informed and involved in decisions about their care. We always have time to listen.

We are inclusive

We believe in making sure our specialist services can be used by everyone who needs them, and we will act on any comments and suggestions which can help us improve the care we offer.

And the following values support us in achieving them:

We believe in our staff

We believe our staff should feel valued and proud of their work and know that we will attract and keep the best people by understanding and supporting them.

We are responsible

We believe in being open about where our money goes, and in making our hospitals environmentally sustainable.

We discover

We believe it is our duty to find and develop new treatments for heart and lung disease, both for today’s patients and for future generations.

We share our knowledge

We believe in sharing what we know through teaching, so that what we learn can help patients everywhere.
During 2016/17 we:

- Cared for more than 200,000 patients in our outpatient clinics
- Cared for nearly 40,000 patients of all ages on our wards
- Received more than 10,000 patient comments, of which more than 90 per cent were positive
- Received a 96 per cent recommendation score in the annual Friends and Family Test
- Helped nearly 14,000 adults who have breathing problems caused by diseases such as COPD (chronic obstructive pulmonary disease) and severe asthma
- Broke ground on a new development at Harefield Hospital to expand the intensive care unit and treat 250 additional patients each year
- Carried out 1,075 coronary artery bypass grafts
- Were one of the top three most highly cited health research teams in England – with 790 papers published in scientific journals
- Saw almost 700 patients in our adult cystic fibrosis (CF) clinics, making us one of the largest and most active adult CF centres in Europe
- Successfully transplanted an artificial heart into a child – the first in Europe
- Maintained one of the fastest arrival to treatment times for heart attack patients in the UK (23 minutes compared to a national average of 56)
- Raised more than £11 million for research
- Performed 475 surgical procedures for congenital heart disease (350 paediatric, 125 adult)
- Recruited 2,700 patients onto 200 research programmes that will contribute towards better patient care and outcomes
- Balanced our books, recording a £2 million financial surplus at year-end.
Baroness Morgan of Huyton joins the Trust

Sally Morgan, Baroness Morgan of Huyton, was appointed chair of the Trust on 1 January 2017.

Baroness Morgan was made a life peer in 2001. She has served as minister of state in the Cabinet Office, political secretary to the prime minister and director of government relations at 10 Downing Street, chair of Ofsted and board member of the Olympic Delivery Authority.

Bob Bell, chief executive, said: “I very much look forward to working with Baroness Morgan. She brings skills and experience that will be extremely valuable during the months and years ahead.”

The Trust’s council of governors commented: “The NHS is experiencing a period of continuing challenge as demand for services rises exponentially. Challenging times require confident and talented leaders and that is exactly what we have in Baroness Morgan. She brings extensive experience at board and advisory level in the public, private and third sectors, along with political acumen.”

After serving as a local councillor and working as a secondary school teacher, Baroness Morgan worked for Tony Blair when he was leader of the opposition. Following the 1997 general election she was appointed political secretary to the Prime Minister and head of the Prime Minister’s political office. She then served as minister of state in the Cabinet Office before returning to Downing Street as director of government relations.

Since leaving government in 2005, Baroness Morgan has held a number of appointments in the public and private sector. She was the chair of Ofsted (the Office for Standards in Education) from 2011 to 2014 and sat on the board of the Olympic Delivery Authority for its six year duration. She is currently a member of the House of Lords Science & Technology Select Committee.

Baroness Morgan has been a lay member of the Council of King’s College London since 2013, and was appointed vice-chair in September 2016. She is also a member of the Council’s Estates Strategy Committee and the Fellowships and Honorary Degrees Committee.

Currently she is chair of Ambition School Leadership (a UK education charity) and board adviser to Ark, which runs academies in the UK and works internationally in education. She is a non-executive director of Dixons Carphone plc and Countryside Properties plc and senior independent non-executive director of Carillion (integrated support services).

Baroness Morgan commented: “I am delighted to be taking on the role of Chair at Royal Brompton & Harefield which has a local, national and international reputation for patient care and for research. Specialist trusts make a vital contribution to pushing the boundaries of modern medicine, developing new treatments that both improve lives and save lives. I am passionate about the NHS and patient-focused research, and very much look forward to building on my experience in business, politics and education to help guide the Trust successfully through a challenging period.”
Research highlights

Our pioneering research into heart and lung conditions continues to play a vital role in developing new treatments and improving care for patients.

In 2016/17, teams at the Trust took part in a number of influential research programmes to discover new ways of treating patients with complex cardiovascular and respiratory conditions.

Our research is a collaborative effort and we work with other NHS trusts, universities and industry to ensure the necessary financial and academic support and expertise is available to make significant medical advances.

The National Heart and Lung Institute at Imperial College London is a vital partner in our research work. We also have a close partnership with the National Institute for Health Research (NIHR).

We have worked with various other NHS trusts this year, including Chelsea and Westminster Hospital NHS Foundation Trust, The Royal Marsden NHS Foundation Trust, and Liverpool Heart and Chest Hospital NHS Foundation Trust, as well as universities such as Oxford University and Imperial College.

Collaboration with the pharmaceutical and medical devices industries has also given our patients the chance to take part in the latest ground-breaking research. This year we have also worked closely with charities such as the British Heart Foundation and British Lung Foundation, and the charitable foundation the Wellcome Trust, to bring together our respective expertise.

To further our world-leading research, we work with other healthcare organisations around the world on major research programmes, including two ground-breaking studies on the genetics of heart conditions.

Major research advances in inherited heart conditions

Several major research advances in inherited cardiac conditions have been made this year.

In a discovery that could open up a new avenue of treatment for inherited heart disease, our researchers have identified the gene responsible for the growth of blood vessels in the heart.

Collaborating with the National Heart and Lung Institute and Imperial College, a research team led by Professor Stuart Cook, director of the genetics and genomics team, has uncovered the importance of the ‘Wars2’ gene. When this gene was turned off in animals, it reduced blood vessel growth in both the heart and the rest of the body, showing it is an essential gene in blood vessel formation (known as angiogenesis).

In some inherited heart conditions, there are too few blood vessels for the heart to function effectively. The discovery of Wars2 could mean that more vessels could be stimulated in people with these conditions.

Our researchers – in collaboration with the Wellcome Trust Sanger Institute – have also been involved in the largest international study looking at heart disease in children. One of the most exciting findings from this study was that a much higher percentage of congenital heart disease (CHD) is caused by genes passed down from apparently healthy parents than was previously thought. Before this, it had been assumed that CHD was often caused by spontaneous gene mutations, rather than inherited genes.

In 2016/17:

- **790 papers were published** in peer-reviewed scientific journals, such as The Lancet, Nature, and The New England Journal of Medicine
- More than **£11 million was raised** in external funding for research, from bodies including the National Institute for Health Research, Wellcome Trust, British Lung Foundation and the private sector
- **£1.2 million was received** in awards for non-medical research at the Trust
- **2,700 patients** took part in **200 Trust research programmes** – including global studies sponsored by industry, trials involving new medicines or devices, and international registry studies.
This research means that in the future doctors may be able to offer much clearer advice to families about the chances of a child being born with a congenital heart defect.

Other advances this year in the genetics of heart conditions include:

- A study in collaboration with Imperial College London, Oxford University and Partners HealthCare Boston that discovered better methods to assess the significance of gene mutations. This could lead to more diagnoses through genetic testing.

- An international study co-led by consultant cardiologist Dr James Ware, in collaboration with the MRC Clinical Sciences Centre, with support from the Wellcome Trust and British Heart Foundation, which showed that around one per cent of the population carry a faulty gene that could predispose otherwise healthy people to heart failure, especially if the heart is put under stress.

- Work supported by the Wellcome Trust, Department of Health, Medical Research Council and British Heart Foundation that developed a tool (the CardioClassifier) to improve and standardise the interpretation of gene sequencing in the genes of patients with inherited heart conditions.

Cystic fibrosis drug found to improve children’s lung function

A combination drug for cystic fibrosis (CF) has been found to improve the lung function of children suffering from the disease.

An international study, which included researchers from Royal Brompton Hospital, showed that Orkambi (a combination of lumacaftor and ivacaftor) can improve lung damage caused by CF in less than two weeks, and could add years to the lives of people with the disease.

CF is caused by mutations in the gene that controls the movement of salt and water in and out of cells. This leads to a build-up of mucus in the lungs and digestive system.

Orkambi is one of the first therapies to target the most common form of mutation, rather than the symptoms. About half of the people with CF in the UK could benefit from the treatment.

Researchers found that the drug could halt or even reverse lung damage in children under 12 years old. It was also found to slow the loss of lung function in older patients.

The trial involved 204 patients aged between six and 11 years. The results were published in The Lancet Respiratory Medicine.

Jane Davies, honorary consultant in paediatric respiratory medicine, who led the Royal Brompton part of this major trial, said: “This is the first time the lung clearance index has been used in this type of clinical trial.

“It shows that even young children with relatively early stage CF can benefit from new treatments.”

The UK is one of the countries with the highest prevalence of CF in Europe, with around 10,500 people suffering from the condition.

While prognosis for people with the disease has vastly improved over the years – a child born today is likely to have a mean life expectancy of over 40-50 years – experts stress that early treatment in children is critical for their long-term outlook.

More than £1 million in research awards for non-medical research

Allied health professionals, healthcare scientists and nurses from across the Trust, were awarded research grants totalling £1.2 million during 2016/17.

These non-medical research awards include competitively-secured funding and prestigious fellowships, and highlight the strength and depth of research activity across the organisation.

The awards have come from organisations such as the Pulmonary Fibrosis Trust (UK), the Health Foundation, Pharmacy Research UK and the NIHR. They cover research into a range of conditions and treatments, including idiopathic pulmonary fibrosis, atrial fibrillation and extracorporeal membrane oxygenation (ECMO).

Several of our researchers have also been offered formal training opportunities, such as Masters or PhDs, including clinical doctoral research fellowships with the NIHR.

Professor Mary Morrell, professor of respiratory and sleep medicine, said: “The recent awards are testament to the calibre of staff across the Trust and demonstrate that important research is being carried out across a number of professions.”
I
n June 2016, the Trust joined the Imperial College Academic Health Science Centre (AHSC), a partnership with Imperial College London, the Royal Marsden NHS Foundation Trust and Imperial College Healthcare NHS Trust.

By aligning the research, education and clinical services of these four internationally-renowned organisations, the AHSC aims to improve the quality of life for patients and communities, by taking new research discoveries and translating them into new treatments and techniques. The AHSC builds on existing collaborative projects between the four partners, including:

- the West London Genomic Medicine Centre, which is playing a key role in the successful delivery of the 100,000 Genomes Project
- the Royal Marsden Partners Cancer Vanguard, which is developing new models of cancer care
- joint lung cancer research projects.

Bob Bell, chief executive, said: “This strategic alliance will promote an integrated research vision with the capacity to strengthen translational research into heart and lung disease.

“Patients will be the ultimate beneficiaries, with our combined expertise offering an unparalleled national collaboration. This will improve outcomes now and support enhanced research for future generations.”

As well as being a driving force for future innovations and patient care, the AHSC is an inclusive learning network for staff at all levels, with an exciting programme of seminars, which are hosted by the partner trusts on a rotational basis and cover topics ranging from how innovative devices are changing the way cardiovascular disease is treated, to understanding and treating the flu virus.

All seminar presentations are recorded and can be viewed by visiting ahsc.org.uk
CQC report 2017:
a solid foundation with some clear highlights

In January 2017 the Trust received its rating from the Care Quality Commission (CQC) – the independent regulator for health and social care in England.

The CQC inspected six core services at both sites: medicine, surgery, critical care, end of life care, and outpatient and diagnostic services, as well as children and young people's services at Royal Brompton.

The inspection criteria are rightly rigid, and although the Trust scored “good” in the majority of categories, the overall score fell just short of that required for a “good” rating, leading to an overall rating of “requires improvement”. Services at Harefield Hospital were rated “good” across the board with an overall rating of “good”.

The CQC inspectors were impressed by a number of aspects of the care at both sites. Particular praise was given to respiratory medicine at Royal Brompton which was rated “outstanding”, the transplant and artificial heart team at Harefield, “one of the most highly skilled in the UK” and “with some of the best outcomes in the country,” our paediatric teams, who were rated “good” or “outstanding” across all categories, and our ECMO life support service for its high survival rates.

Other areas of outstanding practice included:

- Harefield’s ventricular assist device team – one of the most highly skilled in the UK.
- Royal Brompton’s medical care.
- Royal Brompton’s internationally-acclaimed research on cystic fibrosis.
- Royal Brompton’s compassionate care programme, which encourages “clinical and service innovation at all levels”.

The main recommendations outlined in the CQC report related to ensuring medical records were kept securely, ensuring hand hygiene rules and hand gel are obvious throughout all wards, and embedding the World Health Organization’s “five steps to safer surgery” checklist across both sites.

The Trust’s Board takes these inspection results very seriously and has endorsed an action plan to address the issues raised.

Harefield Hospital was rated “good” across the board – in all categories and for all services.
Our specialist heart services

Clinical teams at Royal Brompton and Harefield hospitals care for patients with a wide range of complex cardiac conditions, both congenital (present at birth), inherited and acquired.

Our teams are based around the following themes: arrhythmias (irregular heart rhythms), congenital heart disease, heart failure, pulmonary hypertension (high blood pressure in the arteries of the lungs that can lead to heart failure), revascularisation (coronary artery disease), structural heart disease, and heart assessment.

The adult congenital heart disease (ACHD) unit at Royal Brompton is one of the largest specialised centres in the world, caring for patients with a variety of conditions.

Our experts care for around 100,000 patients and carry out more than 2,000 outpatient appointments each year, with many patients receiving care from the first days of their lives, through into adulthood.

The unit is also a major research facility, producing more highly-cited research papers than any other, and a world-leading training centre for cardiologists, cardiothoracic surgeons and other clinicians. During 2016/17, this vital service was once again under threat of closure – see page 28 for more information.

A major study to see if surgery could be an effective treatment for atrial fibrillation will help patients make an informed choice about their treatment.

The study, led by Royal Brompton and Harefield consultants Dr Tom Wong and Dr Shouvik Haldar, launched in 2015 and will run for four years, supported by Imperial College London and Liverpool Heart and Chest Hospital.

Following a successful pilot, the National Institute for Health Research has committed £1.2 million to enable a full multi-centre randomised controlled trial.

Typically, atrial fibrillation (a disorder that causes an irregular, often abnormally fast, heart rhythm) is treated using catheter ablation, where a catheter is inserted through a vein and used to destroy small areas of tissue that are causing the rhythm problem, combined with drug therapy.

Persistent longstanding atrial fibrillation is harder to treat and patients often need repeat procedures, so the study aims to determine if surgery would be better for this group of patients.

It brings together physicians and surgeons, who will take an unbiased look at the pros and cons of their approach in order to develop evidence-based advice for patients.

Dr Haldar, study coordinator, explained: “The pilot study suggested surgery offers better outcomes with just one procedure. We will use the full study to prove that hypothesis.

“We have been asked, as physicians, whether we are putting ourselves out of a job by doing this study, but what is most important is doing a ‘real world’ study to look at what is best for patients.

“In fact both approaches have advantages and disadvantages. Surgery seems to get better first time results, but it is more invasive so there is more risk of complications. It also involves a much longer stay in hospital, which is not suitable for all patients.

“The most important thing is that by thoroughly exploring both techniques, we can give patients a genuine, informed choice about which route will be best for them.”

As well as analysing patients’ experiences, and data from a small implantable recorder that detects any abnormal heart rhythms after a procedure, a full economic analysis will look at the cost benefits of both approaches.

The ultimate aim is to influence national guidelines on treatment of atrial fibrillation. Four separate publications by Trust experts are already cited in the current guidelines for this condition.
Transplant patient comes face to face with his old heart

A patient who donated his old heart for research following a transplant returned to see how it has helped doctors learn more about congenital heart disease (CHD).

Kieran Sandwell was born with transposition of the great arteries, a condition where the pulmonary artery – which takes blood to the lungs, and the aorta – which takes blood to the rest of the body, are the wrong way round.

By the time he was 35 Kieran developed severe heart failure, and in 2009 he had a transplant at Harefield Hospital, insisting his heart was donated for medical research.

Seven years later, Kieran visited Royal Brompton to see his old heart. He said: “I was amazed at the size of it. Hearts are normally the size of a fist, but it looked like two fists. The right ventricle had severely dilated where the muscle wasn't working.

“I thought I’d be calm but when they brought it out I froze. It was a very strange experience.”

The heart was used by consultant cardiologist Dr Sonya Babu-Narayan for her research, funded by the British Heart Foundation, investigating whether a risk of sudden heart failure can be predicted in adults with CHD.

She said: “My research tries to reduce early deaths by improving investigations and treatments for abnormal heart rhythms.

“Kieran’s heart has been crucial and has helped validate some of my findings. We were able to confirm that the MRI he had before his transplant had identified scars in his heart, caused by previous surgery. My research explores whether this scarring can be used to decide if patients are at risk and how best to treat them."

“Thanks to Kieran's help, we are confident we can use imaging to assess the scarring. This will now be part of the care of adult patients with congenital heart disease, so Kieran’s heart has made a real difference to diagnosis and treatment of the condition.”

Kieran added, “Thinking about all the research that has been done, and how that is going to improve the outcomes for patients who are born with heart conditions, is amazing.”

In the 1950s, only about 20 per cent of babies with a serious congenital heart defect survived their first year, while today around 90 per cent live to adulthood, many leading relatively normal lives. Research like Dr Babu-Narayan’s means their prognosis continues to improve every year.

Thanks to Kieran’s help, we are confident we can use imaging to assess the scarring. This will now be part of the care of adult patients with congenital heart disease, so Kieran’s heart has made a real difference to diagnosis and treatment of the condition.
Eating cancer is a major achievement for any patient, and increasing numbers of people are surviving the disease every year.

A significant side effect of cancer treatment for some patients is damage to the heart caused by chemotherapy drugs, and more and more people are living with heart problems caused by their cancer medication.

In response to this emerging challenge, consultant cardiologist Dr Alexander Lyon teamed up with neighbouring specialist cancer hospital The Royal Marsden – to create the first dedicated cardio-oncology clinic in the UK.

The clinic, which this year celebrated its fifth anniversary, now sees 200 patients each year, some of whom are still fighting cancer, and others who are in remission. Patients are referred to Dr Lyon by oncologists, surgeons and anaesthetists at The Royal Marsden.

Services offered by the clinic include identifying early signs of cardiotoxicity – a type of heart failure that can be caused by some chemotherapy drugs – in patients undergoing cancer treatment, and a risk assessment service for people with pre-existing heart conditions to ensure they are fit to undergo surgery where required, or to support their heart function so they can receive the optimal cancer drugs.

Dr Lyon said of the service:
“...This is a partnership that truly has the patient at its heart. Working in close collaboration with colleagues here and at The Royal Marsden, we can ensure every individual receives both the very best cancer and cardiac care.

“My first question to the oncologist when I have a patient who is having heart problems, is ‘is the cancer responding to this drug?’ because if it is, we will move mountains to support the heart so that they can continue the drug.

“What we are doing has two clear benefits for the patients – it helps prepare heart patients for the rigours of cancer treatment by ensuring they are in the best possible health at the outset, and it helps cancer patients go on to live as full a life as possible after treatment.

The clinic is an efficient one-stop-shop: patients have cardiac scans and blood tests in the morning, results are reviewed by Dr Lyon and his team of cardiologists, clinical fellows and clinical nurse specialists, and are discussed with patients on the same day.

Royal Brompton hosts Europe’s first cardio-oncology conference

Royal Brompton was asked to host the annual international cardio-oncology conference in 2017 – the first time this event has ever been held outside the USA.

A total of 325 experts from 33 countries attended to discuss best practice and latest research developments in this growing branch of medicine.

Dr Lyon said: “The organising committee greatly appreciated the support of the Trust as official academic and institutional partner. There was an outstanding series of lectures on a range of topics in modern cardio-oncology, ranging from immunotherapy, radiation induced cardiovascular disease, and myeloma drugs and heart disease, through to how to set up and run a cardio-oncology service – as well as an inspirational talk from a patient.”

What we are doing has two clear benefits for the patients – it helps prepare heart patients for the rigours of cancer treatment by ensuring they are in the best possible health at the outset, and it helps cancer patients go on to live as full a life as possible after treatment.
Award-winning bra helps women recover from heart surgery

In July 2017, the innovation won a National Patient Safety Award for the ‘Best Product or Innovation for Patient Safety – Public Sector’ and was praised by the judges for being “grounded in evidence”.

Nurses from Royal Brompton and Harefield have designed an innovative, award-winning bra that helps wounds heal after heart surgery.

A team led by Melissa Rochon, clinical nurse specialist in surveillance, worked with medical manufacturer CUI to design and manufacture a bra for patients who have trouble with wound healing after cardiac surgery.

Research shows that women are more likely to have surgical site infections (SSIs) than men, because if their chest area is not properly supported, pressure can be put on the chest incision, causing the wound to gape.

Existing post-surgery bras with removable straps were only available up to a D cup, but fluid weight gain is common after heart surgery and around half of all women need this size or bigger after their operation.

The bra that the team designed (the BHIS™ bra) has side support to reduce tension on the wound and adjustable fastenings to allow for fluid gain and different sized wound dressings.

During a trial period at the Trust, the proportion of women suffering SSIs reduced significantly.

The new bras are now being used at Royal Brompton and Harefield hospitals, and teams from other hospitals are interested in using them.

Heather Lynch, who has used the BHIS bra, said: “It proved to be a great help upon my return home. It is both comfortable and supportive and alleviated any concern I had about my chest wound.”

The BHIS bra is just one example of successful collaboration between infection control and surgical teams during 2016/17. They also jointly launched the Photo at Discharge scheme, to help with wound care and reduce surgical site infection for heart and other surgical patients. The idea is simple – at discharge, patients receive a pack containing a colour photograph of their surgical wound and advice on aftercare. This can be shared with carers or healthcare workers and helps ensure wounds are properly looked after on leaving hospital, by providing a reference point to check any changes in the appearance of the wound that may indicate infection.

The project has proved highly effective, with reduced readmissions releasing up to 336 bed days per year. It has been widely featured in national journals and has won several high profile accolades including a National Patient Safety Award and a commendation at the RCNi awards.
3D printing helps our experts plan complex surgery

Our specialists can now use 3D imaging and printing to create exact replicas of patients’ hearts to help them plan and carry out surgery.

The technique requires specialist cardiovascular magnetic resonance (CMR) imaging, which uses powerful magnets and radio waves to take hundreds of detailed pictures of the heart. From these, an exact 3D digital replica is created, allowing clinicians to view the patient’s entire heart structure – including muscles, chambers and valves.

But experts at the Trust are going one step further, using 3D printing to turn the digital replica into an exact model of a patient’s heart. The techniques are used in diagnosing and treating conditions such as congenital heart disease, wear and tear of heart valves, and other types of damage.

Dr Sonya Babu-Narayan, honorary consultant cardiologist and British Heart Foundation Imperial College clinical senior lecturer, is interested in the role of CMR in preventing and treating heart rhythm disturbances in patients born with congenital heart disease, as well as using 3D imaging during invasive heart procedures.

She said: “The availability of 3D modelling when preparing for and performing heart surgery or other cardiac procedures allows surgeons and other clinicians to better grasp how a patient’s heart is affected by their condition. This leads to better care and allows us to diagnose and repair conditions with less need for invasive diagnostic procedures.

“Secondly, a 3D model can be a huge help with the communication between the clinical team and the patient. A 3D visual representation of the heart is so much clearer than anything we could put into words.

“Coming in for surgery can be a worrying time for a patient, so we always like to fully explain what will happen to help put their mind at rest as much as possible.”

A further advantage of producing a 3D model of the human heart is improved training opportunities. Heart disease comes in many different forms, and the more cardiologists can learn about the structure of hearts with these problems, the better they can treat them.

Trainees can also practise on exact replicas of hearts, including ones with congenital disease. The models used for this training are made of material that allows doctors to simulate a real-life situation. Some even look like a real human heart under x-ray.

Jonathan Havre is a Royal Brompton patient with repaired tetralogy of fallot, one of the most common congenital heart conditions, which is characterised by four structural defects in the heart. As an adult, Jonathan’s CMR images were used for his electrophysiology procedure, to see how ‘at risk’ he was of heart rhythm disturbance related to scars in his heart caused by previous operations.

The team used the CMR images to produce detailed prints of his heart muscle, including scarred areas, and were able to show him a 3D printed life size model of his own heart.

He said: “I found the model of the heart gave me a real understanding of what was happening. It really put me at ease knowing exactly what my heart looks like.

“It is sometimes hard to picture what I’m being told. With the 3D model I could hold my own heart; an experience I never thought I’d have.”

Dr Babu-Narayan is certain 3D technology will feature more prominently in the hospitals of the future.

“Across the world techniques are continually evolving. Some healthcare settings are testing virtual reality headsets, which let clinicians become fully immersed in the digital image of the scan away from a computer screen.

“There is also interactive 3D technology that combines the tactile advantages of a printed model with the immense detail offered by the digital image. The future really is bright in this revolutionary field.”
A pioneering procedure to fix leaking heart valves without the need for open-heart surgery was carried out at Royal Brompton Hospital, in a UK first.

Around one in 50 adults in Britain is thought to have mitral valve disease. The mitral valve separates the upper and lower left heart chambers. Problems with the mitral valve can make the heart less effective at pumping blood around the body, which can cause breathlessness, fatigue, dizziness and chest pain. If not treated, it can lead to heart failure and death.

Repairing a leaking mitral valve usually requires open heart surgery. This new innovative technique uses a ‘Harpoon’ device to repair the valve through a small incision in the chest, meaning the procedure can be carried out while the heart is still beating, unlike in open heart surgery where the heart is stopped and the patient is attached to a heart-lung machine.

It takes half as long to perform and leads to shorter recovery times.

The technique was first performed at Royal Brompton Hospital in April 2016 as part of a clinical trial. Consultant cardiac surgeon Mr Neil Moat carried out the procedure, with the help of imaging colleague Dr Alison Duncan. The first patient to benefit was 63-year-old Jennie Keeffe, from Tadworth in Surrey, who had mitral valve disease and had her mitral valve repaired using the new procedure.

She said: “I’m privileged to be the first person in the UK to be offered this new technique. I’m improving every day, which has given me a more positive outlook. I’m self-employed so the shorter recovery time was really beneficial.”

The clinical study was funded by Harpoon Medical, the company that manufactures the device. Royal Brompton is also the first UK hospital to be part of the Mitral Trans-Apical Chordal Echocardiography Repair (TRACER) Trial, which will involve other hospitals in the UK and Europe.

In the spirit of collaboration and sharing their specialist knowledge, many of our clinical experts hold positions within professional societies and on advisory panels, at home and abroad. Both heart divisions saw a number of new appointments to prestigious roles in 2016/17, including:

Dr Susanna Price, consultant cardiologist and intensivist, became president-elect of the European Society of Cardiology’s Acute Cardiovascular Care Association (ACCA).

Dr Price said: “I am delighted and honoured to take up this new post and look forward to working with colleagues in Europe and beyond to improve the quality of care for patients with acute cardiovascular diseases.”

Dr Shelley Rahman Haley, consultant cardiologist and lead for echocardiography at Harefield Hospital, was elected to the British Cardiovascular Society’s (BSC) clinical standards committee. The committee is responsible for standards of care in cardiovascular medicine across the UK.

Dr Rahman Haley said: “My team at Harefield delivers an excellent service that is highly tailored to our patients’ needs, and I’m looking forward to bringing my experience to my new role in the BCS.”

Professor Martin Cowie, consultant cardiologist, was appointed non-executive director on the board of the National Institute for Health and Care Excellence (NICE). Professor Cowie will lead on hospital medicine, guiding NICE in this key area of its work.

He said: “I’m delighted to support NICE in improving outcomes for patients across the country. My experience working at the Trust will be invaluable and I look forward to sharing this with the board.”
Chloe Narbonne is 13 years old, bright and thoughtful, with a love of tending her garden and learning to play golf. She is also medically unique, as the youngest person in Europe to have received a completely artificial heart.

Chloe, who was diagnosed with dilated cardiomyopathy four weeks after birth, was placed on the transplant list after her heart failed at age 11. While waiting for that crucial operation she suffered complications including a stroke, and when her transplant finally came, her body rejected the new organ and she was left close to death.

The only option to keep Chloe alive until another donor could be found was a total artificial heart, but this device had never been used in a patient as young as Chloe – anywhere in Europe.

However, thanks to a seamless collaboration between Royal Brompton and Harefield hospitals, the procedure was a success.

Chloe was kept stable until another donor heart became available a few weeks later – and that heart is still working perfectly.

The artificial heart operation took nine hours and involved 30 staff from Royal Brompton, Harefield and Great Ormond Street Hospitals – including Harefield director of transplantation André Simon, who flew back early from a conference in the USA to undertake the pioneering procedure.

Mr Simon, who has carried out all 13 artificial heart surgeries that have occurred in London hospitals, said: "I thought there was a 50/50 chance Chloe would still be alive when I got back."

While the Trust’s transplant theatres are at Harefield Hospital, the crucial post-operative life support that Chloe would need was in the paediatric intensive care unit at Royal Brompton. To overcome this, the entire transplant and mechanical support team from Harefield relocated to Royal Brompton for Chloe’s operation, bringing with them all the equipment needed.

Dr Margarita Burmester, paediatric intensive care consultant, said: "The teamwork was fantastic."
Chloe undoubtedly owes her life to that teamwork.”

Speaking to the Guardian newspaper, Chloe’s mother Fabienne Narbonne, said: “How they saved Chloe should be recognised for what it is – a miracle. Without the artificial heart she would be dead. It kept her alive for those crucial few weeks. By the time she got it she had run out of options.”

Chloe said: “They’ve been so wonderful, you can’t thank them enough, I love it when I go back to the hospitals and see everyone.”

Today, Chloe is back at school for the first time in three years, and has tackled some important personal challenges, including experiencing her first plane ride, and conquering a 10-metre high treetop obstacle course on the first anniversary of her successful transplant.

While Chloe’s story stands out in so many ways, she is a member of a large and ever-growing community of transplant patients given a second chance at life because of the work of our world-class transplant teams.

“How they saved Chloe should be recognised for what it is – a miracle. Without the artificial heart she would be dead. It kept her alive for those crucial few weeks. By the time she got it she had run out of options.”
Working together to protect our CHD service

When NHS England (NHSE) announced plans to decommission Royal Brompton’s world-leading CHD services, we received overwhelming support from patients and their families, charities and pressure groups, parliamentarians, local government and other key partners.

Background

Congenital heart disease, as the name suggests, is heart disease that is present at birth. It can now be diagnosed in the womb, and one of the great strengths of the care offered at Royal Brompton is that the specialist pregnancy service run in conjunction with Chelsea and Westminster Hospital means that our patients are cared for from the womb through infancy, childhood, adolescence and into adulthood. We believe this is the best way to approach a life-long disease: by giving life-long care.

Royal Brompton has one of the biggest, best and safest CHD services in the UK (with UK CHD services as a whole being among the best in the world). Our adult CHD research programmes are also widely recognised as world leading.

Although they planned to close the service, NHSE expressed no concerns at all about the quality of congenital heart disease care at the Trust. In fact, at a public consultation event, they repeatedly stressed that the care offered to patients at Royal Brompton was of a high standard.

So why were services under threat?

NHSE believed that Royal Brompton did not meet one of around 470 new ‘standards’ for CHD services. This ‘standard’ required all Trusts providing a CHD service to have certain other children’s services such as gastroenterology (for problems with digestion) and general surgery based on the same site, in case they are needed. This is called same site ‘co-location’.

Specialist trusts such as Royal Brompton have partnerships with other hospital trusts so that clinical opinion across a wide number of other specialties, in addition to their own heart and lung expertise, is readily available. Our formal (contractual) partnership with Chelsea and Westminster, just a few minutes’ walk away, has been in place for several years, and means that expert opinion can be gained within a short timeframe across a number of services, both during and outside normal working hours, without patients needing to move.

Consultants, such as gastroenterologists and general surgeons, are jointly appointed between the two trusts and part of their contract (job plan) is allocated to Royal Brompton work. They attend weekly joint clinical meetings, joint ward rounds, use shared systems, and some nursing staff take part in shared staff rotations. Chelsea and Westminster clinicians are familiar faces around our paediatric unit and for many parents they are indistinguishable from their Royal Brompton counterparts. When emergency care is needed – within a 30 minute timeframe – colleagues at Chelsea and Westminster have a 100% record of providing it. This is only a feature in 1% of cases (around five children each year).

During the review that led to the creation of the new ‘standard’, it became obvious that most doctors did not consider same site co-location essential, yet these views were overruled when the standards were finalised. In fact, the final review report acknowledged that some clinicians felt that “the link between paediatric CHD and adult CHD services is more important than the link between paediatric CHD and other specialist paediatric services.”

Implementing NHSE’s plan would therefore have serious knock-on effects:

- **It would not improve patient care**
  NHSE was not able to provide any clinical evidence to explain how closing one of the biggest, best-performing and safest CHD services in the UK would improve the care patients receive.

- **It would disrupt vital research**
  Royal Brompton is recognised as a world-leading centre for research into new treatments for adult CHD, publishing more research papers on...
adult CHD than any other centre. Breaking up teams whose collective expertise has been built up over a period of years would set back the search for better treatments and jeopardise the UK’s status as a leader in this field.

It would impact other vital services
As explained above, no part of the Trust operates in isolation, and closing the CHD service could force other interdependent heart and lung services – including those for children’s cystic fibrosis, severe asthma and muscular dystrophy – to close, leaving 14,000 patients to get their care elsewhere.

It would have significant cost implications
The cost of closing the service and attempting to re-provide it at a number of other centres would cost the NHSS millions of pounds, at a time when the NHS is desperately trying to save money nationally.

It would have implications for staff
We employ some of the best doctors and nurses in the country, and they are proud to work at the Trust. Many of our most talented staff have purposely relocated from overseas due to the Trust’s reputation. Forcing them to move to other hospitals could result in some leaving the NHS altogether.

Strong support to protect patient care
Throughout 2016/17 our supporters lobbied, wrote, petitioned, tweeted and even marched on our behalf against NHSE’s plans. Many thousands of them responded to the public consultation on NHSE’s proposals.

Here are just a few of the many highlights of the campaign:

- Nearly 2,000 doctors, nurses, patients, family members and other supporters marched along King’s Road in Chelsea, in a protest organised by the Royal Brompton & Harefield Hospitals Charity.
- More than 200 leading medical experts from top institutions in 30 different countries wrote a joint letter in opposition to the plans.
- 80 MPs were contacted by their constituents about the proposals. Many raised the concerns in Parliament and a number of them – including former Attorney General Dominic Grieve and Hammersmith MP Andy Slaughter – visited the hospital to see the service in action.
- 43 written questions were asked in the House of Commons.
- 21 MPs issued a joint letter to Jeremy Hunt, Secretary of State for Health.
- 13 peers gave impassioned speeches in support of the Trust during a House of Lords debate secured by Royal Brompton patient and former House of Commons speaker Baroness Boothroyd.

On November 30th NHS England endorsed a proposal for a joint CHD service with Guy’s and St Thomas’ NHS Foundation Trust as part of a collaboration with King’s Health Partners (the Academic Health Sciences Centre comprising Guy’s and St Thomas’, King’s College Hospital and South London and Maudsley NHS Foundation Trusts and King’s College London) across all the Trust’s cardiac and respiratory medicine and research.

Facts about our CHD service
- Each year we conduct around **14,000 outpatient appointments** and **1,300 surgical procedures** – more than any other trust in England
- Our 30-day survival rate for paediatric CHD surgery is **98.3 per cent**
- In 2016, **98.4 per cent** of cardiology patients said they would recommend the hospital to a friend or family member
- An independent review in the International Journal of Cardiology named Royal Brompton the **most influential research unit in the world**
- We have a **100 per cent record** of providing the additional services that NHSE says need to be co-located on the same site.
Our specialist lung services

Royal Brompton and Harefield hospitals are world leaders in the diagnosis, management and treatment of lung disease.

Patients from the UK as well as overseas are treated for the full range of respiratory disorders including: asthma and allergy, cancer services, lung inflammation and cystic fibrosis, lung infection and immunity, lung failure (including transplant, COPD and sleep and ventilation), and lung assessment (including sleep studies, lung function and physiology).

Our teams run the largest interstitial lung disease clinic in the UK, the largest asthma clinic in London and the south east, and the biggest occupational lung disease service in the UK. We are also home to the largest cystic fibrosis clinic in the UK, and the largest centre for surgical treatment of lung cancer.

Patient becomes first person with cystic fibrosis to conquer Everest

Nick Talbot on the summit of Everest

A Royal Brompton patient has entered the record books as the first person with cystic fibrosis (CF) to get to the top of the world's highest mountain, in a feat that seemed impossible after two dramatic failed attempts.

Nick Talbot, 40, was diagnosed with CF when he was 12, after twice developing a rapidly-progressing and potentially fatal lung disease. He has benefited from being able to take a new medication (ivacaftor) which has led to his lung function improving, as well as his overall health. Over the years Nick has pushed himself with various impressive climbing challenges. His ascent of Everest is part of his attempt to climb the highest mountains on each continent, raising money for CF charities as he goes. He has so far got to the top of four of the summits, with three left to conquer. He has already raised over £100,000.

This was Nick’s third attempt to get to the top of Everest. In 2014 his first attempt failed when all expeditions had to turn back following a number of deaths on the mountain passes. Then, in 2015, during Nick’s second attempt, an earthquake triggered an avalanche, leading to the tragic death of his friend and climbing companion, Dan, and leaving him seriously injured.

Nick’s third, and successful, climb took seven weeks – the same length of time that it generally takes someone with normal lung function.

Nick has been a patient at Royal Brompton since moving to London 19 years ago. In November 2016, he gave a motivational speech during a course for exercise practitioners from across the UK, run by the CF team.

On his health, he said: “I am lucky to have a less debilitating form of the condition and doubly lucky in having great doctors and access to ivacaftor, which means I have far fewer infections and less need to come to hospital for additional medication.

“The new medication has meant that I can no longer participate in medical trials and so I have been looking for new ways to help the CF Trust and people who are suffering from CF.”

During 2016/17 we saw almost 700 patients in our adult cystic fibrosis clinics
Thanks to significant advancements in care and treatment, cystic fibrosis (CF) is no longer a disease of childhood: individuals with CF now routinely live well into adulthood, starting families of their own and developing successful careers.

Adults with CF are increasingly busy with work and families, and getting into central London for regular appointments can be time consuming and expensive. CF experts at Royal Brompton have been exploring ways to make it easier to keep up with appointments – wherever patients may be.

Dr Su Madge, consultant nurse and associate director of the adult CF centre, explained: “We have been using Skype for Business, so that we can conduct ‘virtual’ clinics with patients in their own homes. This appears to be a win-win solution – no journey times, no travel costs and the risk of cross-infection is completely eliminated.

“Currently we use this for patients whose condition is well-managed and for whom we know it is safe. Anyone who needs a more thorough check-up will of course continue to come to the hospital as normal.

“This is only the first phase though: the Skype clinics allowed us to establish proof of principle – that we can do effective consultations remotely – the next phase will involve working with the technology sector to develop equipment and apps that patients can use at home to measure lung function, oxygen saturation and have blood tests done.”

New director to lead Royal Brompton’s cystic fibrosis centre

Professor Stuart Elborn CBE, internationally-recognised specialist in CF, joined Royal Brompton in October 2016 as clinical professor of respiratory medicine, and centre director for specialist adult CF.

Professor Elborn was previously dean of the school of medicine, dentistry and biomedical sciences at Queen’s University, Belfast. He trained in Belfast and helped develop CF centres in Nottingham and Cardiff, before returning to the city to set up a clinical centre for adults with CF in Belfast City Hospital in 1995. The centre has developed to become one of the largest and most influential in Europe.

A great advocate of harnessing new technologies to better centre care on the needs of patients, Professor Elborn has plans to make even greater advances to the virtual clinics programme in the coming year.
A pioneering new treatment for people with chronic obstructive pulmonary disease (COPD) was trialled by experts at Royal Brompton Hospital in partnership with neighbouring Chelsea and Westminster Hospital.

The trial was part of the international AIRFLOW-1 clinical trial, examining the safety of a new treatment for COPD patients called ‘targeted lung denervation’.

The new procedure uses electrodes to destroy branches of the vagus nerve in the lungs. In patients with COPD these nerves are over-active, usually as a result of damage caused by smoking. By blocking the actions of the vagus nerve, it is hoped that patients’ symptoms, lung function and quality of life will be improved.

Experts hope that the one-off treatment will have permanent benefits, and may replace the need for the long-term use of anticholinergic drugs, which are often prescribed for patients with COPD.

Professor Pallav Shah, consultant respiratory physician, tested the procedure on patients with moderate to severe COPD. He said: “Treating the nerves in this way blocks their actions more efficiently than anticholinergic inhalers, which only work temporarily, can have irregular distribution within the lungs and may cause side-effects such as blurred vision and urine retention in a small number of patients.”

Exercise rehabilitation found to help older people with COPD

Exercise rehabilitation could help older people with COPD and even make them less frail, according to a study by Royal Brompton & Harefield and King’s College London.

The joint study found that one in four COPD patients responds favourably to exercise rehabilitation, despite being frail.

Conventional rehabilitation of older people has focused on improving balance to prevent falls. But the surprising outcome of this study provides evidence for exploring the use of pulmonary rehabilitation – which targets many components of frailty, including slowness, fatigue, weakness and physical inactivity – in frail older patients.

COPD, a collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease, affects one in 10 people over the age of 65 and is associated with greater risk of falls, disability, hospitalisation and death.

The study involved more than 800 COPD patients from Harefield Hospital completing an eight-week rehabilitation programme. Those who were frail scored consistently better in measures of performance, breathlessness, exercise, physical activity and health status, compared to non-frail patients. By the end of the programme, 61 per cent of previously frail patients no longer met the criteria for frailty.

Consultant chest physician Dr William Man said: “Although COPD is primarily a lung disease, many organ systems can be affected, contributing to the syndrome of frailty.

“This research shows the importance of taking a holistic approach to care and identifies that interventions such as exercise training can bring great benefits to people with lung disease, without necessarily treating the lungs.”
Sleep assessment rooms made accessible to all

The sleep labs at Royal Brompton were completely overhauled during 2016/17 so that they are accessible for all patients, regardless of their care needs.

The area has also been transformed with the addition of a series of artworks, including a whole-wall mural, by renowned artist and illustrator Steven Appleby.

The sleep ward has been converted from four bedrooms to three, allowing each bedroom to be larger and have accessibility features such as wet rooms and automatic doors.

The renovation means the sleep labs are accessible for patients with conditions such as cystic fibrosis, curvature of the spine and neuromuscular disorders. Many of these patients develop sleep disorders, which can be diagnosed in the sleep labs.

Professor Anita Simonds, consultant in thoracic medicine, said: “We are seeing a lot more of these patients in the sleep labs now, as many more are living to adulthood due to ventilation therapy.

“Previously they would have to be on the ward in order to have their sleep disorder assessed. Now they can come and stay in one of our sleep rooms, which are comfortable and accessible for them.”

To make the newly-renovated area even more inviting, artist Steven Appleby, best known for his comic illustrations in a number of national newspapers, was commissioned to produce a series of artworks. Steven had previously produced more than 50 works of art for the Royal Brompton Centre for Sleep.

These new artworks adorn the walls of the new bedrooms, as well as the eye-catching whole-wall mural, to provide an interesting, thought-provoking environment for patients and staff alike.

Major UK trial reveals effectiveness of lung cancer screening

The Trust was a partner in a major clinical trial to provide evidence for a national lung cancer screening programme.

The UK Lung Cancer Screening Trial (UKLS) found that patients at high risk of developing lung cancer have a 73 per cent chance of living for five years or more if the disease is identified at an early stage.

The trial was carried out by teams from the Trust along with the University of Liverpool, Liverpool Heart and Chest Hospital, and Papworth Hospital. It was funded by the National Institute for Health Research (NIHR) health technology assessment programme.

The trial involved over 4,000 people aged 50 to 75 who are at high risk of developing lung cancer. It compared screening with computed tomography (CT) scans to existing care. All CT scans were reviewed at Royal Brompton Hospital.

Dr Anand Devaraj, co-investigator on the UKLS trial and radiologist, said: “For this trial, selected participants were randomly split into two groups: screening using CT and non-screening.

“Over two per cent of high-risk individuals in the screening group were diagnosed with lung cancer. Importantly, in over 80 per cent of these cases, lung cancer was diagnosed at an early stage, which is crucial to improving survival rates.”

The results of the trial will provide the UK National Screening Committee with evidence to make a decision on a national lung cancer screening programme.
Paralympian’s career-saving throat surgery at Royal Brompton

Just two months before winning three medals at the Paralympic Games in Rio, swimming star Jessica-Jane Applegate MBE had career-saving throat surgery at Royal Brompton Hospital.

The 21-year-old Paralympian became ill in January 2016, during a vital stage in her preparation for heading out to Rio, and found herself struggling to breathe and unable to train.

After initially putting it down to asthma, a chest infection, or the stress of training for a major event, Jessica-Jane eventually met Dr James Hull, honorary clinical fellow in respiratory medicine at Royal Brompton, who tested her for exercise induced laryngeal obstruction (EILO).

Jessica-Jane explained: “I looked at all options and tried everything else before resorting to surgery, but I was really struggling in the pool training and nothing was helping.

“I thought I was going mad but Dr Hull really understood how I was feeling. It was a really difficult choice, because I had qualified for the Rio Paralympic Games and there was no guarantee that I would recover in time to get enough training in.”

Royal Brompton is the only hospital in the UK that offers a unique exercise test that records what is happening to the vocal cords when people exercise. In some athletes, the voice box closes, leading to breathlessness. This is known as EILO and is often misdiagnosed as asthma.

EILO is scored for severity on a scale of 0 to 3. Jessica-Jane scored 2.5 – and was operated on the day after her test.

Jessica-Jane made it to the Rio games nine weeks after her operation. She won two silver medals and a bronze medal in the S14 classification for those with an intellectual disability.

She added: “I had the operation nine weeks before I was due to meet the team for the Rio holding camp. Everyone was so helpful throughout my stay in hospital and kept telling me how well I had done to even qualify struggling the way I was.

“After the operation I had to have three weeks of complete rest, which as an athlete is so frustrating, but I knew that if I did anything that caused any damage that could be the end of Rio for me.

“After a few more weeks British swimming wanted to assess my fitness to see if they would still take me to Rio. I worked so hard to make that team that there was no way I was going to fail a fitness test and be left behind!”

“I passed the test, flew out to Rio and competed in my events. I was five 100ths of a second off my personal best time, so in just a few weeks not only had I recovered – I was swimming the best I had in 18 months.”

Jessica-Jane is fully back in training and has set six new world records since Rio. She will be going for gold at Tokyo 2020, and the Royal Brompton team wishes her every success.
A dedicated service for children and young people

Royal Brompton & Harefield is a national specialist referral centre for children with a range of heart and lung conditions. Our clinicians often provide care from before a child is born, throughout childhood and into adolescence, before managing a smooth transition to our adult teams.

We are a leading centre for the treatment of paediatric congenital heart disease (CHD), inherited cardiac conditions, fetal cardiology, paediatric cystic fibrosis and severe asthma, as well as rare lung conditions such as primary ciliary dyskinesia (PCD). We are the largest UK centre for children with heart rhythm problems and the third largest for paediatric cardiac surgery.

Our children’s and adult teams liaise closely to ensure a seamless transition between services as a child reaches teenage years. This is increasingly common as survival rates for conditions such as CHD, cystic fibrosis and severe asthma continue to improve year-on-year.

Discovery of the faulty gene linked to rare lung condition

Specialists at Royal Brompton and University College London (UCL) have identified a new gene that causes the rare lung condition primary ciliary dyskinesia (PCD).

The PCD specialists, who sit within our paediatrics team, worked with researchers from around Europe on the ground-breaking study, including hospitals in Italy, France and Switzerland.

In patients who have PCD, the cilia (tiny moving structures that line the airways, ears and sinuses) are unable to function, meaning the body is unable to keep these areas clean and free from infection. It is an inherited condition that affects around one in 20,000 people. It is thought to be inherited in a similar way to cystic fibrosis, but is often much more difficult to diagnose.

3D technology enables researchers to have a more detailed understanding of PCD. In people with the faulty gene, tiny parts of the lung, as small as nine millionths of a millimetre, were missing.

Dr Claire Hogg, Trust PCD lead, said: “Children with PCD are often diagnosed late, by which time significant lung damage can occur. Our gene discovery programme, in partnership with UCL, is allowing us to make an earlier, more accurate diagnosis. This in turn results in less lung damage.”

Royal Brompton is one of only three diagnostic and four management centres for PCD in England, and teams at the hospital treat around 400 patients every year.

Fiona Copeland, Chair of PCD Family Support Group and mother of two sons with the condition, said: “We discovered that my sons both had PCD when they were four and six years old, by which time my eldest had already developed bronchiectasis [irreversible lung damage] on a third of his right lung. Earlier diagnosis may have prevented this from happening.

“We welcome any research that will help diagnose children quicker so they can start their treatment regime earlier and help them stay as well as possible for longer.”
Consultant paediatric and congenital cardiac surgeon, Mr Olivier Ghez, was awarded a Children’s Health Star award by ITV’s Good Morning Britain.

The awards recognise those who have gone the extra mile to treat someone or save a life. Mr Ghez was nominated by four families for the life-saving surgery he carried out on their children, all of whom were born with congenital heart disease (CHD).

Mr Ghez said: “I am so humbled – it is a great honour to receive such a testimony from the families of my patients. However it is our whole team at Royal Brompton which allows us to deliver the best possible specialist care for children with congenital heart disease.”

Lydia Strachan and Crispian Wilson nominated Olivier for his work saving the life of their daughter Hester, who was diagnosed with a serious congenital condition called tricuspid atresia and coarctation of the aorta before birth. She was delivered at 34 weeks weighing just 2lb 8oz. During her 497 days in hospital, Hester underwent three major heart operations and numerous smaller procedures.

Lydia said: “Olivier performed multiple operations on Hester to repair her heart, which, because she was so fragile and tiny, were not straightforward procedures.

“It was just before Hester’s first birthday that he decided to perform complex open heart surgery when her heart was only about one and-a-half inches in size. It was extremely risky but we knew we couldn’t wait any longer and this operation would give her a much better chance of survival.”

The operation took 10 hours and was a complete success. Lydia said, “What really stands out is Olivier’s level of commitment to the families. As parents we literally put our child’s life in his hands but there’s nothing more reassuring than having someone like Olivier, who obviously has the technical skills but is also completely committed to caring for his patients.”

Despite her difficult start to life, Hester’s parents report that she now has good heart function – a result they hadn’t dared to hope for during her multiple surgeries and struggles against infection.

Lydia said: “There was one night – the worst of my life – when we thought Hester was going to die… every parent I know whose child has a serious heart condition has had that moment. That she has the chance of a normal life, or as close as possible, is as hard to process as getting the news about Hester’s condition. There are not words to describe what Royal Brompton, or the NHS, has done for us.”

The couple praised the psychological support the Trust offers, and are still in contact with Claire Cooley, paediatric clinical psychologist, saying her help was crucial to settling down at home.

Hester’s father, Crispian, added: “Going home is not the end, it’s the beginning. The challenge is not the illness – we know about that – it is all the ‘life admin’ that goes around it. Hester is much more than just a medical case. She’s a fully formed person with her own personality, who loves books, dinosaurs, orchestras, and all sorts of things.”

Hester’s parents formed a special bond with the team who cared for her during the 16 months she spent at Royal Brompton, and one year on from her discharge they returned to deliver a masterclass to nurses taking part in the Introduction to Congenital Heart Disease course at the National Heart and Lung Institute.

As well as providing a vital insight into the emotional impact CHD has on parents, they gave practical advice on how staff can support parents whose children are undergoing treatment for a heart condition.

Practice educator Kumi de Costa, who organised the session, said: “We really appreciate Lydia and Crispian giving their time to come back and give this presentation to our staff.

“Hester made a lot of friends during the time she spent with us – she’s a happy and fearless little character and we were delighted to see her again.”
The Trust’s hospital school has been sharing its experience in providing education to children who are in hospital to help both private sector and international organisations.

The Chelsea Community Hospital School, which supports three other NHS hospitals in west London including Chelsea and Westminster Hospital, provides education for inpatients aged four to 18 years.

In January 2017 the school started providing education services to two private hospitals in London, the Harley Street Clinic and The Portland Hospital. They are the first private hospitals in the country to offer hospital schooling to their patients, and they came to the Chelsea Community Hospital School as experts in the field.

Providing this service to the private sector will mean a boost in funding for the Trust’s school and a chance to spread our learning and expertise.

International partnerships have long been forged by the school and this year, through the Well at School initiative (www.wellatschool.org), the school has been reaching further afield.

Representatives travelled to Chile to attend the first conference in Latin America to focus on education for children in hospital. Later this year the destination will be Moscow.

Janette Steel, headteacher at the Chelsea Community Hospital School, said: “We need to recognise that patients are not just bodies that we need to make better, they are minds too. We have years of experience of educating children in hospital and can help other countries and organisations who are only just beginning on their hospital education journey.”

The hospital school is open 50 weeks of the year and is a registered exam centre, ensuring that patients can sit exams if well enough to do so.
CHILDREN AND YOUNG PEOPLE
Trust experts focus on diagnosis and care for children with asthma

Experts at the Trust have helped develop a new online toolkit for children with asthma, and have highlighted the importance of diagnosing the condition correctly.

Dr Louise Fleming, honorary consultant in paediatric respiratory medicine and expert in problematic, severe asthma, worked with Healthy London Partnership to help develop an innovative toolkit, which gives those who support children and young people with asthma access to practical resources and information.

The London Asthma Toolkit is an online resource that contains practical, downloadable tools and advice, including job descriptions and service specifications, and examples of best practice in children’s asthma care across London.

There are sections aimed at hospital and community clinicians, commissioners, pharmacists, GPs, schools, and parents/carers.

Dr Fleming said: “It’s really important that we work in partnership with parents, schools, GPs and other hospitals to improve the standard of care for children with asthma.

“This toolkit enables examples of best practice to be shared across sectors and is a valuable resource for all those involved in the care of children with asthma.”

Dr Fleming has also highlighted the importance of properly diagnosing children with asthma, in an editorial written with Professor Andrew Bush, consultant paediatric chest physician and professor of paediatric respirology (Imperial College, London).

The editorial in Archives of Disease in Childhood suggests that asthma in children is often misdiagnosed, potentially leading to unnecessary side effects for young patients who may be using steroid inhalers when they don’t need to.

It acknowledges that asthma was under-diagnosed in the past, but that the pendulum has now swung too far the other way. Children often outgrow symptoms or have changing symptoms, and progress should therefore be monitored regularly.

Teams at the Trust see children from all over England at specialist asthma clinics, where assessments are undertaken by a multi-disciplinary team of consultants, specialist nurses, psychologists and physiotherapists.

Sensory play area part of playroom makeover

A sensory play area, including a flashing lightbox, infinity tunnel and bubble tube, has been opened on the children’s ward – giving patients a welcoming, stimulating area to play in.

The play area is part of a £100,000 makeover of the playroom on Rose Ward, which also includes a section aimed specifically at older children, with a large TV, PlayStation and DVDs designed to make them feel more at home.

The new sensory ‘hub’ means two children with cystic fibrosis (CF) can now play in the room at the same time, with one in the hub and the other in the main part of the playroom. Previously only one child with CF could be inside the playroom at one time because of the risk of cross infection. The hub has its own source of ventilation, which reduces the amount of germs in the air, allowing children with CF to play safely without feeling isolated.

Joanne Knowles’ two-year-old son, William, has received care at Royal Brompton since birth. She said: “The new playroom is absolutely amazing – it’s really bright and welcoming.”

The makeover was made possible due to funding from the Brompton Fountain charity and the Royal Brompton and Harefield Hospitals Charity, as well as money raised by staff and donations from parents.

Maxine Ovens, play service manager, said: “Having a welcoming, well-equipped playroom is so important for the children staying in the hospital. In addition to keeping children occupied and distracted from their conditions, play relieves anxiety and helps children to cope with their recovery.

“The playroom is a place where the dedicated play team can ensure that children are fully prepared for their experiences in hospital and help them to understand their illnesses and the importance of their medication in a relaxed, non-clinical environment.”
Pulmonary hypertension –
a disease of heart and lung

Our pulmonary hypertension (PH) service uniquely brings together specialists in both cardiac and respiratory medicine, as PH is one of the few conditions that cuts across both disciplines equally.

Pulmonary hypertension is a serious condition that causes high blood pressure in the pulmonary arteries – the blood vessels that connect the heart and lungs. Treatable forms of PH are rare – affecting around 4,000 to 5,000 people in the UK.

The Trust’s specialist PH service brings together experts from a range of different disciplines to manage the condition which, in its most serious sub-type, has a life expectancy without treatment of just three years following diagnosis – a poorer prognosis than many cancers.

Dr John Wort, consultant in pulmonary hypertension, said: “Diagnosing pulmonary hypertension involves a lot of detective work, as the symptoms can be typical of many more common conditions. Once these are ruled out, we can start to make a diagnosis.”

The PH team has a close relationship with imaging colleagues, as highly detailed imaging is needed to make the correct diagnosis. The team also collaborates closely with psychological and palliative care services, as the personal toll of living with PH can be significant.

But perhaps one of the most important partnerships is with the obstetrics department at Chelsea and Westminster Hospital.

Dr Wort explains: “For reasons we don’t yet understand, PH is more common in women than in men, and the single biggest risk for women with the condition is getting pregnant. The strain that childbirth places on the heart means that up to 30 per cent of pregnant PH patients are at risk of dying.

“We know how important motherhood is for many women, so we have a dedicated service that looks after them during pregnancy and childbirth, run by Dr Lorna Swan and Professor Michael Gatzoulis. We arrange for the birth to take place at Royal Brompton, so that when the child is born, the mother is taken straight to our intensive care unit, while the baby goes to Chelsea and Westminster to be checked out before mother and baby are reunited.”

Research is another strong theme for the service, trying to understand more about the causes of this rare condition and making it possible to identify risk factors. For example, a faulty gene has been identified, which when present gives a one in five chance of developing a rare form of the condition; families of such diagnosed patients are all offered follow up if they wish, to pinpoint their chances of developing the condition.

All PH patients are encouraged to be involved in research whenever possible. The Trust’s research partners include Imperial College and Cambridge University Hospitals NHS Foundation Trust.

“...The strain that childbirth places on the heart means that up to 30 per cent of pregnant PH patients are at risk of dying. We know how important motherhood is for many women, so we have a dedicated service that looks after them during pregnancy and childbirth.”
ECMO: evolution of a life-saving service

A redesign of the Trust’s ECMO (extracorporeal membrane oxygenation) service has led to a 60 per cent increase in referrals, offering highly specialised life support techniques to more patients than ever before.

ECMO supports recovery after major life-saving surgery or life-threatening illness by oxygenating blood outside the body – effectively doing the work of a patient’s lungs and enabling theirs to rest.

In 2016/17 the Trust’s ECMO service was redesigned and remains one of just five commissioned centres nationwide. The redesigned service has greater capacity, with 73 patients being brought to Royal Brompton’s adult intensive care unit for treatment in the past year, up from 48 the previous year.

The redesign was led by Mr Richard Trimlett, consultant adult cardiac surgeon at Royal Brompton, and Dr Susanna Price, consultant cardiologist and intensivist, with support from Trust management, nursing staff, and perfusionists (specialists in heart/lung bypass machines and associated technology). Guy’s and St Thomas’ NHS Foundation Trust also supported the process, and colleagues there continue to work closely with the Trust’s team as part of the wider national ECMO service.

Mr Trimlett explained that the new ECMO service was deliberately designed to be collaborative and outward looking. He said: “Our ECMO team is massive and very inclusive. We have a huge number of people working with these patients, including surgeons, cardiologists and radiologists, and palliative care and respiratory experts.

“We seek everyone’s opinions right from the start, so we have an inclusive approach that ultimately benefits the patient by bringing in a range of expertise.”

ECMO patients are referred from clinicians in other hospitals. When consultants identify patients who need such specialist support, they contact the ECMO team directly. They then gain access to a unique online system – developed by Trust clinicians – that enables everyone involved in a patient’s care to follow progress from referral right through to discharge. The system also allows multidisciplinary team discussions to happen across different hospital sites, and when patients have recovered enough to return to the referring hospital or go home, their discharge can be planned efficiently.

The new service is also designed to be built upon and expanded still further, with plans to provide more cardiac ECMO for patients suffering cardiogenic shock (a condition where the heart is suddenly unable to pump enough blood to meet the body’s needs).

Mr Trimlett concludes that ECMO is the intensive care service of the future, and something the Trust will continue to develop and grow in the coming years: “This truly is where the future of the specialist cardiac hospital lies – in these high-end, highly specialised services, carried out at a very few centres, to the very highest standards. We have as much capacity to provide ECMO as the demand for it will dictate.”
The Trust’s Hospital to Home programme is an innovative scheme that focuses on service improvement and quality, with a special focus on digital technology, and developing web-based pathways for patients with complex needs. This year it has extended its reach to cover extracorporeal membrane oxygenation (ECMO) and lung transplant pathways, as well as further developing its successful long-term ventilation pathway.

Developing the children’s long-term ventilation pathway

The Hospital to Home pathway for children on long-term ventilation (LTV) provides a structured process for hospital discharge. It is a single care pathway that can be accessed online by appropriate healthcare professionals from any NHS organisation, in hospitals or the community.

This year, the Hospital to Home team has developed and improved the pathway. The team worked alongside NHS England, NHS clinical commissioning groups and other partners such as the Wellchild charity, to develop a range of clinical and non-clinical courses to upskill those working with children on LTV to meet ever-changing patient needs.

The digital pathway has also been redesigned to offer a better experience for users. In recognition of this, the Hospital to Home team was ‘highly commended’ at the HSJ Value in Healthcare Awards, in the ‘Use of information technology to drive value in clinical services’ category.

Implementing a web-based ECMO care pathway

Recognising that the principles of the LTV pathway could be applied to other clinical pathways, the Hospital to Home team this year completed a pathway for patients needing ECMO for severe acute respiratory failure.

Like the LTV population, the needs of patients who are referred for ECMO support are very complex.

The Hospital to Home team collaborated with the Trust’s ECMO team to map patients’ routes through the hospital system and identify areas for improvement. The recent redesign of the ECMO service (more information on page 43) is now supported by a web-based pathway and referral system as a result.

Since going live, there have been 189 referrals from 62 different hospitals. The electronic pathway improves the quality of data and referral information. Users report that it saves time in gathering information and helps make patient-centred decision making more accurate.

Developing a new lung transplant referral pathway

Work also began this year on a new web-based pathway for lung transplant patients. Working closely with the lung transplant team, the Hospital to Home team has looked at how the process for patients undergoing assessment for lung transplant at Harefield Hospital could be improved, and has made many positive improvements to the pathway.

Thanks to this project, clinicians now have a comprehensive and efficient online referral system, can share images and reports more easily, can transfer information more securely, and can better track their patients’ progress – including with real-time updates.

A multi-professional paediatric tracheostomy course, in collaboration with the London Network
One of the Trust's core values is treating patients with respect, dignity and courtesy, and making sure they are well informed and involved in decisions about their care. We always have time to listen.

Patient feedback plays an important role in helping us to improve, which is why we continually collect and act on it.

In 2016/17 the Trust received in excess of 10,000 patient comments, more than 90 per cent of which were positive. In the monthly Friends and Family Test, an average of 96 per cent of patients said they would recommend our hospitals for treatment. Negative feedback is uncommon, but plays a valuable role in identifying where improvements can be made.

During this year, the Trust scored well in the national inpatient survey, national young people’s survey and national cancer survey. Highlights include:

- 99 per cent of inpatients described their ward or room as being clean
- 96 per cent said they had enough privacy and dignity when being examined
- 94 per cent of adult inpatients, and 96 per cent of parents of child patients, rated the care received at seven or more out of 10.

An increasingly important feedback mechanism for patients is social media, as it allows them to share their thoughts with other people in real time. The Trust’s communications team monitors feedback on Twitter and Facebook, responding appropriately. In 2016/17, 96 per cent of comments about our care were positive.

**Improving patients’ experience**

**Compassionate care programme**

This programme, run in collaboration with the Royal College of Nursing (RCN), is now in its fourth year and is designed to support Band 6 and 7 nurses to build leadership skills and improve the care offered to patients and their families.

The programme is built around Appreciative Inquiry, a philosophy for promoting positive organisational change. It is underpinned by practical experience and supports nurses to identify areas for improvement in their team or place of work, and to think differently about how they view and respond to the needs of patients, their families, and other staff members.

**Patient advisory group (PAG)**

In January 2017 the PAG celebrated its first year anniversary. The group comprises representatives from both Royal Brompton and Harefield, patients and carers, across both adult and paediatric services. The group meets quarterly, and this year its areas of focus have been: infection prevention and control, the psychology of having a chronic illness, safeguarding, and consent. The group represents the patient voice and a set of unique insights that help inform Trust decision making and co-design of services.

**Atrial Fibrillation (AF) support group**

Harefield consultant cardiologists Dr Wajid Hussein and Dr Karthik Viswanathan worked with the arrhythmia nurse team to set up the first AF patient support group for north west London and surrounding areas.

The group held its first meeting in January 2017, in direct response to a need for peer support for AF patients in north west London, Berkshire, Buckinghamshire and Herefordshire. AF is a condition that causes an irregular and often abnormally fast heart rhythm. Comments following the first meeting included:

“I feel more prepared to support my Mum going forward for ablation and the questions to ask.”

“I think when you suffer from AF all sorts of scenarios go through your mind. This has put my mind at ease.”

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**Patient advisory group (PAG)**

In January 2017 the PAG
Medical education

We believe in sharing what we know through teaching, so that what we learn can help patients everywhere.

Continuing professional development ensures the delivery of high-quality care and promotes professional confidence and competence. Staff at the Trust are able to take advantage of a range of training programmes both in-house and through external education and training programmes. We also collaborate with other healthcare organisations to share our learning and knowledge.

Human factors programme

Human factors education is well-established at the Trust, forming part of our patient safety training programme since 2005. The current multi-professional in-house training programme was launched in 2015, and more than 600 members of staff have attended the one-day course to date. The course is open to all staff and introduces a basic understanding of the aspects of human factors that are likely to affect staff and patients in the healthcare setting.

Two-day ‘master class’ courses and ‘train the trainer’ sessions are also available. Imperial College Health Partners (an expert partnership of healthcare providers in north west London) and commissioners were enthusiastic about the Trust’s education model, in particular the multi-professional aspect of it, and will look to learn from our experience in this area.

Simulation-based non-invasive ventilation training

The pilot of a training programme to improve confidence in delivering non-invasive ventilation (NIV) has been held at the Trust, with overwhelmingly positive feedback from participants. Evidence existed to suggest that medical and nursing staff felt unprepared to deliver NIV in accordance with British Thoracic Society guidelines. To address this, a one-day training programme was designed, aiming to improve the confidence and competence of technical and non-technical staff.

The interactive course provided practical experience for any professional involved in NIVs. It involved part-task training workshops and high-fidelity simulation sessions. Scenario participants acted in their usual professional roles, and semi-structured debriefs were held after each simulation, covering technical and non-technical skills.

Those taking part included doctors, nurses and physiotherapists, all of whom regularly manage NIV. They commented that their confidence and skills had significantly improved following the training. Positive feedback was received from all attendees and it is intended that the course will now run three to four times a year.

Multidisciplinary approach to airway management

Managing airway emergencies, particularly those involving patients with a tracheostomy (a tube inserted into the airway to help a person breathe) or laryngectomy (removal of the part of the throat that houses the vocal cords), requires a strong multidisciplinary approach. The Trust has introduced an Altered Airway Care Inter-Professional (AACIP) course, which ran five times during 2016/17. A study day on paediatric and neonatal tracheostomy emergencies also ran for the first time this year, giving staff the practical skills needed to provide high-quality care for young patients with a newly formed tracheostomy.

Optimising strength and resilience

It has long been recognised that psychological factors play a significant role in overall health and wellbeing. A new Trust project, ‘Optimising Strength and Resilience’, has been launched to address the problems of psychological distress in patients, occupational stress in NHS staff, and poor organisational culture.

The programme, which is supported by an award from the Health Foundation, promotes an integrated approach to physical and psychological health through education and training. The training is based on the latest advances in health, stress management research and third-wave cognitive behavioural therapies.
The training is offered to patients, relatives and staff.

Resilience is especially important for healthcare professionals, who often face challenging and complex situations in their daily work.

Dr Anne-Marie Doyle, consultant clinical psychologist, said: “In the world of medicine, there is a lot of talk about compassion for patients, but clinicians also benefit from compassion for themselves.

“The training echoes the Trust’s organisational values, particularly ‘we believe in our staff’, by supporting them in their work to provide the best healthcare they can.”

The staff training sessions aim to build on individuals’ strengths, support effective team-working, increase staff engagement and contribute to the delivery of the best possible specialist treatment.
Our charity

Royal Brompton & Harefield Hospitals Charity raises substantial funds to support the Trust’s pioneering work in heart and lung disease diagnosis, treatment and research.

Using money from grants, donations, legacies and investments, the charity funds projects that fall outside NHS funding but are often vital to patients’ health and wellbeing.

The charity’s major appeals in 2016/17 were:

**Building for Brighter Futures**

Raising £1.1 million to help redevelop Harefield’s intensive care unit and scanner centre

After a second successful year of fundraising to extend Harefield’s intensive care unit by six state-of-the-art rooms and a brand new scanner centre, funds raised sailed past the £1 million mark. Several large charity events, a series of ‘talks and tours’ and hundreds of supporters taking on their own fundraising challenges meant the charity was well on its way to meeting its substantial target.

**One Gene, All the Difference**

Raising £500,000 to expand Royal Brompton’s genetics and genomics testing service

In June 2016, the charity launched its appeal to expand the clinical genetics and genomics testing service for families showing signs of inherited heart and lung conditions. By the end of March 2017, £276,000 had been raised and the NextSeq550 sequencer purchased enabling more efficient testing for both cardiac and respiratory conditions.

Dr Deborah Morris Rosendahl, head of clinical genetics, said: “The charity’s support has enabled the continued success of the service, which is so critical for patients and their families.”

**The Patients’ Fund**

Making £100,000 available annually for staff to nominate projects that will benefit patients

As part of this appeal, the charity raised funds to help transform the children’s play area at Royal Brompton Hospital into an exciting, colourful and interactive space for children, adolescents and their parents to enjoy. See page 41.

**rb&hArts**

Providing £128,000 annually for this innovative arts programme

Charity funding helped boost patient participation in arts and music activities to around 5,000. rb&hArts introduced ‘Vocal Beats’ – participatory music-making and beatboxing activities for young patients – and digital artwork to its programme, while mainstays including ‘Singing for Breathing’ went from strength to strength.

For more about the work of rb&hArts in 2016/17, see page 50.

Royal Brompton & Harefield Hospitals Charity redeveloped its website in early 2017, providing a far more user-friendly platform for staff to sign up to events and learn more about the charity’s work.

Visit: www.rbhcharity.org
100 Hearts Comedy Night: 1,400 comedy fans and 20 comedy stars, including Michael McIntyre and Rowan Atkinson, raised £29,000 to help expand Royal Brompton's genetic testing service.

Grand Canal Challenge: 148 cyclists, runners and walkers took on 26 miles of canal towpath and raised £41,500 to benefit patients at both hospitals.

Don’t Break a Beating Heart campaign march: three hospital charities collaborated to organise a 2,000 strong march against the proposed closure of Royal Brompton’s congenital heart disease services.

35th Annual Harefield Fun Run and Family Day: 1,000 attendees including 30 transplant patients raised £46,000 for the redevelopment of Harefield’s intensive care unit.
The healing arts

The Trust’s world class hospital arts programme, rb&hArts, delivers a comprehensive programme of high quality creative arts to increase levels of wellbeing and enhance our buildings and environment for patients. As well as curating the Trust’s permanent collection of 1,200 valuable artworks, the rb&hArts team organises 250 workshops per year with around 5,000 people taking part – many of whom are accessing arts for the first time.

Enhancing the healing environment and improving patient experience through visual art

Digital artists SDNA, working with members of staff, devised a digital artwork to relax patients before surgery called Botanical Mandala, now permanently on display in the patient reception area of Harefield’s theatres.

Jacqueline Seifert brought the outside inside with her Everyday Landscapes installation on Royal Brompton’s Foulis Ward. Cystic fibrosis patient Lauran Judd commented: “The art is fabulous, it’s vibrant, and opens up the ward. The use of colour is uplifting, which is essential in helping healing and recovery time.”

Will Clarke wrapped London architectural scenes on the pillars in Royal Brompton’s Outpatients East, and his work leads patients on a journey from reception to waiting rooms, to help them find their way to their clinic.

Live music for adult inpatients

Live music can aid recovery and soothe pre- and post-operative patients, providing distraction, amusement and joy. Adrian Garratt (violin) and Mark Levin (celtic harp) provided more than 250 hours of live music in 2016/17, reaching 500 patients and their visitors.

Patient Lisa Higgins said: “I was on Paul Wood Ward during the summer and the harpist came in and played, it was fantastic, really therapeutic and calming. All the patients seemed to relax and benefit from it and it made a real difference to our day.”

Vocal Beats: for young inpatients

The arts team provides two afternoons per week of participatory music-making and beatboxing activities for young patients of all ages. It could be bedside lullabies, creative music-making in the bays, or one-to-one vocal coaching for young people living with cystic fibrosis. Vocal beats is led by musician Heather McClelland, with support from beatboxers MC Zany and Grace Savage.

Transplant & Life, by Wynne and Wainwright at Hunterian Museum, Royal College of Surgeons

Artists often explore the human experience and issues pertinent to health. Transplant & Life was a sonic and visual arts project investigating the experience of transplantation and organ donation with patients from Harefield and Royal Free...
Singing for Breathing

Singing for Breathing provides two hours of vocal coaching every week to support people living with chronic obstructive pulmonary disease (COPD) and other respiratory diseases. Workshops are highly valued by participants and include warm ups, relaxation and the teaching of new breathing techniques through breath workouts and vocal exercises, as well as singing a wide range of songs. The programme continues to be very popular, delivering 96 workshops in 2016/17, with 1,303 instances of participation from 71 singers.

Akademi and Dance Well

Akademi, a South Asian dance organisation, ran a series of creative movement workshops to increase levels of physical activity for older adults, to improve fitness, mobility and posture. The workshops were inclusive and offered peer-support and opportunities to socialise, and promote mental wellbeing.

The workshops have proven popular, with a regular core attendance of 30 people each week, and participants reported feeling engaged, happy, fitter, energised and more confident about themselves.

Thank you

rb&hArts is charitably funded. None of its work would be possible without the support of its main funder, Royal Brompton & Harefield Hospitals Charity, plus other donors including Arts Council England, The Brompton Fountain, Co-op Community Fund, Doyle Carte Charitable Trust, Heathrow Community Fund, Patient Amenity Fund, ReBeat, Royal Borough of Kensington & Chelsea – Arts Grants Scheme, Samuel Gardiner Memorial Trust and Youth Music.
OUR PROFILE IN THE MEDIA

Our profile in the media

Working in a specialist Trust brings with it a responsibility to innovate and break new ground in treatment and research. In an effort to share examples of exceptional patient care and research breakthroughs, the Trust’s communications team works closely with newspapers, television and radio broadcasters, digital and social media and other channels. Here are some examples of coverage during 2016/17:

April 2016

CNN’s medical programme “Vital Signs” was invited into Harefield’s transplant theatres to report on how the team routinely uses organ retrieval technology when carrying out heart transplants. Mr André Simon, director of transplantation, explained how Harefield surgeons are leading the way with this innovative technique.

Speech and language therapist Julia Selby helped BBC presenter Nick Robinson regain his voice after successful lung cancer surgery at Royal Brompton, prompting widespread praise in the national media.

Features in the Daily Mail and i newspaper described Julia’s “heroic work”, explaining how her skill and expertise enabled him to get back to his role as a political correspondent in time to report on the general election.

May 2016

Presenter Dr Michael Mosley visited Royal Brompton for a BBC Horizon programme on e-cigarettes. Dr Mosley visited Royal Brompton’s specialist airway lab and met consultant respiratory physician Dr Omar Usmani and respiratory research nurse Sally Meah, for lung function tests. Dr Usmani detected subtle short-term damage to Michael Mosley’s airways and explained how more research was needed to establish the true impact of e-cigarettes.

The latest novel treatment being trialled at Royal Brompton for patients with COPD (chronic obstructive pulmonary disease) was featured in the Daily Mail. The paper reported a trial by consultant respiratory physician Professor Pallav Shah, for patients with chronic bronchitis. See page 33 for more on this trial.

June 2016

Dr Omar Usmani from Royal Brompton’s specialist chronic cough clinic provided expert comment on different types of cough and appropriate treatments. Dr Usmani told the Daily Mail that diagnosis hinges on whether the cough is productive or non-productive (i.e. whether a person is coughing up sputum), and described various symptoms of underlying conditions.

August 2016

The first UK patient to benefit from a new cutting-edge procedure to treat mitral valve disease, carried out at Royal Brompton by consultant cardiac surgeon Mr Neil Moat and imaging specialist Dr Alison Duncan, was featured in the Daily Mail. To read more about the Harpoon device and the experience of patient Jennie Keefe, see page 24.

September 2016

Dr Andrew Menzies-Gow, clinical lead for the lung division, discussed the new drug benralizumab for a Daily Telegraph report. The drug is part of a new wave of biological treatments for people with severe asthma, designed to treat the underlying cause of the disease, rather than its symptoms, and Dr Menzies-Gow spoke of the benefits it could have for those with the condition.

October 2016

A new therapy that corrects the underlying cause of cystic fibrosis and could transform treatment, trialled by patients at the Trust, attracted widespread media attention. The drug Orkambi slows irreversible lung damage by more than 40 per cent. Professor Stuart Elborn, director of Royal Brompton’s adult cystic fibrosis service, said: “I’m really excited by the therapy and also the pipeline of other powerful drugs that could get us closer to a cure.” The trial was covered by the Daily Mail, BBC and nearly 300 regional media titles. See page 14 for more about this trial.

November 2016

Dr James Hull, consultant in respiratory medicine at Royal Brompton, shared his expertise on hypersensitivity pneumonitis and misdiagnosis of asthma with the Daily Mail. In an article highlighting the impact allergies can have on the lungs, Dr Hull explained the common causes of wheeziness and how people
January 2017

Professor Fan Chung, professor of respiratory medicine, spoke to BBC London News about how air pollution can affect people’s health, following a report that found diesel cars can be more polluting than diesel lorries.

The Trust’s reputation for innovative care was highlighted with articles in the Nursing Times, Nursing Standard and Daily Mail on a special bra designed by a nursing team to help women recover from cardiac surgery. The bra, designed by clinical nurse specialist in surveillance Melissa Rochon, is a solution to promote better wound healing for women who are recovering from cardiac surgery (see page 22).

Dr Isabel Skypala, consultant dietitian and clinical lead for food allergy, spoke to BBC World Service about common food allergies for the ‘Food Chain’ programme, which focused on smoothies, juices and ‘liquid food’. The interview was also covered by BBC Radio Wales and BBC Radio 4.

February 2017

Dr Sanjay Prasad, consultant in cardiology and cardiovascular magnetic resonance, was interviewed live on BBC News about new research on inherited heart disease, following reports that singer George Michael was suffering from cardiomyopathy before his death.

Professor Sir Magdi Yacoub, former director of transplantation at Harefield, told the Evening Standard that plans to decommision congenital heart disease services from Royal Brompton were a “crime”, telling the paper the hospital “has been a lead hospital in the world on congenital heart disease”.

One of the largest hay fever trials of its kind found that being exposed to controlled doses of pollen over three years led to a significant improvement in symptoms. The study, led by Professor Stephen Durham, clinical lead for allergy services at Royal Brompton and head of allergy and clinical immunology at Imperial College’s National Heart and Lung Institute, received extensive coverage including The Sun, The Times, Independent, Daily Telegraph and BBC Radio 4’s ‘The World at One’.

March 2017

Royal Brompton’s children’s ward and children’s intensive care unit invited the Guardian to spend two days talking to patients, parents and staff, to give readers a rare insight into a “typical day” in children’s intensive care. The photo essay was published online and in the prestigious ‘Eyewitness’ double-page spread across the print edition’s centre pages, and was followed by a live blog about the impact closing the CHD service would have on patients.

The Trust was listed in the top 10 Trusts with the best manager engagement rates, in a Health Service Journal (HSJ) feature on the annual NHS staff survey results. The HSJ is a specialist publication that reaches an audience of 17,000 healthcare professionals.

Dr James Hull was interviewed in the Daily Mail

can control their inflammations to avoid any further damage.

In a feature with the Guardian, honorary consultant chest physician and clinical lead for COPD, Dr Nicholas Hopkinson, discussed how prompt diagnosis of the disease could save patients from its worst effects. Meanwhile, Dr Alexander Lyon, consultant cardiologist, provided expert commentary to the Daily Mail on the latest research on maintaining a healthy lifestyle.

December 2016

The Brompton Fountain charity delivered a giant Christmas card to Secretary of State for Health, Jeremy Hunt MP, asking him to overturn plans to decommision congenital heart services at Royal Brompton. The card, signed by hundreds of patients, their families and supporters, featured on BBC London News and in the Evening Standard, and highlighted Royal Brompton’s excellent outcomes when caring for children with complex cardiac conditions.

At Harefield, cystic fibrosis patient Kimberly Chard underwent a double lung transplant and featured in a BBC One Wales documentary series on organ donation, ‘The Greatest Gift’.
As a foundation trust, we are governed by an elected council of governors and are independently regulated by NHS Improvement. We have around 11,000 members who we regularly consult with on Trust strategy and service planning.
## Our board

### Executive directors – full year
- **Professor Robert J Bell**
  - Chief executive
- **Dr Richard Grocott-Mason**
  - Medical director/senior responsible officer
- **Mr Robert Craig**
  - Chief operating officer
- **Mr Richard Paterson**
  - Associate chief executive – finance
- **Ms Joy Godden**
  - Director of nursing and clinical governance
- **Mr Nicholas Hunt**
  - Director of service development

### Non-executive directors – part year
- **Baroness (Sally) Morgan of Huyton**
  - Chair

### Non-executive directors
- **Mr Neil Lerner**
  - Deputy chairman; and acting chairman 1st April 2016 – 31st December 2016
- **Mrs Lesley-Anne Alexander CBE**
- **Professor Kim Fox**
- **Ms Kate Owen**
- **Dr Andrew Vallance-Owen MBE** (senior independent director)
- **Mr Richard Jones**
- **Mr Philip Dodd**

## Our council of governors

### Public governors – full year
- **Mr George Doughty**
  - North West London
- **Mr Anthony Archer**
  - Bedfordshire and Hertfordshire
- **Mr Robert Parker**
  - South of England
- **Ms Jennifer Sano**
  - Rest of England and Wales

### Patient and carer governors – full year
- **Mrs Chhaya Rajpal**
  - North West London
- **Mr Tim Mack**
  - North West London
- **Mrs Brenda Davies**
  - Bedfordshire and Hertfordshire
- **Mr Edward Waite**
  - South of England
- **Mr Stuart Baldock**
  - Elsewhere
- **Dr Ejikeme Uzoalor**
  - Elsewhere
- **Ms Caroline Karlsen**
  - Representing patients and carers

### Patient and carer governors – part year
- **Mr Peter Kircher**
  - Bedfordshire and Hertfordshire

### Staff governors – full year
- **Dr Charlie Butcher**
- **Dr Claire Hogg**
- **Ms Anne McDermott**
- **Mrs Elizabeth Henderson**

### Staff governors – part year
- **Dr Andrew Morley-Smith**
- **Dr Laura Price**

### Appointed governors – full year
- **Mrs Victoria Borwick**
  - London Borough of Kensington and Chelsea
- **Professor Mary Morrell**
  - Imperial College London

### Appointed governors – part year
- **Mr Ray Puddifoot**
  - London Borough of Hillingdon

## During 2016/17

We balanced our books, recording a £2 million financial surplus at year-end.

During 2016/17 we welcomed our new Trust chair Sally Morgan, Baroness Morgan of Huyton.
## Statement of comprehensive income as at 31 March 2017

<table>
<thead>
<tr>
<th></th>
<th>Year ended 31.03.17 £000</th>
<th>Year ended 31.03.16 £000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Operating income from patient care activities</td>
<td>329,780</td>
<td>328,957</td>
</tr>
<tr>
<td>Other operating income</td>
<td>47,550</td>
<td>33,342</td>
</tr>
<tr>
<td><strong>Total operating income from continuing operations</strong></td>
<td><strong>377,330</strong></td>
<td><strong>362,299</strong></td>
</tr>
<tr>
<td>Operating expenses</td>
<td>(386,151)</td>
<td>(368,279)</td>
</tr>
<tr>
<td><strong>Operating deficit from continuing operations</strong></td>
<td><strong>(8,821)</strong></td>
<td><strong>(5,980)</strong></td>
</tr>
<tr>
<td>Finance income</td>
<td>42</td>
<td>47</td>
</tr>
<tr>
<td>Financial liabilities</td>
<td>(1,036)</td>
<td>(564)</td>
</tr>
<tr>
<td>Unwinding of discount on provisions</td>
<td>(2)</td>
<td>(11)</td>
</tr>
<tr>
<td>PDC dividends payable</td>
<td>(6,063)</td>
<td>(6,671)</td>
</tr>
<tr>
<td><strong>Net finance costs</strong></td>
<td>(7,059)</td>
<td>(7,199)</td>
</tr>
<tr>
<td>Losses on disposal of non-current assets</td>
<td>(59)</td>
<td>(17)</td>
</tr>
<tr>
<td>Movement in the fair value of investment property</td>
<td>27,206</td>
<td>3,476</td>
</tr>
<tr>
<td><strong>Surplus/(deficit) for the year</strong></td>
<td>11,267</td>
<td>(9,720)</td>
</tr>
</tbody>
</table>

### Other comprehensive income (will not subsequently be reclassified to I&E)

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<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Revaluations of operational properties and other non-current assets</td>
<td>(9,176)</td>
<td>7,148</td>
</tr>
<tr>
<td>Other reserve movements</td>
<td>–</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Total comprehensive income/ (expense) for the period</strong></td>
<td><strong>2,091</strong></td>
<td><strong>(2,575)</strong></td>
</tr>
</tbody>
</table>

## Statement of financial position as at 31 March 2017

<table>
<thead>
<tr>
<th></th>
<th>As at 31.03.17 £000</th>
<th>As at 31.03.16 £000</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-current assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intangible assets</td>
<td>14,983</td>
<td>12,054</td>
</tr>
<tr>
<td>Property, plant and equipment</td>
<td>186,525</td>
<td>195,510</td>
</tr>
<tr>
<td>Investment properties</td>
<td>37,294</td>
<td>34,088</td>
</tr>
<tr>
<td><strong>Total non-current assets</strong></td>
<td>238,802</td>
<td>241,652</td>
</tr>
</tbody>
</table>

### Current assets

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Inventories</td>
<td>9,957</td>
<td>9,043</td>
</tr>
<tr>
<td>Trade and other receivables</td>
<td>45,950</td>
<td>32,512</td>
</tr>
<tr>
<td>Cash and cash equivalents</td>
<td>32,668</td>
<td>13,777</td>
</tr>
<tr>
<td><strong>Total current assets</strong></td>
<td>88,575</td>
<td>55,332</td>
</tr>
</tbody>
</table>

### Current liabilities

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade and other payables</td>
<td>49,566</td>
<td>49,597</td>
</tr>
<tr>
<td>Borrowings</td>
<td>(5,610)</td>
<td>(3,070)</td>
</tr>
<tr>
<td>Provisions</td>
<td>(2,011)</td>
<td>(1,019)</td>
</tr>
<tr>
<td><strong>Total current liabilities</strong></td>
<td>(57,187)</td>
<td>(53,686)</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total assets less current liabilities</strong></td>
<td><strong>270,190</strong></td>
<td><strong>243,298</strong></td>
</tr>
</tbody>
</table>

### Non-current liabilities

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Borrowings</td>
<td>(52,147)</td>
<td>(27,500)</td>
</tr>
<tr>
<td>Provisions and liabilities</td>
<td>(638)</td>
<td>(690)</td>
</tr>
<tr>
<td><strong>Total non-current liabilities</strong></td>
<td>(52,785)</td>
<td>(28,190)</td>
</tr>
<tr>
<td><strong>Total assets employed</strong></td>
<td>217,404</td>
<td>215,108</td>
</tr>
</tbody>
</table>

### Financed by

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Public dividend capital</td>
<td>108,567</td>
<td>108,362</td>
</tr>
<tr>
<td>Revaluation reserve</td>
<td>47,894</td>
<td>57,070</td>
</tr>
<tr>
<td>Income and expenditure reserve</td>
<td>60,943</td>
<td>49,876</td>
</tr>
<tr>
<td><strong>Total taxpayers’ equity</strong></td>
<td>217,404</td>
<td>215,108</td>
</tr>
</tbody>
</table>