GETTING IT RIGHT FIRST TIME

Paediatric General Surgery and Urology

GIRFT Programme National Specialty Report

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GIRFT clinical lead for paediatric surgery

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GIRFT is delivered in partnership with the Royal National Orthopaedic Hospital NHS Trust, NHS England and NHS Improvement

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Foreword from Professor Tim Briggs GIRFT Programme Chair

I am delighted to recommend this Getting It Right First Time review of paediatric general surgery and urology, led by Simon Kenny.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The unprecedented events of 2020/21 - and the extraordinary response from everyone working in the NHS – add greater significance to GIRFT's recommendations, giving many of them a new sense of urgency.

Actions in this report, such as increasing the use of day case surgery, improving the care of children requiring emergency surgery and reducing unnecessary surgical procedures and outpatient follow ups, can all help release capacity for the NHS as it faces the substantial challenge of recovering services, while remaining ready for any future surges, by operating more effectively and safely than ever before.

Simon has applied the GIRFT approach to paediatric surgery, a specialty that provides life-changing surgery to infants and children, with potentially transformative and lifelong benefits. This report is of particular importance to the wider GIRFT programme as it marks our first national report to focus on infants and children and the care the NHS provides to them.

Paediatric surgery was the first paediatric workstream to be initiated by the GIRFT programme, and has been followed by workstreams in paediatric trauma and orthopaedics, paediatric critical care and neonatology. As in several other specialties, which focused on adult services in their first set of deep-dive visits to trusts, paediatric services will be addressed when the trusts' data packs are refreshed and revisits are carried out.

The findings and recommendations in this report are based on GIRFT deep-dive visits to 89 trusts. Implementing these recommendations will help to reduce and avoid unnecessary operations and hospital stays for children, and will make our hospital environments safer and friendlier for children.

Recommendations for system change will ensure that clinicians in non-specialist centres are better trained to provide less-complex paediatric care, while children with complex conditions are treated in larger, specialist centres with access to appropriate expertise and facilities. These larger, specialist centres will also improve the specialist training the NHS can offer and maximise our contributions to research.

We know that in the process of improving the quality of treatment and care we provide for children, the NHS will also be operating more effectively. The recommendations set out in this report present a notional financial opportunity for trusts of around £19m a year, as well as savings in avoiding costly complications and litigation.

On his visits to trusts, Simon has identified many examples of excellent paediatric care, some of which are highlighted in this report. Like GIRFT clinical leads in other workstreams, Simon has been encouraged by the high level of support and interest for his review. It is pleasing to hear that there is a significant appetite for delivering improvement in paediatric services.

GIRFT can only succeed with the backing of clinicians, managers and all of us involved in delivering care. I hope that with this shoulder-to-shoulder ethos, GIRFT will provide further impetus to keep improving the quality of treatment and care we provide for children in the NHS.

Professor Tim Briggs *CBE*

GIRFT Programme Chair and National Director of Clinical Improvement for the NHS.

Professor Tim Briggs is Consultant Orthopaedic Surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs. He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs.

Professor Briggs is also National Director of Clinical Improvement for the NHS.

Introduction from Professor Simon Kenny

At a time when global health services face increasing fiscal pressure from rising costs of treatment coupled with an ageing population, with chronic disease there may be a tendency to focus on the older population. However, there is substantial evidence that a healthy childhood leads to healthy adults with a lower burden of disease. To lose focus on the health of the young would be to ignore a huge opportunity to reduce the overall costs of healthcare – now and in the future – by raising our children into healthy adults.

In general, the last 40 years has been a success story in this regard. Infant and child mortality have dropped dramatically: between 1980 and 2018, child mortality rates fell from 14 to 4.4 children per 1,000 live births dying before their fifth birthday (Office for National Statistics). In absolute numbers, this means around 6,400 fewer children will have died in the UK in 2018 than would have died 38 years earlier.

The reasons for this dramatic drop are multiple and include reductions in levels of child poverty and improvements in living standards, home and road safety, antenatal and neonatal care, and management of acute and chronic disease.

Building a service to meet current and future needs of children and their families

The NHS Long Term Plan[1] recognises children as a priority and sets out clear ambitions to ensure 'a strong start in life for children and young people' and 'accelerating action to achieve 50% reductions in stillbirth, maternal mortality, neonatal mortality and serious brain injury by 2025'.

The findings and subsequent recommendations in this report complement and support the ambitions of the NHS Long Term Plan. They will help deliver a sustainable service, that will meet the current and future needs of children and their families, which must include:

- developing and implementing a sustainable model of care;
- ensuring absolute equity of treatment – in the right place and at the right time;
- maintaining and improving current high-quality services that 'get it right first time'.

The support and action of trusts and clinicians in carrying out the recommendations will help to deliver those ambitions.

Reducing unwarranted variation

Carrying out this GIRFT review has deepened my insight into the challenges and opportunities for children's surgery in England.

We have found that the organisation of children's surgery has evolved organically in a range of ways. I have also found that children's surgical services generally face challenges of poor infrastructure, significant demand, and a lack of data to help them benchmark their services nationally.

This report and its recommendations focus on reducing the unwarranted variation across the country and complement the NHS Long Term Plan's stated five-year ambition: 'Paediatric critical care and surgical services will evolve to meet the changing needs of patients, ensuring that children and young people are able to access high quality services as close to home as possible. Paediatric networks, which will involve hospitals, NHS staff and patients and their families, will ensure that there is a coordinated approach to critical care and surgical services, enabling children and young people to access specialised and non-specialised services in times of urgent, emergency and planned need.'

Clinical leadership and relationships between management and clinicians

Finally, I have been hugely impressed by the enthusiasm and drive of clinicians in delivering paediatric surgery. However, on many visits, I found this was accompanied by a sense of resignation among clinical teams. They could clearly see where improvements in quality and productivity are needed but achieving these was being stifled by lack of formal lines of communication with management.

This is why I believe the GIRFT programme is so important, since it is clinically led and contains findings built on the clinician experience. Developing stronger clinical leadership and responsive relationships between management and clinicians will be crucial to improving our specialty.

Professor Simon Kenny *BSc ChB(Hons) MD FRCS(Paed) FAAP*
GIRFT Clinical Lead for Paediatric Surgery

Professor Kenny is the National Clinical Director for Children and Young People with NHS England and NHS Improvement and a consultant paediatric surgeon and urologist at Alder Hey Children's Hospital in Liverpool. He is the chair of the Clinical Outcomes Committee of the British Association of Paediatric Surgeons.

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[1] *NHS Long term Plan www.longtermplan.nhs.uk/*

COVID-19 observations

Since the writing of this report the country has been hit by the COVID-19 pandemic, with the NHS throwing all its resources at generating enough ventilatory capacity to look after the needs of adults with COVID-19 in the first and second waves.

Children's services were not immune to the pandemic, however, with community services stood down and surgical and clinical teams grappling with the challenges posed by delivering safe emergency surgery. Sadly, some of our paediatric colleagues died from COVID-19.

The restoration of elective services faces formidable obstacles, including ongoing pressure from COVID-19 admissions, reduced efficiency due to revised operational procedures and the use of personal protective equipment, staff absences, a requirement for pre-operative testing and isolation regimes, and the growing backlog of elective surgery.

There has been an unprecedented response to these challenges. Outpatient consultations, especially follow-ups, almost instantly became virtual by default and we are now learning which consultations can be done remotely and which need to be done in person. Teams have reconfigured to provide responsive, senior-led, emergency surgical services. Overnight, the debate over operative versus non-operative management of appendicitis has shifted towards non-operative management. Long postponed dialogues over seven-day services have resumed with new purpose, as clinicians and management grapple with the pressure on services.

Paediatric Intensive Care Units (PICUs) dramatically increased their surge capacity by training cadres of theatre staff and anaesthetists and calling on colleagues with intensive care experience. 111 algorithms were changed, and a body of paediatricians recruited to provide specialist advice within 111.

The Digital Child Health Record and 'early warning' digital physiological measurements (System-wide Paediatric Observation Tracking, SPOT) are being rolled out in all care settings to aid in identification of the deteriorating child. Children's Surgical Operational Delivery Networks are now all up and running and are focusing on the use of GIRFT to improve outcomes for children at a population level. GIRFT data for paediatric surgery, urology and ENT is now available in the Model Health System.

All of these advances offer significant opportunities to improve children's heath in the long run. That said, the core messages in this GIRFT report remain valid. We address unnecessary surgery – now that there is a different perception of risk, we hope the report will help drive significant reductions in unnecessary surgery that lacks an evidence base. In addition, the messages around reducing the incidence of necrotising enterocolitis (NEC), concentrating expertise on rare surgical conditions and procedures into fewer centres, and boosting general surgeons' exposure to paediatric surgery, remain key to improving the outcomes for children who require surgery.

We know that many improvements have already begun, following our deep dives and prior to publication of this report. For example, the rate of negative appendicectomy has almost halved to 6.5% and minimally invasive appendicectomy rates have risen to 78% (Source: Model Hospital). There has also been a reduction in circumcision rates in the under-fives.

We are very glad to see such significant progress being made, and we offer huge congratulations to the clinical and managerial staff who have focused on this.

Now is the time to complete our journey.

Professor Simon Kenny *BSc ChB(Hons) MD FRCS(Paed) FAAP*
GIRFT Clinical Lead for Paediatric Surgery

Statements of support

British Association of Paediatric Surgeons

The British Association of Paediatric Surgeons (BAPS) welcomes the publication of the paediatric general surgery and urology GIRFT report which contains much of significance and has the potential to improve the provision of care for children in the UK.

As a speciality, we provide a very broad range of care, ranging from the highly complex to simple, performed by a variety of surgeons including specialist paediatric surgeons, general surgeons, plastic surgeons and urologists.

The NHS Long Term Plan published in January 2019 made a commitment to provide children and young people with access to high-quality services as close to home as possible with networks ensuring a coordinated approach enabling access to specialised and non-specialised services.

BAPS fully supports the NHS Long Term Plan and will work with NHS England and NHS Improvement and GIRFT to deliver specialised and non-specialised services within the developing Operational Delivery Networks.

The provision of non-specialised services has seen a significant shift in the delivery of elective surgery into tertiary units, a trend we would wish to reverse, whilst preventing a similar trend in emergency services. To achieve this will necessitate careful workforce planning by the Operational Delivery Networks including BAPS, general surgeons, plastic surgeons and urologists.

Whilst the organisation of tertiary paediatric surgery has evolved without a co-ordinated national approach, the proposal to create 3a and 3b units is radical. A networked model of specialised surgery co-ordinated by the Operational Delivery Networks concentrating expertise between units has many advantages, maintaining skills and avoiding the added expense of providing additional beds, neonatal cots, staff and transport services.

Operational Delivery Networks can be effective by mandating the use of evidence-based measures in the management of Necrotising enterocolitis (NEC) and improving the environment of care for children and young people undergoing surgery.

We support the requirement for participation in centrally funded national surgical registries and would encourage the development of clinical outcome databases specifically for complex children's surgery.

Finally we would welcome the participation of families and children with BAPS and would support their involvement with Operational Delivery Networks.

We express our thanks to Simon Kenny and the GIRFT team for their dedication and hard work in producing this document.

Richard J Stewart

Past president of the British Association of Paediatric Surgeons

TOFS

Tracheo-Oesophageal Fistula Support (TOFS) is a registered, UK-based charity dedicated to providing emotional support to families of children born with Tracheo-Oesophageal Fistula, Oesophageal Atresia (OA) and associated conditions. TOFS is also part of EAT, an international federation of member support groups each associated with the rare congenital condition of oesophageal atresia.

The main goals of TOFS, in addition to the provision of pastoral support to patients and their families, are to help patients with oesophageal atresia and health professionals share their knowledge and experience, and support worldwide research and collation of information concerning the treatment and care of people born with oesophageal atresia.

In this respect we are pleased to endorse the findings and recommendations of the paediatric general surgery and urology GIRFT report which we believe will lead to a more sustainable model for specialist paediatric surgery capable of delivering consistently high and improved outcomes for OA patients.

Graham Slater

Trustee & Hon. Secretary
Chair of the TOFS Medical Liaison Subcommittee
Chair, EAT (The International Federation of Esophageal Support Groups)

Executive Summary

Our GIRFT review has found a significant degree of unwarranted variation in the delivery of paediatric general surgery and urology.

These findings suggest that there are significant opportunities to improve the care and outcomes of children requiring paediatric general surgery and urology. In addition to improving quality of care, there is a notional financial opportunity of up to £19.4 million annually, plus up to £4.3 million in procurement.

The GIRFT programme

Funded by the Department of Health and jointly overseen by NHS England and NHS Improvement and the Royal National Orthopaedic Hospital NHS Trust, GIRFT seeks to identify variation within NHS care and then learn from it. GIRFT is one of several programmes designed to improve operational efficiency in NHS hospitals. In particular, it is part of the response to Lord Carter's review of productivity and is providing vital input to the Model Hospital project. It is also closely aligned with programmes such as NHS RightCare, and working with sustainability and transformation partnerships (STPs)/integrated care systems – all of which seek to improve standards while delivering efficiencies.

Under the GIRFT programme, data from many NHS sources is consolidated and analysed to provide a detailed national picture of a particular area of practice. This process highlights variations in care decisions, patient outcomes, costs and other factors across the NHS. The data is reviewed by experienced clinicians, recognised as experts in their field, who visit individual hospital trusts to discuss the data with senior management and the clinical teams involved in the specialty under review. This is an opportunity for both parties to learn; the individual trust can understand where its performance appears to be below average and draw on clinical expertise to identify ways to address that, while the visiting clinicians can gain an insight into emerging best practices, to feed into the national picture and make recommendations for service-wide improvement.

The analysis and visits lead not only to targeted action within individual trusts, but also to the production of this national report and its recommendations, backed by an implementation programme to drive change and address unwanted variation.

About our analysis

In developing this report, we used existing sourced data, questionnaires and deep dive visits to specialist and non-specialist trusts. We have looked at complex and low-complexity paediatric surgery, and emergency, elective (planned), and urgent elective care.

The report is divided into two parts. During our visits and in the writing of this report, we realised that addressing the challenges faced in paediatric surgery will involve a combination of change to current systems, as well as focusing on local delivery. Alone, neither approach will be likely to change outcomes and experience of care for children, but by addressing our key challenges now, we can continue to improve life for children and the adults they will become. The first part explores the pressures and challenges faced by the existing model of care and makes recommendations on how the quality and effectiveness of care can be improved. The second part examines unwarranted variation in specific common conditions and makes recommendations to address these.

What we found

The existing model of care

Complex paediatric surgery and urology is delivered by a relatively small (~200) cadre of specialist paediatric surgeons spread across 22 specialist trusts. They also deliver the bulk of low complexity elective surgery. General surgeons and urologists in non-specialist hospitals deliver most of the emergency care for appendicitis and testicular torsion, together with some low complexity elective surgery. The trend is for increasing amounts of low-complexity, elective and emergency work to be concentrated in specialist trusts which is increasing pressure on scarce specialist resources.

Expertise is spread too thinly

We found that the surgical care of babies and children with the rarest and more complex surgical conditions is being done in 22 specialist trusts across England, several of which are only a few miles apart, spreading expertise too thinly. This has resulted in:

- Reduced individual surgeon, team and centre experience;
- Reduced training opportunities;
- Reduced innovation and research;
- Lack of infrastructure to deliver future services and respond to challenges / innovation;
- Variation in the availability of critical co-dependencies such as interventional radiology;
- Poor productivity and higher costs.

We have recommended that the surgical care of babies and children with the rarest and more complex surgical conditions are treated in fewer specialist trusts to give surgeons and teams greater experience. This will permit adequate training of the next generation, allow world leading research and innovation, and allow access to critical services such as interventional radiology. In addition, it will enable the further development of teams of specialist nurses who are vital in supporting children and their families. The newly developed Operational Delivery Networks (ODNs) across England[2] together with the GIRFT regional implementation teams will play a key role in delivering these recommendations.

An unequal system for preterm infants

We found that only 22 of 48 level 3 neonatal units looking after preterm babies have rapid access to paediatric surgeons, leading to:

- Delays in delivery of surgical assessment and care;
- Slow or no adoption of measures likely to halve necrotising enterocolitis (NEC) mortality, which could prevent up to 50 deaths a year.

We recommend increased focus on the use of breast milk in feeding preterm babies (including donor breast milk where indicated), together with the introduction of probiotics. In addition, we recommend all level 3 units devise ways to permit early surgical review of babies with suspected NEC. The evidence base shows that these measures are safe and could potentially halve mortality from this lethal condition.

The care for children with acute appendicitis needs to improve

We found that 10% of children undergoing appendicectomy were having a normal appendix removed. This compares unfavourably with the USA and other European countries in which the rate was 2.5% or lower. Furthermore, there is unwarranted variation in the use of laparoscopic (keyhole) appendicectomy between trusts. There is also significant variation in the lengths of hospital stay of children with simple and complex appendicitis.

There are several reasons for this:

- low emphasis on emergency surgery in the general surgery curriculum;
- specialist paediatric surgeons undertaking the bulk of elective surgery as a result of organic over planned development of care delivery model, further reducing general surgical experience and sense of ownership;
- relatively low usage of diagnostic tools such as ultrasound, exacerbated by a national shortage in trained radiologists / radiographers;
- low use of peri- / post-operative care pathways.

We recommend strengthening the training of general surgeons in paediatric surgery to improve leadership and outcomes in non-specialist trusts. We also recommend that the care of each child with possible appendicitis in non-specialist trusts is shared between general surgeons and paediatricians. Furthermore, the use of 7-day diagnostic imaging needs to improve, either by increasing the numbers of radiographers and radiologists, or by seeking novel solutions. In addition, children should be cared for within defined care pathways to reduce the variation in care, improve outcomes and shorten lengths of stay.

Boys with suspected testicular torsion need prompt surgery

Testicular torsion is a time-critical surgical emergency. We found that too many boys are being transferred for surgery, leading to unacceptable delays and increasing the risk of testicular loss. Scrotal exploration for suspected testicular torsion

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[2] *NHS England & NHS Improvement (2019) Paediatric critical care and surgery in children review summary https://www.england.nhs.uk/wp-content/uploads/2019/11/paediatric-critical-care-and-surgery-in-children-review-summary-report-nov-2019.pdf*

is a straightforward procedure that all general and urological surgeons can perform. We found wide variation in the age at which surgeons and anaesthetists were prepared to treat boys with this condition and no evidence to support this variation. We recommend that all boys with suspected testicular torsion are assessed promptly and treated close to home to reduce the incidence of testicular loss.

We need widespread adoption of evidence-based children's surgery

We need to improve the way we decide which children require surgery for common conditions.

Across conditions, children are undergoing unnecessary surgery – up to 4,000 boys annually undergo unnecessary circumcision as a result of a lack of evidence base and training in alternative treatments. We see a similar situation in both hydrocele and umbilical herniotomy, where conditions usually resolve over time.

NHS England and NHS Improvement are running an evidence-based interventions (EBI) programme which aims to prevent avoidable harm to patients, to avoid unnecessary operations, and to free up clinical time by only offering interventions on the NHS that are evidence-based and appropriate.

This programme has contributed to reducing unwarranted variation and in its first phase included surgical interventions including tonsillectomy and grommets. The programme is currently in its next phase, which is considering additional paediatric surgery interventions. This programme may support the reduction of unnecessary surgery taking place for medically indicated circumcisions, umbilical herniotomy and hypospadias surgery. More detail on the programme is available on the EBI website[3].

We need to improve children's experience

The way we deliver care does not always provide an optimal experience for children and their families already suffering stress from emotional and financial burdens.

Increasing numbers of children with less complex conditions, who could be treated locally, are transferred to specialist centres unnecessarily, necessitating families to travel long distances.

We also saw examples where the environment of care for children with surgical problems in theatres and in clinic was not child-friendly. This can lead to a frightening and upsetting experience for children and also can lead to safeguarding concerns.

We saw numerous examples where staff have used existing resources in an imaginative and child-friendly way. We recommend attention to the child's journey on the day of surgery. Not only will this improve experience it will also likely increase efficiency and resource utilisation. Furthermore, children should be seen in children's outpatient settings with paediatric trained nurses in attendance.

We found that there was no easy way of measuring child experience in hospitals where adults are treated as well as children. Changes to the Friends and Family Test could improve this.

The NHS Long Term Plan

The NHS Long Term Plan recognises children as a priority and sets out clear ambitions to ensure 'a strong start in life for children and young people' and 'accelerating action to achieve 50% reductions in stillbirth, maternal mortality, neonatal mortality and serious brain injury by 2025'. We believe our recommendations will help to close this gap with respect to paediatric surgery, in particular our recommendation for necrotising enterocolitis (NEC), where mortality rates could be significantly reduced.

The NHSE/I review of specialised children's surgery proposes three levels of units delivering paediatric surgery. The units delivering complex neonatal and paediatric surgical care are designated as Level 3. In order to concentrate expertise, we propose that Level 3 centres are further split into two levels, designated 3A and 3B based on their ability to treat sufficient numbers of children with index conditions and provide necessary co-dependent services. This change will mean that children and families are treated by teams with enough experience and expertise to provide world class care and to continue to innovate and research into these rare surgical conditions. It also means that the right teams of experienced nurse specialists can support families and children. Importantly, Level 3A centres should have the back up of 24-hour access to interventional radiology.

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[3] *See https://www.england.nhs.uk/evidence-based-interventions/*

ODNs should ensure that non-specialist care networks have the right workforce and resources to deliver low-complexity, emergency, and elective child surgery.

ODNs and providers should ensure that providers meet key performance indicators (KPIs) in order to prevent unnecessary surgery in children as well as promote evidence-based practice.

Neonatal networks should devise systems to allow seamless communication with and access by paediatric surgeons for pre-term neonates.

The Royal Colleges should ensure that general surgical trainees have sufficient exposure to children's surgery for them to feel competent and confident to deliver high quality emergency surgical care to children with common surgical conditions.

Managing care delivery

Wide variations in management and planning of children's surgery leads to reduced efficiency and higher costs - for example, the the significant variation in day case surgery rates for common conditions and the practice of admitting the day prior to procedure.

Providers and ODNs should monitor day case rates and share experience and expertise to ensure that most children are treated as day cases and that resources are utilised efficiently.

There needs to be a meaningful link between trust boards and children's care. Currently, this link is weak, particularly in trusts struggling with the pressure of providing care for older people with complex needs.

Strengthening data sharing and analysis

We have found that there is a lot of data available to help clinicians, providers and networks understand their services. Most staff were unaware of how their activity and outcomes benchmarked with others and did not know the costs of the care they deliver.

NHS England and NHS Improvement should support initiatives such as the National Clinical Improvement Programme (NCIP), developed by GIRFT in association with surgical specialty associations, that will allow clinicians and providers to understand their outcomes. In time, NCIP will be able to benchmark times in theatre with other providers to help understand differences in costs and productivity.

In addition, the surgical specialty associations, together with Royal Colleges and NHS England and NHS Improvement, should work to develop linked data sets via the electronic patient records that permit measurement of meaningful outcomes for babies undergoing surgery, particularly by using Core Outcome Sets (see page 109). These are co-created by clinician, patients and parents and represent true measures of success following surgical interventions.

Litigation

In the five years between 2012/13 and 2016/17 total litigation costs related to paediatric surgery are estimated as between £10.3 million and £21.4 million per year, meaning that the average estimated cost of litigation per paediatric surgical admission is high at £144. In fact, many trusts have no litigation bill, but costs per claim can be very high as they reflect the higher damages awarded to younger patients because of the lifetime effect of injury and costs of care. It was clear that trust clinicians were unaware of the details of the claims against them, raising the prospect that the problems underlying the claim had not been resolved.

We recommend that providers employ GIRFT's 5-point plan to help reduce litigation.

Procurement

In this report we looked at typical products used by paediatric surgery departments across the NHS. We found variation in products, brands and suppliers used, but also in prices paid. If all trusts were able to purchase at the lowest price, annual savings would exceed £4 million. These savings are likely to be higher if suppliers and brands are switched. One issue is knowing whether different brands have clinical impacts. NHSE/I is launching 'Scan for Safety' in which individual products can be traced to individuals. Creating links between NCIP and Scan for Safety has significant potential in identifying efficacy of different brands and, perhaps most importantly, will allow tracking of new implants or procedures across the NHS.

We recommend that providers adopt the GIRFT 3-point strategy to improve procurement of devices and consumables. In addition NCIP and Scan for Safety should work together to link databases and allow tracking of products against clinical outcomes.

Recommendations

In this report, we make the following recommendations.

Recommendation	Actions	Timescale
1. Use the newly established Operational Delivery Network (ODN)-based model of care in children's surgery to ensure that all children requiring surgery are treated by experienced teams with the right infrastructure and support.	**a** GIRFT to support NHS England and NHS Improvement in the development of a paediatric surgery service delivery model, which is informed by the findings in the GIRFT paediatric surgery report.	To be aligned with NHS England and NHS Improvement's timescales.
	b GIRFT to support NHS England and NHS Improvement to develop and implement ODNs across England, including defining KPIs and ensuring neonatal surgery is fully integrated with network governance processes.	
	c NHS England and NHS Improvement, ODNs and trusts to work together to deliver the model of care, by ensuring: • Expertise and resources for children with the rarest surgical problems are concentrated into, indicatively, 10 centres; • Specialist centres managing less rare conditions are able to provide appropriate care for urgent conditions; • Staffing arrangements are in place to ensure common surgical emergencies can be managed promptly in local hospitals close to home.	
2. Reduce the mortality rates in premature babies with necrotising enterocolitis by encouraging breast feeding, use of probiotic nutritional supplements and rapid surgical review of babies with suspected NEC.	**a** Trusts to encourage maternal breast feeding for premature babies, drawing on evidence from the East of England Perinatal Network and elsewhere as helpful, with a view to maximising breast feeding/donor milk rate at discharge.	Within six months of publication
	b GIRFT and NHS England and NHS Improvement to develop plan aimed at provision of probiotic nutritional supplements in all neonatal units. In the interim, trusts are encouraged to expand use of supplements and share implementation experiences with GIRFT.	Within six months of publication
	c Trusts and Operational Delivery Networks to ensure rapid surgical review of babies with suspected necrotising enterocolitis.	Within nine months of publication
3. Increase the use and scope of day case surgery in paediatric surgery and urology by taking action within trusts across Operational Delivery Networks (ODNs).	**a** Trusts and Operational Delivery Networks should routinely monitor day case rates compared to their peers using Model Hospital/ GIRFT data to identify opportunities to increase day case rates.	Ongoing
	b Where opportunities appear to exist trusts and Operational Delivery Networks should identify local improvements, review variations in trust policies on day surgery, review how consistently trust policies are followed, and review list utilisation using theatre productivity data Monitoring day case theatre productivity to ensure efficient list utilisation	Ongoing
	c GIRFT to work with professional bodies to review and establish any new or amended clinical guidance needed.	As required
4. Improve the care of children requiring emergency paediatric surgery for appendicitis and testicular torsion.	**a** NHS England and NHS Improvement, Royal College of Surgeons (RCS), Royal College of Paediatrics and Child Health (RCPCH), Royal College of Anaesthetists (RCA) and Royal College of Radiologists (RCR) to produce a model appendicectomy pathway which includes: • ED to diagnosis (ultrasound, assessment decision units) • preoperative care • surgery • postoperative care	Within 12 months of publication Within 18 months of publication
	b Trusts and Operational Delivery Networks to reduce the incidence of negative (normal) and complex appendicectomy rate by employing shared care between paediatricians and surgeons and adopting the appendicectomy model.	As per their plan
	c GIRFT and Public Health England to investigate regional variation in the rates of complex appendicitis.	Within nine months of publication
	d Operational Delivery Networks to review capacity as necessary to ensure that all boys with suspected testicular torsion are assessed promptly and treated close to home to reduce the incidence of testicular loss.	

Recommendation	Actions	Timescale
5. Reduce unnecessary surgical procedures through Operational Delivery Networks by applying evidence-based surgical decision-making.	**a** Trusts and Operational Delivery Networks to continually review and improve surgical decision making, based on the priorities outlined in box A. (below)	Ongoing
	b GIRFT and NHS England and NHS Improvement to consider paediatric procedures for inclusion in the Evidence Based Interventions Programme.	Within nine months of publication
6. Provide patients with a clinic review if necessary, after routine low risk procedures, without requiring routine out-patient follow-up appointments.	**a** Trusts and Operational Delivery Networks to review existing practice against this goal, and change processes as necessary, for the following procedures: circumcision, inguinal or umbilical herniotomy.	Within nine months of publication
7. Drive improvements in patient outcomes by strengthening how clinical data is collected, shared and analysed. This includes exploiting innovations in health data analytics by using the National Clinical Improvement Programme to monitor outcomes at clinician, provider, network and national level.	**a** GIRFT and specialist societies to review existing paediatric general and urology surgery registries and audits. Review to include understanding the gaps and barriers (eg; participation) and where data collected from HES can support monitoring of outcomes.	Ongoing
	b GIRFT, specialist societies and NHS England and NHS Improvement to develop a plan based on action a, which includes how NCIP can support in developing data tools in paediatric surgery and linking with existing data sources to drive improvements in outcomes.	Ongoing
	c Updated guidance to be sent to trusts and ODNs to support participation and advise on how the tools can enable continuous improvement.	Ongoing
8. Take steps to improve the environment of care for children and young people undergoing surgery.	**a** Trusts and Operational Delivery Networks to review facilities compared to expectations for child-friendly environments as described or referenced in health building notes and children's RCS standards for children's surgery consider business case for any improvements apparent, and implement as appropriate.	Within 12 months of publication
9. Improve how we gather and respond to the experience of children and their families / carers while in hospital.	**a** Review what mechanisms (including Friends & Families Test and CQC Children and Young Person's Inpatient and Day Case Survey), are available to enable the capturing of children, young people's, and their families/carers' experiences.	Within six months of publication
	b Based on action a, liaise with NICE, NHS England and NHS Improvement, ODNs and trusts to produce and implement a plan to enable the improvement in how we gain and use children's and their families' experience of care at hospital-level.	Within 12 months of publication
10. Ensure the children's voice is heard in hospitals by implementing ward to board representation of children's services, and by trusts active participation in Operational Delivery Networks.	**a** Trusts to review their governance arrangements compared to the goals described by RCS Children's Surgical Forum, consider any possible improvements and implement as appropriate, sharing experiences in doing so with GIRFT. Operational Delivery Networks should also share experiences across trusts in the network.	Within six months of publication
	b GIRFT and NHS England and NHS Improvement to consider any further policy development based on action A.	Within six months of publication

Recommendation	Actions	Timescale
11. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	**a** GIRFT to use sources of procurement data, such as SCS and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	Ongoing
	b GIRFT to identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	Ongoing
	c Trusts, STPs and GIRFT to use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Ongoing
12. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT litigation data pack.	For immediate action.
	b Clinicians and trust management to discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via *CNST.Helpline@resolution.nhs.uk*.	Upon completion of 12a.
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trusts panel firm should be able to provide support.	Upon completion of 12b.
	d Claims should be triangulated with learning themes from complaints, inquests and serious untoward incidents (SUI) serious incidents (SI)/ patient safety incidents (PSI) and where a claim has not already been reviewed as SUI/SI/PSI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all frontline clinical staff in a structured format at departmental/directorate meetings (including multidisciplinary team meetings, morbidity and mortality meetings where appropriate).	Upon completion of 12c.
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional hub directors to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	For continual action throughout GIRFT programme.

About paediatric surgery

Paediatric surgeons treat diseases, trauma and birth malformations from the foetal period through to young adults. The huge physiological differences between a foetus or premature baby and a teenager represents one of the key challenges to clinicians and service providers.

Our review focuses on complex and low-complexity paediatric and neonatal surgery.

It does not include:

- nationally commissioned **highly** specialised surgical services *(see appendix 1)*;
- transitional care from children to adult services – this aspect of paediatric surgical care will be covered in future GIRFT work;
- foetal surgery.

Complex paediatric and neonatal surgery

We cover complex and rare conditions including urology, oncology, thoracic and general surgery, and surgery of neonates.

These cases are often urgent and require treatment through emergency (non-elective) pathways. Patients are generally treated by specialist trusts with specialist facilities and expertise.

There is a significant caseload of children with complex medical needs[4]. These children may develop surgical disease or require surgical intervention to promote independence or improve their quality of life.

One of the most specialised areas of paediatric surgery is neonatal surgery, that is surgery on babies less than four weeks old and/or 44 weeks' gestational age. Neonates often have life-threatening conditions that require intensive care facilities. Specialist transport services are required if neonates need to be moved to a specialist neonatal unit.

Neonatal surgery can be further divided into three groups:

- premature babies;
- babies with antenatally diagnosed congenital abnormalities;
- babies with non-antenatally diagnosed congenital abnormalities.

Low-complexity paediatric surgery and urology

Low-complexity paediatric surgery and urology covers elective general paediatric caseload such as inguinal herniotomy, circumcision, orchidopexy (treatment for undescended testes), hydrocele and umbilical herniotomy.

Most low-complexity conditions can be treated as day cases in non-specialist trusts.

However, there is a large emergency caseload, mainly comprising appendicectomy, acute scrotal exploration and abscess drainage.

The report does not cover:

- paediatric cardiac surgery;
- paediatric trauma and orthopaedics;
- paediatric neurosurgery;
- paediatric ENT surgery;
- paediatric plastic surgery.

We do discuss co-dependencies relating to other areas of paediatric surgery, for example, cardiac, trauma and neurology and how to address and manage these later in this report. Furthermore, discussions with GIRFT leads who are also looking at different elements of paediatric surgery would suggest our key recommendations are applicable to their findings too.

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[4] *Simon, T.D., Berry, J., Feudtner, C., Stone, B.L., Sheng, X., Bratton, S.L., Dean, J.M. and Srivastava, R. (2010). Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics, [online] 126(4), pp.647–655.*

Clinicians involved in providing paediatric surgery

Clinicians involved in providing paediatric surgery include:

- specialist paediatric surgeons;
- adult general surgeons;
- adult urologists;
- plastic surgeons;
- paediatric anaesthetists;
- general anaesthetists;
- paediatric nurses, advanced nurse practitioners (ANPs) and specialist nurses in paediatric surgery.

The majority of references to clinicians in this report refer to surgeons practicing paediatric general surgery and urology. However, the term is also used inclusively of all MDT colleagues, as clinicians performing all of the roles above were invited to our deep dives.

Specialist paediatric surgeons

Specialist paediatric surgeons are mainly found in specialist trusts. Specialist paediatric surgery is a relatively new specialty that grew out of adult general surgery.

Specialist paediatric general surgeons undertake a six-year dedicated training programme in paediatric surgery following two years of core surgical training.[5] Specialty trainees are required to produce evidence of training in paediatric surgery and urology.

Training includes neonatal surgery, oncology, urology, upper and lower gastrointestinal surgery, thoracic surgery, hepatobiliary surgery, vascular access and general surgery of childhood.

Specialist paediatric urologists are specialist paediatric surgeons with expertise in the treatment of paediatric genitourinary conditions.

Adult general surgeons

We found that adult general surgeons deliver most emergency, low-complexity paediatric surgical care (over 50%). A smaller number of adult general surgeons and adult vascular surgeons with an interest in paediatric surgery are involved in the delivery of elective low-complexity surgery.

The general surgery of childhood is currently a mandatory part of general surgical training, but structured exposure to childhood surgery is not; clinicians can choose paediatric surgical attachments as options in later stages. Trainees who wish to develop an interest in the general surgery of childhood are attached to a specialist paediatric surgical unit to increase their experience.

Generally, all trainees will receive some form of exposure to children with acute surgical disease during their training. The curriculum requires all accredited general surgeons to be able to diagnose and manage general surgical emergencies in childhood, including appendicitis and testicular torsion.

Adult urologists

Adult urologists provide a significant proportion of general paediatric surgery in non-specialist trusts.

Adult urological surgeons undertake a five-year training programme in urology following two years of core surgical training.[6] All urologists are expected to have significant knowledge of paediatric urology and to be able to perform circumcision and scrotal exploration in the paediatric age group. It is also considered desirable for urologists to be competent in treating paediatric hydrocele and undescended testis.

Urologists have the option of completing a final-year module in paediatric and congenital urology.

Plastic surgeons

Plastic surgeons undertake six years of specialty training following two years of core surgical training. Children feature on the curriculum principally in the context of burns and limb injuries.

Genitourinary reconstruction also features in the syllabus and all trainees are expected to understand the principles of hypospadias reconstruction and to take part in some of the more straightforward procedures involved in hypospadias repair.

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[5] *The Intercollegiate Surgical Curriculum: Paediatric Surgery In: Training TJCoS, editor. London 2015.*

[6] *The Intercollegiate Surgical Curriculum: Urology Surgery. In: Training TJCoS, editor. London2016.*

Paediatric anaesthetists

Paediatric anaesthesia is a subspecialty of anaesthesia. Paediatric anaesthetists have received specific training that gives them expertise in the perioperative care of babies and children, including premature neonates.

Experienced paediatric anaesthetists are as essential to successful outcomes in specialist children's surgery as the surgeons themselves. Their experience and knowledge in delivering care and coping with complications is key to successful outcomes.

General anaesthetists

All general anaesthetists are expected to be able to deliver anaesthesia to children over three years of age. Most of the elective and emergency anaesthesia in children in non-specialist trusts is delivered by general anaesthetists.

All anaesthetists will have received a minimum of three months of training in paediatric anaesthesia. Many anaesthetists have undergone longer term attachments in paediatric anaesthesia.

Paediatric nurses, advanced nurse practitioners (ANPs) and specialist nurses in paediatric surgery

Paediatric nurses are registered nurses who have received specialised training in addition to their nursing degree to support them to care for and work with children and their families. Paediatric nurses dedicate their careers to working with children of all ages, from infancy through the teen years, often advancing their specialist skill sets within complex areas of paediatric care to meet the needs of those they care for and work with.

Paediatric specialist nurses are registered nurses who have been educated to degree level or above and who hold specialist knowledge, skills, competencies and experience. This role has a clinical focus, but also provides consultancy support to the wider MDT as well as clear links to education, research activities. Paediatric specialist nurses perform at a highly sophisticated level of practice, often working independently with sole responsibility and accountability for an episode of care for defined patient or client populations. They plan, assess and initiate treatment, including prescription-only medicine, and evaluate, with patients and their families, the effectiveness of the treatment and care provided, making changes as needed and ensuring the provision of continuity of care across the MDT.

Advanced nurse practitioners (ANPs)and nurse consultants are registered nurses, educated to Masters level or equivalent, with the skills and knowledge to allow them to expand their scope of practice to better meet the needs of the people they care for, in this case children and their families. ANPs work at a level that pulls together the four advanced clinical practice pillars of clinical practice: leadership, management, education and research. Advanced clinical practice is delivered by experienced, registered nurses. It is a level of practice characterised by a high degree of autonomy and complex decision making. Advanced clinical practice embodies the ability to manage clinical care in partnership with individuals, families and carers. It includes the analysis and synthesis of complex problems across a range of settings, enabling innovative solutions to enhance people's experience and improve outcomes.

Paediatric surgery commissioning arrangements

Paediatric Surgery is commissioned by both Clinical Commissioning Groups (CCGs) and NHS England Specialised Commissioning. CCGs commission most of the planned hospital care and urgent and emergency care (including out-of hours) for children. NHS England Specialised Commissioning commissions paediatric surgery for children which includes rare surgical conditions and procedures, surgery in neonates, and simpler surgery in children with complex medical needs.

Photo courtesy of Sheffield Children's Hospital

About our analysis

We carried out our analysis following the established GIRFT model[7].

Data

We asked trusts to complete a structured questionnaire that collected information about service provision, in addition to reviewing existing, source data.

Data sources

We used the following data sources during development of this report:

- Service questionnaire
- Hospital Episode Statistics (HES)
- BAPS-CASS national audits
  - Gastroschisis
  - Oesophageal atresia
  - Congenital diaphragmatic hernia
  - Hirschsprung's Disease
- National Neonatal Research Database Procurement costs
- NHS Digital
- NHS Resolution
- NHS Reference Costs
- PICANET (Paediatric Intensive Care Network)

Providers of paediatric surgery

From the data, we identified 153 trusts that carry out some general paediatric surgery. Table 1 shows a breakdown.

Table 1: Number of non-specialist and specialist trusts that carry out general paediatric surgery

	Non-specialist trusts	Specialist trusts
Caseload	Low-complexity	Low-complexity
		Complex
		Neonatal surgical
		Rare conditions
Number of providers	131	22

Specialist trusts have been defined as trusts providing neonatal surgery.

Low volume trusts

The elective caseload in the 71 lowest volume trusts was insufficient to allow meaningful individual measurement of outcomes. In order to review data for low volume providers, we pooled data for all low volume providers and compared the pooled data to higher volume providers.

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[7] *see https://gettingitrightfirsttime.co.uk/what-we-do/*

Deep dive visits

We carried out deep dive visits to 89 trusts – all the specialist trusts (22) and 67 of the non-specialist trusts. Ahead of each visit we provided a report with data on the trust's outcomes and performance. These reports provided the basis for our discussions.

During visits we met frontline clinicians, nurses, administrative and finance staff, and managers. The clinicians included surgeons, anaesthetists, neonatologists, intensivists, paediatricians and radiologists – reflecting the broad range of clinical staff involved in providing surgical care for children.

We saw numerous examples of excellent outcomes and practices being delivered by dedicated and committed staff in the context of difficult circumstances. However, we also found evidence of unwarranted variation in service provision and outcome.

We have used the qualitative information gathered during our visits to inform our key themes and findings.

Challenges in reviewing patient experience

We were not able to review variation in patient experience because there is no routinely collected and benchmarked measure of patient experience specifically for children in hospital. This deficit is the subject of one of our recommendations.

Stakeholder consultation

This report has been informed by feedback we have collected from stakeholders. As part of our consultation, we have liaised with NHS England and NHS Improvement on the outcomes of their review of paediatric critical care and specialised surgery in children.[8]

Photo courtesy of Sheffield Children's Hospital

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[8] *NHS England and NHS Improvement (2019) Paediatric critical care and surgery in children review: Summary report https://www.england.nhs.uk/publication/paediatric-critical-care-and-surgery-in-children-review-summary-report/*

Part 1: Today's delivery model

The report is divided into two parts. During our visits and in the writing of this report, we realised that addressing the challenges faced in paediatric surgery will involve a combination of change to current systems, as well as focusing on local delivery. Alone, neither approach will be likely to change outcomes and experience of care for children. But by addressing the key challenges we have found during this review now, we can continue to improve life for children and the adults they will become.

Part 1 explores how the organisation of paediatric surgery has evolved organically and whether the current service model is able to meet the current and future needs of children and their families.

We look at the trends and pressures for specialist and non-specialist trusts in delivering complex and low-complexity paediatric surgery, and what impact these have.

Our first recommendation supports the development of a new model of care delivery that seeks to extend existing good practice, and enables a "coordinated approach to surgical services, enabling children and young people to access specialised and non-specialised services in times of urgent, emergency and planned need", a goal outlined in the NHS Long Term Plan.

We also suggest steps that can be taken to reduce mortality rates in necrotising enterocolitis (NEC), in line with the NHS Long Term Plan goal to reduce infant mortality.

Variation in volume and casemix in specialist and non-specialist trusts

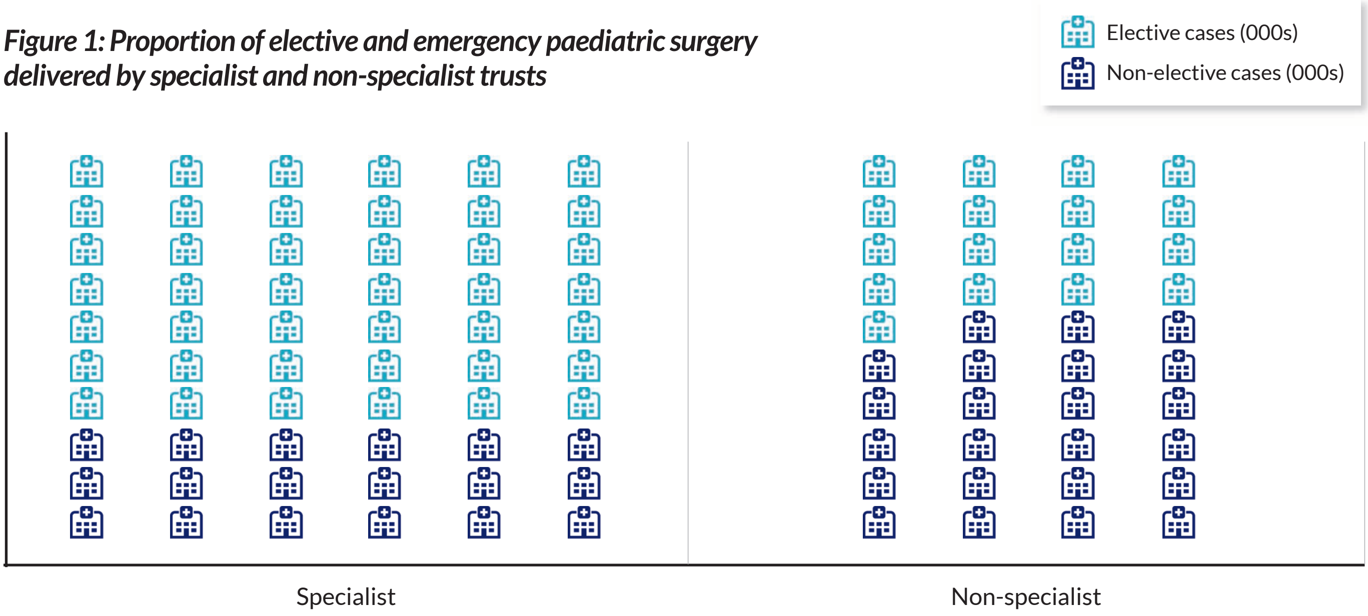
Rising surgery volumes in specialist trusts and falling volumes in non-specialist trusts

Increasingly, more paediatric surgery is taking place in specialist trusts, and less is taking place in non-specialist trusts, particularly in the case of elective surgery.

In a 2007 study,[10] Tanner found that the volume of surgery taking place in non-specialist trusts was falling. At that time most surgery, both elective and non-elective, took place in non-specialist trusts but today that is no longer the case.

Most surgery (59%) now takes place in specialist trusts (Figure 1). The shift has principally been in elective surgery (Figure 1), with 71% currently performed in specialist trusts; with one striking exception: over half of all non-elective (emergency) surgery is still delivered in non-specialist trusts.

Figure 1: Proportion of elective and emergency paediatric surgery delivered by specialist and non-specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

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[9] *see NHS long term plan, https://www.longtermplan.nhs.uk/*

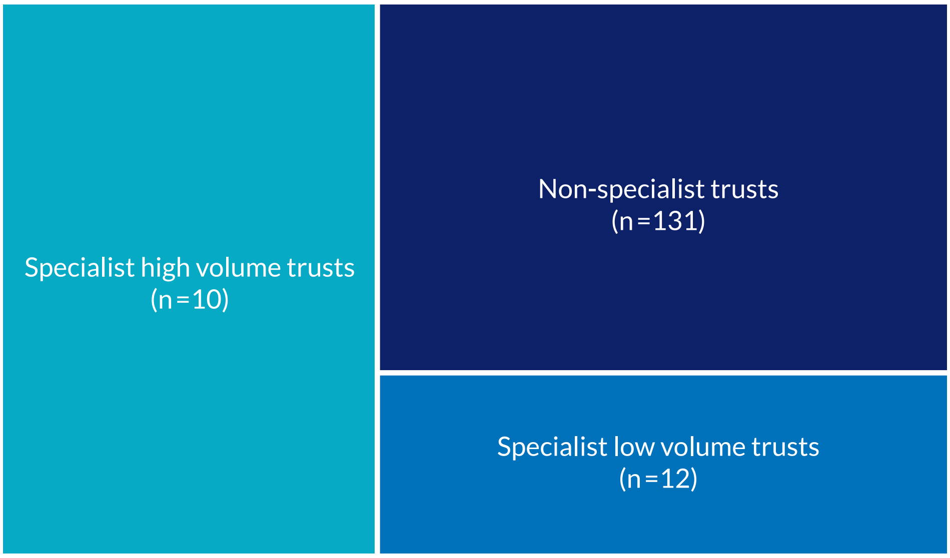
[10] *Tanner, S. (2007). Trends in children's surgery in England. Archives of Disease in Childhood, 92(8), pp.664–667*

We found that this shift is largely due to a growing perception within the adult general surgical community that paediatric surgery should be performed by paediatric surgeons in specialist paediatric trusts.

Variation in volumes of surgery between trusts

Looking more closely at the data reveals under 50% of specialist trusts are taking on 59% of all paediatric cases.

Figure 2: Total proportions of elective and emergency operations performed by specialist high and low volume trusts, and non-specialist trusts.



The size of the box maps to total number of operations.

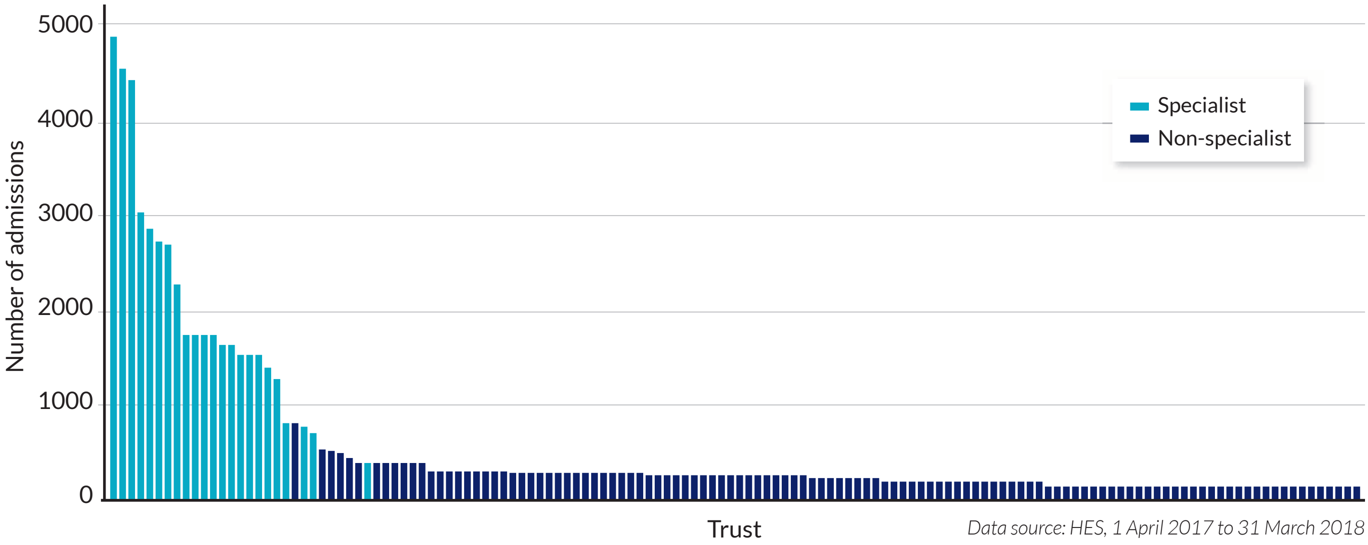
Data source: HES, 1 April 2017 to 31 March 2018.

Although 59% of all paediatric surgical episodes take place in specialist trusts, there is wide variation between high and low volume specialist trusts. As few as 10 specialist trusts are responsible for 38% of all episodes (Figure 2).

Looking at the spread of elective activity (Figure 3), the volume of activity taking place in some specialist trusts is very low. In 2018, the busiest specialist trust treated 4,903 children, in comparison with one specialist trust which treated just 368 children – evidencing this marked disparity in volume.

We can also see that some non-specialist trusts treated as many or more children than the specialist trusts treating the smallest volumes of cases.

Figure 3: Volumes of elective paediatric surgery in specialist and non-specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

A key cause for the variation in volumes being delivered by specialist paediatric surgical trust services is organic development as a result of a lack of centralised planning.

At trust level, developing a paediatric surgery service has often been seen as essential to providing specialist medical paediatric services, such as oncology. Such developments have not always been accompanied by a wider analysis of the population requirements.

Birth rates have been falling since 2012, and total fertility rates are the lowest they have ever been.[11] There are, however, significant regional differences in fertility rates reflecting socioeconomic changes, particularly in south-east, compared to the rest of the country.

Conversations during deep dives showed that although there is some awareness of this issue, there isn't wider regional planning to 'future proof' services to allow for the changing demographic and population needs. This issue affects all paediatric services, that may need to rapidly adapt to population shifts due to construction of new towns, transport links, and movement of people of child-bearing age.

We also repeatedly heard that smaller volume trusts are by-passed in favour of larger volume trusts outside the geographic area because paediatricians feel the larger volume trusts are more suitably equipped with the expertise to deal with certain conditions.

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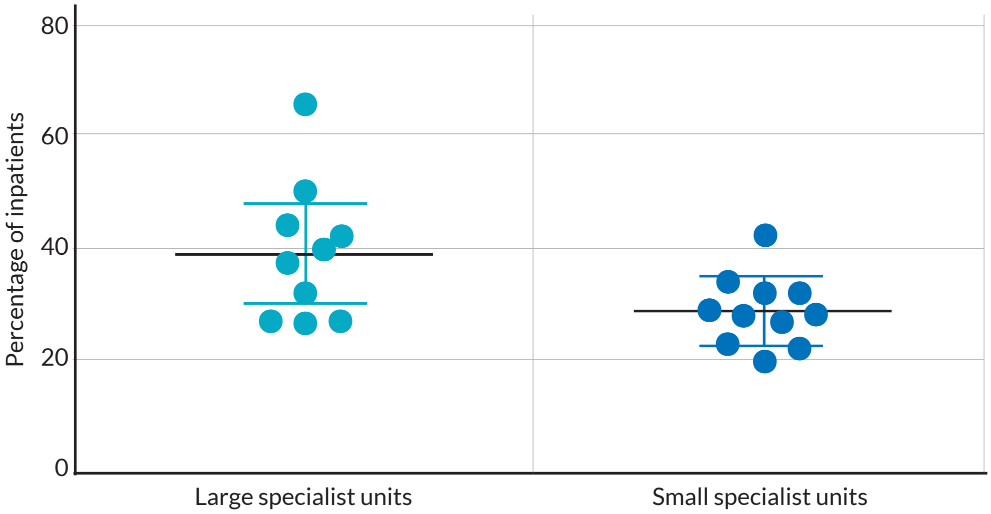
[11] *See births in England and Wales: 2018, https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2018*

Impact of variation in specialist trust volumes

We have found productivity is 25% lower in smaller volume specialist trusts than larger specialist trusts (Figure 4). This has had a 'domino effect' on the ability of trusts to build and maintain the infrastructure and workforce needed to provide a high-quality, cost-effective, child-friendly service (see Environment of care, page 111).

Figure 4: Total inpatient (elective and non-elective) activity delivered per consultant programmed activity (PA) by trust size (10 largest by volume versus 11 smallest by volume)



Error bars = SD

Data source: HES and PA data returned by trusts on GIRFT questionnaire. All specialist trusts returned PA data.

Note: Figures do not include activity at spokes as this data is not captured. However, most trusts have similar spoke arrangements, meaning any effect would be consistent across all trusts.

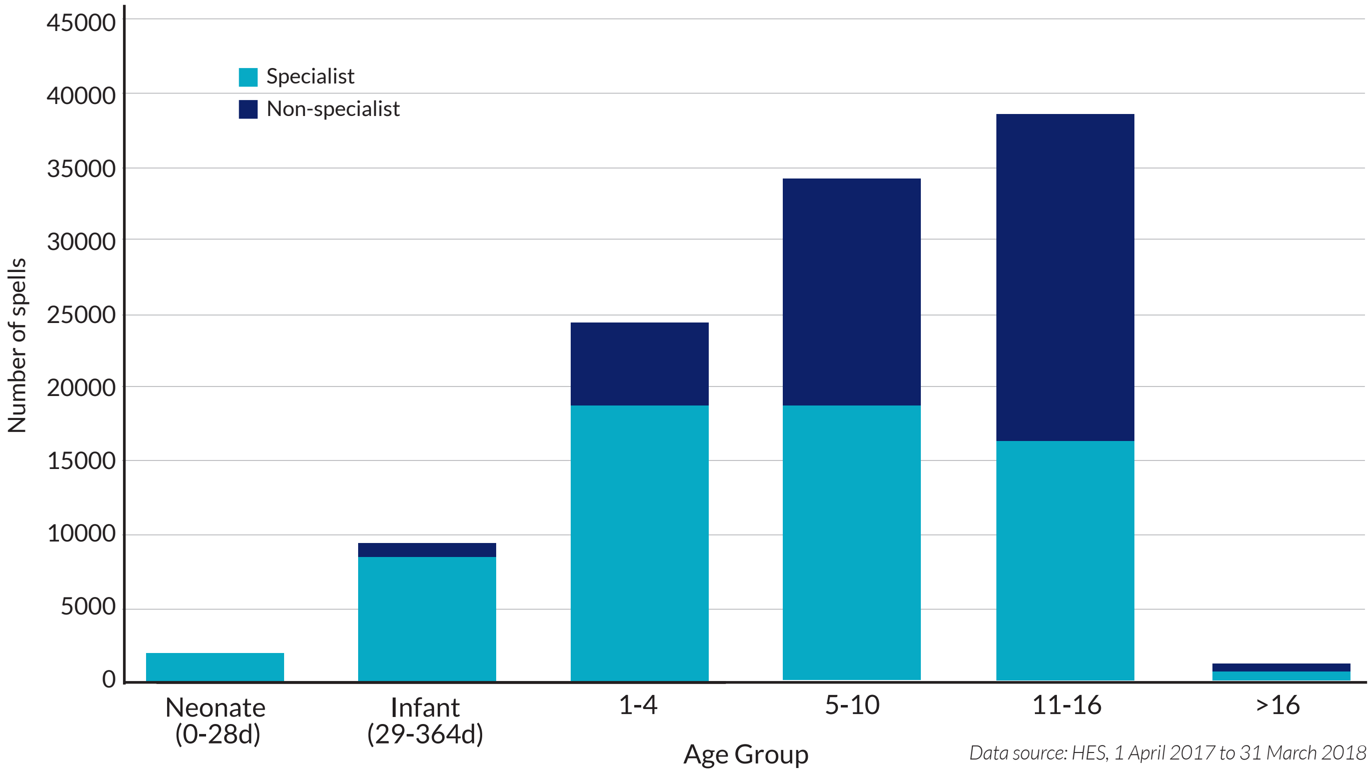
Variation in casemix (age groups)

We found wide variation in the proportion of age groups seen by specialist and non-specialist trusts. Most infants are being appropriately treated in specialist trusts (Figure 5). (In this report, 'infant' will be used to mean children from zero to one year of age. The term 'under five' will mean this group in addition to children up to the age of four.)

All neonates and almost all infants requiring surgery are treated in specialist trusts (see Figure 5). This is because they require specialist anaesthetic, surgical and nursing expertise and specialist facilities. However, when we look at the volumes for infants, we can see that approximately 500 infants per year are treated by non-specialist trusts, which is a very small number across the number of non-specialist trusts. With such low volumes, it is inevitable that non-specialist trusts find it difficult to meet their specific needs.

By contrast, the proportion of the paediatric surgical caseload treated by non-specialist trusts increases with patient age, rising to 58% of cases in the 11 to 16 age bracket. It is appropriate for children in this age group to be treated in non-specialist trusts, with the support of specialist surgeons and trusts, so this percentage could be lowered.

Figure 5: Paediatric surgery episodes by age group



Data source: HES, 1 April 2017 to 31 March 2018

A small number of young adults (over 16 years of age) continue to be cared for by paediatric surgeons. These patients are treated almost equally by specialist and non-specialist trusts. This is typically because of the nature of their underlying disease or associated problems and is consistent with the NHS Long Term Plan, which states:

"By 2028, we aim to move towards service models for young people that offer person-centred and age-appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need."[12]

Infants, for example, have very different needs to children over ten and, as such, a wide casemix in terms of age requires a trust to have necessary infrastructure to support all age groups.

Conclusions

There has been a trend towards specialist trusts delivering the majority of elective paediatric surgery, with non-specialist hospitals still delivering most of emergency care. There is also an imbalance, with just ten high-volume specialist trusts taking on over a third of paediatric surgical episodes. This indicates that the organisation of paediatric surgery has evolved organically, with a concern as to whether the delivery of care is able to meet the current and future needs of children and their families.

To further understand the current model of care delivery we look separately at how low complexity care and complex care are delivered.

Although we look at these separately, they are not isolated issues and have key challenge and opportunities in common.

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[12] *https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/, page 55*

The impact of variation in delivery of low-complexity care

We looked at how low-complexity paediatric surgery is delivered across the country and what this means for the patient and the challenges faced by the trusts.

Current delivery models

There is wide variation in how low-complexity general paediatric surgery is delivered, whether elective or emergency, across the country:

Elective low-complexity surgery is delivered in the following ways:

1. **Centralised:** child and family travel to the **specialist trust** for clinic and surgery.
2. **Hub and spoke (network):** specialist paediatric surgeon travels to non-specialist 'spoke' trusts to deliver clinic and surgery locally. One of the key reasons that non-specialist trusts gave for establishing network delivery models was the difficulty they found in recruiting surgeons with the required expertise to replace retiring adult general surgeons with paediatric surgical skills.
3. **Local care:** general surgeon or urologist with paediatric interest delivers clinics and surgery locally. This may or may not be augmented with specialist paediatric surgery clinics.

Emergency low-complexity surgery is delivered in the following ways:

1. **Local: non-specialist trust:** In most areas, emergency care for children with conditions such as appendicitis and testicular torsion is provided by the local non-specialist trust.
2. **Urban: specialist trust:** In urban areas, when the specialist trust has an emergency department, emergency care is generally centred within those specialist trusts.

Key impacts of current delivery models

We have found the organic evolution of the delivery of low-complexity care as outlined above has resulted in geographical inequality and unwarranted variation in the care provided.

Key impacts to the patient are felt in the ability to provide:

- emergency care;
- care close to home;
- coordinated care.

As shown in Figure 1, the majority of emergency care is taking place in in non-specialist trusts. When we look at Figure 6 in comparison to Figure 3, we can see the marked difference between non specialist trusts undertaking emergency surgery compared to elective surgery.

Care close to home

Being able to access care close to home reduces the financial, emotional and physical impact on both the child and their family. At its best, it means parents can look after the whole family, take other children to school, and minimise work disruption.

In large urban centres with short travel times and good public transport, it is effective to deliver care solely through specialist trusts. This is less achievable in large areas of rural England where the distances are greater and using public transport is more challenging. Furthermore, travel costs and time have a disproportionate effect on low income families.

Coordinated care

Surgical procedures are only part of what may be a lifetime of care and follow-up for a child. Complex care often leads to ongoing, wide-ranging care needs, and these may need to be delivered through:

- a multidisciplinary team, both at the specialist trust and at the child's local hospital;
- other support services, such as local paediatric continence, child development, social work and educational teams.

Ensuring joined-up care for children with specialist conditions requires effective communication between specialist trusts, non-specialist trusts, and local paediatric and community teams. For example, local services need to understand specialist management plans, while specialist trusts need to be able to liaise with school nurses.

We examined the relationship between specialist trusts and non-specialist trusts and found variation in how care was integrated between regions. Often lines of responsibility and 'ownership of patients' were blurred between treatment in non-specialist trusts and in specialist trusts.

We found that the most effective models of care were where there were supportive formal and informal networks of care. Specialist surgical outreach clinics allow discussions on plans of care between specialists and local care services to occur. In addition, many diagnostic investigations can be delivered locally. Perhaps most importantly, lines of communication are established between trusts to allow effective delivery of care in the correct environment.

Transitional care for adolescents with long term surgical conditions is another important consideration here. However, this is outside the scope of this review.

The challenges to the trust of addressing these impacts are:

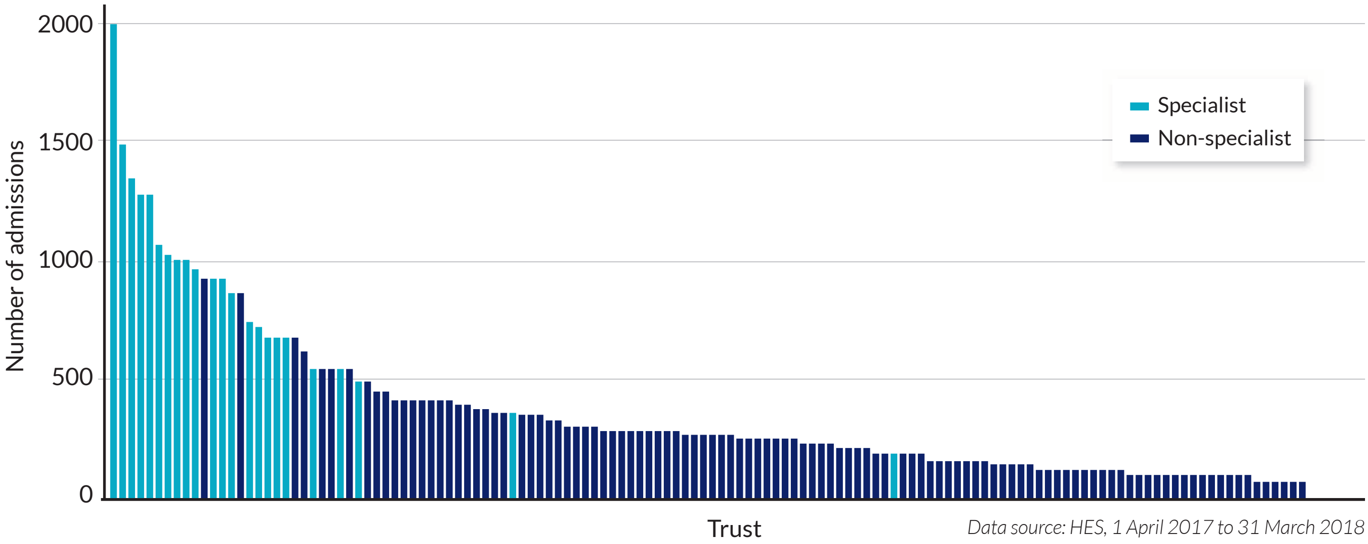
- workforce and expertise;
- lack of policy on transfer of children;
- capacity of specialised trusts.

Emergency care

We have found the current models of delivery are having an impact on the delivery of emergency paediatric surgical care. Most emergency cases are children with appendicitis, testicular torsion, or soft tissue infections.

As shown in Figure 1, the majority of emergency care is taking place in in non-specialist trusts. When we look at Figure 6 in comparison to Figure 3, we can see the marked difference between non specialist trusts undertaking emergency surgery compared to elective surgery.

Figure 6: Volumes of emergency paediatric surgery in specialist and non-specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

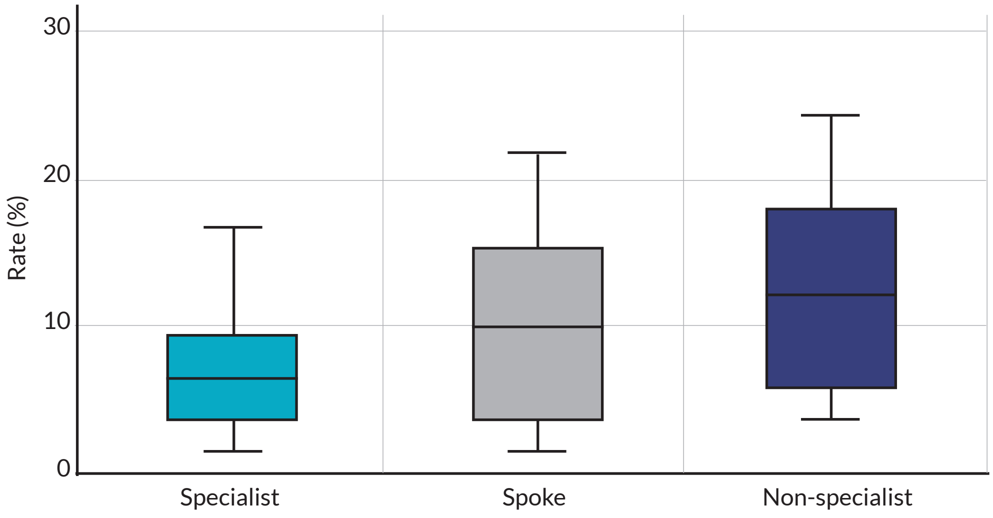
We found variation in the outcomes of emergency general and urology paediatric surgery between the different models of care that have evolved. Most emergency paediatric surgery involves the surgical assessment and treatment of children with abdominal pain or emergency scrotal exploration in boys.

Example: Negative appendicectomy rates

To highlight the impact on clinical outcomes, we looked at variation in negative appendicectomy rates (NAR) between specialist trusts, non-specialists trusts and hub and spoke models. Figure 7 shows there is a higher rate of NAR in non-specialist trusts, while specialist trusts have a lower rate of NAR than both hub and spoke model and non-specialist trusts.

In a negative appendicectomy the appendix is removed for suspected appendicitis but is subsequently found to be normal. We found that NAR is significantly higher in non-specialist trusts than in specialist trusts. The reasons for this are complex and involve access to imaging, as well as surgical decision-making. We have seen that while there is no difference in the quality of surgery delivered by specialist paediatric surgeons and general surgeons doing appendectomy, there are differences between the decisions they make about surgery. Appendicectomy is discussed in more detail later in this report.

Figure 7: Negative appendicectomy rate by service delivery model



Box: 25-75th centile
whiskers: 5-95th cetile
Kruskal-Wallis test centile line: median

Source: HES Apr 17 to Mar 18

Key challenges

As a result of the current service delivery model, we have identified the following key challenges for trusts delivering non-complex care:

Workforce and expertise

The key risk of the reduction in volumes of elective paediatric surgery and anaesthesia in non-specialist trust is the reduced exposure to paediatric anaesthesia and surgery.

We found as a result of lower volumes there was less investment and opportunity for continuous professional development.

There is also generally a lack of emphasis on training in paediatric emergency and elective surgery in the general surgical curriculum, with similar issues in anaesthesia.

This is concerning when general surgeons are still required to deliver emergency surgery.

We found significant variation in the confidence non-specialist trusts had in their ability to deal with paediatric emergency surgery, which has led to delays in treatment due to the requirement for transfer to specialist services.

However, there are mitigating examples of good practice where senior management have clear sight of the risks. In these cases, there were appropriate policies in place, with paediatric surgeons embedded in the life of the hospital and involved in advice and support for both elective and emergency care. Examples include:

- In departments facing the retirement of general surgeons with paediatric experience, surgeons were being supported by the trust to work with specialist trusts to gain appropriate experience.
- Care for children with surgical problems was shared between adult general surgeons and the paediatrician. This means that children are benefitting from the oversight of a physician trained in the care of sick children in addition to general surgical input. The involvement of paediatricians was widely welcomed by surgeons.
- Parallel clinics run by specialist paediatric surgeons and non-specialists to provide advice and support.

In many trusts, paediatricians were involved in:

- initial assessment of children with abdominal pain;
- resuscitation and fluid management;
- safeguarding;
- management of associated medical conditions.

In some areas where a hub and spoke model had been adopted, we found variable levels of interaction between the visiting paediatric surgeon and adult surgical colleagues. Too often, both adult surgeons and visiting paediatric surgeons told us they had never met. Where effective communication between adult and visiting paediatric surgeons is not taking place, there is a missed opportunity for supporting local delivery of surgery. Adult surgeons might be enabled to deliver more, and better, care where the support from specialist colleagues is available and used.

In addition, reduced volumes of paediatric elective surgery in non-specialist trusts have led to reduced investment and focus on support services, such as paediatric radiology. This has then led to reduced capability, increasing the need for transfer to specialist trusts. This becomes cyclical, with low investment resulting in fewer cases being seen, in turn resulting in lower investment.

Lack of policy on transfer of children

We found a general lack of clarity and written guidance on which children should be transferred for specialist care. In acute cases, decisions are generally appropriately made by clinicians assessing the capabilities of the on-call team. Where possible, the on-call expertise is supplemented by off-duty colleagues, which shows great commitment. However, it was clear that in most trusts the decision to transfer was dependent on the skill mix of the team rather than trusts ensuring that all team members were competent to a minimum age.

Children who are being unnecessarily transferred to specialist trusts are therefore experiencing delays. Delays in treatment cause distress to children and their families, and may increase the risk of adverse outcomes including death.[13]

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[13] *Are we there yet? A review of organisational and clinical aspects of children's surgery. In: p 55, National Confidential Enquiry Into Perioperative Death, editor. London2011 https://www.ncepod.org.uk/2011sic.html*

However, we repeatedly heard that issues over responsibility of care are left unresolved. Out of hours, this leaves clinicians in difficult positions and leads to avoidable delays in the delivery of time-critical care. The most contentious issues were around surgical responsibility for boys with acute testicular pain, which is discussed in greater detail later in this report.

Capacity of specialist trusts

We heard that specialist trusts can find it challenging to balance the contrasting requirements of providing emergency and elective care.

In 2011, the Royal College of Surgeons of England (RCSE) published Standards for Emergency Surgery (SES).[14] The standards require all trusts to:

- prioritise acutely ill patients over elective activity;
- provide a consultant-led service with timely senior decision-making.

Since general paediatric surgery includes a large emergency workload, meeting the standards means trusts must have:

- at least one consultant surgeon free of elective commitments and nominated as the emergency duty surgical consultant at any time;
- an emergency theatre and team available 24 hours a day to avoid unnecessary delays in scheduling of emergency surgery;
- an escalation plan in place should emergency theatre capacity be overwhelmed.

The most effective trusts arrange their workload around the SES standards and run dedicated emergency surgical consultant rotas where staff are free of elective commitments. However, the size of the paediatric surgical workforce in specialist trusts, which varies from four to 15 members of staff (whole time equivalents) according to trust size, has a negative impact on their ability to manage these standards.

Often, smaller specialist trusts find it much harder to balance emergency and elective care than larger specialist trusts. Having fewer staff means they face a greater impact and risk to service continuity due to staff illness or absence. Surgeons reported an increasing out-of-hours workload that had the potential to impact on elective activity the following day.

We heard of cases where neonates had been transferred because of a lack of capacity. There were also reports of difficulties in staffing junior on-call rotas in smaller trusts.

In addition, several smaller specialist trusts do not have daytime emergency lists, leading to delays in treatment and increased ward care costs.

Conclusions: delivery of low-complexity care

The delivery of low-complexity care has evolved organically, with differences in how low-complexity elective and emergency surgery is delivered across specialist and non-specialist trusts.

This is having a series of effects:

- the capacity of specialist trusts is being stretched since they are having to deliver increasing volumes of low-complexity care;
- reduced elective activity in non-specialist trusts is significantly limiting their ability to grow and develop local services to manage urgent, emergency and planned needs of the local child population;
- children and families are having to travel further and wait longer for treatment that should be offered locally.

The time-sensitive nature of emergency surgery plus lack of specialist trust capacity means that non-specialist trusts are best placed to provide emergency care, but with the support of the specialist centre. This should follow network-agreed, evidence-based care pathways to ensure uniformity of provision. However, there is currently no robust regional model for delivering low-complexity paediatric surgical care. We now need a formulised model to cement these pathways, and ensure a system of support for non-specialist trusts.

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[14] *England RCoSo. Emergency Surgery. Standards for unscheduled surgical care. Guidance for providers, commissioners and service planners. Southampton: Royal College of Surgeons of England; 2011.*

In our first recommendation we outline an approach to a new model of care delivery. This approach is needed to reduce inequality across the country and provide treatment in the right place, in good time. This will be achieved by:

- formalising pathways across healthcare settings and ensuring that effective delivery of emergency surgery is intrinsic to the future model of care;
- reducing variation in the standard of care between trusts;
- building effective networking between specialist and non-specialist trusts, with IT systems allowing visibility of a child's healthcare record between trusts;
- establishing clear governance systems and policies;
- establishing key performance indicators (KPIs) to monitor and drive improvements in quality of care;
- carrying out workforce planning, including:
  - making more effective use of in-house resources, such as joint working between paediatricians, radiologists and surgeons;
  - increasing training exposure for general surgeons;
  - linking up visiting paediatric surgeons with local paediatric and surgical teams;
  - maintaining paediatric anaesthetic expertise in non-specialist trusts.

CASE STUDY

Anaesthetists and surgeons create networks of support

Devon and Cornwall peninsula

An excellent example is in the South West, in which the geography of the Devon and Cornwall peninsula has led to trusts clearly identifying provision of children's surgery and anaesthesia as a priority. Over the last ten years, anaesthetists and surgeons have created networks that provide support, standards and governance in the region with the support of clinicians from Bristol Royal Hospital for Children. In discussions with all parties the GIRFT team found that these networks were real and useful and founded on mutual respect. In addition, all trusts were aware of the need to have adult general surgeons with a specialist interest in paediatric surgery and were prepared to send newly appointed consultant general surgeons to Bristol Royal Hospital for Children to receive further training prior to taking up their post if required. This network is being formalised in 2020 as the Surgery in Children Operational Delivery Network.

Variation in the delivery of complex care

We found that the surgical care of infants and under-fives with the rarest and more complex surgical conditions is being carried out in 22 hospitals across England, several of which are only a few miles apart, spreading expertise too thinly and necessitating the transfer of patients to these centres.

Spread of index cases: impact

We looked at how complex paediatric surgery is delivered across the country and found the surgical care of neonates, infants and children with the rarest and more complex surgical conditions is being carried out in the 22 specialist trusts across England. We found there were two main challenges:

1. The more complex and rarest index conditions are being carried out in too many specialist trusts, several of which are only a few miles apart, which is resulting in:

- variation in the availability of critical co-dependencies;
- reduced individual surgeon and team experience;
- reduced scope for innovation and research;
- reduced training opportunities.

2. Pre-term babies are not always receiving timely and necessary surgical assessment, or appropriate preventative measures, which is resulting in high mortality rates.

We discuss six separate index conditions (including necrotising entercolitis) to provide more context to the above challenges.

Importance of co-location of critical services

Delivering complex paediatric care requires the expertise of a wide range of specialist services, of which paediatric surgery/urology is just one. For example:

- babies born with congenital heart disease frequently have other birth defects requiring surgical correction or medical treatment from a range of specialties;
- babies born with neural tube defects (spina bifida) require treatment and monitoring by neurosurgeons, orthopaedic surgeons, paediatric surgeons and paediatric urologists;
- children with cancer require care from numerous specialties in addition to oncologists – surgical interventions may require collaboration between surgical specialties including paediatric surgery/urology, cardiothoracic surgery, neurosurgery, ENT, orthopaedics and plastics, clinical radiologists and interventional radiologists. In addition, children who have had specialised surgical procedures may develop complications that need specialist surgical assessment and management.

Co-locating these services offers several benefits, including:

- the benefits of multidisciplinary working in making the right choices;
- synergies and additive capability – the wider the range of services a trust has, the broader its capabilities can become;
- economies of scale in procuring and running intensive care services, such as extracorporeal membrane oxygenation;
- improved cost effectiveness of high value capital equipment, such as MRI scanners;
- the ability to meet surgical interdependencies in trauma services.

Lack of co-location leads to:

- disjointed care for children with complex needs;
- care being delivered by surgical and anaesthetic teams with less experience;
- children being transferred between sites;
- inefficiencies in the duplication of staffing and equipment resources.

The issues around co-location have been previously addressed[15] in the Commissioning Safe and Sustainable Specialised Paediatric Services report of 2008, and emphasise the complexity of interrelated services in designing children's specialist services. It identifies four core services which are the basic requirement for specialised children's services as:

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[15] *Health Do. Commissioning Safe and Sustainable Specialised Paediatric Services. In: Health Do, editor. 2008*

- paediatric critical care;
- specialised paediatric anaesthesia;
- ear, nose and throat (ENT);
- paediatric surgery.

However, from our visits we have learned that the findings from this earlier report have not, to date, been followed through. We can see this in the case of Paediatric Critical Care units (PCCUs).

Paediatric Critical Care units (PCCUs)

When we looked at paediatric critical care, we found that there was variation in access to PCCUs among specialist trusts, which brought challenges such as those trusts not taking certain elective cases, and transfer of children away from those trusts. PCCUs provide support for children with multi-organ failure due to disease or surgical procedure.

These children may need surgeons to support life-saving procedures, such as vascular access, chest drainage, laparostomy /laparotomy, thoracotomy and peritoneal dialysis catheter placement.

Service provision

PCCUs are stratified according to the level of care they can deliver (Table 2).[16]

Table 2: Paediatric critical care units (PCCUs) levels

PCCU level	Location	Activity	Commissioning body
Level 1	All hospitals providing in-patient care to children	Non-specialised	Non-specialised
Level 2 (formerly classified as high dependency units)	Tertiary hospitals and a limited number of general hospitals	Specialised or non-specialised	NHS England and NHS Improvement
Level 3	Tertiary centres or specialist hospitals	Advanced respiratory and organ support, including high frequency oscillatory ventilation (HFOV), inhaled nitric oxide (iNO) therapy and haemofiltration. Some have a respiratory extra corporeal membrane oxygenation (ECMO) service.	NHS England and NHS Improvement

Variation in access

Four specialist trusts stated that they did not have access to a level 3 PCCU.

This resulted in:

- emergency cases being transferred out of the catchment area of the specialist trust;
- trusts restricting the elective cases they would consider, leading to out-of-area transfers;
- children being managed on high dependency units, with the risk of requiring a transfer to PCCU at some point.

Six specialist trusts stated that they were unable to offer haemofiltration (a form of renal dialysis, mainly used in a critical care setting, which removes waste products from the blood and returning it, cleaned, to the body[17]) for children requiring renal support. Again, this results in transfers to other specialist trusts.

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[16] *Service Specification - Level 3 Paediatric Critical Care (PCC). In: England N, editor. London 2019*

[17] *See NHS Data Dictionary online at https://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/h/haemofiltration_de.asp?shownav=1*

Other critical co-located services

Beyond the four ‘core’ services, we looked at the benefits of co-locating the following services:

- cardiac, trauma and neurosurgery services;
- maternity;
- radiology;
- palliative care;
- transitional care;
- neonatal services.

We looked at the current level of co-location of these services, and how co-location of these services can benefit children and their families.

Co-location of cardiac, trauma and neurosurgery services

The co-location of paediatric surgery with cardiac, trauma, urology and neurosurgery services allows coordinated care to be delivered more effectively. This is because the teams are frequently involved in shared care and means that paediatric intensive care and anaesthetic resources can be efficiently utilised.

We found a mixed picture of co-location of cardiac, trauma and neurosurgery service across the 22 specialist trusts (Table 3). Five trusts have no co-located services at all. This limits the service that the surgical teams in these sites can provide, meaning that the experience for the child and family is poor. Fragmented care can also lead to failures in communication between teams. From a cost perspective, there is an efficiency cost from poor resource utilisation and reduced productivity.

The situation is particularly poor in London where none of the seven specialist trusts have co-located paediatric surgery, trauma, neurosurgery and cardiac services.

Table 3: Co-location of specialist paediatric trauma, cardiac and neurosurgical services in specialist paediatric trusts

Paediatric Service				Number of specialist trusts
General	Cardiology	Neurosurgery	Trauma	
✓	✓	✓	✓	5
✓		✓	✓	7
✓			✓	2
✓				5
✓	✓	✓		1
✓	✓			1
✓			✓	1
			✓	1

Data source: GIRFT questionnaires and NHS England and NHS Improvement Major Trauma Network

We looked at each of the services in more detail.

Cardiac surgical centres

There are ten paediatric cardiac surgical centres that perform cardiac surgery on neonates. Many of these neonates have or develop conditions that require paediatric surgical input.

Seven of these paediatric cardiac centres are physically co-located with paediatric surgical specialist centres. Outreach services exist for the other three.

The seven co-located centres generally treat the most complex neonatal surgical cases, such as multiple congenital malformations, including cardiac, thoracic, gastrointestinal, urological, musculoskeletal, neurological and chromosomal. Neonates with these complex needs are channelled towards these centres.

In addition, these centres are equipped with the capability to deliver extra corporeal membrane oxygenation (ECMO) (the use of an artificial lung located outside the body that puts oxygen into the blood and continuously pumps this blood into and around the body)[18]. This is usually deployed in children in support of paediatric cardiac surgical procedures, but several centres have been designated as regional respiratory ECMO centres. On occasion, infants and children with non-cardiac conditions requiring paediatric surgery may require ECMO. It makes sense to ensure that such surgical procedures are performed in centres with the ECMO capability.

Trauma

The role of critical surgical interdependencies in the delivery of care in children's trauma was recognised as part of the commissioning of major trauma centres in 2012, with 11 critical co-dependencies being listed. Many of these interdependencies also hold true for complex cardiac, neurosurgical and paediatric surgical cases.

Neurosurgery

Paediatric neurosurgery incorporates surgical treatment of children with brain and spinal conditions or injury. Around 70% of the 4,200 children treated per year have problems associated with trauma, the others have tumours, hydrocephalus or vascular problems. Many of these latter conditions are rare and children often require care from many other specialties including paediatric surgery.

There is a strong case for mirroring the commissioning arrangements for major trauma centres in commissioning specialised paediatric and neonatal surgical services. The existing (draft) guidance places emphasis on the minimum co-located services that are required. Future commissioning standards should have clarity on what co-located services are required to achieve a holistic approach to the child and delivery of world-class children's surgical care overall.

Co-location of maternity services

The 2013/14 draft specialised commissioning documents specified co-location of maternity and specialised paediatric surgery services. Such co-location may allow mother and baby to remain together in the peri-partum period and avoid the need for neonatal transfer. However, three of the largest paediatric surgery trusts - who treat the largest number of infants - do not have co-located maternity and paediatric surgery services. There is a gap in evidence as to whether co-location improves outcomes, but service design should take this into account when planning services.

Co-location of radiology services

A 24-hour radiology service is essential in providing diagnostic and therapeutic support to paediatric services.

During our visits we found that some specialist trusts had significant gaps in the availability of paediatric radiologists. This meant there was no out-of-hours cover, resulting in children being transferred to other specialist trusts.

Such arrangements mean there are inevitable delays in treatment as well as greater inconvenience to families who must travel further.

Example: reduction of intussusception

Intussusception is mainly treated by radiologists. Intussusception is a condition where the bowel 'telescopes' in on itself. This causes the bowel walls to press on one another, blocking the bowel.

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[18] *see Extracorporeal Membrane Oxygenation, https://www.gosh.nhs.uk/conditions-and-treatments/procedures-and-treatments/extracorporeal-membrane-oxygenation-ecmo*

We identified that one specialist trust (Hospital A) with a shortage of paediatric radiologists treated only ten children a year. Its neighbouring specialist trust (Hospital B) treated 45.

When we mapped the source of these children, we found that significant numbers were either being treated or transferred from the normal referral area of Hospital A to Hospital B.

Responsiveness to in-patient requests

Another important consideration when considering radiology services is their responsiveness to in-patient requests. Delays in investigations, such as ultrasounds, computerised tomography (CT), or Magnetic Resonance Imaging (MRI) scanning, provide a poor experience for children and their families. They are also a drain on NHS finances.

Some of the variation in time from admission to surgery that we found was likely due to a lack of radiology services.

Impact of trust size and co-location

We found that appropriate radiology services were more readily available in the larger specialist trusts with larger radiology departments.

Furthermore, we found that co-location with paediatric cardiac, neurosurgical and orthopaedic services improved the availability of sufficient radiological capacity.

Current data limitations

Ideally, we would assess variation in the use of radiological investigations for paediatric surgical conditions. This would enable us to assess variation in responsiveness and in the use of diagnostic investigations of no proven benefit. An example of this is the use of ultrasound in the diagnosis and assessment of impalpable testes.

There is currently no link between the coded diagnosis, procedural data (Hospital Episode Statistics) and radiology databases. This means that, although we heard anecdotal evidence of variation in the availability and use of radiology, it was not possible to produce data on this.

Co-location of palliative care

Palliative care is a critical interdependent service.[19] Not all conditions are curable, and the aim is to ensure that children with life-limiting disease have a 'good' death. Providing the right level of expertise and support for these children is essential. Recent high profile end-of-life cases in children highlight the importance of trusts and clinicians working with families whose children are nearing end of life. Palliative care services play a key role in this. Therefore, we were greatly concerned to find that nine specialist trusts reported having no formal paediatric palliative care service.

Co-location of transitional care

As they reach adulthood, children with complex needs and those with ongoing surgical issues must be safely transferred to clinicians in the adult care sector with the necessary expertise to provide ongoing care.

The principles of transition are outlined in NICE guideline NG43: 'Transition from children's to adults' services for young people using health or social care services'.[20] The NHS Long Term Plan for children and young people will specifically examine this.

Transitional care is beyond the scope of this report, and it is anticipated that the GIRFT programme will cover this aspect of children's surgical care in future visits to specialist trusts.

Co-location of neonatal services

Neonatal surgical specialist centres are commissioned by NHS England and NHS Improvement and follow a standard service specification.[21] This specification notes that major non-cardiac congenital malformations needing surgical correction are rare and requires that neonatal surgery and anaesthesia:

"… should only take place in designated neonatal surgical centres, within a managed network of care."

The specification also states that:

"Neonatal surgery services will be co-located with neonatal intensive care units (NICUs) providing complex level 3 care, specialist paediatrics, specialist children's surgery/anaesthesia, and maternity services."

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[19] *NHS Commissioning Board (2013) Standard Contract for Paediatric Medicine: Palliative Care.*

[20] *National Institute for Clinical Excellence (2016) Transition from children's to adults' services for young people using health or social care services.*

[21] *HM Government (2013) 2013/14 NHS Standard Contract for Paediatric Surgery: Neonates. p. 1-19.*

The specification sets out standards concerning these services and provides a framework for commissioning.

Variation in co-location of Neonatal Intensive Care units (NICUs) and neonatal surgery

Despite the service specification, a recent audit showed that 84% of babies require transfer to receive surgical care. Delays occur in 10% of transfers.[22]

We found that there is significant variation (see Figure 8) in the availability of paediatric surgical expertise to neonates in NICUs across England:

- 20 of the 47 NICUs do not have a co-located paediatric surgical centre – the most remote NICU is at Derriford, which is 119 miles (around two hours by road) from its nearest surgical centre. Therefore, babies in those level 3 units who develop surgical problems will require transfer.
- 19 of the 21 neonatal surgical centres incorporate a co-located NICU.

Arrangements for review, transfer and treatment for neonates with potential surgical pathology need to be robust, particularly in the 20 trusts that are not close to neonatal surgical services (see the section on Necrotising enterocolitis, page 55).

CASE STUDY

Surgical review for neonates

Bedfordshire Hospitals NHS Foundation Trust

Bedfordshire Hospitals NHS Foundation Trust has employed an adult general surgeon with a paediatric surgical interest who has spent a year in a paediatric surgical specialist trust. It now has a service in which that surgeon can provide clinical review for the neonates on the level 3 unit and participate in decisions around the need to transfer to a specialist surgical unit as clinically appropriate.

Photo courtesy of
Alder Hey Children's Hospital

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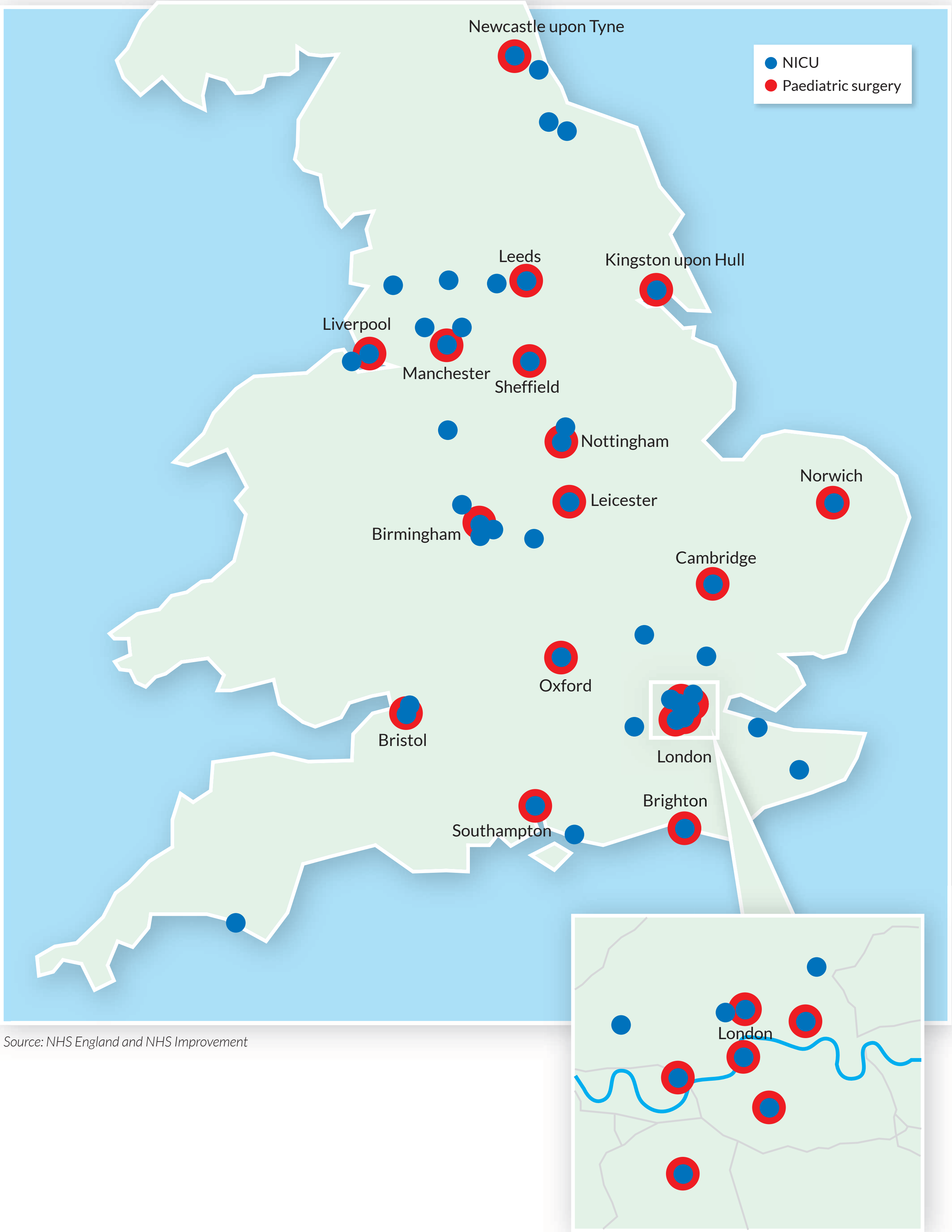
[22] *Mason DG, Wilkinson, K., Gough MJ, Lucas SB, Freeth H, Shotton H, et al. Are we there yet? A review of organizational and clinical aspects of children's surgery. In: Death NCEIPOa, editor. London: National Confidential Enquiry Into Patient Outcome and Death; 2011*

Figure 8: Map showing location of NICUs and paediatric surgical centres in England. (Inset shows London).



Source: NHS England and NHS Improvement

Integrating neonatal surgery into ODNs

During our deep dive visits, we found substantial variation in how neonatal Operational Delivery Networks (ODNs) integrate neonatal surgery. For example, surgeons in only a handful of centres told us that they attend ODN meetings.

Closer collaboration between neonatal surgeons, PCCUs, and ODNs will be essential to improving integration.

BadgerNet

BadgerNet is a platform for recording and sharing maternity data. Although it allows units to share data and clinical information when they transfer neonates to another unit, the operating record is not automatically visible.

As neonates move around neonatal networks this information should be available to all treating clinicians.

Other critical interdependencies

Paediatric surgical and urological services coexist with a wide range of interdependent services. These range from pharmacy and pathology services to clinical services such as clinical genetics, nephrology and gastroenterology. It was not possible to assess variation in access to and quality of these services as part of this GIRFT review. However, we note that larger children's units are more likely to deliver the full spectrum of interdependent services.

Benefits of co-locating workforce expertise

In addition to looking at the benefits of co-locating services, we look at co-locating workforce expertise. A lack of workforce expertise could lead to delayed and poorer care. We looked at:

- interventional radiologists;
- paediatric surgical nurse specialists.

Interventional radiologists

Interventional radiologists are key to being able to provide minimally invasive alternatives to surgery, such as:

- working as part of a comprehensive vascular access team;
- draining collections;
- carrying out biopsies of lesions;
- arresting haemorrhage by embolising bleeding points;
- treating vascular malformations;
- stenting airways;
- relieving organ obstruction, for example kidney or biliary obstruction.

Often these procedures need to be performed urgently out of hours.

There is a national shortage of interventional radiologists with a specific interest in paediatrics. This means children are having to undergo invasive treatments that could otherwise be performed using a minimally invasive alternative. Furthermore, only in the largest volume trusts is the centre-level workload sufficient to warrant employing the number of interventional radiologists needed to provide a full out-of-hours service.

Example: feeding tube placement

Many children with neurodisability require tube feeding to make sure they get adequate nutrition. This is mainly done through the stomach (percutaneous endoscopic gastrostomy (PEG)). However, some of the most severely affected children are unable to tolerate gastrostomy feeds. In these cases, interventional radiologists can pass a tube through the PEG into the small bowel (PEG-J) without requiring the child to undergo a further general anaesthetic.

In trusts without interventional radiology, children are undergoing insertion of surgically placed feeding jejunostomies or roux-en-Y jejunostomies. These are more complex and invasive procedures with attendant risks that put this vulnerable group of children through a painful procedure with no demonstrable improved outcome.

Potential initiatives to address the shortage of interventional radiologists

The Royal College of Radiologists (RCR) and the Royal College of Paediatrics and Child Health (RCPCH) recognised the challenges in provision of paediatric interventional radiology as long ago as 2010. Change appears to have been slow.

As well as increasing the numbers of radiologists, various solutions have been proposed. These include:

- Building links with adult interventional radiologists and supporting them in the delivery of a paediatric practice. Very often, children's hospitals struggle to provide out-of-hours interventional radiology services whilst adult hospitals in the same city have a full service. Clearly, covering two trusts carries risks in terms of prioritising care. Networks should put protocols in place to ensure that children are treated in the right place where they can access interventional radiology.
- Training surgeons and anaesthetists to perform some of the more straightforward interventional radiology procedures. For example, many surgeons and anaesthetists already use ultrasound guidance to place vascular access devices (for administration of drugs, nutrition and fluid) rather than traditional open surgical insertion techniques.
- Radiographers, with skills of advanced practice, who have completed the appropriate training are supporting delivery of interventional radiological procedures, including feeding tube placement, vascular access, draining collections and biopsies. This practice enables the capacity of interventional radiologists for those procedures that require their specific skill set.
- Increasing training in paediatric interventional radiology.

These initiatives offer considerable promise in reducing the number of unnecessarily invasive surgical procedures in children. To ensure that all regions in England have equitable access to paediatric interventional radiological services will require national and network level coordination.

Paediatric specialist nurses, advance nurse practitioners (ANPs) and nurse consultants

Paediatric specialist nurses, advanced nurse practitioners (ANPs) and nurse consultants establish long-term relationships with children and families and provide support and guidance to local care teams, particularly on continence issues.

We found considerable variation in the number of paediatric specialist nurses, advanced nurse practitioners and nurse consultants in surgery and urology employed by specialist trusts. Many smaller trusts had no nurse specialists at all, while larger trusts have large teams. In one large trust, urology nurses are carrying out over half of all urology out-patient consultations.

A mixed medical and nursing workforce offers much to strengthen paediatric surgical care. For example, we have seen the high quality outpatient care nursing colleagues can provide working as part of a surgical MDT, and the improvement in surgical throughput and outcomes this brings. We have also seen how the use of care pathways by nurse specialists can reduce local variation in care.

Coordination of care beyond the hospital

Care coordination should not just include other hospital-based services (as discussed on p30), but all healthcare services and health visitors, and interaction with family and school. Building an overall picture of a child's life will help all those involved in their care better understand their needs in terms of care delivery and ongoing support.

Conclusions

Co-location of services is variable across England, and co-location of 'core' services is particularly limited in London.

Co-location of services is vital for good quality of care for children, as it prevents delays to timely diagnosis and interventions, limits the need for transfers, and provides a better care experience for children and their families.

It is not just essential to have co-location of services, such as PCCUs and trauma units, but of workforces. Interventional radiologists can provide timely diagnosis and interventions, and have skills and expertise not readily available among surgery teams. Specialist paediatric surgical nurses provide a range of ongoing care for children and families, reducing the burden on surgeons, and potentially allowing earlier discharge.

Co-locating the right services and workforce will reduce the variation in care for children, and ensure that all children have the adequate level of care at all stages of their treatment.

Individual surgeon and team experience

It is generally accepted that there is a volume-outcome relationship in surgery: surgeons with higher volumes of a certain case have improved outcomes for that case. This relationship helps to determine the minimum levels of caseload needed to achieve competence.[23]

As well as the experience of individual surgeons, the overall volumes of patients treated by a hospital is also important – especially when considering the experience of the anaesthetists, nursing, and intensive care staff.[24] It is important to recognise that successful outcomes and the ability of children born with major congenital malformation to achieve their lifetime potential is also dependent on the experience and availability of all relevant clinicians and allied health professionals (AHPs). An example would be children born with multiple congenital malformations, for example children born with VACTERL association, who need input from many different clinicians and AHPs. Case volume is also crucial in securing appropriately resourced after-care and follow-up care pathways.

There is a conspicuous lack of research into the volume-outcome relationship for individual surgeon caseload in paediatric surgery. Exceptions are for pyloromyotomy for infantile hypertrophic pyloric stenosis (no evidence of volume-outcome relationship)[25] and hypospadias surgery (evidence of volume-outcome relationship).[26]

In adults, the evidence is particularly strong in colorectal cancer, breast cancer and bariatric surgery. The Association of Upper Gastrointestinal Surgeons (AUGIS) recommend that individual specialist surgeons undertaking oesophageal and gastric cancer resections should carry out a minimum of 15 to 20 resections per year, working within a trust comprising 6-8 surgeons.[27] The response to this was to centralise surgery into fewer high-volume trusts in England, resulting in improved outcomes for these conditions and emergency upper gastrointestinal surgery.[28]

Larger specialist trusts do high-impact research

We found that larger volume specialist trusts do more high-impact research.

To measure this, we mapped the impact of surgical research undertaken by each specialist trust against their case volumes. We used the sum of the h-index for publications authored by all members of a trust as a measure of the total impact of that trust's research. The h-index is a measure of the productivity and impact of publications based on how often publications are cited by other authors.

There is an overall relationship between trust-level h-index and the number of annual admissions (Figure 9). Two trusts with low volumes are exceptions to this general pattern. The explanation for this is that one has a very specialist workload while the other is associated with a world-leading university. These outliers show that while volume of cases is important, there are other factors in play, such as being associated with a world leading university.

It is important to emphasise that volume is not the only factor: trusts with the highest impact research also had clinicians who were actively engaged in research with strong links to academic institutions. Larger trusts are undoubtedly better placed to carry out this research as well as having access to the number of patients needed for successful research.

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[23] *Morche, J., Mathes, T. and Pieper, D. (2016). Relationship between surgeon volume and outcomes: a systematic review of systematic reviews. Systematic Reviews, 5(1)*

[24] *Hannan, E.L., Racz, M., Kavey, R.-E., Quaegebeur, J.M. and Williams, R. (1998). Pediatric Cardiac Surgery: The Effect of Hospital and Surgeon Volume on In-hospital Mortality. PEDIATRICS, 101(6), pp.963–969.*

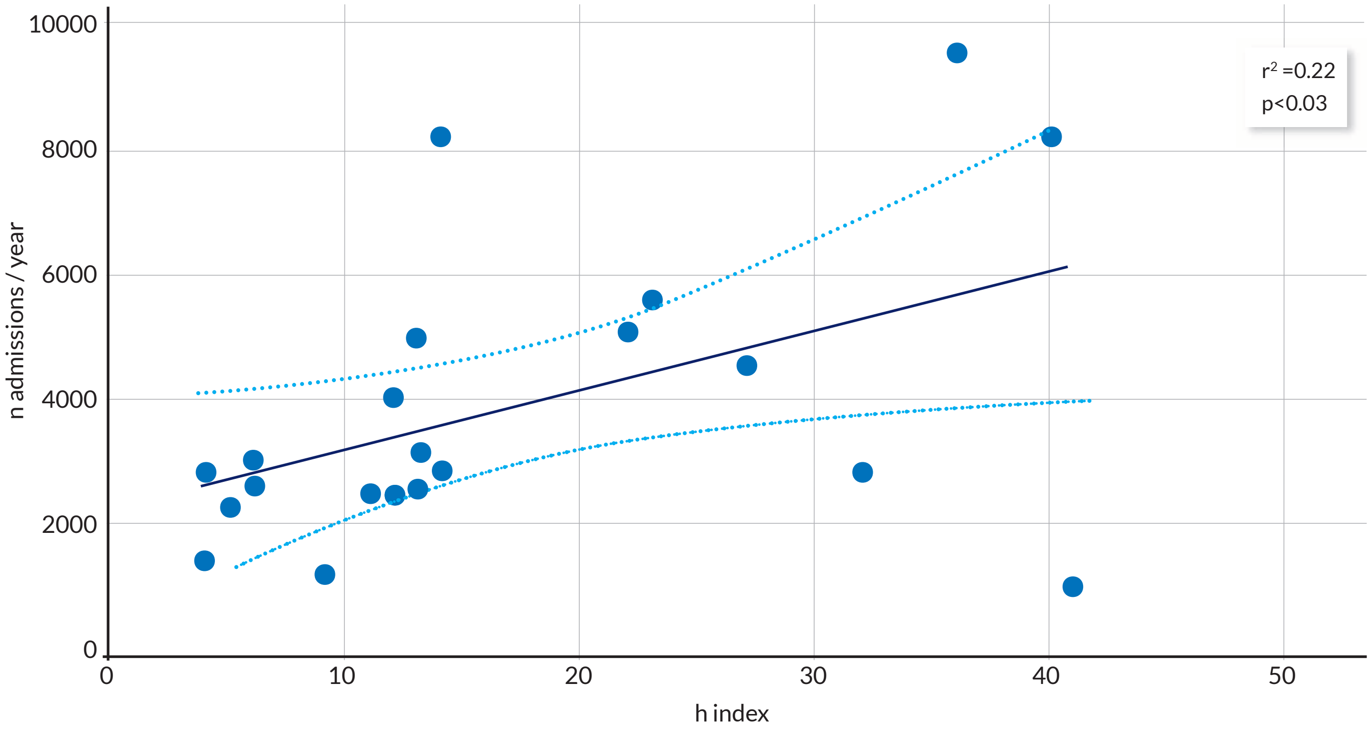
[25] *Ly, D.P. (2005). Effect of Surgeon and Hospital Characteristics on Outcome After Pyloromyotomy. Archives of Surgery, 140(12), p.1191*

[26] *Wilkinson, D.J., Green, P.A., Beglinger, S., Myers, J., Hudson, R., Edgar, D. and Kenny, S.E. (2017). Hypospadias surgery in England: Higher volume centres have lower complication rates. Journal of Pediatric Urology, 13(5), pp.481.e1-481.e6*

[27] *Markar, S.R., Mackenzie, H., Wiggins, T., Askari, A., Karthikesalingam, A., Faiz, O., Griffin, S.M., Birkmeyer, J.D. and Hanna, G.B. (2017). Influence of national centralization of oesophagogastric cancer on management and clinical outcome from emergency upper gastrointestinal conditions. British Journal of Surgery, 105(1), pp.113–120*

[28] *Mason DG, Wilkinson K, Gough MJ, Lucas SB, Freeth H, Shotton H, Mason M (2011) Are we there yet? A review of organisational and clinical aspects of children's surgery. NCEIP https://www.ncepod.org.uk/2011report1/downloads/SIC_fullreport.pdf*

Figure 9: Relationship between number of children admitted annually to paediatric specialist trusts and impact of research output (h-index)



Source: HES for number of admissions, Google scholar for h-index. H-index was calculated for each specialist trust by searching for articles published by surgeons within each trust 2014-2019 and calculating a trust level h-index.

Solid navy line: linear regression line
Dotted cyan line: standard error of mean

Trainee exposure

It is important to support effective training for the next generation of surgeons and anaesthetists. We have found there is a significant variation in caseload which will inevitably impact trainees' exposure during training. Table 4 summarises the total calculated exposure of trainees to some of the index conditions we have looked at in this section. There is significant variation in both the number of neonatal index cases a paediatric surgeon will have been exposed to and the number of cases they will have performed during their training. Trainees in the South East consortium, where there is a high density of low-volume specialist trusts, will be exposed to almost half the number of index cases during their entire training compared to other consortia with a preponderance of high volume trusts (see Table 4).

The detailed examples of specialist conditions / procedures we highlight in this section of the report show the substantial variation in surgeon and trust level caseload that, together with high trainee numbers in some consortia, mean it is difficult to ensure adequate specialist training. These findings are concerning when the specialty has a responsibility to train the next generation of paediatric surgeons to perform complex neonatal surgery to the highest standards.

Table 4: Six-year mean cumulative neonatal surgery experience of paediatric surgical specialty trainees by training consortium

Index caseload: oesophageal atresia, congenital diaphragmatic hernia, abdominal wall defects, duodenal atresia, intestinal malrotation.

Constortium	Total n trainee index case exposure	Total n of index case trainee performed
South East	56.5	25.8
Midlands/South West	72.8	43.8
North West	86.3	49.3
North	79.3	41

Data source: With thanks to Mr Liam McCarthy, Chair, Paediatric Surgery Training and Education Committee, 2017

Examples of complex conditions / procedures

To help further understand the challenges we have discussed so far in this section, on the delivery of complex care, we outline below six conditions.

The first five examples have specifically been chosen as they are low volume index cases:
1. Oesophageal atresia;
2. Congenital diaphragmatic hernia;
3. Hirschsprung's disease;
4. Nephrectomy for malignancy;
5. Nephrectomy for non-malignant disease;
6. Necrotising enterocolitis (NEC).

In the last example, necrotising enterocolitis (NEC), we discuss we discuss further the second main challenge: pre-term babies are not always receiving timely and necessary surgical assessment, or appropriate preventative measures.

1. Oesophagael atresia

Oesophageal atresia is a congenital condition (birth defect) that affects the alimentary tract (the system of organs used to digest food). It causes the oesophagus to end in a blind-ended pouch rather than connecting normally to the stomach. Babies often present after birth with shortness of breath and choking during feeds.

Treatment

Corrective surgery has traditionally involved opening the chest cavity (thoracotomy) and reconstructing the oesophagus, which often must be disconnected from the respiratory tree (also called the tracheobronchial tree). In the last 18 years, some trusts have reported successful thoracoscopic (keyhole) repair.

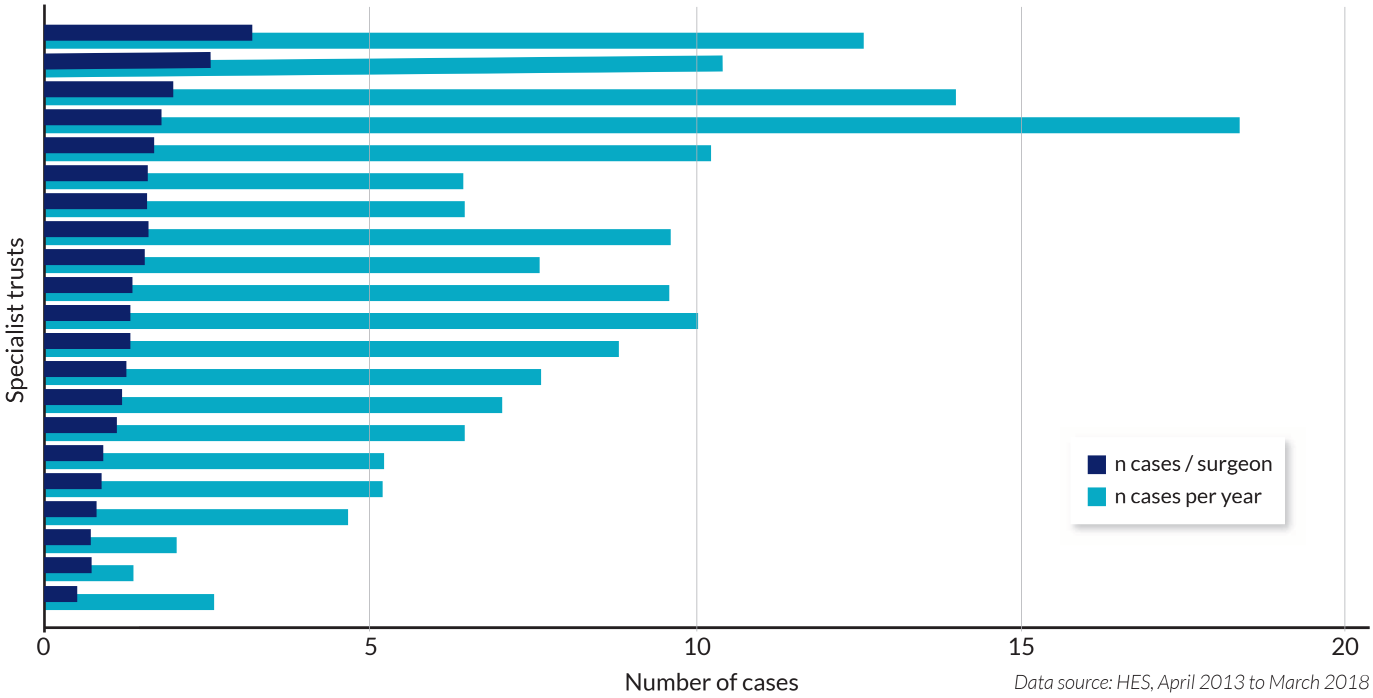
Caseload volumes

Just 160 babies are born with oesophageal atresia each year. With so few cases being spread across 21 specialist trusts, the caseloads for both trusts and surgeons are exceptionally low (see Figure 10). The trusts with the highest volumes treat an average of 18.5 cases per year – while those with the lowest volumes treat just 1.4 cases per year.

When we look at individual surgeon experience, we found that the busiest surgeons perform an average of just three cases per year, while the national average is as low as 1.4 cases per surgeon per year.

In mitigation, many trusts said they often had two consultants operating during these cases, but this would not change the overall picture in a major way.

Figure 10: Mean annual trust and surgeon level caseload for oesophageal atresia repair April 2013-Mar 2018



Data source: HES, April 2013 to March 2018

Sub-specialisation

Sub-specialisation – where a group of surgeons take on exclusive responsibility for oesophageal atresia – improves surgeon volumes. However, when trust level volumes are so low, even sub-specialisation is not enough to match surgeon experience in larger trusts. Even in large trusts with sub-specialisation, the mean annual caseload per surgeon is just three. Such low numbers are likely to have an impact on outcome, and have significant implications for training, research and innovation.

Assessing volume-outcome relationships

We discuss the volume-outcome relationship, and what it means for care in individual surgeon and team experience (page 39). The overall low levels of surgeon exposure make it impossible to demonstrate a volume-outcome relationship. Surgical technique is more likely to play a role in optimising the repair to reduce complications, such as narrowing of the oesophagus and recurrent chest infections. In addition, higher volume trusts have teams who can detect potential complications such as displaced nasogastric tubes earlier and take appropriate remedial action.

Long-gap oesophageal atresia

Not all oesophageal atresia cases are equal as some cases have a wider gap between the two ends of the oesophagus – termed long-gap atresia.

Approximately 16 of the 160 babies born with oesophageal atresia in England each year have 'long-gap' oesophageal atresia. In these cases, as the name suggests, the gap (between oesophagus and stomach) is even wider.

With long-gap oesophageal atresia, it is not possible to join the oesophagus together during the first operation. Treatment options include oesophageal lengthening procedures or oesophageal replacement using part of the stomach, small intestine or colon.

At present, there is no clear evidence on which approach is best – each has significant risks and drawbacks, and there is substantial incidence of complications.

With such low volumes, research and innovation becomes extremely difficult: surgeons rely on techniques they were taught in training rather than evolving new ones. This is particularly worrying when many of the challenges in oesophageal atresia surgery are in optimising treatments to reduce long-term morbidity and complications.

Given the complexity of the procedure to correct long-gap oesophageal atresia and the low case volume, we are greatly concerned that 40 surgeons identify themselves as competent in oesophageal replacement surgery.

These numbers would give an average annual operative exposure to long-gap oesophageal atresia of 0.4 cases per surgeon per year (Table 5). Given this finding, there is a strong case for the surgical care of these babies to be undertaken in fewer centres in alignment with recommendations in the Position Paper of the International Network of Esophageal Atresia (2017).

Table 5: Average operative exposure to long-gap oesophageal atresia per year

Cases per year	Number of surgeons claiming competency in oesophageal replacement surgery	Average operative exposure per surgeon per year
16	40	0.4 cases

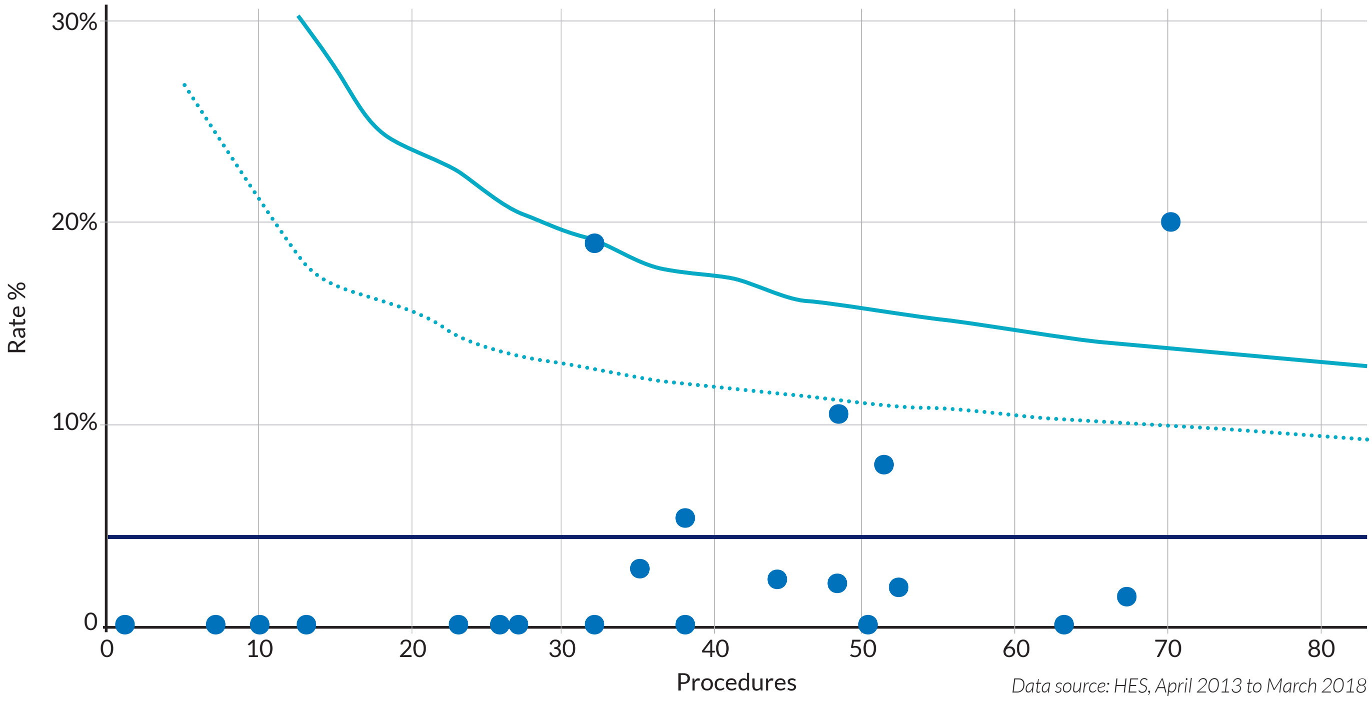
Data source: HES and GIRFT questionnaire

Thoracoscopic repair

We can see evidence of inertia in the development of surgical technique when we look at the adoption rates of thoracoscopic repair of oesophageal atresia. Thoracoscopic repair is a minimal access technique that was first described 18 years ago. Currently, the benefits versus traditional open repair are unproven. Proponents suggest that there may be benefits from reduced surgical stress on the infant and less impact on chest wall development.

Even in the trusts that perform the most repairs, only 20% have been done thoracoscopically (Figure 11). Such a low number precludes any meaningful analysis of benefits and risks as well as inhibiting innovation.

Figure 11: Rate of thoracoscopic (minimal access) repair of oesophageal atresia



Data source: HES, April 2013 to March 2018

Oesophageal dilatations

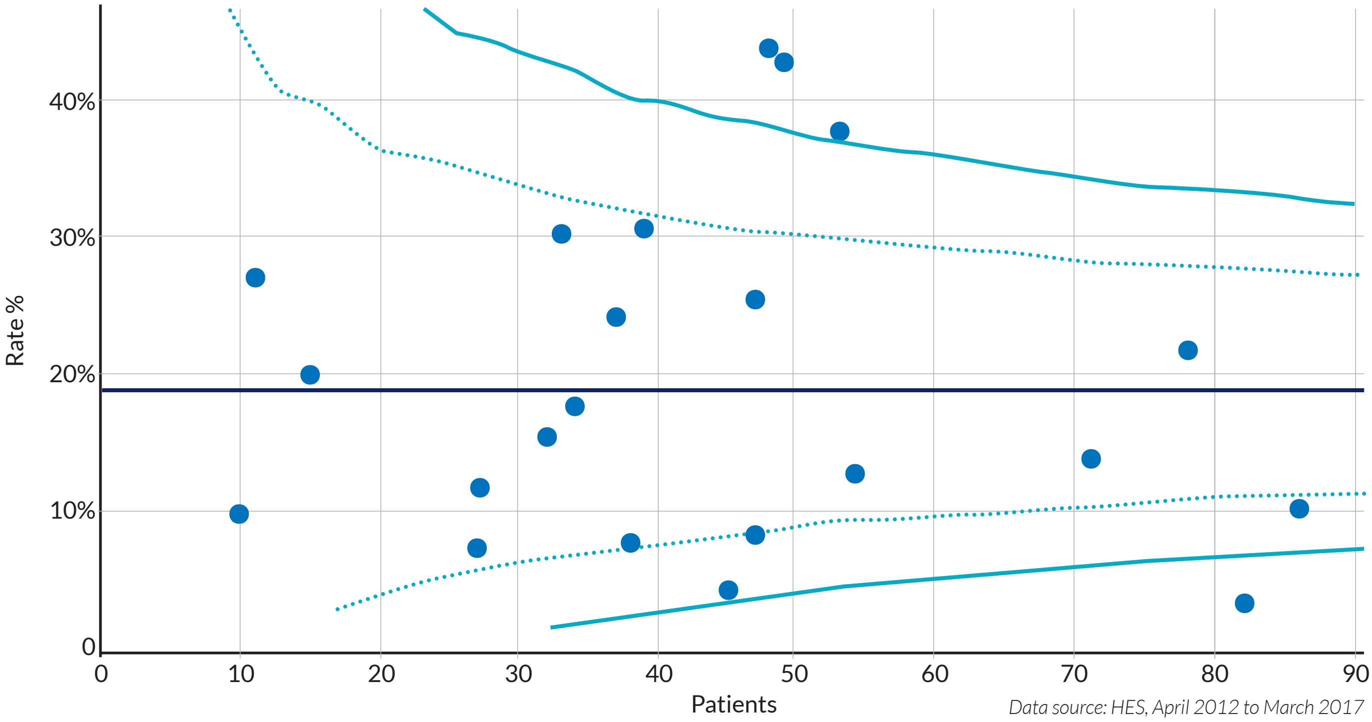
Oesophageal dilatation treats stricture (narrowing) that occurs at the site of the surgical anastomosis[29] in 39% of children following their repair.

The number of children requiring more than one oesophageal dilatation in the first year of life following oesophageal atresia repair offers a surrogate measure of the rate of oesophageal stricture.

We found wide variation in rates between trusts. Several lower volume trusts breach the 99.8 percentile with >40% of children requiring more than one dilatation. In contrast many trusts, including the two busiest trusts, have a dilatation rate of <10% (Figure 12).

Our evidence indicates some correlation between low volume caseload and frequency of dilatation.[30]

Figure 12: Percentage of children requiring more than one oesophageal dilatation in the first year of life following oesophageal atresia repair



Data source: HES, April 2012 to March 2017

Training

If consultant surgeons are performing a mean of 1.4 cases of oesophageal atresia repair per annum, this creates difficulty in training paediatric surgeons, as this does not give the surgeon enough experience to be confident in teaching to others.

Conclusions

We found that the increased number of paediatric surgical specialist trusts and specialists has resulted in the annual oesophageal atresia caseload for trusts and surgeons reducing to exceptionally low levels.

Even in large trusts with sub specialism, the mean annual caseload per surgeon is three. Such low numbers are likely to have an impact on outcome.

At present, when surgeons are performing an average of 1.4 cases per year and centres treat a mean of only 7.9 cases per year, it is hard to deliver effective training to the next generation of surgeons, anaesthetists and the wider team.

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[29] *Ilin, B., Knight, M., Johnson, P. and Burge, D. (2014). Outcomes at One-Year Post Anastomosis from a National Cohort of Infants with Oesophageal Atresia. PLoS ONE, 9(8), p.e106149*

[30] *Svoboda, E., Fruithof, J., Widenmann-Grolig, A., Slater, G., Armand, F., Warner, B., Eaton, S., De Coppi, P. and Hannon, E. (2018). A patient led, international study of long term outcomes of esophageal atresia: EAT 1. Journal of Pediatric Surgery, [online] 53(4), pp.610–615*

2. Congenital diaphragmatic hernia

Congenital diaphragmatic hernia (CDH) is a congenital defect that affects around 140 babies per year in England.

Babies with CDH have part of their diaphragm absent, which causes abdominal organs to herniate from the abdominal cavity into the thoracic cavity. Often the lungs of affected babies have not grown properly.

Surviving babies commonly have neurodevelopmental, respiratory and gastrointestinal problems requiring long term management. Surviving babies commonly have neurodevelopmental, respiratory and gastrointestinal problems requiring long term management, as well as musculoskeletal problems and failure to thrive.

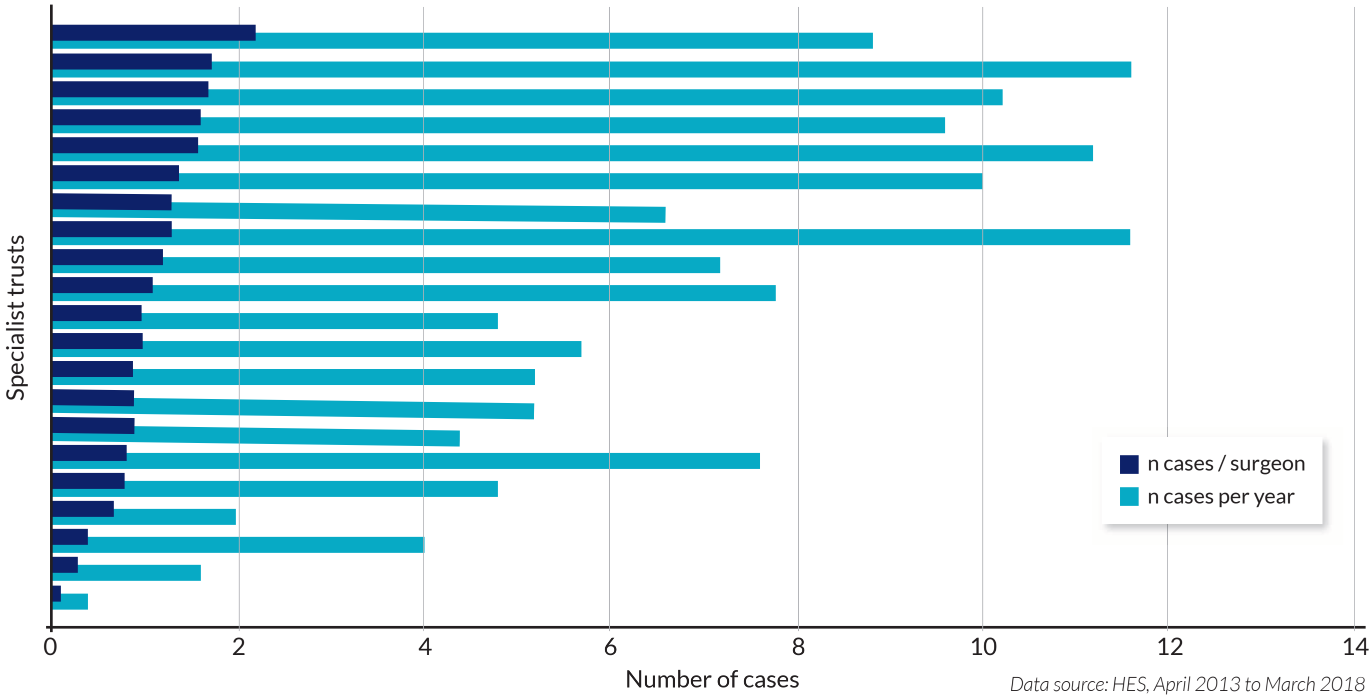
Those babies with associated genetic or cardiac anomalies have a worse prognosis.[31]

Diagnosis and treatment

CDH is diagnosed antenatally in 60% of cases.[32] Antenatal diagnosis enables cases to be managed from before birth. Parents can meet with paediatric surgeons, neonatologists and foetal medicine specialists for counselling and to make decisions on the fate of the pregnancy, and place and timing of delivery. One specialist trust, King's College Hospital NHS Foundation Trust, performs foetal interventions in a small number of cases. The role of foetal intervention in improving survival is an area of active research.

Currently, the overall survival rate for babies diagnosed with CDH at around 20 weeks' gestation is 50%. Treatment is usually by diaphragmatic repair, which can be complicated.

Figure 13: Average annual trust and surgeon caseload for repair of congenital diaphragmatic hernia



Data source: HES, April 2013 to March 2018

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[31] *British Association Perinatal Medicine (2018) National Care Principles for the Management of Congenital Diaphragmatic Hernia. https://www.bapm.org/resources/22-national-care-principles-for-the-management-of-congenital-diagphragmatic-hernia-2018*

[32] *Davis, C. and Walker, G.M. (2018). Challenge of determining true outcome of congenital diaphragmatic hernia. Archives of Disease in Childhood - Fetal and Neonatal Edition, [online] 103(6), pp.F504–F505. Available at: https://fn.bmj.com/content/fetalneonatal/103/6/F504.full.pdf [Accessed 20 Aug. 2019]*

Co-location of maternity and surgical services

Only five of the ten trusts that carry out the highest volumes of CDH repair provide maternity, neonatology and surgical services on the same site. Paradoxically, three out of four of the highest volume trusts do not have co-located maternity and paediatric surgical services. The impact of this arrangement on outcomes is unknown.

Until recently, only four of the ten trusts that carry out the highest volumes of CDH repair provided neonatology services (these were limited services in some cases). However, we found encouraging signs of increased involvement of neonatologists in the ten high volume trusts. This includes the introduction of dedicated NICUs so that post-operative care can be delivered at the specialist trust, reducing the need for ambulance transfers.

Principles for managing congenital diaphragmatic hernia

In 2018, the British Association of Perinatal Medicine (BAPM) published national care principles for antenatal, perinatal and postnatal management of CDH. The principles were endorsed by several parent and patient charities.

BAPM identified that the existing organisational model of care for congenital diaphragmatic hernia hindered patient care and outcomes. They concluded that the care pathway outlined in the national care principles should be delivered through a small number of highly specialist trusts. Geographic and travel considerations should be balanced by the potential to provide psychological, social and financial support. BAPM also highlighted that having a small number of specialist trusts would enable research to be concentrated, including reporting to national registries.

We found that the current provision of services for the treatment of CDH in England falls short of BAPM guidance.

In conclusion, congenital diaphragmatic hernia (CDH) is a congenital defect that affects around 140 babies per year in England.

These cases are spread across 23 trusts, resulting in an average trust caseload of just 4.7 babies per year (with a 0.2 average in one trust). The average surgeon caseload was just 1.1 cases per year.

Such low trust and surgeon caseloads are likely to have a negative impact on outcomes, training, research and innovation.

Current provision of services for the treatment of congenital diaphragmatic hernia also falls short of the consensus document on National Care Principles for the Management of Congenital Diaphragmatic Hernia which calls for fewer trusts to treat this condition.

3. Hirschsprung's disease

Hirschsprung’s disease is a congenital bowel condition that principally affects the large intestine (colon). Missing nerve cells in the muscles of the intestine mean babies have problems passing stools.

Diagnosis

Hirschsprung’s disease is not diagnosed antenatally (before birth). Children usually present with life-threatening bowel obstruction in the first few days following birth.

Diagnosis is confirmed by rectal biopsy, which requires skilled pathological assessment.

Treatment

Treatment takes place in two main stages:

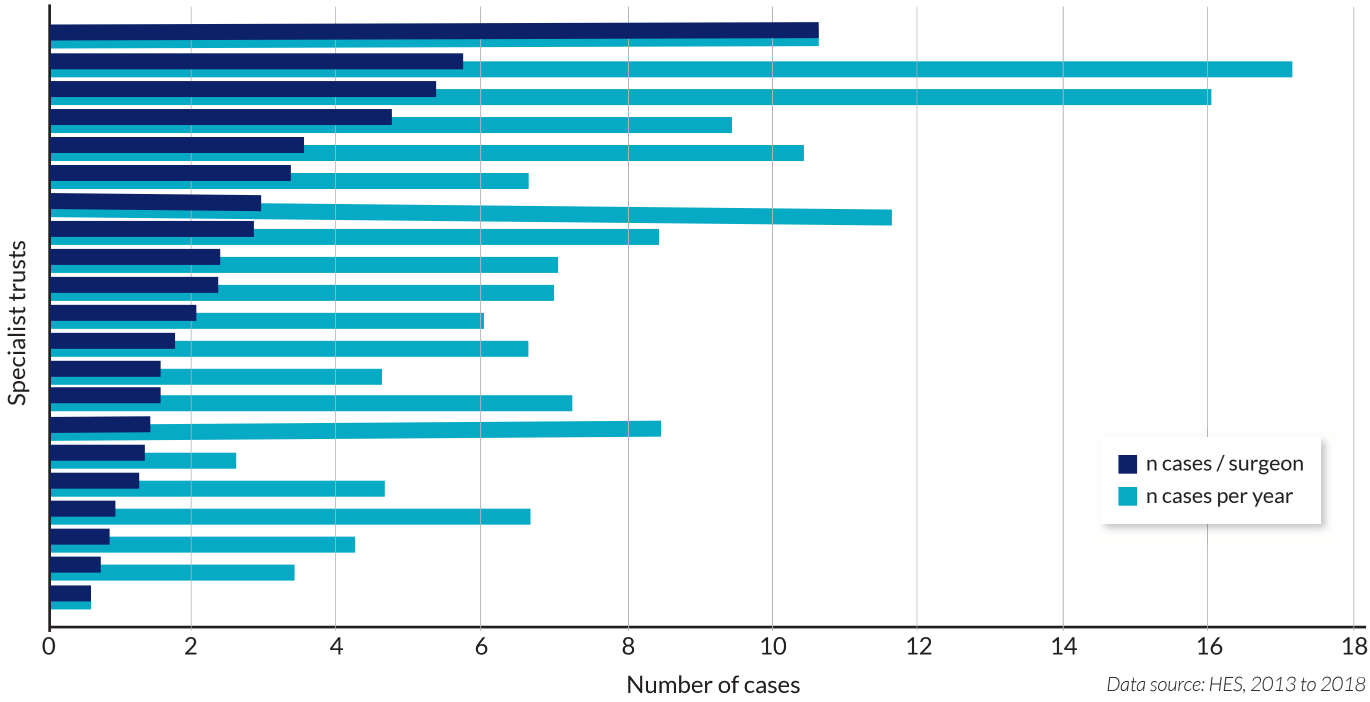
- initial treatment to remove the bowel obstruction;
- definitive treatment to remove the affected segment of colon and carry out a ‘pull-through’ procedure to join the unaffected colon at or near the anal margin.

Caseload volumes

Hirschsprung’s disease affects around 1 in 5,000 babies. Between 2013 and 2018, there was an average of 159 cases per year in England.

We found there is wide variation in trust and individual surgeon caseload for Hirschsprung’s disease (Figure 14).

Figure 14: Average trust and surgeon caseloads for children diagnosed with Hirschsprung’s disease



Data source: HES, 2013 to 2018

Sub-specialisation

We found a limited degree of sub-specialisation in Hirschsprung's disease. Average caseload per year for these surgeons is 2.7 cases.

However, because of variation in the trust caseload and degree of sub-specialisation, the mean annual caseload per surgeon is less than two in ten of the specialist trusts.

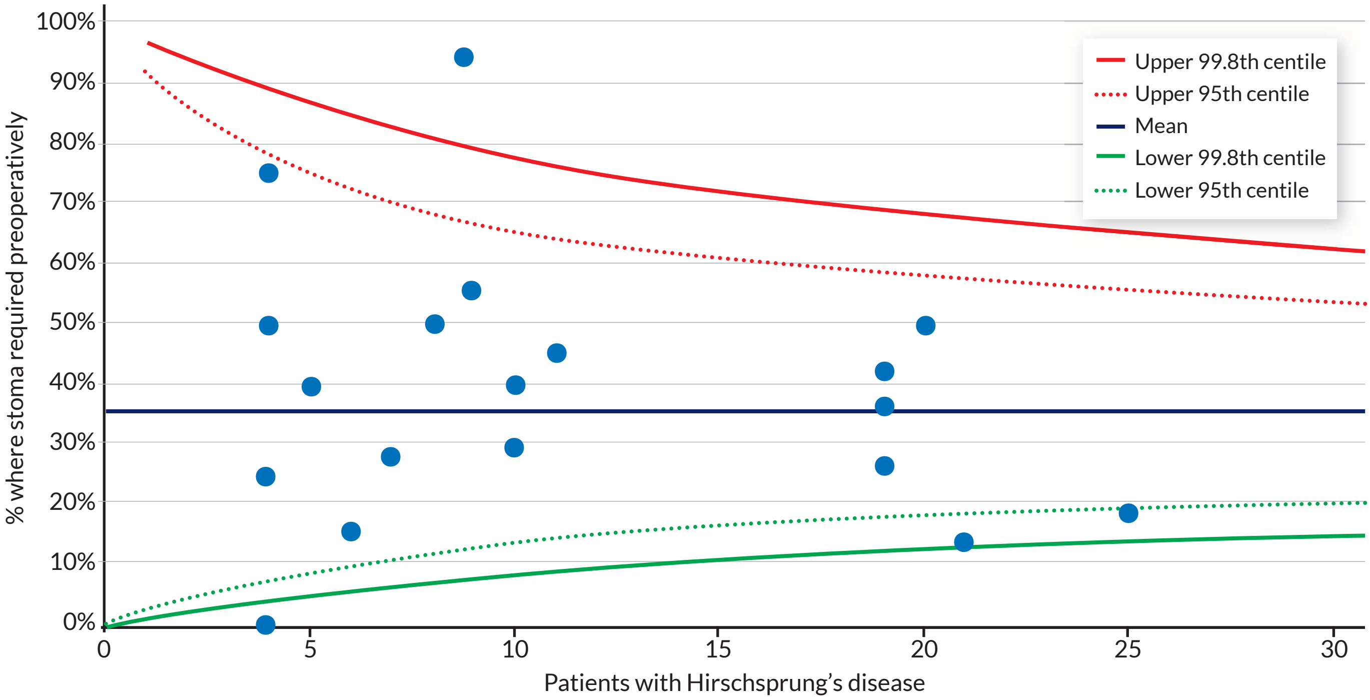
Low caseloads will also impact on the experience, expertise and training of nursing and anaesthetic staff, particularly continence nurse specialists.

Emergency colostomy

The British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS) studied the rates of children having an emergency colostomy related to Hirschsprung's disease between 2010 and 2012. Current evidence suggests that many babies can be managed without requiring a colostomy prior to definitive 'pull-through' surgery.

BAPS-CASS found that an average of 37% of children had a pre-operative colostomy. However, this figure masks an alarming level of variation between trusts, with rates varying from 0% to 90% (Figure 15).

Figure 15: Percentage of children requiring a preoperative stoma by specialist trust



Data source: BAPS-CASS, October 2010 to March 2012

Trusts that carry out the highest volumes had rates between 10% and 15%.

From discussions during our deep dive visits, we believe a combination of two reasons leads to the huge variation:

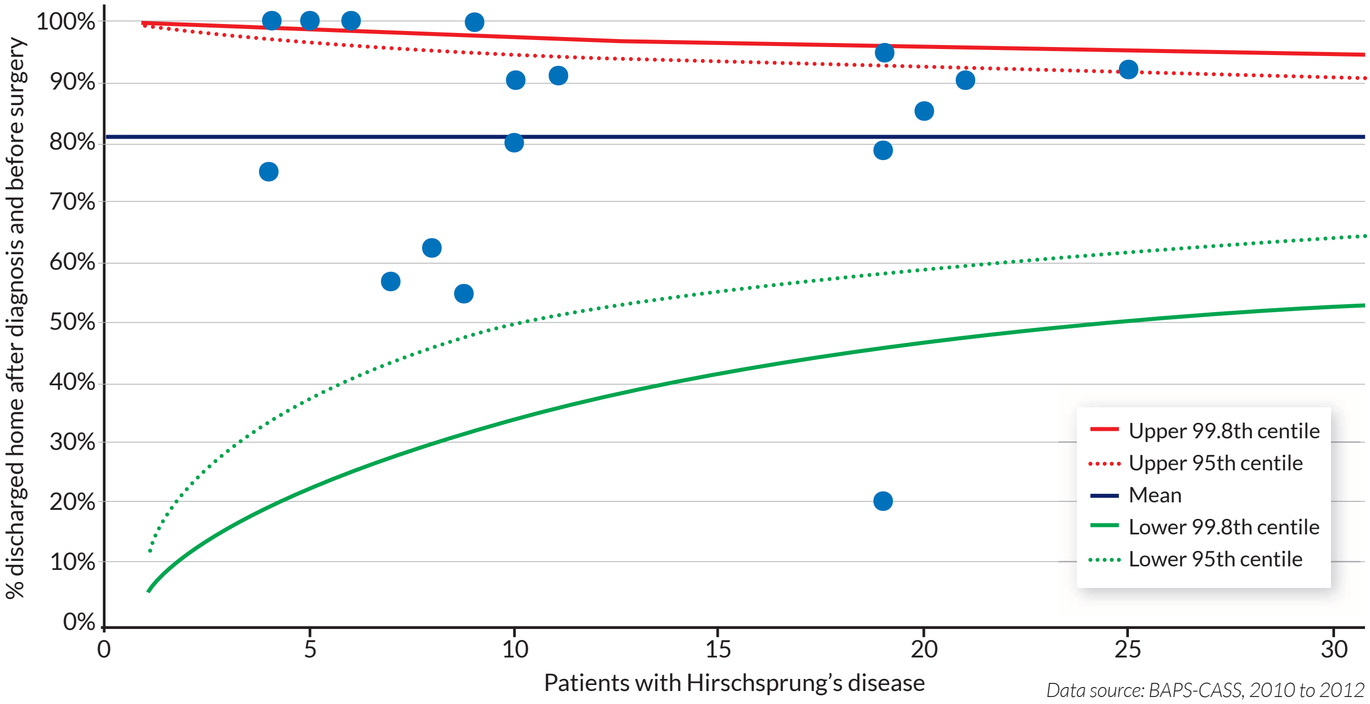
- Inertia – in the past, it was standard practice to carry out an emergency colostomy before carrying out definitive treatment. This is no longer the case in contemporary evidence-based practice.
- Experienced surgeons and nurses are able to carry out decompression of the colon by non-operative means. Low volumes mean the opportunities to learn and practise the necessary skills are not there.

Discharge before definitive surgery

Being able to discharge babies to home before surgery reduces stress on families, giving them time and space to spend time with their newborn baby. It also frees trust resources so that they can be made available to other babies.

There is huge variation in the average number of babies with Hirschsprung's disease that are discharged home prior to definitive surgery – from 20% to over 90% (Figure 16).

Figure 16: Percentage of babies discharged from hospital after diagnosis of Hirschsprung's disease and prior to definitive surgery in England 2010-2012



Data source: BAPS-CASS, 2010 to 2012

Definitive treatment

Definitive treatment involves removal of the affected part of colon and a 'pull-through' procedure to link the unaffected part of colon at or near the lower part of the anal canal. Frozen section pathology, a process to perform rapid microscopic analysis of a specimen, is required during pull-through.

Current treatment methods are far from perfect,[33] with long term outcome data showing that as few as 40% of children achieve normal bowel actions following reconstructive surgery.

There are three possible pull-through procedures, each with different advantages and disadvantages. Until recently there was a lack of population-based data to establish which is the superior technique. BAPS-CASS is now providing growing evidence that the 'Swenson'[34] procedure is associated with a higher rate of post-operative complications with no improvement in long-term outcomes. As the evidence base builds, it may prove necessary for surgeons to switch to a different procedure than the one they currently use.

We found that surgeons' preference for a particular procedure was mainly due to what they had been taught during training. We have seen that mean annual caseload per surgeon is 2.7. This limits the ability of surgeons to retrain in new techniques. Only in larger trusts, with high enough caseload, was there evidence that surgeons were adapting and switching technique.

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[33] *Baillie, C.., Kenny, S.., Rintala, R.., Booth, J.. and Lloyd, D.. (1999). Long-term outcome and colonic motility after the Duhamel procedure for Hirschsprung's disease. Journal of Pediatric Surgery, 34(2), pp.325–329*

[34] *Swenson procedure: all layers of the bowel lacking ganglion (nerve cells) are removed from 1cm above the dentate line (the line demarcating the anus). Bowel containing nerve cells is 'pulled-through' and anastomosed (joined) at this level.*

Continence support and the role of paediatric specialist nurses, advanced nurse practitioners (ANPs) and nurse consultants

As we have seen, around 60% of children with Hirschsprung's disease will not attain normal continence.[35]

It is essential that these children and their parents get expert support in dealing with continence issues. For example, significant improvements to a child's quality of life can be achieved with effective bowel management. This requires ongoing support, typically provided by local child continence teams with back-up from paediatric specialist nurses, advanced nurse practitioners or nurse consultants. We discuss the importance of co-location of critical services and workforces earlier in this report.

We found wide variation in the number of paediatric specialist nurses, advanced nurse practitioners and nurse consultants employed by specialist trusts in their paediatric surgical and urology services. Three specialist trusts employed no specialist nursing staff at all and in the other 17 trusts, specialist nurse numbers varied from 1.6 to over 10 nurse whole-time equivalents.

From our deep dive visits, it was clear that the role of paediatric specialist nurses, advanced nurse practitioners and nurse consultants also varies widely. In trusts with large numbers of paediatric specialist nurses, those nurses were enabled to establish nurse-led clinics in which they diagnose conditions, prescribe treatment within guidelines and evaluate the impact of ongoing care.

Given the low index caseload for paediatric surgeons and future training requirements in paediatric surgery, there is considerable merit in increasing the specialist nurse workforce to draw in additional skill sets and enable enhanced and advanced practice. Specialist nurses are well placed to provide a significant proportion of bowel and urinary management services within specialist trusts. Paediatric specialist nurses, advanced nurse practitioners and nurse consultants could provide a significant proportion of bowel and urinary management services within specialist trusts.

Note: The data we were able to collect means it was not possible to model the financial impact of using specialist nurses

Total colonic Hirschsprung's disease

Of children born with Hirschsprung's disease, 3% have total colonic Hirschsprung's disease.[36] This rare form means that the entire colon, and often parts of the small intestine, are lacking in nerve cells. Children with this condition require different surgical procedures to those with Hirschsprung's disease, such as ileal pouch surgery. Given the low annual caseload of all forms of Hirschsprung's disease, it follows - similar to long-gap oesophageal atresia - that centre and surgeon experience of this condition is low. There is a strong case for commissioning a smaller number of centres to care for these children.

> **Diagnosis:** Pull-through procedures are more complex in children with total colonic Hirschsprung's disease. It is essential that cases are diagnosed before any reconstructive surgery is attempted.
>
> **Treatment:** No single procedure has been demonstrated to be superior in treating total colonic Hirschsprung's disease. Most paediatric surgeons would rarely perform the type of surgery required other than during surgery for inflammatory bowel disease. In those cases, it is often performed as a joint procedure with adult lower gastrointestinal surgeons experienced in the surgical management of inflammatory bowel disease.

In conclusion, Hirschsprung's disease affects 1 in 5,000 babies in the UK. We found that the spread of cases means individual surgeons, even those who sub-specialise in Hirschsprung's disease, see a very low average caseload. This means that innovation is slow, with many surgeons relying on outdated techniques taught during training and which have now been shown to result in complications.

There is also unwarranted variation in which trusts send children home to be with families before surgery, while post-operatively, some trusts do not have access to specialist nurses who can advise and support families with ongoing care, particularly for continence, an usually lifelong impact of the disease.

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[35] *Allin B (2019) NETS2HD study: School age outcomes for children with Hirschsprung's disease. United Kingdom Pediatric Colorectal Group Meeting; Oxford.*

[36] *Bradnock, T.J., Knight, M., Kenny, S., Nair, M. and Walker, G.M. (2017). Hirschsprung's disease in the UK and Ireland: incidence and anomalies. Archives of Disease in Childhood, 102(8), pp.722–727*

4. Nephrectomy for malignancy

Fortunately, solid tumours of the kidney in children are rare. Typically, around 80 children per year in the UK present with Wilm's tumour, which arises from immature embryonic cells within the kidney. Most children present under the age of five.

Survival is now greater than 90%.

Treatment

Malignant kidney tumours require surgical removal, an intervention called nephrectomy.

Treatment usually requires a combination of chemotherapy, surgery, and occasionally radiotherapy. Surgery to remove the kidney can be challenging, particularly if the tumour has not been shrunk by chemotherapy. The cancer can invade the large abdominal vein (vena cava) and even extend into the heart, posing specific surgical challenges.

Paediatric surgeons are part of the multidisciplinary team that cares for the child.

Some children will be at risk of further tumours in the other kidney. Children at risk may benefit from 'nephron-sparing' surgery in which only the tumour and a margin of renal tissue are removed from the kidney.

Outcome data

Currently, there are no surgical outcome databases in children's oncology surgery that we could analyse to assess variation in care. Instead, we analysed HES data alongside asking trusts how they organise their oncology service. Although this data is relatively superficial, it gives the best picture available to us.

There is a need for robust surgical oncology databases to link to the other children's cancer databases to inform practice and commissioning of children's surgical treatment.

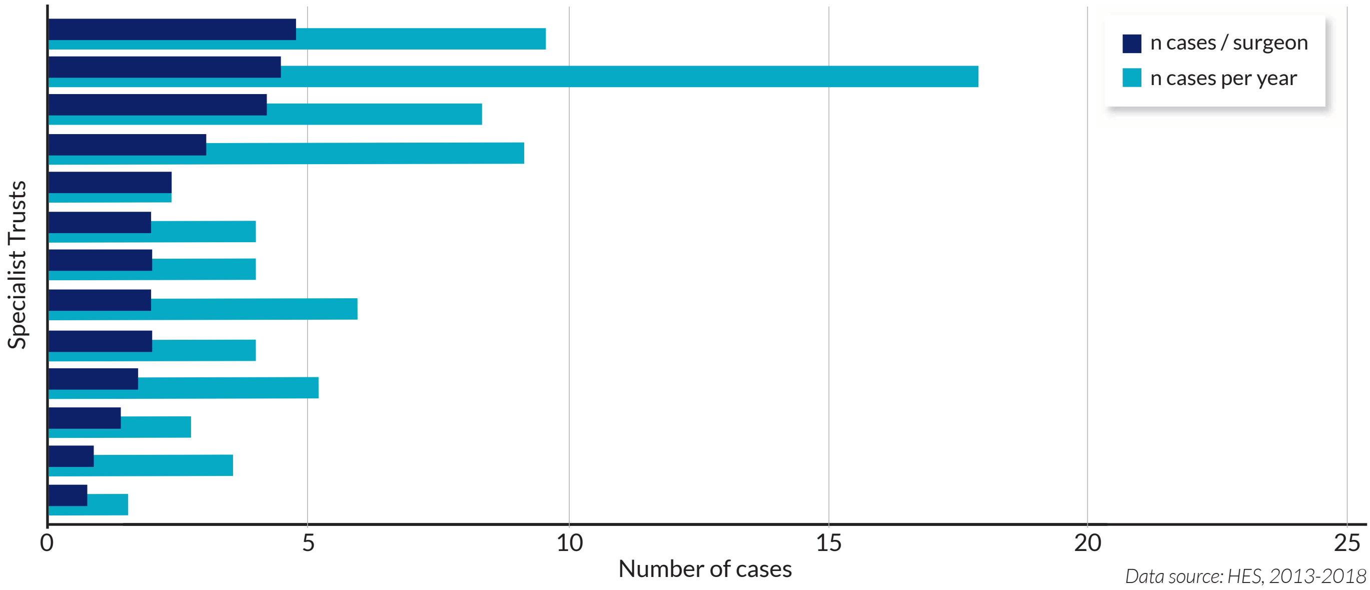
Caseload

Treatment of children with kidney cancer/Wilm's tumour takes place in 15 Principal Treatment Centres (PTC). PTCs were established to provide cancer treatment for children and young adults.

There is variation in the average caseload per trust from two to 22.5. The mean caseload per surgeon in England is three cases per year, varying from one to six (Figure 17). One centre has a substantially higher workload than all other centres, suggesting that centralisation of care is already occurring particularly for more complex cases.

Subspecialisation plays a role in increasing individual caseload. This often means only two surgeons in a single trust perform nephrectomy for malignancy, raising concerns about the sustainability of the service if surgeons are absent for any reason.

Figure 17: Mean annual trust caseload and caseload per surgeon by principal treatment trust



Data source: HES, 2013-2018

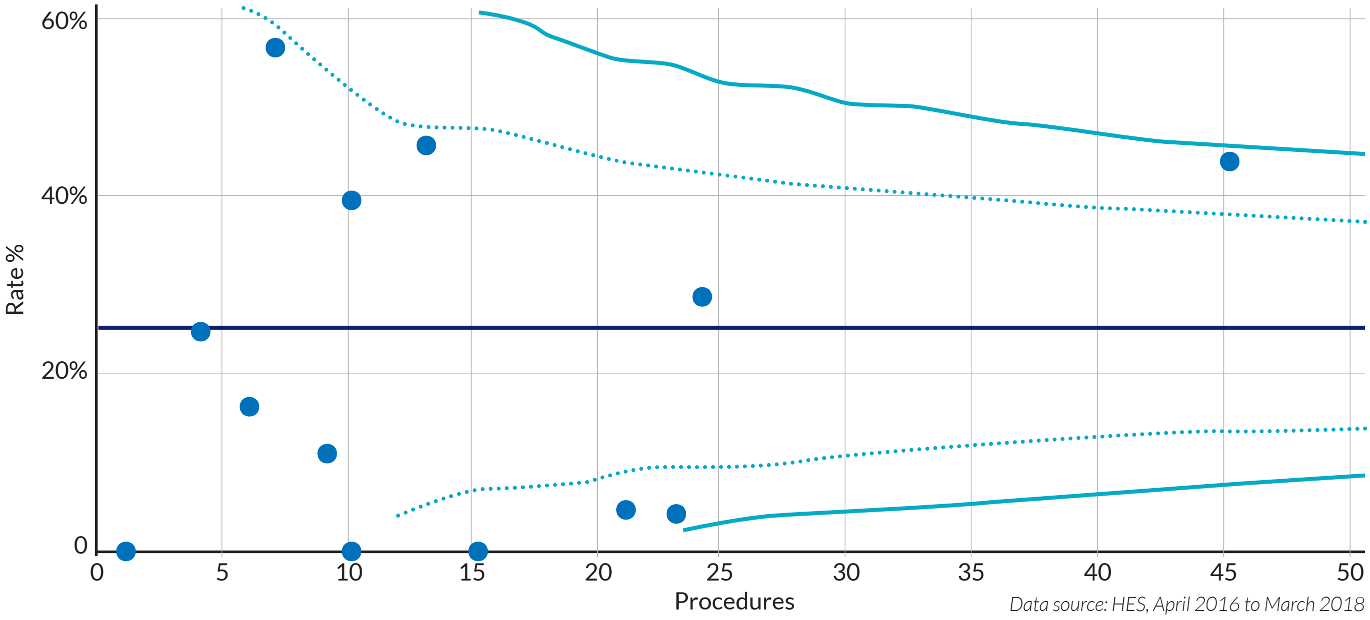
Length of stay

There is significant variation in the length of stay between trusts (Figure 18). This suggests that avoidable factors are leading children to remain in hospital longer than normal.

One trust breached the 95th centile, with 45% of children staying longer than one week. Yet three trusts were below the 5th centile, with only 2-3% of children staying more than one week. (Data not adjusted for casemix)

Some of the variation undoubtedly depends on the complexity of the caseload. For example, children with very advanced tumours requiring extensive surgery or dialysis are likely to stay longer. However, some of the variation in length of stay will be due to variation in efficiency in achieving early discharge.

Figure 18: percentage of children whose length of stay exceeded the national upper quartile (7days) following nephrectomy for malignancy



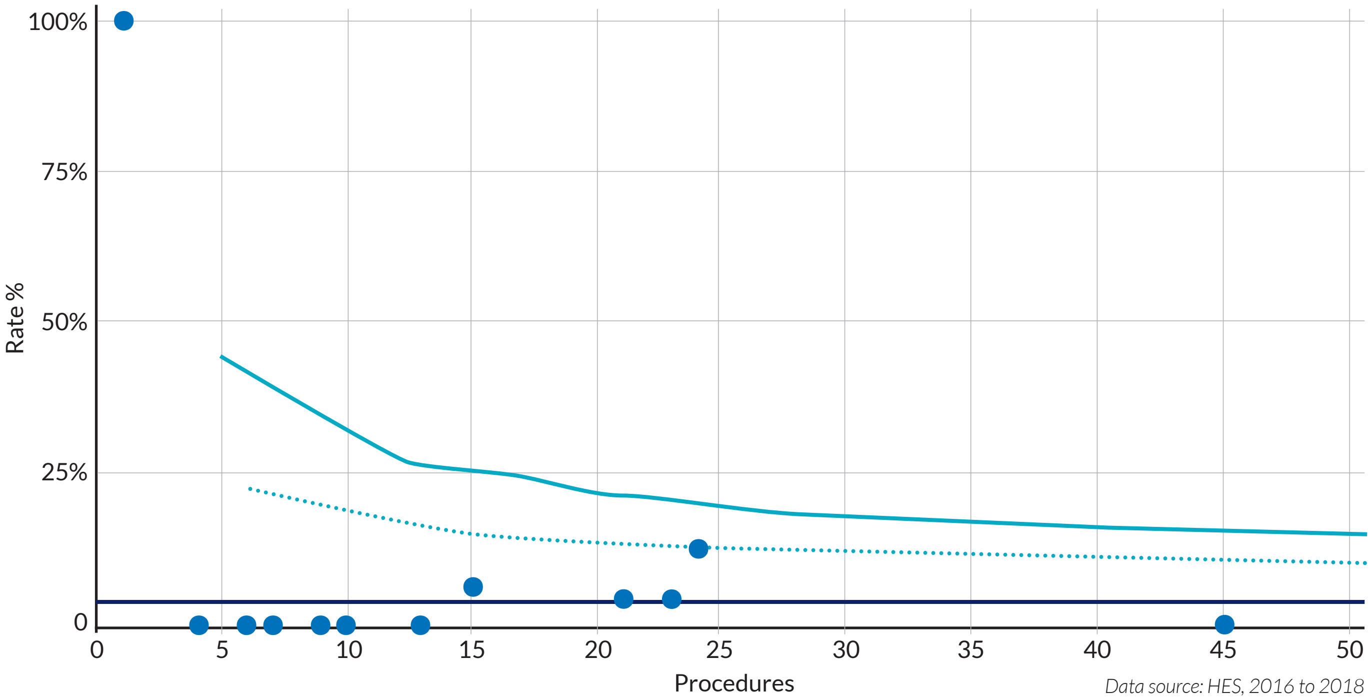
Data source: HES, April 2016 to March 2018

Uptake of minimal access surgery – laparoscopic nephrectomy

Laparoscopic nephrectomy is a growing field that offers potential benefits in long term outcomes in the treatment of smaller renal tumours.[37, 38]

The potential benefits of this minimal access surgery include reduced adhesion-related complications and scarring.

Figure 19: Proportion of nephrectomies for malignancy performed using laparoscopy by trust



Data source: HES, 2016 to 2018

We found variation in the uptake of laparoscopic nephrectomy, even in relatively high-volume trusts (Figure 19). While it is essential to carefully select appropriate cases to ensure that the risks of tumour recurrence are not increased, it seems that many surgeons are choosing not to use this minimal access technique.

This may reflect the low individual surgical workload or lack of experience in transperitoneal or retroperitoneal laparoscopic nephrectomy for non-malignant disease.

In conclusion, the mean caseload per surgeon for Wilm's tumour (kidney cancer) is just three cases per year– varying from one to six. Although subspecialisation is increasing individual caseload, that also means there may be as few as one surgeon in a trust performing this surgery. This raises concerns about the sustainability of the service at times of sickness and absence.

Low caseloads also appear to be impacting variation in care, practice and the scope for innovation. Variation in length of stay indicates evidence of variation in care.

Low uptake of minimal access procedures may be due to a lack of expertise or because the caseload is insufficient to introduce new techniques.

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[37] *Bouty, A., Burnand, K., Nightingale, M., Roberts, A., Campbell, M., O'Brien, M. and Heloury, Y. (2018). What is the risk of local recurrence after laparoscopic transperitoneal radical nephrectomy in children with Wilms tumours? Analysis of a local series and review of the literature. Journal of Pediatric Urology, 14(4), pp.327.e1-327.e7*

[38] *National Institute for Health and Care Excellence (2005) Laparoscopic nephrectomy (including nephroureterectomy) https://www.nice.org.uk/guidance/ipg136/resources/laparoscopic-nephrectomy-including-nephroureterectomy-pdf-304243741*

5. Nephrectomy for non-malignant disease

Indications for nephrectomy in children with non-malignant disease are relatively rare. They include removal of part or all non-functioning kidneys to prevent infection, treating high blood pressure, and treating nephrological disease.

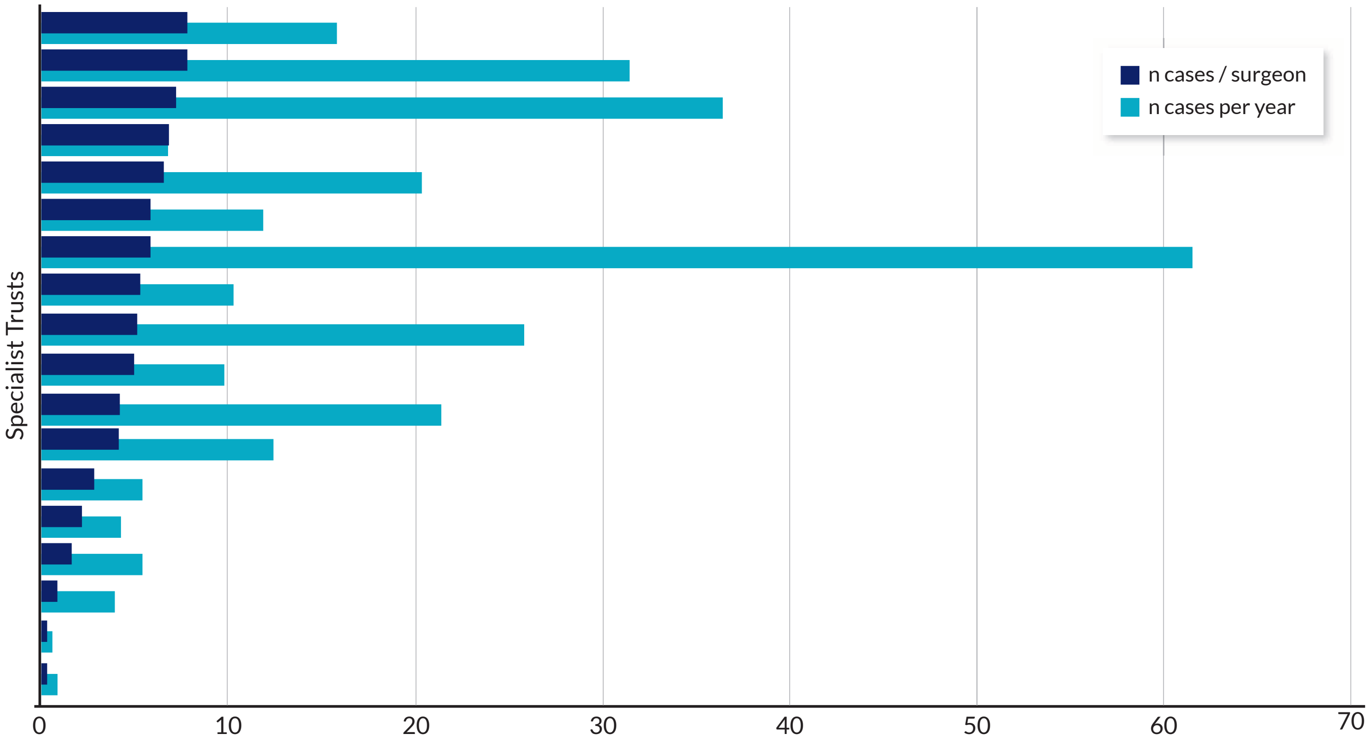
Caseload and subspecialisation

There is a marked level of variation in the average number of nephrectomies performed in each trust – from 0.5 to 61.5 cases per year (Figure 20).

We found clear evidence of trust level subspecialisation which meant individual surgeon caseload was higher, with an average caseload of 4.5 nephrectomies per surgeon per year. There is however variation in these rates from 0.3-8 cases per year.

Differences in size and referral patterns are undoubtedly playing a part in the variation between trusts.

Figure 20: Average annual caseloads for nephrectomy for non-malignant disease by surgeon and trust



Data source: HES, April 2013 to March 2018

Surgery thresholds

There is an element of subjectivity in decision-making for nephrectomy: some surgeons will advocate removal of a non-functioning kidney, while others will adopt a more conservative stance and wait for the onset of symptoms.

Some of the variation in volumes of surgery between trusts will reflect differences in the threshold at which surgery would be considered.

Length of stay

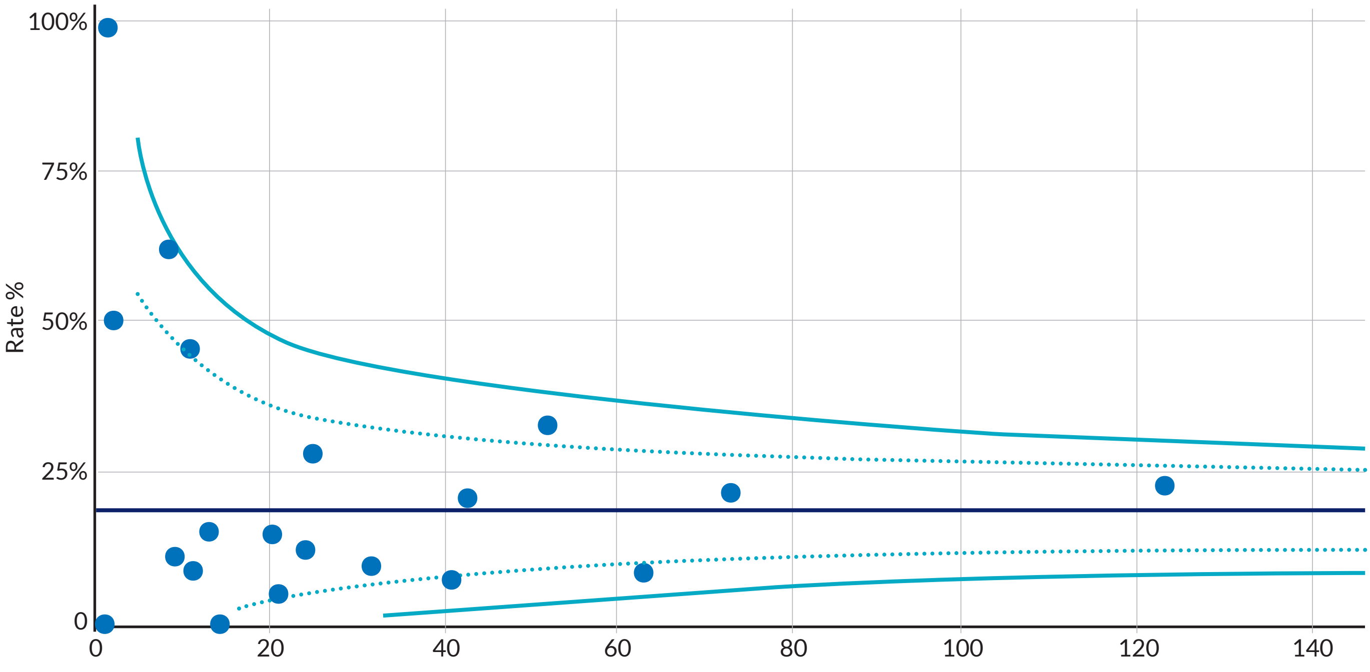
There is a marked variation in length of stay between trusts – even in those with similar volumes of activity (Figure 21).

In several trusts, only 5% of children stay longer than three days (below the 5th centile), whereas in four trusts, 30 60% of children stay longer than three days (above 95th centile).

This variation suggests that there are institutional rather than clinical differences influencing length of stay in children following nephrectomy.

If all trusts matched the best quartile for average length of stay (1.8 days), 412 inpatient bed days would be saved annually.

Figure 21: Percentage of children staying more than three days following nephrectomy by trust



Data source: HES, April 2013 to March 2018

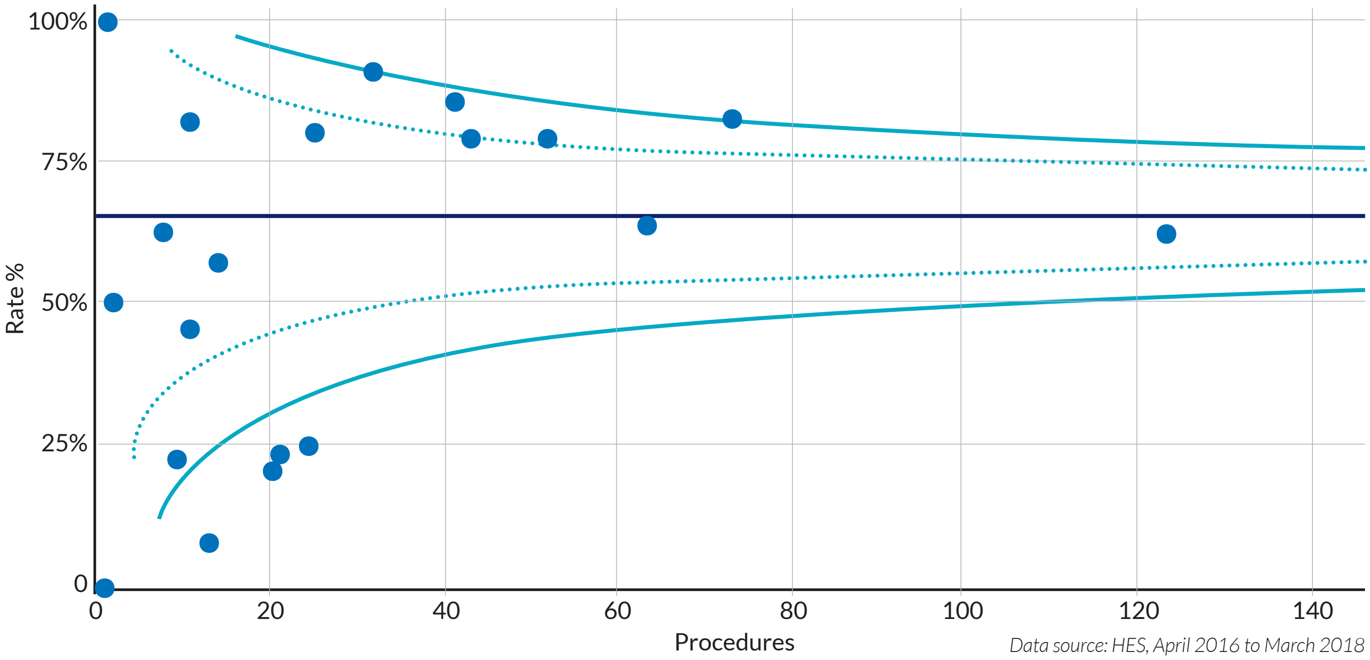
Uptake of minimal access surgery – laparoscopic nephrectomy

As with nephrectomy for malignancy, laparoscopic nephrectomy offers the potential benefits of reduced adhesion-related complications and scarring.

We found huge variation in the rates of laparoscopic nephrectomy for non-malignant disease – between 5% and 90%, including some outliers above and below the 99.8 centile (Figure 22).

Lower volume trusts have the lowest rate of laparoscopic nephrectomy. This may reflect lack of laparoscopic experience of established consultants and / or unwillingness to learn minimal access techniques.

Figure 22: Rate of laparoscopic nephrectomy for non-malignant conditions by trust



Data source: HES, April 2016 to March 2018

In conclusion, low caseloads in nephrectomy for non-malignant disease appear to be impacting variation in care, practice and the scope for innovation such as laparoscopic nephrectomy.

6. Necrotising enterocolitis (NEC)

Necrotising enterocolitis (NEC) is a life-threatening bowel infection that mainly affects premature infants, and a minority of term infants.

The infection is progressive and can affect all layers of the bowel, leading to necrosis (death) of the bowel and perforation. The initial extent of infection varies from relatively small areas of bowel to the entire bowel. Prompt treatment involving withholding of feeds and administration of broad-spectrum intravenous antibiotics can halt and reverse the disease's progress, meaning that not all affected babies require surgery.

High mortality rates

In 2011, the National Confidential Enquiry into Perioperative Death (NCEPOD) in Children's Surgery found that NEC accounted for a quarter of deaths in children following surgery.[39] In one in five deaths, the review considered there had either been a delay in seeking a surgical opinion or a delay in transfer.

A recent prospective study by the British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)[40] on babies receiving surgery for NEC found that overall mortality was 18% at 28 days and 29% at one year. Almost half of babies born with NEC in England die in the first year of life.

When we look at the data by networks, we found it is comparable to the BAPS-CASS study and similar to that seen in the USA based Vermont Oxford Network.

Figure 23 shows the mortality rates for babies with NEC by network from January 2014 to December 2016. The overall 28-day mortality is 21%. There is network-level variation in mortality from 10% to 38%. There may be more than one paediatric surgical unit in each network and some babies are transferred out of network due to lack of NICU/PCC capacity in the surgical centre.

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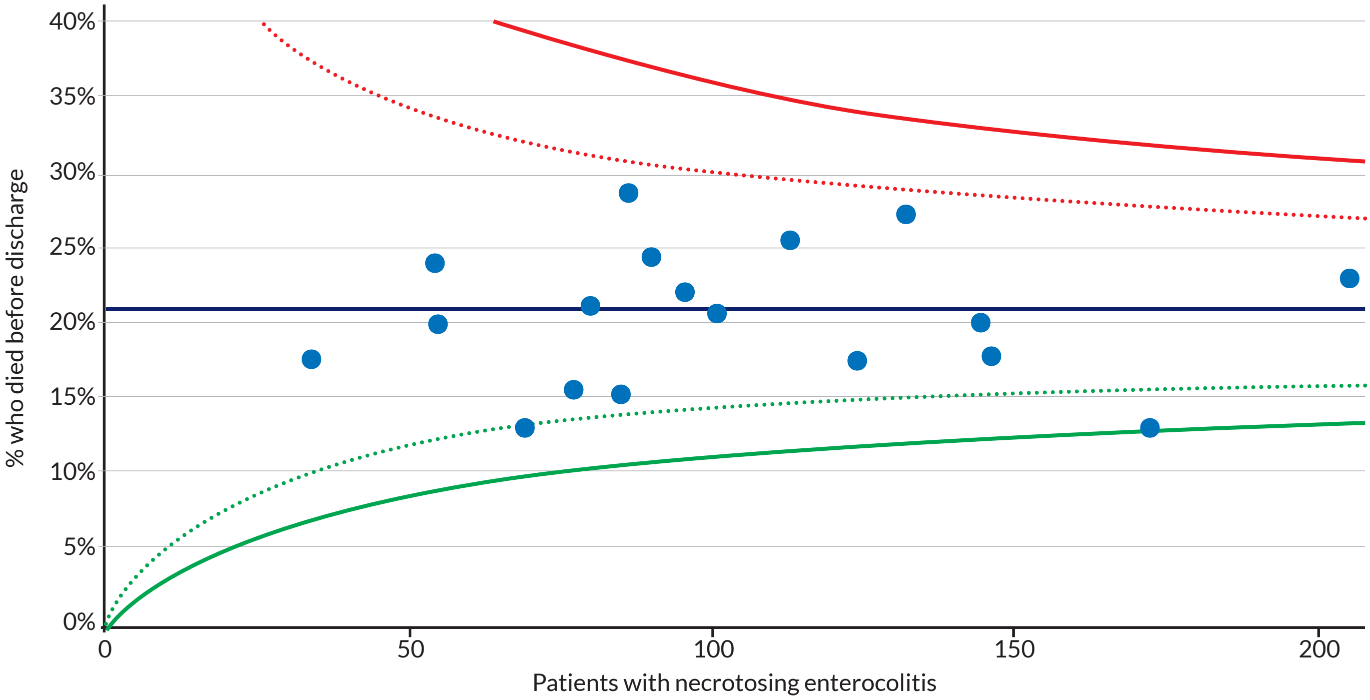
[39] *Hull, M.A., Fisher, J.G., Gutierrez, I.M., Jones, B.A., Kang, K.H., Kenny, M., Zurakowski, D., Modi, B.P., Horbar, J.D. and Jaksic, T. (2014). Mortality and Management of Surgical Necrotizing Enterocolitis in Very Low Birth Weight Neonates: A Prospective Cohort Study. Journal of the American College of Surgeons, 218(6), pp.1148–1155*

[40] *See https://www.baps.org.uk/professionals/clinical-outcomes/baps-cass/*

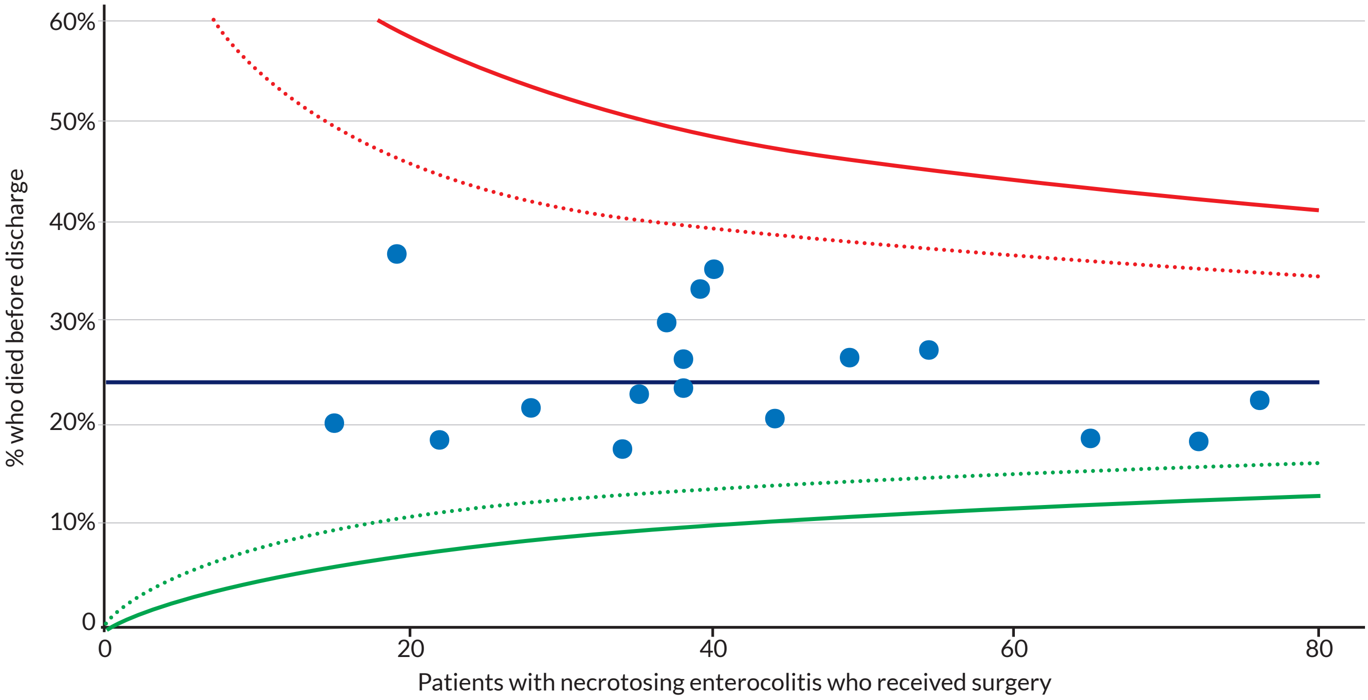
Mortality is higher in babies who undergo surgery (24%) compared to those who do not have surgery (19%). Babies requiring surgery are overall likely to be a sicker group.

Figure 23a: Mortality for babies diagnosed with necrotising enterocolitis



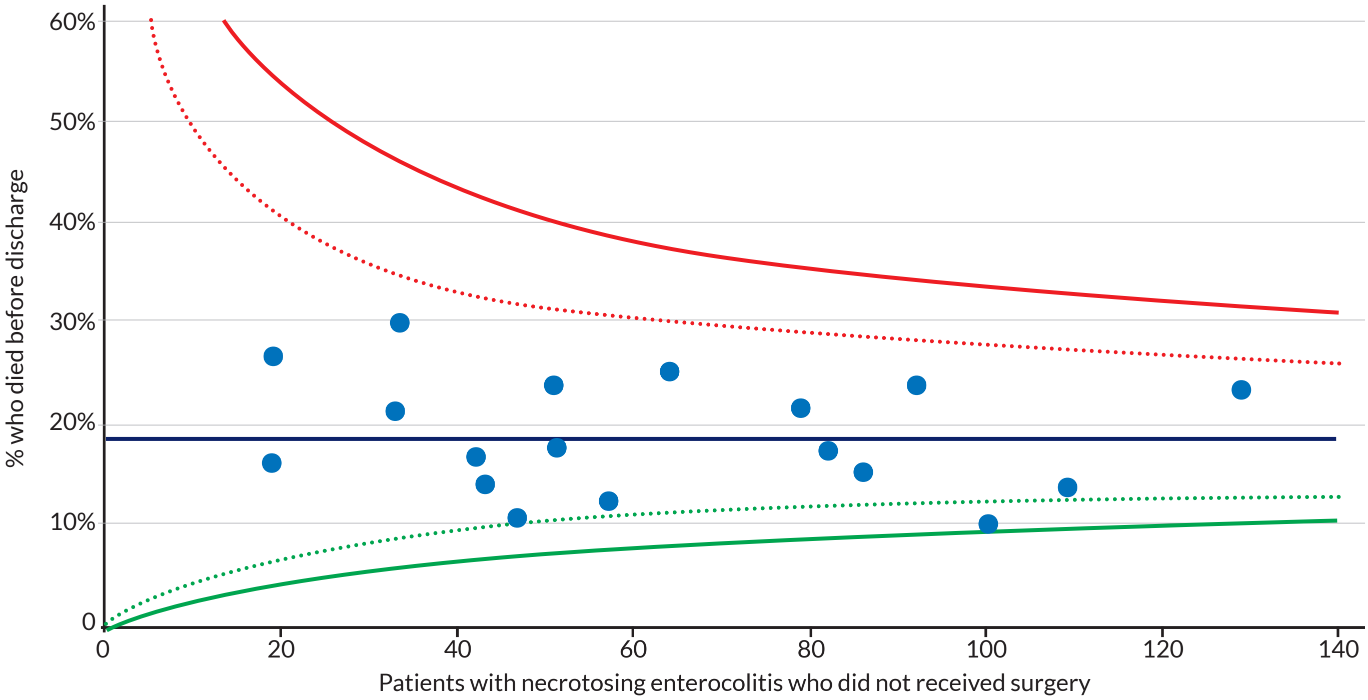
Data source: National Neonatal Research Database, January 2014 to December 2016.

Figure 23b: Mortality for babies diagnosed with necrotising enterocolitis who received surgery



Data source: National Neonatal Research Database, January 2014 to December 2016.

Figure 23c: Mortality for babies diagnosed with necrotising enterocolitis who did not received surgery



Data source: National Neonatal Research Database, January 2014 to December 2016.

Surgery threshold

Prompt treatment involving withholding feeds and administering a spectrum of intravenous antibiotics can halt and reverse disease progression. If this is successful, the baby may not require surgery.

The precise timing and role of surgery in neonates with NEC is contentious. Different trusts and surgeons have different thresholds for intervention. What is not contentious is that surgery is indicated in neonates with at least one of the following:

- radiological evidence of an intestinal perforation indicative of the disease process having resulted in intestinal necrosis;
- evidence of persistent inflammatory mass resulting in intestinal obstruction.

More subjective is the role of surgical intervention in a neonate who is clinically deteriorating despite maximum non-operative treatment in the absence of clinically detectable perforation. The threshold for surgery can also be governed by the size and general condition of the baby. In some cases, clinical deterioration can be so rapid that surgical intervention is unwarranted and futile.

Access to surgery

Over half of level 3 NICUs lack immediate access to paediatric surgical services.

Not having access to surgical services may lead to delays in paediatric surgical review. Babies that do need surgery will require specialist neonatal transport services. These are high risk transfers of extremely premature and unwell babies, which inevitably delay treatment, risking possible deterioration in the baby's condition. In 2018, 85% of transfer teams attended the neonate within 3.5hrs of the referral call and the median stabilisation time was 100 minutes.[41] This illustrates the delays involved in delivering surgical care.

We do not know if the outcomes in trusts that lack immediate access to paediatric surgery differ from the outcomes in trusts with immediate access.

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[41] *See Neonatal Transport Group https://ukntg.net/*

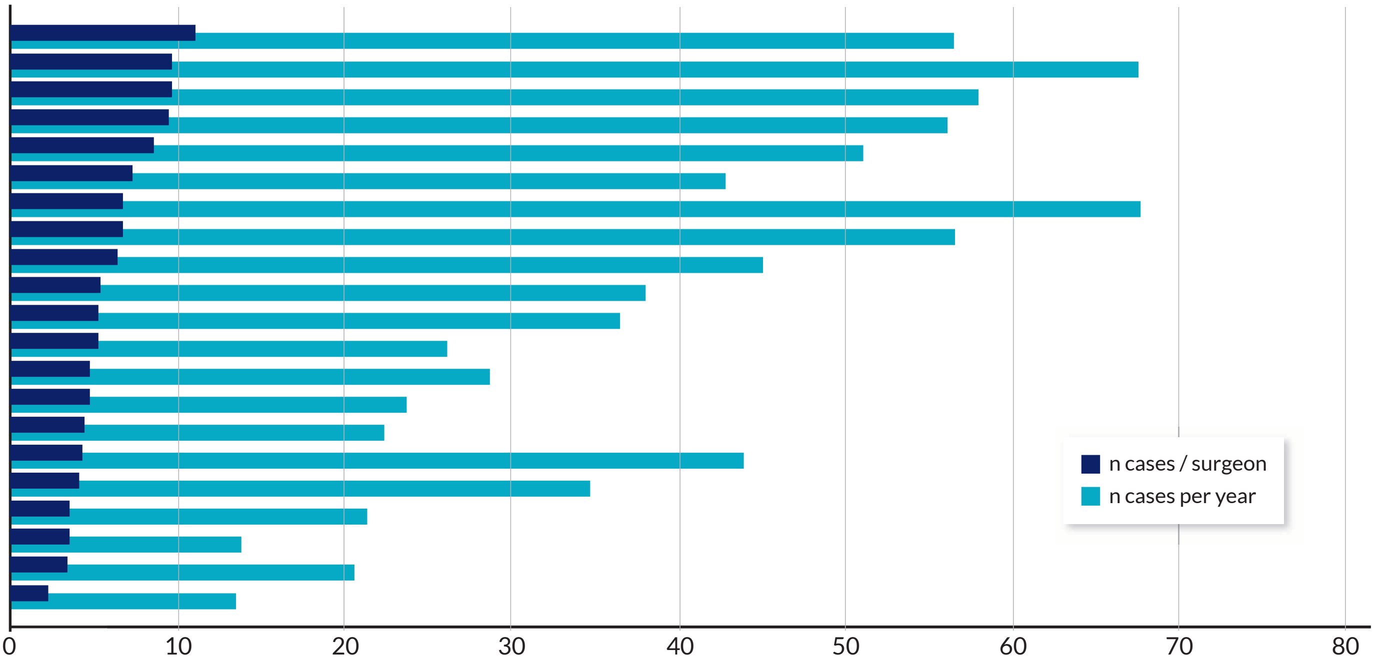
Volumes

Approximately 230 babies in England per year born at <32 weeks' gestation develop severe NEC.

There is a fivefold variation in the caseload volumes for surgical NEC between trusts and surgeons. The range in annual surgeon caseload is between two and 11.3 cases (Figure 24).

As would be expected given the emergency nature of surgery for babies with NEC, all surgeons participating in the on-call rota at specialist trusts were involved in emergency laparotomies for babies with NEC.

Figure 24: Total trust and surgeon caseload of surgical necrotising enterocolitis (NEC) Apr 2013 - Mar 2018



Data source: HES, April 2013 to March 2018

Preventing and reducing severity of necrotising enterocolitis

It is clear that there are simple measures that neonatal units could take nationally that could reduce the:

- incidence of NEC;
- need for surgical intervention;
- number of neonates that die from this complication of prematurity.

Neonatal networks and trusts should review their policies and performance as well as monitoring network level rates of NEC.

Breast milk

It is well established that feeding preterm infants breast milk rather than formula feed reduces NEC[42, 43, 44] as well as improving overall outcomes. Although supplementing feeds with formula can increase the energy content and improve growth, this comes at the cost of increased morbidity and mortality from NEC.

Given this, it is concerning that only 31% of babies are discharged having been exclusively breast fed/fed donor breast milk, and 51% partially breast fed. We have included provision of breastmilk in our recommendation 2, part a.

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[42] *Lambeth, T., Rojas, M., Lightbourne, T., Barahona, M., Anthony, E., Auringer, S. and Sisk, P. (2016). Necrotizing Enterocolitis and Growth in Preterm Infants Fed Predominantly Maternal Milk, Pasteurized Donor Milk, or Preterm Formula: A Retrospective Study. American Journal of Perinatology, 34(07), pp.676–683*

[43] *Sisk, P.M., Lovelady, C.A., Dillard, R.G., Gruber, K.J. and O'Shea, T.M. (2007). Early human milk feeding is associated with a lower risk of necrotizing enterocolitis in very low birth weight infants. Journal of Perinatology, 27(7), pp.428–433.*

[44] *Vohr, B., Poindexter, B., Dusick, A. and Mckinley, L. (2007). Age Care Unit on Outcomes of Extremely Low Birth Weight Infants at 30 Months of Persistent Beneficial Effects of Breast Milk Ingested in the Neonatal Intensive. Pediatrics, [online] 120(4).*

Probiotics

There is a growing evidence base that the routine use of probiotics in preterm neonates could reduce both the incidence and severity of NEC. [45, 46, 47, 48, 49, 50, 51]

It has been estimated that widespread UK-wide adoption of routine probiotics could half the number of very low weight babies contracting NEC and save the lives of 50 very low birthweight babies per year. As well as the benefits for babies and their families, there are potential cost-savings for the NHS in avoiding the need for surgery.

Given these benefits, it is concerning that a recent audit of probiotic use in UK NICUs showed that only 17% of trusts were routinely using probiotics and that there had been no increase in usage since 2014.[52]

Taken together, if increased breast milk use and probiotics were universally adopted, potentially over 100 babies each year would not develop NEC with a concomitant reduction in death rate.

Limitations to understanding outcomes in NEC

We analysed data from two sources:

- the Neonatal Research Database (NNRD), which shows outcomes for all babies within each neonatal network;
- Hospital Episode Statistics (HES), which shows outcomes for individual trusts.

The correlation with trust level data (HES) and network level data was not strong since trusts receive patients from more than one network and vice versa.

Trust-level outcome data proved difficult to interpret because neonatal populations differ between specialist trusts that have an NICU and those that do not have an NICU.

Future GIRFT workstreams should focus on the comparative outcomes for NEC in NICUs where there is immediate neonatal surgical availability, versus outcomes in NICUs lacking neonatal surgical input.

Interpreting the data was complex because there are areas of the country with more than one specialist trust within a network, and others were babies are transferred out of network.

Case definition in Badgernet

The case definition of necrotising enterocolitis is subjective in Badgernet (the platform used to record and share maternity data). Currently, babies with spontaneous intestinal perforation - which is a distinct clinical entity - may be incorrectly recorded as having NEC. In 2017, new guidance was issued to aid in diagnosis.

We further suggest consideration is given to a nationwide NEC data registry that collects all relevant NEC related information in one place and works with developed definitions of NEC.

It is concerning that babies who have died, and who haven't had surgery or post-mortems, are having NEC recorded on death certificates as their cause of death, often alongside prematurity as a secondary cause, but parents are told that NEC cannot be confirmed unless a surgery or a post-mortem has occurred. It is unclear where such cases sit in data inclusion and statistics.

Diagnosis

There is some evidence of variation between networks in the number of babies with an NEC diagnosis (data not controlled for population). However, there is no definitive way to confirm diagnosis of NEC in babies who either die before surgery and don't have a post-mortem, or who are treated for NEC and get better without surgery.

This means it is difficult to draw definitive conclusions from the data available. Analysis should improve as case definitions are revised.

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[45] *Battersby, C., Santhakumaran, S., Upton, M., Radbone, L., Birch, J. and Modi, N. (2014). The impact of a regional care bundle on maternal breast milk use in preterm infants: outcomes of the East of England quality improvement programme. Archives of Disease in Childhood - Fetal and Neonatal Edition, 99(5), pp.F395–F401*

[46] *Probiotics: live microorganisms intended to provide health benefits when consumed, generally by improving or restoring the gut flora.*

[47] *Athalye-Jape, G. and Patole, S. (2019). Probiotics for preterm infants - time to end all controversies. Microbial Biotechnology, 12(2), pp.249–253.*

[48] *Pell, L.G., Loutet, M.G., Roth, D.E. and Sherman, P.M. (2019). Arguments against routine administration of probiotics for NEC prevention. Current Opinion in Pediatrics, 31(2), pp.195–201*

[49] *Rees, C.M., Hall, N.J., Fleming, P. and Eaton, S. (2017). Probiotics for the prevention of surgical necrotising enterocolitis: systematic review and meta-analysis. BMJ Paediatrics Open, 1(1), p.e000066*

[50] *Singh, B., Shah, P.S., Afifi, J., Simpson, C.D., Mitra, S., Dow, K. and El-Naggar, W. (2019). Probiotics for preterm infants: A National Retrospective Cohort Study. Journal of Perinatology, 39(4), pp.533–539*

[51] *Underwood, M.A. (2019). Arguments for routine administration of probiotics for NEC prevention. Current Opinion in Pediatrics, 31(2), pp.188–194*

[52] *Duffield, S.D. and Clarke, P. (2018). Current use of probiotics to prevent necrotising enterocolitis. Archives of Disease in Childhood - Fetal and Neonatal Edition, 104(2), pp.F228–F228*

Surgical site infection benchmark

There is currently no benchmark for surgical site infection following neonatal laparotomy for NEC. This made it impossible to review performance against an agreed rate.

Further analysis

Further questions that are currently unanswered include:

- the role of primary anastomosis in NEC;
- timing of stoma closure;
- early warning signs of NEC, including biomarkers.

In conclusion, NEC is a highly complex, life-threatening bowel infection that mainly affects premature infants.

Preventative measures will reduce the need for surgery, and most importantly lower morbidity and mortality in these vulnerable infants. There is significant variation in the adoption of preventative measures across England.

Almost half of level 3 neonatal intensive care services do not have immediate access to paediatric surgical services. Delays in surgical review and neonatal transfer may be contributing to mortality.

In cases where surgery is needed, trusts should be able to provide the necessary surgery and post-operative care.

There is a fivefold variation in surgeon and trust-level caseload. The impact of this on decision-making and outcome is unknown. Optimising surgeon caseload volumes must be balanced against the logistical challenges of transporting sick neonates over long distances in a timely manner.

Data and collection sharing practices should be strengthened for research and audit purposes.

Conclusions: delivery of complex surgery

Overall, the delivery of complex paediatric surgery has evolved organically, resulting in a wide range of unwarranted variation across the country.

Complex surgical practice in children is spread too thinly across specialist trusts, leading to extremely low numbers of cases per trust, and per surgeon. This is resulting in reduced experience for individuals and teams, reduced training opportunities, and limited scope for innovation, which in turn is affecting care.

Based on the volumes undertaken by trusts for oesophageal atresia repair and congenial diagragmatic hernia, for example, if the AUGIS model was to be adopted surgery would be rationalised to one trust in England, with that trust performing three repairs per week. This would result in that trust becoming expert in this surgery, and would motivate innovation and infrastructure development.

It is worth noting that the UK is not alone in this: a similar situation exists in many developed nations, including the USA and Germany.

Having a specialist paediatric surgical workforce comes at significant cost, both to individual trusts and to the NHS as a whole. If a team exists, it should have all the interdependent services - such as urology, PICU, NICU, specialist nurses, imaging and image guided intervention - needed for that team to perform its role fully.

A national and regional network level approach should be adopted in the diagnosis and management of complex paediatric surgical conditions to deliver care on a wider footprint than the specialist trust where the index procedure is performed. For example: in paediatric solid tumour surgery, trust A might perform the biopsy and obtain central vascular access for treatment, while trust B would perform the resectional surgery.

There is a strong case for neighbouring specialist trusts within networks to form consolidated subspecialist teams to perform specialist cases. This would enable an increased surgical caseload and improve the sustainability of services. We saw examples of this working effectively.

Our six index cases exemplify these challenges. In the case of NEC, we have seen in addition to these challenges specific opportunities to reduce mortality. Making breastmilk and probiotics more readily available to pre-term neonates to help prevent NEC, and ensuring co-located NICU and paediatric surgery services to prevent delays in access to surgery. We strongly recommend that action is taken (recommendation 2) in support of the NHS Long Term Plan's ambition to accelerate a 50% reduction in neonatal mortality.

Towards a new service delivery model

Part 1 of our review explores how the organisation of paediatric surgery has evolved organically and asks whether the current service model is able to meet the current and future needs of children and their families. The case for change is compelling and will require a coordinated approach. We recommend that children's surgical networks are developed regionally and nationally to achieve the following goals:

- deliver a sustainable model of care;
- improve equity of access to treatment in the right place at the right time;
- maintain and improve current high-quality services.

Our findings and recommendations complement NHS England and NHS Improvement's Paediatric Critical Care and Specialised Surgery in Children Review.[53] Both reviews have concluded that children's surgical networks are required.

Model of care

NHS England and NHS Improvement's Paediatric Critical Care and Specialised Surgery in Children Review proposes a model of care based on three levels of care (Figure 25). The NHS Long Term Plan (section 3.46) requires that, over the next five years 'paediatric critical care and surgical services will evolve to meet the changing needs of patients', and NHS England is supporting this goal through the commissioning of Paediatric Surgery (PS) ODNs.

Based on our findings on the provision of complex paediatric surgery, we recommend that level 3 paediatric surgery/urology should be split into two further sub classifications (Table 6). We summarise the necessary standards of care, critical interdependencies, and safe/sustainable staffing levels.

Table 6 lists the proposed index conditions to be treated in Level 3a centres. We have provided detailed findings for the neonatal index conditions and we have based those findings on the proposed paediatric index conditions.

There is a balance to be struck between individual centre and surgeon caseload, and distance of children and their families from surgical centres. Given that many conditions such as oesophageal atresia are lifelong and require further procedures, it is reasonable to recommend that ten centres in England are categorised as 3a centres, meaning that facilities and expertise are concentrated and allow for training, research and innovation. This should mean that England has world-leading neonatal centres of excellence for the 21st century.

Within each level 3a service, there should be at least three surgeons with a subspecialty interest in the procedure. This minimum number of subspecialty surgeons is important for service sustainability and so that each trust or network has a peer group.

A peer group is useful for sharing resources, providing support, operating, governance and audit.

Figure 25: NHS England and NHS Improvement's proposed model of care

Surgery in Children Level 1	Surgery in Children Level 2	Surgery in Children Level 3
Day case only (no inpatient provision)	In patient and day case provision	In patient and day case provision
Non-specialised activity	Non-specialised activity	Delivery in specialised trusts and commissioned trusts
Delivered by a small number of providers	Delivered in District General Hospitals	Specialised activity (including routine care for complex patients)
No alignment with PCC levels of care	Aligns to PCC Level 1	Aligns to PCC level 2 in general
		Provision in limited number of hospitals for low volume specialties
		A small number of specialties align to level 3 PCC

Source: Paediatric Critical Care and Specialised Surgery in Children Review, NHS England and NHS Improvement, [2019]

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[53] *https://www.england.nhs.uk/wp-content/uploads/2019/11/paediatric-critical-care-and-surgery-in-children-review-summary-report-nov-2019.pdf*

Table 6: GIRFT-recommended sub-classification for level 3 paediatric surgery services

Level	Standard of care provided	Critical interdependencies	Clinician safe-staffing levels
3a	• Plus level 1 & 2 • Specialised neonatal surgery • Indexed neonatal surgery • Indexed specialised paediatric surgery • Specialised paediatric surgery	• Plus level 3b • Level 3 PCC • Specialist paediatric radiology • Paediatric urology • Co-location with cardiac, neurosurgery, trauma, specialised orthopaedics, neonatology • Paediatric nephrology	• Plus level 3b • Upper GI: 4 specialist paediatric surgeons (on-call rota 24/7)* • Lower GI: 4 specialist paediatric surgeons (on-call rota 24/7)* • Urology: 3 specialist paediatric urologists (on-call rota 24/7)
3b	• Plus level 2 • Neonatal surgery (excl. indexed) • Specialised paediatric surgery (excl. indexed)	• Plus level 2 • Level 3 NICU • Level 2 PCC • Specialist paediatric radiology Integrated fetomaternal medicine service • Palliative care • Gastroenterology • Dietetics/nutrition	• Plus Level 2 • Minimum 4 specialist paediatric surgeons (on-call rota 24/7, available within 30 mins) • Specialist paediatric anaesthetists (on-call rota 24/7, availability 30 mins) • Paediatric ODP on site 24/7

*it may be possible to create larger rotas over a bigger footprint

Table 7: Proposed index cases for neonatal and complex paediatric surgical cases to be treated in Level 3a specialist paediatric surgical services.

Index neonatal conditions (minimum 10/year per centre)
Congenital diaphragmatic hernia
Oesophageal atresia (long-gap: 3 centres nationally)
Hirschsprung's disease (total colonic: 3 centres nationally)
Anorectal malformation

Index complex paediatric surgical conditions
Paediatric solid tumour surgery
Paediatric endocrine surgery
Thoracic lobectomy
Oesophageal replacement procedures
Nephrectomy
Anti-reflux procedures
Bladder augmentation; mitrofanoff; artificial sphincter insertions.

Operational Delivery Networks (ODNs)

Operational Delivery Networks (ODNs) bring clinicians, providers, commissioners and patients together to change complex systems of care in order to improve care quality and outcomes.

Following the successful introduction of ODNs in other specialties, NHS England and NHS Improvement is establishing funded children's surgical ODNs across the country. The ODNs will encompass all children's surgery and anaesthesia in children, as well as networked paediatric imaging and interventional radiology

Networks will be commissioned to cover both complex and low-complexity care, not just specialised activity.

They will:

- implement the model of care based on the local population/area, improve local pathways and provide governance structures over surgical activity within network;
- manage capacity and patient flows so that patients receive care from the most appropriate provider, as close to home as possible, and so that quality of care across the area improves;
- identify unwarranted variations in operational performance of trusts that may be driving higher costs, for example average lengths of stay, and standardise processes;
- help to improve data collection, clarify service specifications, tier services from different providers, share learning, standardise requirements and protocols, for example in workforce skill levels and triage.

This GIRFT report will inform the ODNs and providers in addressing variations in elective and emergency paediatric surgical care. In revisits to specialist trusts, we will review services against the new ODN footprints.

Workforce

Having a workforce that is the right size and appropriately trained across the network is key to the delivery of safe and sustainable services.

To support this, and in the context of the intentions set out in the Interim People Plan[54], we suggest consideration is given to:

- Workforce planning in alignment with the model of care, for example:
  - increasing the number of nurse practitioners and advanced clinical practitioners able to deliver care;
  - increasing the number of adult general surgeons with a subspecialty interest in paediatric surgery at secondary level.
- National implications for paediatric surgical trainee numbers;
- Whether paediatric surgical training should parallel systems in the USA and Canada, in which trainees first accredit in general surgery or urology prior to commencing a two-year paediatric surgical specialty training. Such a scheme would ensure that:
  - trainees entering paediatric surgery have significant general surgical exposure to major caseload;
  - the short lead time from entry to completion of paediatric surgical training would enable better matching of training numbers to consultant vacancies;
  - competency maintenance;
  - general surgical trainees interested in pediatrics spending time in a specialist trust;
  - alternative approaches to training.

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[54] *See https://improvement.nhs.uk/resources/interim-nhs-people-plan/*

Recommendation	Actions	Timescale
1. Use the newly established Operational Delivery Network (ODN)-based model of care in children's surgery to ensure that all children requiring surgery are treated by experienced teams with the right infrastructure and support.	**a** GIRFT to support NHS England and NHS Improvement in the development of a paediatric surgery service delivery model, which is informed by the findings in the GIRFT paediatric surgery report.	To be aligned with NHS England and NHS Improvement's timescales.
	b GIRFT to support NHS England and NHS Improvement to develop and implement ODNs across England, including defining KPIs and ensuring neonatal surgery is fully integrated with network governance processes.	
	c NHS England and NHS Improvement, ODNs and trusts to work together to deliver the model of care, by ensuring: • Expertise and resources for children with the rarest surgical problems are concentrated into, indicatively, 10 centres; • Specialist centres managing less rare conditions are able to provide appropriate care for urgent conditions; • Staffing arrangements are in place to ensure common surgical emergencies can be managed promptly in local hospitals close to home.	
2. Reduce the mortality rates in premature babies with necrotising enterocolitis by encouraging breast feeding, use of probiotic nutritional supplements and rapid surgical review of babies with suspected NEC.	**a** Trusts to encourage maternal breast feeding for premature babies, drawing on evidence from the East of England Perinatal Network and elsewhere as helpful, with a view to maximising breast feeding/donor milk rate at discharge.	Within six months of publication
	b GIRFT and NHS England and NHS Improvement to develop plan aimed at provision of probiotic nutritional supplements in all neonatal units. In the interim, trusts are encouraged to expand use of supplements and share implementation experiences with GIRFT.	Within six months of publication
	c Trusts and Operational Delivery Networks to ensure rapid surgical review of babies with suspected necrotising enterocolitis.	Within nine months of publication

Part 2: Variation in practice

In Part 1 we looked at the existing model of care delivery and how to improve this model (see Recommendation 1, page 65).

In Part 2 we look in further depth at the variation between trusts in aspects of delivering paediatric surgery. The key aspects we review are:

- optimising secondary care;
- variations in elective and emergency surgical practices.

Later, we also look at measuring clinical outcomes, the environment of care, measuring patient experience and leadership.

These are areas which, on both a regional and national level, can contribute to lessening unwarranted variation in care delivery to children and their families. Environment of care, leadership, and patient experience all contribute to improved experience for children and families during periods of high stress and potentially high financial burden. We have seen how improving data collection, collecting data meaningful to patients and families, and talking to patients and families about the way care is delivered are essential to ensuring that the medical care is exemplary, but also that the way in which it is delivered gives patients and families the best experience possible.

Photo courtesy of Birmingham Children's Hospital.

Optimising secondary care

During our deep dive visits we found unwarranted variation within emergency care, urgent elective care and elective care which includes:

- balancing emergency and elective care, particularly urgent elective care;
- low rates of day case surgery for low-complex procedures;
- high rates of cancellation;
- unnecessary pre-operative stays for elective inpatients;
- high rates of readmissions.

Understanding and reducing unwarranted variation, through agreed best practice in each of these areas, will help improve care and release capacity.

Emergency surgery

The Royal College of Surgeons of England Report 'Emergency surgery: standards for unscheduled care' (2011) emphasised the need for emergency care to be prioritised over elective care, as often emergency patients are the sickest and most in need. Furthermore, the report highlighted that delays in care were by their very nature inefficient and added to the financial burdens of the NHS.

In general, surgical teams have adopted the recommendations outlined in the report: they have a dedicated consultant surgeon free of elective commitments in order to provide timely emergency surgical care. However, we still found some trusts, both specialist and non-specialist, in which there was either no 24-hour emergency list or in which the emergency list was oversubscribed.

To the credit of non-specialist trusts, it was apparent that children's emergencies were prioritised, and delays minimised. Counterintuitively, the longest delays in access to emergency surgery were in specialist trusts where all specialties were paediatric, and prioritisation was on clinical need rather than age alone.

Although all trusts had guidelines for timing of emergency surgery, very few trusts have routine reporting systems in place to allow emergency surgical teams to analyse their performance in 'real-time' against agreed guidelines. An example included a trust which introduced emergency list software to allow monthly reporting of performance of emergency theatre against time targets, in addition to providing a platform to allow efficient list management of emergency cases.

The inpatient costs of patients waiting for emergency surgery are a hidden cost to the NHS and visibility on this issue, through improved reporting on 'real time' versus agreed guidelines (as outlined above), may provide the evidence to motivate an increase in the resource required to enlarge emergency surgical capacity.

The issues around anaesthetic and surgical workforce, particularly in non-specialist trusts, have been discussed in Part 1 (see page 64).

Urgent elective surgery

The distinction between elective and emergency surgery can be blurred. Many complex elective specialist procedures are urgent. However, there is widespread variation in how urgent elective surgery is scheduled. Dependencies include:

- performing within an optimum age window;
- the amount of time patients spend in trust prior to surgery;
- the age of the patient.

These factors can and do impact patient experience and increase costs to the trust.

Some elective reconstructive paediatric surgical procedures have an optimum age window; delays in scheduling of elective surgery can mean that the time window is missed. An example that we examine in further detail is hypospadias surgery, which is best performed between one and two years of age.

During the visits to specialist trusts, a recurrent theme described by surgeons was the difficulties they experienced in accessing operating lists to perform urgent elective surgery. Often, children need to be kept in hospital until they have their procedure which places a strain on families, as well as increasing bed pressures. Examples include:

- a tumour resection for a child with cancer;
- a thoracic lobectomy for a child with recurrent chest infections;
- a pyeloplasty for a child in pain with an obstructed kidney;
- an anti-reflux procedure for a child with recurrent life-threatening episodes.

We found a trust which regularly runs lists with planned space for urgent elective neonatal surgery. This allows urgent elective cases to be scheduled, freeing the emergency list for true emergencies as they arise and means that neonates can receive surgery in a timely manner.

When we looked at reference costs for inguinal herniotomy in children under one year of age, we found that costs in this trust were £882 per case, whereas the national average costs were £1,827 per case (elective, day surgery and emergency combined corrected for casemix). It is likely that costs are lower as babies are not kept in hospital waiting for their surgery.

Data such as this strongly supports the provision of additional operating capacity for urgent cases. Achieving this will improve the experience for children and their families, reduce the costs of inpatient stays, as well as reducing complications from delays in surgery.

Elective surgery: day case

During the deep dives we found very few trusts are aware of their day case rate and how they compared to other similar trusts nationally. We look separately at non-specialist and specialist trusts, and the variation in day case rates.

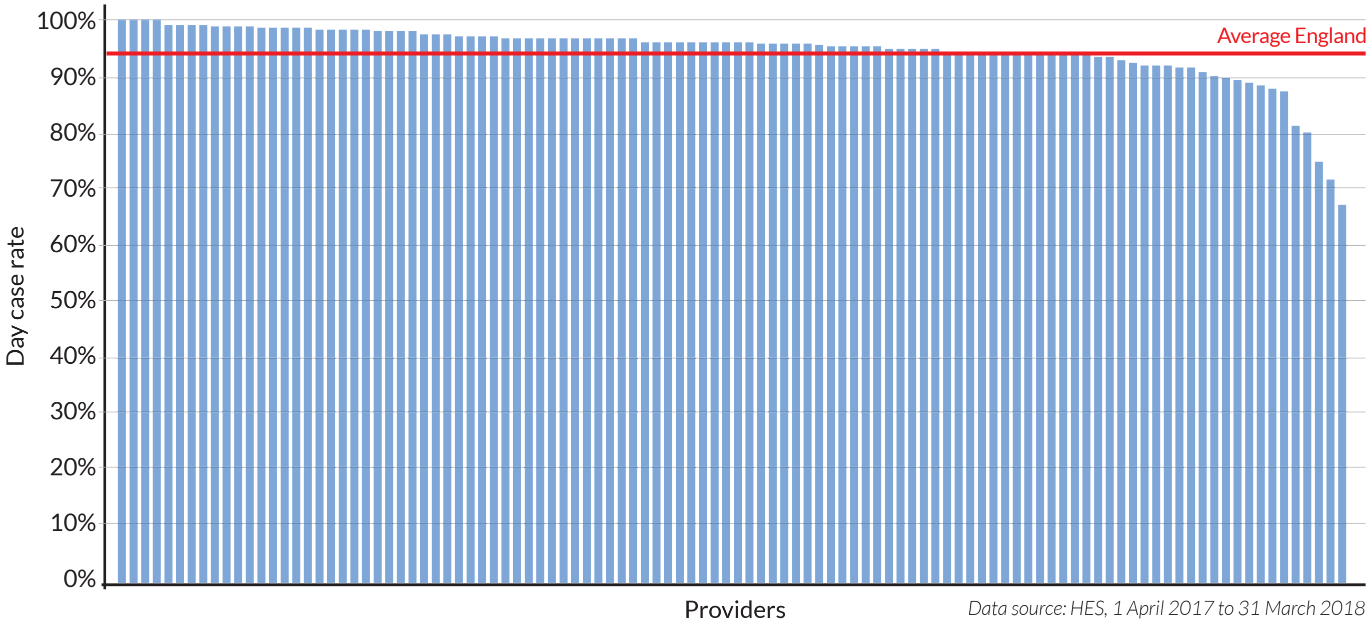
Day case surgery for low-complexity cases are desirable in most cases, as carrying out surgery on the day of admission means less stress on families and less financial burden (time off work, hotel stays).

Day case rates in non-specialist trusts

Most elective paediatric surgical cases are low-complexity procedures that can be performed as day cases, so it was not surprising to find that most elective cases in non-specialist trusts are treated as day cases.

The overall average day case rate in non-specialist trusts was 93.5% (Figure 26). A few non-specialist trusts deliver some complex care and this has an impact (although minor) on their day case rates. However, if all trusts were to achieve a 98% day case rate in elective surgery, 700 overnight admissions per year could be saved (see Figure 26).

Figure 26: Day case rate for elective paediatric surgery spells in non-specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

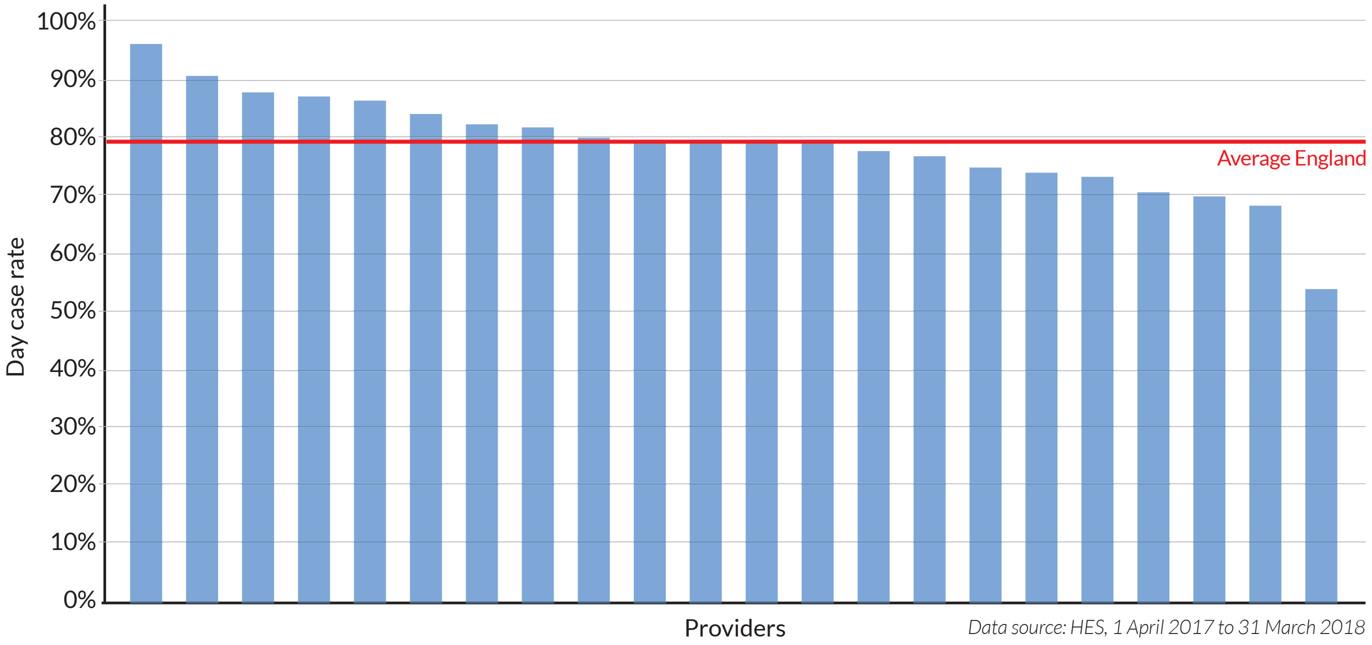
Red line = national average of 93.5%
Day case defined as any elective spell with length of stay = 0

Day case rates in specialist trusts

There is a much more marked variation in the day case rates for elective surgery in specialist hospitals – from 90.5% to 54.5% (Figure 27).

The overall average rate is 79.3%.

Figure 27: Day case rates for elective paediatric surgery in specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

Red line = national average of 79.3%
Day case defined as any elective spell with length of stay = 0

Relationship between case load complexity and day case

The marked difference (14.2%) in average day case rates between non-specialist and specialist trusts suggests there is a clear relationship between overall caseload complexity and day case rates (Figure 28), with more complex cases occurring within specialist trusts and therefore reducing the capacity for less complex day cases through the increased length of stays required.

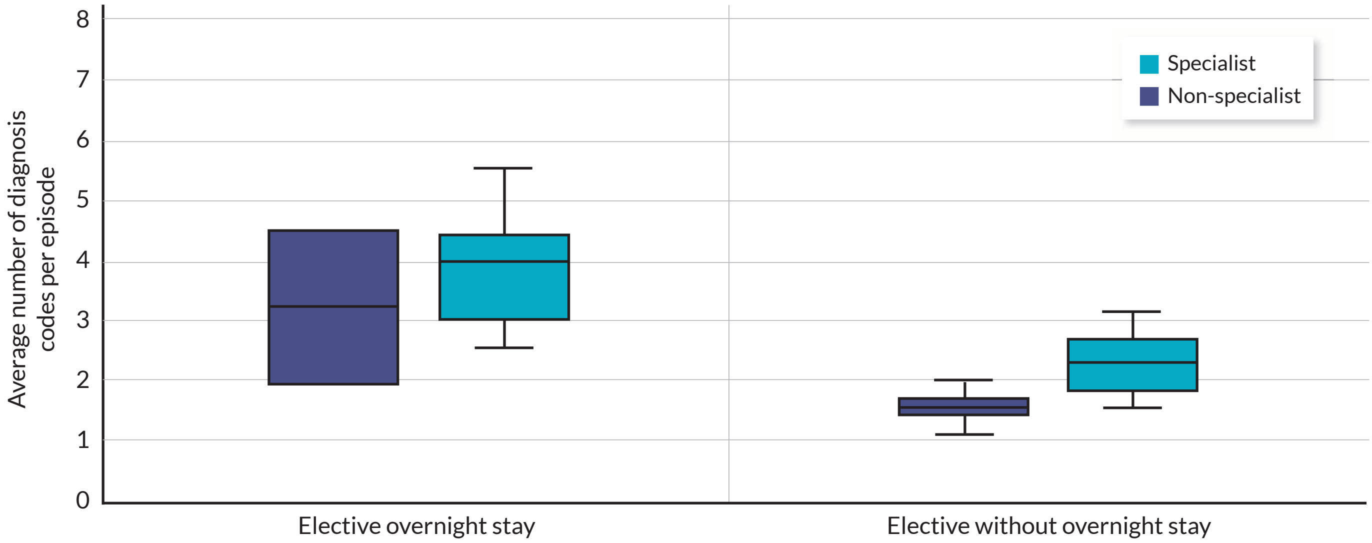
We analysed this by mapping the average number of diagnostic codes per episode against day case and overnight stay. The higher the number of diagnostic codes, the more complex the case. The number of diagnostic codes can, therefore, be used as an indicator for the complexity of a case. For example, Child A will have a higher number of diagnostic codes per episode than Child B if:

- Child A: Inguinal hernia + neurodevelopmental delay + epilepsy = 2 codes;
- Child B: Inguinal hernia = 1 code.

In specialist trusts, children requiring an overnight stay following surgery have 4.3 diagnostic codes per episode versus 2.4 diagnostic codes per episode for children having day case surgery.

As we saw in Part 1, specialist trusts are taking on the majority of complex cases, and the majority of neonate and under five cases. It therefore follows that specialist trusts will see more complex cases, leading to a higher proportion of longer duration stays.

Figure 28: Average number of diagnosis codes recorded per paediatric surgery episode in specialist and non-specialist trusts



Source: HES Apr 17 to Mar 18

These findings suggest that trusts are generally selecting the appropriate groups of children to undergo day case surgery.

Variation in policy impacting day case rates

Reducing variation has been clearly shown to improve outcomes and resource utilisation in healthcare. We found evidence that trusts had local policies in place that did not meet current evidence-based practice regarding day case surgery. Day cases can turn into overnight stays as a result of variation in trust policies which impacts on day case rates and indeed practices of care. This also impacts the patient experience as overnight stays increase stress for babies and their parents and occupies scarce cot space.

For example, there can be substantial variation in trust policy on the use of day case for specific complex and low-complex procedures, such as hypospadias surgery (Figure 51) and orchidopexy (Figure 58).The data suggests that established practice and inertia are key factors affecting the use of day case in many trusts.

Furthermore, from our deep dive visits, we found variations in anaesthetic policy between trusts as to whether babies needed to stay overnight following inguinal herniotomy. Many infants over a month of age can be safely sent home on the same day of surgery. However, while the Association of Paediatric Anaesthetists has produced a wide range of useful guidelines,[55] no national guidance exists on which babies should be kept overnight following inguinal herniotomy.

In the absence of consensus guidelines, individual trusts have different policies, resulting in the observed variation.

Capacity and planning

Many specialist and non-specialist trusts expressed their frustration at the practice of list capping – where a trust places a cap on the maximum number of children that can be admitted as a day case. Trust management may choose to do this because their paediatric day care facilities are oversubscribed and face competing pressures, for example from children with medical conditions requiring investigations. To get around such caps, some trusts resort to admitting children into inpatient beds the night before their day surgery.

Furthermore, if the time allocated for the list is not fully used, the costs of surgery are higher and theatre capacity is unused.

Some trusts have adopted innovative solutions to allow day surgery facilities to run lists at full capacity. For example, Blackpool Teaching Hospitals NHS Foundation Trust runs dedicated paediatric lists one day a week through three full day theatres. Trusts should also examine their day case and theatre scheduling to ensure that day care facility utilisation is smooth throughout the week. Other options are to reduce the number of paediatric day case lists but put more cases on them to match day case capacity.

CASE STUDY

Dedicating a day case unit to paediatric surgery on a specific day

Blackpool Teaching Hospitals NHS Foundation Trust

Blackpool Teaching Hospitals NHS Foundation Trust runs dedicated paediatric lists one day a week through three full day theatres.

Patients are seen and listed at outpatient appointments and an anaesthetic preoperative assessment is completed at this time by an experienced paediatric nurse. In addition, the team carries out follow up phone call preassessments. If any health issues or concerns are raised, then notes are sent to the anaesthetic office for review by a paediatric anaesthetist and a decision is made upon suitability for surgery. A small proportion of the more complex cases are referred onto a tertiary centre, particularly if patients have not been anaesthetised before and have complex health needs. Frequent reviews are carried out to safeguard the unit, allowing rapid identification of, and solutions to, problems arising.

The model day case list

We found that very few surgeons, anaesthetists or managers were aware of either the income associated with surgical procedures or the costs associated with running a day case list.

NHS England and NHS Improvement has introduced a programme called Patient Level Information and Costing System (PLICS). PLICS has significant potential in informing managers and clinicians of the costs of care by attributing elements of costs of theatre time, wards, drugs etc. to each patient. In 2018, 80 acute trusts were able to return PLICS data to NHS Digital. We found that although all finance directors were aware of PLICS, clinical engagement was low and restricted to clinical directors. Often, when we presented reference cost data to clinicians, this was the first time that they had thought about the costs associated with treatments.

Day case paediatric surgery is not a high cost specialty. Nonetheless, it costs approximately £4,500 to run a four-hour day surgery session. Clearly, if money allocated to run the services is less than the cost of running it, then lists will be run at a loss.

In a large acute trust, the situation is more nuanced in that trusts may consciously run services at a deficit as they are obliged to provide that service. However, we were surprised by the lack of financial knowledge of clinicians and management involved in delivery of care. PLICS is clearly a way to improve this, but urgent attention needs to be given to making PLICS data available and useful for clinicians and management.

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[55] *See apagbi.org.uk/guidelines*

It was not possible to obtain list utilisation data (data on cases per list, or cases per theatre session) for our first GIRFT visits. During these visits it was clear that there was significant variation in the numbers of day cases that were accommodated in each session. We have seen that some lists were capped at three children. This will mean that the list is loss-making, as the number of children being seen is less than the funding allocated allows. In broad terms, paediatric day case lists should have five low-complexity cases on it to break even.

Unnecessary follow-up following day case surgery

Most routine day surgical operations do not require routine follow-up. We looked to see how many children were being followed up after circumcision (excluding those conditions for which circumcision is performed that do require follow-up) and following inguinal herniotomy (excluding preterm babies or neonates) and found that for these two procedures alone, there were 2,300 unnecessary outpatient appointments. We make specific recommendations within Recommendation 6 for herniotomy and circumcision.

Elective surgery: inpatient

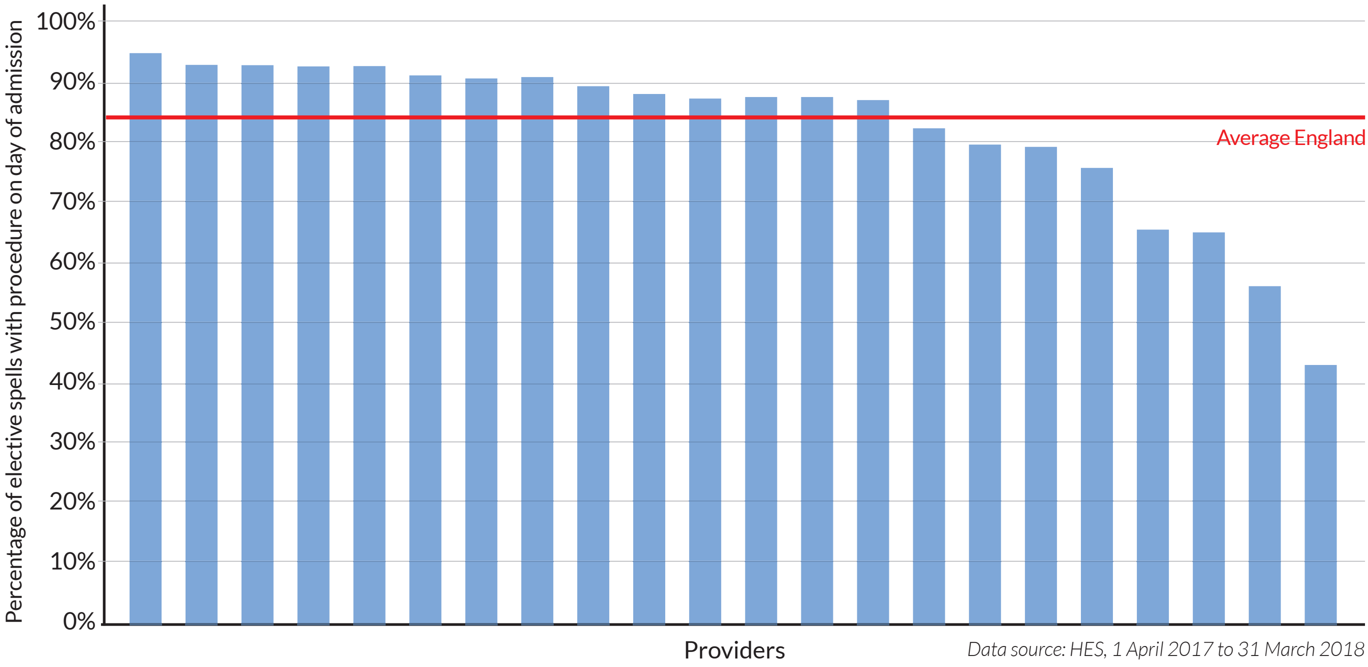
Some elective surgery will require longer stays. We saw, however, variation in the length of stay between trusts: some children were staying longer than necessary in hospital for reasons not related to their care, such as limited access to staff who could process discharge. Longer stays in hospital are distressing for children and their families, increase their time and financial burden, and are a poor use of resources within trusts.

Variation in pre-operative stays

We found significant variation in the number of children who were admitted into hospital and stayed overnight prior to their elective procedure. In many cases, surgery can take place on the day of admission, followed by any necessary post-operative, overnight stays.

In one trust, only 43% of procedures were performed on the day of admission in contrast to 95% in the best-performing trusts (Figure 29).

Figure 29: Day of surgery admission rates in specialist trusts



Data source: HES, 1 April 2017 to 31 March 2018

Reasons for pre-operative overnight stay

The most common reason trusts gave for admitting patients on the day before surgery was to make sure that children had a bed so that surgery could start promptly. This is understandable given that hourly theatre costs are over £600.

Another concern was that an otherwise empty bed would be taken by an emergency case, leading to cancellation of the elective procedure (see page 66 on Emergency surgery).

Other reasons for pre-operative stay include:

- child's family needs to travel a long distance;
- need for bowel or skin preparation;
- to carry out blood tests, consent, or anaesthetic assessments.

Impact of pre-operative overnight stays on inpatient surgical wards and families

We found that admitting children pre-operatively adds to the workload of the inpatient surgical ward. As well as caring for post-operative children and discharging others who can go home, nursing teams have to:

- admit, prepare and care for children ahead of their surgery;
- physically take children from ward to theatre.

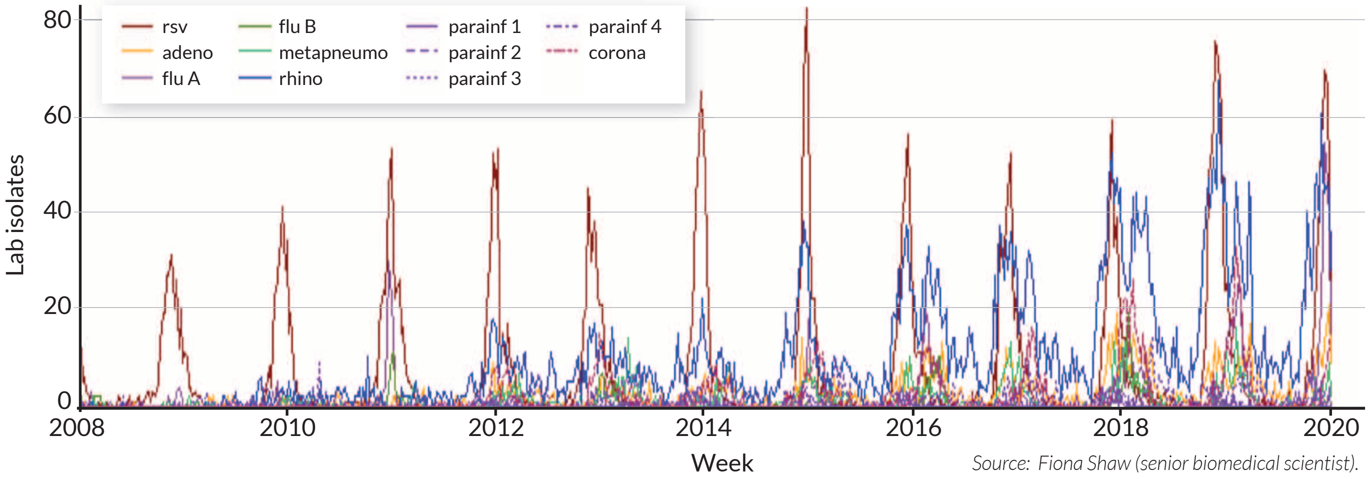
This all adds to the complexity of workload and is likely to impact care and delay discharges, which can also indirectly impact children and their families.

There are several advantages to minimising the delay between a child being admitted and surgery:

- families are better able to arrange leave from work and make arrangements for other children and family members;
- it reduces the demand on inpatient beds – especially during times of high demand, such as during winter pressures;
- it reduces the impact on the efficient running of the inpatient surgical ward.

As we have seen, admitting children pre-operatively is complex and consequently it is essential to manage inpatient admissions carefully. One particular issue is seasonal variation in viral respiratory infections that often overwhelms elective bed capacity (Figure 30). We know that this peak occurs between November and February. The common respiratory viruses demonstrate predictable seasonality with peak numbers in December and January each year. Planning can reduce the impact that this has on elective activity.

Figure 30: Laboratory detections at Alder Hey Children's Hospital microbiology lab between week 1 of 2008 and week 52 of 2019



Source: Fiona Shaw (senior biomedical scientist). Figure is based on a script produced by Dr Roberto Vivancos (consultant epidemiologist, Public Health England). Authorised by Dr Chris Parry (consultant microbiologist).

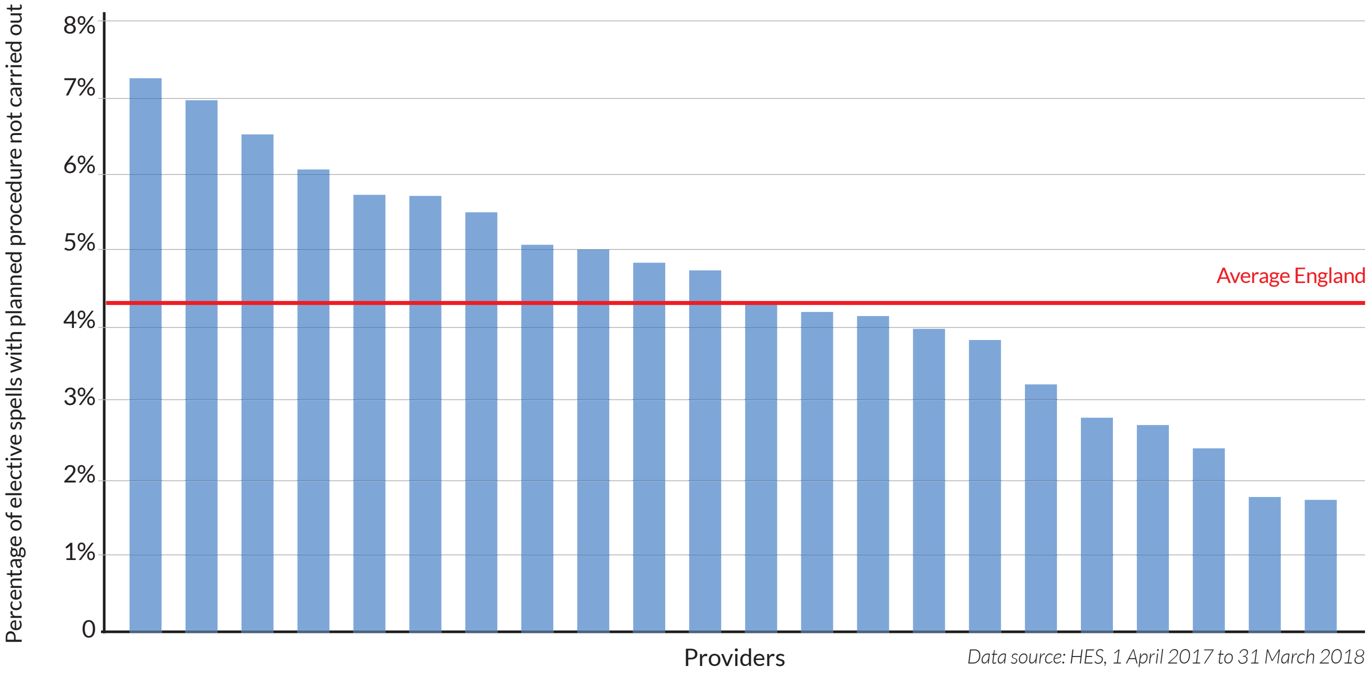
Cancellations: inpatient

The average cancellation rate for inpatients in specialist trusts is 4.3%, with a range of 1.7% to 7.2% (Figure 31).

Overall, around 1,900 children a year have their elective general or urology surgery cancelled on the day of surgery.

Cancellation on the day of surgery has both a significant impact on children and their families and is likely to result in lost theatre productivity. If the national cancellation rate matched that of the best-performing specialist trust, Nottingham University Hospitals NHS Trust, at 1.9%, 1,500 more children per year would not have their procedure cancelled.

Figure 31: Elective admissions followed by no procedure



Data source: HES, 1 April 2017 to 31 March 2018

The most common reasons for cancellation include:

- lack of an inpatient bed;
- patient illness;
- change in the surgical condition;
- staffing or theatre issues;
- inadequate pre-operative preparation.

There are disadvantages to pre-operative overnights stays, as previously discussed, but if there is inadequate pre-operative preparation this can have a negative impact and lead to cancellations. It is therefore necessary to balance these competing challenges.

Length of post-operative stay and readmission rates post-surgery

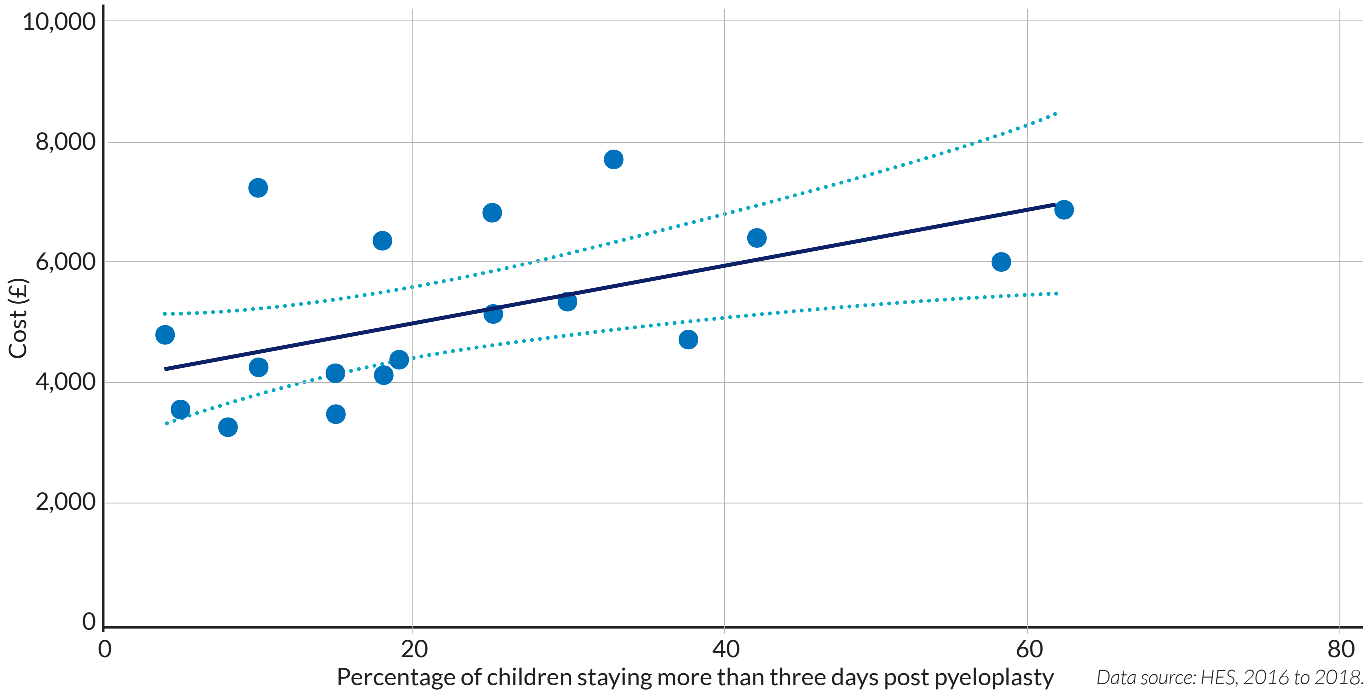
We found significant variation in post-operative length of stay and in readmission rates for some elective procedures.

The reasons for variation in post-operative length of stay appear to be related to one or a combination of the following:

- surgical approach by procedure type;
- custom and practice – there is sometimes an expectation between surgeons, teams and parents that a longer stay is safer / required;
- delay in discharge decision;
- delay in medication prescriptions.

We found, for example, there is huge variation in the numbers of children staying in hospital longer than three days following pyeloplasty (from 4% to 62%). The data shows an increase in length of stay which results in an increase in reference costs (Figure 32). Surgical approach may be playing a role here; the mean proportion of children staying more than three days was 13.3% following laparoscopic or robotic pyeloplasty vs 36.1% following open pyeloplasty.

Figure 32: Relationship between reference cost of admission and percentage of children staying more than three days post pyeloplasty[56]



Data source: HES, 2016 to 2018.

It was found that some trusts perform most pyeloplasties as day cases or with a single night stay. However, achieving this requires MDTs of surgeons, anaesthetists and nursing teams to work closely together to optimise each aspect of care, such as:

- avoiding unnecessary use of opiate infusions;
- establishing criteria-based nurse-led care and discharge pathways;
- laparoscopic or robotic pyeloplasty where appropriate.

We also found significant variation in 30-day readmission rates following pyeloplasty, from zero to 100%. These readmissions excluded routine procedures such as stent removals or dressing changes.

During deep dive trust visits, it was found that teams were unaware that they had high readmission/reoperation rates (excluding routine procedures such as stent removals or dressing changes). It was also found that there is a wide range in two-year reoperation rates from zero to 50%. The reasons for this are likely to be multifactorial.

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[56] *Solid line is linear regression plus 95% confidence interval (dotted line).*

Taken together, clinicians, providers and Operational Delivery Networks (ODNs) should monitor lengths of stay / readmission and reoperation rates as this data highlights both high and low performing units and gives insight into variations in the child's experience of surgery.

Conclusions

We found there are opportunities to release capacity and optimise the secondary care pathway by reducing unwarranted variation within emergency care, urgent elective care and elective care. These include:

- balancing emergency and elective care, particularly urgent elective care;
- increasing day case surgery rates;
- reducing cancellations;
- reducing unnecessary pre-operative stays for elective inpatients;
- reducing readmissions.

From our deep dives we identified the following steps, which may support improvement:

1. **Use an ambulatory (out-patient) pre-operative assessment service**
    - This avoids using inpatient beds and reduces the risk of on-the day cancellation.
2. **Use a pre-operative admissions lounge.**
    - This means that children are only admitted to inpatient wards following surgery, increasing nursing capacity.
3. **Ensure that clinicians and management carry out tactical planning together especially around winter pressures.**
    - This will help to ensure good prospective capacity and demand modelling. Within the usual constraints of clinical urgency, it is possible to change casemix during periods of high predicted emergency demand. For example, switching to one big case requiring one overnight bed as opposed to five smaller cases requiring five overnight beds.
4. **Increase day case rates at times of high emergency demand, for example, during times of high viral respiratory infection prevalence.**
    - This helps to reduce cancellations due to the lack of an inpatient bed.
    - Better recording and monitoring of emergency paediatric surgery through PLICs would help trusts plan their lists to ensure emergency care is delivered without impacting negatively on elective care.
5. **Establish patient hotels.**
    - These are a cost-effective way to avoid pre-operative inpatient stays.
6. **Start operating lists if predictive discharges indicate that a bed will be available 'just in time'.**
7. **Use clinical prioritisation tools to ensure that beds are allocated based on clinical need rather than occupancy of an inpatient bed.**

This last point becomes significantly easier to manage where trusts have access to theatre utilisation data. This would allow trusts to make a more comprehensive assessment of:

- why patients are in hospital;
- the legitimacy of admitting children the day before surgery;
- the reasons for variation in length of stay for both elective and emergency patients;
- variation in time taken for each procedure.

The Clinical Utilisation Review (CUR) is a clinical decision support tool that enables clinicians to make impartial and objective, evidence-based assessments of whether patients are receiving the right care, in the right place, at the right time and for the right length of time, according to a patient's individual needs. It was adopted as a mandatory Commissioning for Quality and Innovation (CQUIN) indicator for specialist providers in 2015-16.[57]

CURs offer considerable potential for trusts to understand theatre data and reference costing data, particularly if linked to HES data.

However, it was not possible to use CUR data for this round of GIRFT visits.

Recommendation	Actions	Timescale
3. Increase the use and scope of day case surgery in paediatric surgery and urology by taking action within trusts across Operational Delivery Networks (ODNs).	**a** Trusts and Operational Delivery Networks should routinely monitor day case rates compared to their peers using Model Hospital/ GIRFT data to identify opportunities to increase day case rates.	Ongoing
	b Where opportunities appear to exist trusts and Operational Delivery Networks should identify local improvements, review variations in trust policies on day surgery, review how consistently trust policies are followed, and review list utilisation using theatre productivity data Monitoring day case theatre productivity to ensure efficient list utilisation	Ongoing
	c GIRFT to work with professional bodies to review and establish any new or amended clinical guidance needed.	As required

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[57] *NHS England (2015) Launch of the National Clinical Utilisation Review Framework. Guide for Clinical Commissioning Groups. https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/08/cur-ccg-guide.pdf*

Variation in practice: emergency

We summarise two emergency conditions and procedures in which we found variation in practice (emergency surgery) during our GIRFT visits:

1. Appendicitis
2. Testicular torsion

These cases provide a snapshot of emergency care, and some of the challenges facing trusts in delivery of care. We make recommendations specific to these conditions and procedures on how unwarranted variation can be reduced to improve care.

1. Appendicitis

It is a progressive inflammation of the appendix and one of the most common general surgical emergencies, which, if left untreated, it can be fatal. The blood supply to the appendix becomes compromised, the appendix becomes necrotic (tissue dies), and perforates. Bacteria then spreads into the abdominal cavity, leading to localised infection causing an abscess, or generalised infection in the entire abdominal cavity.

Each year, over 10,000 children undergo appendicectomy in England (the standard treatment for most cases of appendicitis is the surgical removal of the appendix). Fatalities are now thankfully rare in the UK due to access to surgery. Most cases of appendicitis are treated in non-specialist hospitals although all specialist trusts with emergency departments (EDs) will treat appendicitis. The sickest and youngest children are also treated by specialist hospitals.

Simple and complex appendicitis

Children with appendicitis are deemed to have either simple or complex appendicitis (Table 8). This distinction is critical as it will affect the required care pathway.

Table 8: Outline of appendicitis stages

Stage	Indications	Typical period before discharge	Risk of post-operative complications
Simple appendicitis	Early, non-perforated appendicitis	Within 24 hours of surgery	Lower risk
Complex appendicitis	Perforated or gangrenous appendicitis	Prolonged admission	Greater risk, e.g. wound infection or pelvic abscess

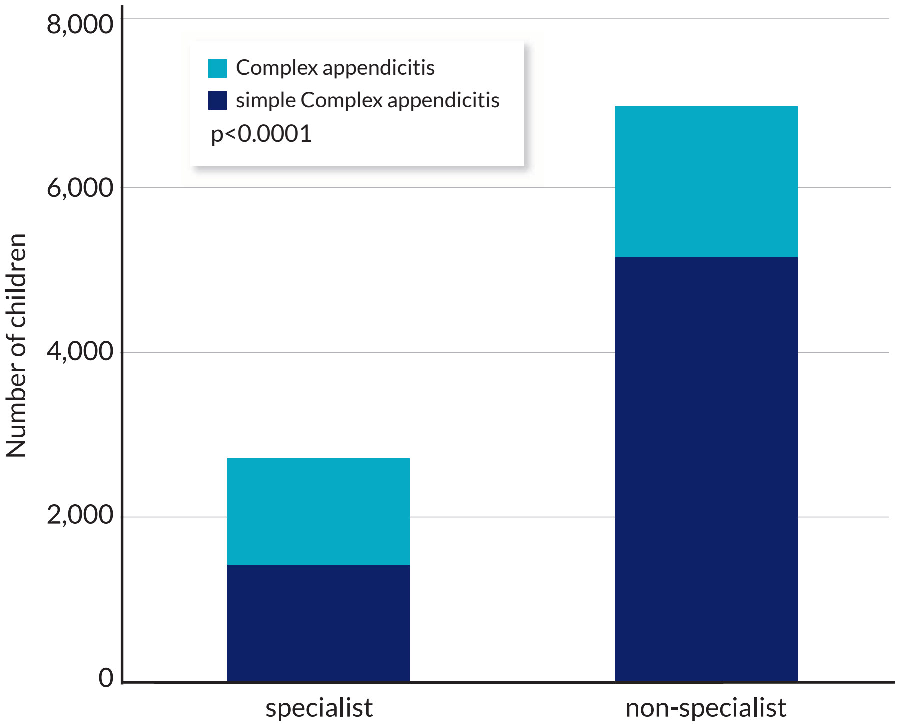
The rate of complex appendicitis in England has risen from 25 cases per 100,000 populations in 2013-14 to 31 cases per 100,000 populations in 2017-18.

This is concerning because a high rate of complex appendicitis has both a human and economic cost. In 2017-18, 3,400 children (32% of all cases) were treated for complex appendicitis (Figure 33). Complex appendicitis is more painful and treatment more distressing for the child. Most children with complex appendicitis stay in hospital for five days or more whereas most children with simple appendicitis stay less than three days. Furthermore, the complication and readmission rate is much higher. The cost of an admission with complex appendicitis is more than twice that of simple appendicitis (£5,829 vs £2,877).

We have found specialist trusts treat a much higher proportion of children with complex appendicitis than non-specialist trusts (Figure 33). This is for several reasons:

- Children who are very unwell are transferred to specialist trusts;
- Children under five are usually transferred to specialist trusts. Because their natural defences are weaker and because they cannot communicate as well, they almost always have complex appendicitis.

Figure 33: Numbers of children treated for simple and complex appendicitis in specialist vs non-specialist trusts



Source: HES, April 2017 to March 2018

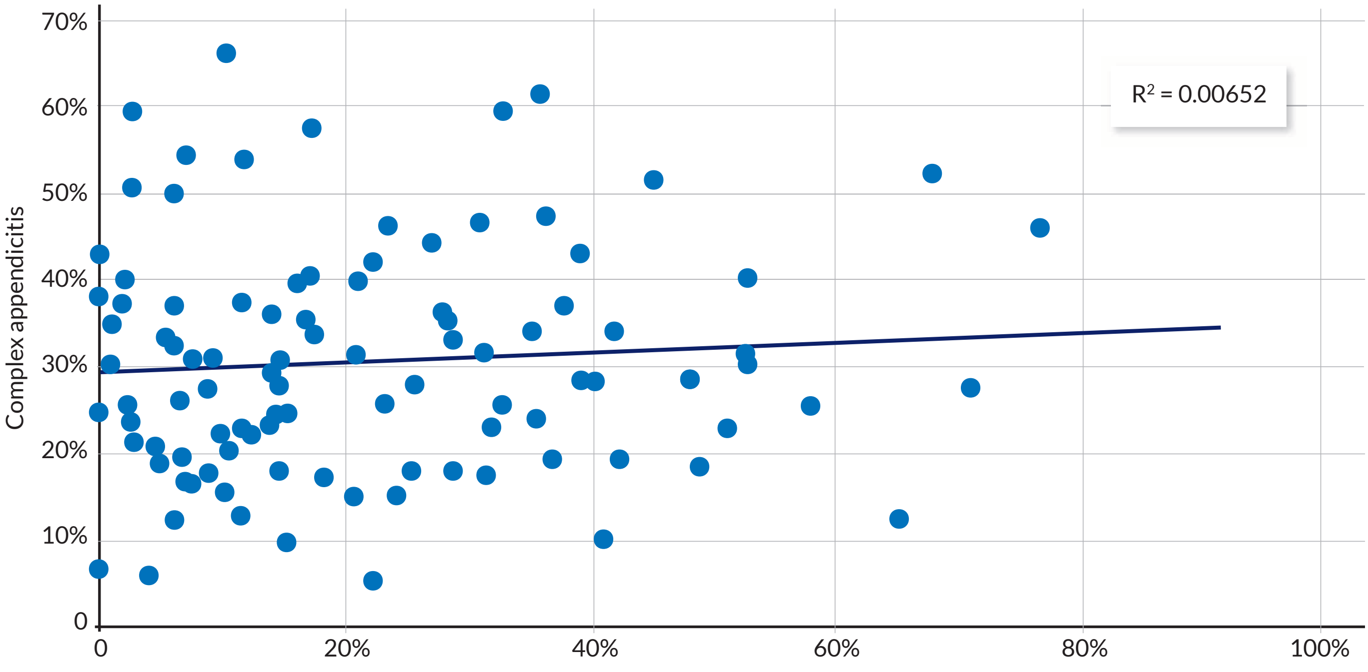
Epidemiology

We found no strong relationship between deprivation (Using Carstairs deprivation index, a tool for measuring deprivation among populations) and incidence of complex appendicitis (Figure 34).

However, what was striking was the clear north-south difference in the incidence of complex appendicitis. For example, between April 2013 and March 2018, the incidence of complex appendicitis in Cumbria and North East England was 42% versus a rest of England average of 32%.

Public Health England and GIRFT are starting to investigate the reasons for this.

Figure 34: Relationship between percentage of children <16 years with complex appendicitis and percentage of children in most deprived quintile by provider*



Data source: HES, 1 April 2017 to 31 March 2018

Negative appendicectomy

Negative appendicectomy is where a patient has an appendicectomy for suspected appendicitis but is then found not to have appendicitis. This is confirmed when the appendix is examined histologically.

It is essential to keep negative appendicectomy rates (NARs) low in order to avoid children unnecessarily undergoing painful surgery, as well as freeing resources for more effective use. A trust's NAR can serve as a good indirect measure of the quality of their emergency surgical service for children (see page 26).

Currently, around 1,000* children have their normal appendix removed each year – a NAR of 10.0%. These figures likely under-estimate the true NAR because of under-recording in HES data.[58] A snapshot national prospective study of paediatric and adult appendicectomy in 2013 found a NAR of 20.6% overall.[59] Significantly, the NAR is much higher in females (17.5%) than males (7%). The reason for the discrepancy is anatomical: ovarian problems in girls can mimic appendicitis.

If the NAR was 5%, around 600 children would avoid unnecessary surgery each year. Figure 35 shows that the NAR is dropping but the decrease is slow.

There is a lack of data on population-level negative appendicectomy rates (NAR). However, large series from the USA, Canada, the Netherlands and Australia suggest significant variation in NAR – between 3.2 and 19%.[60, 61]

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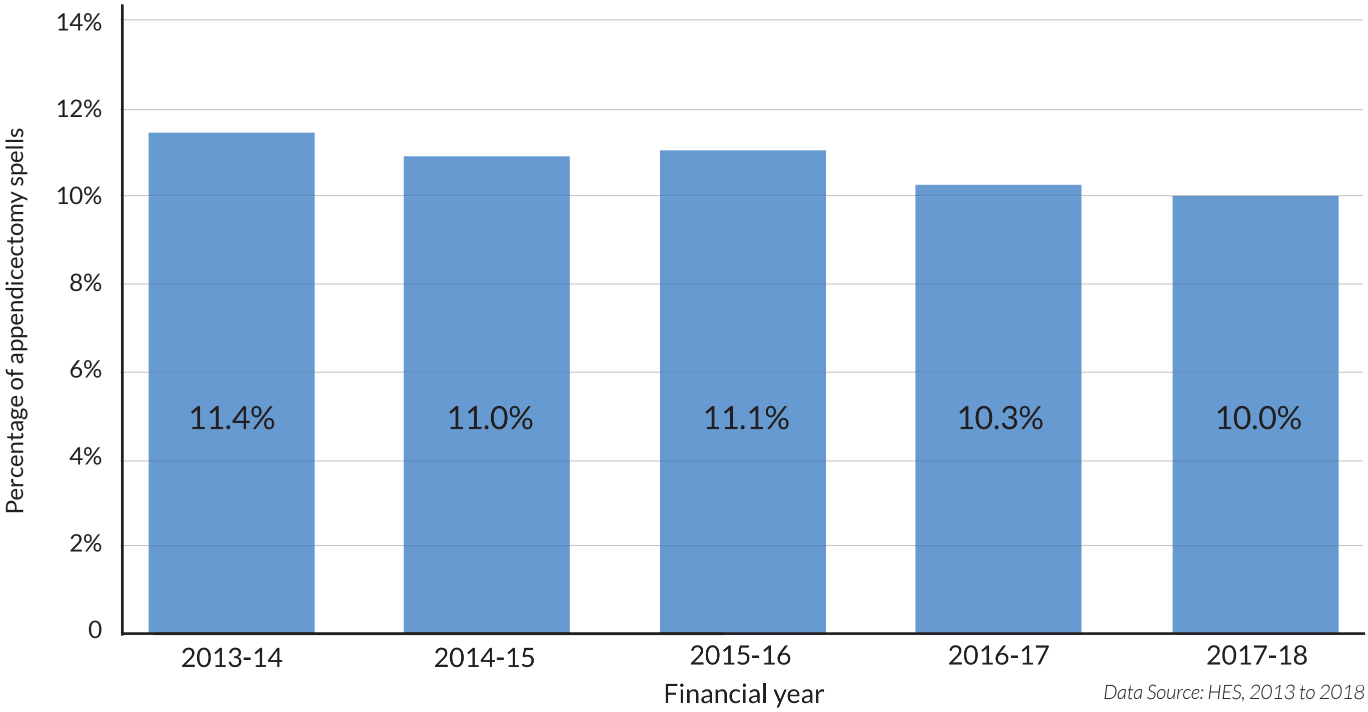
[58] *Bhangu, A., Nepogodiev, D., Taylor, C., Durkin, N. and Patel, R. (2012). Accuracy of clinical coding from 1210 appendicectomies in a British district general hospital. International Journal of Surgery, 10(3), pp.144–147*

[59] *Bhangu, A. et al, (2013). Multicentre observational study of performance variation in provision and outcome of emergency appendicectomy. British Journal of Surgery, 100(9), pp.1240–125*

[60] *Cheong, L.H.A. and Emil, S. (2014). Outcomes of Pediatric Appendicitis. JAMA Surgery, 149(1), p.50*

[61] *Arthur, T., Gartrell, R., Manoharan, B. and Parker, D. (2017). Emergency appendicectomy in Australia: findings from a multicentre, prospective study*

Figure 35: National negative appendicectomy rate by financial year, 2013-2018

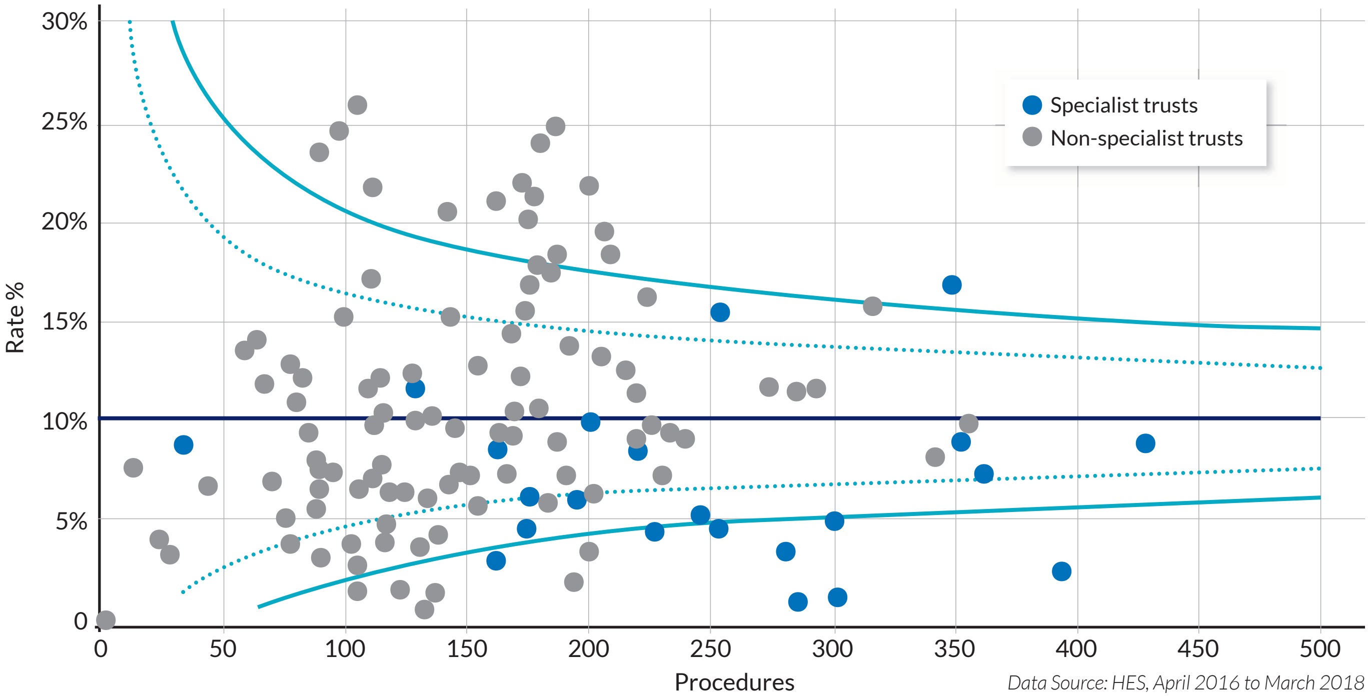


Data Source: HES, 2013 to 2018

Variation in NAR across trusts

We found considerable variation in NAR between trusts overall (Figure 36) with a variation in NAR ranging from 1-28%. The biggest variation in NAR is in girls – from 1-43%, possibly related to the fact (previously mentioned) that ovarian problems in girls can mimic appendicitis. This means that in the worst-performing trust almost half of appendicectomies in girls proved to be negative, and therefore unnecessary.

Figure 36: Normal appendicectomy rates by specialist and non-specialist trust



Data Source: HES, April 2016 to March 2018

Paediatricians are more experienced at dealing with children with unexplained symptoms and their families than general surgeons. Where clinical examination and investigations suggest that the child does not have appendicitis, a watch and wait strategy is preferable to surgery with a high risk of negative findings. This may contribute to the fact that generally, specialist trusts have a lower NAR than non-specialist trusts. This seems likely to reflect specialist trusts having greater access to:

- specialist paediatric surgical assessment;
- paediatric imaging services, e.g. the imaging rate was very low in the non-specialist trust with the highest NAR.

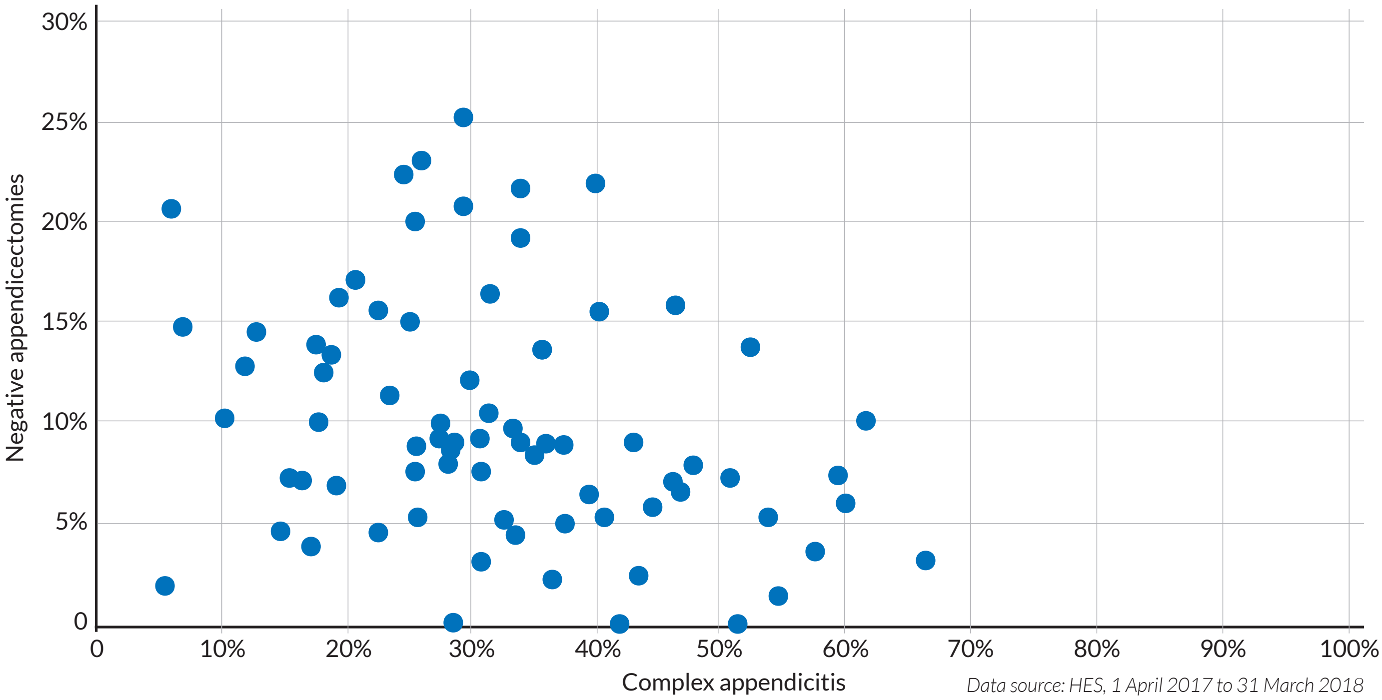
However, when non-specialist trusts have access to high levels of consultant surgical and paediatrician involvement in a joint care model, and better access to imaging, they can also achieve a low NAR.

NAR is not affected by complexity

There is no evidence of an association between complex appendicitis and NAR (Figure 37).

This rules out any hypothesis that trusts with a high incidence of complex appendicitis would have a low NAR and vice versa. We therefore set out to look at other factors across the pathway that may contribute to variations in NAR.

Figure 37: Relationship between percentage of patients with complex appendicitis and negative appendicectomy rate



Data source: HES, 1 April 2017 to 31 March 2018

Looking across the whole appendicitis pathway

In order to understand the reasons for the variation in NAR and complex appendicitis we looked at the whole appendicitis pathway.

Abdominal pain and issues with diagnosing appendicitis

Children with appendicitis are part of a larger group of children presenting with abdominal pain. Most cases of abdominal pain are mild and self-limiting (have a definite and limited course), but the challenge for primary and secondary care providers is identifying cases of appendicitis and other serious causes of abdominal pain correctly.

To be effective, rapid access to senior review and appropriate diagnostic investigations, including radiological imaging, are key to making the right decision and avoiding unnecessary admission. Children who are discharged following these investigations can be followed up through telephone consultations and ambulatory clinics.

Data limitations in diagnosis

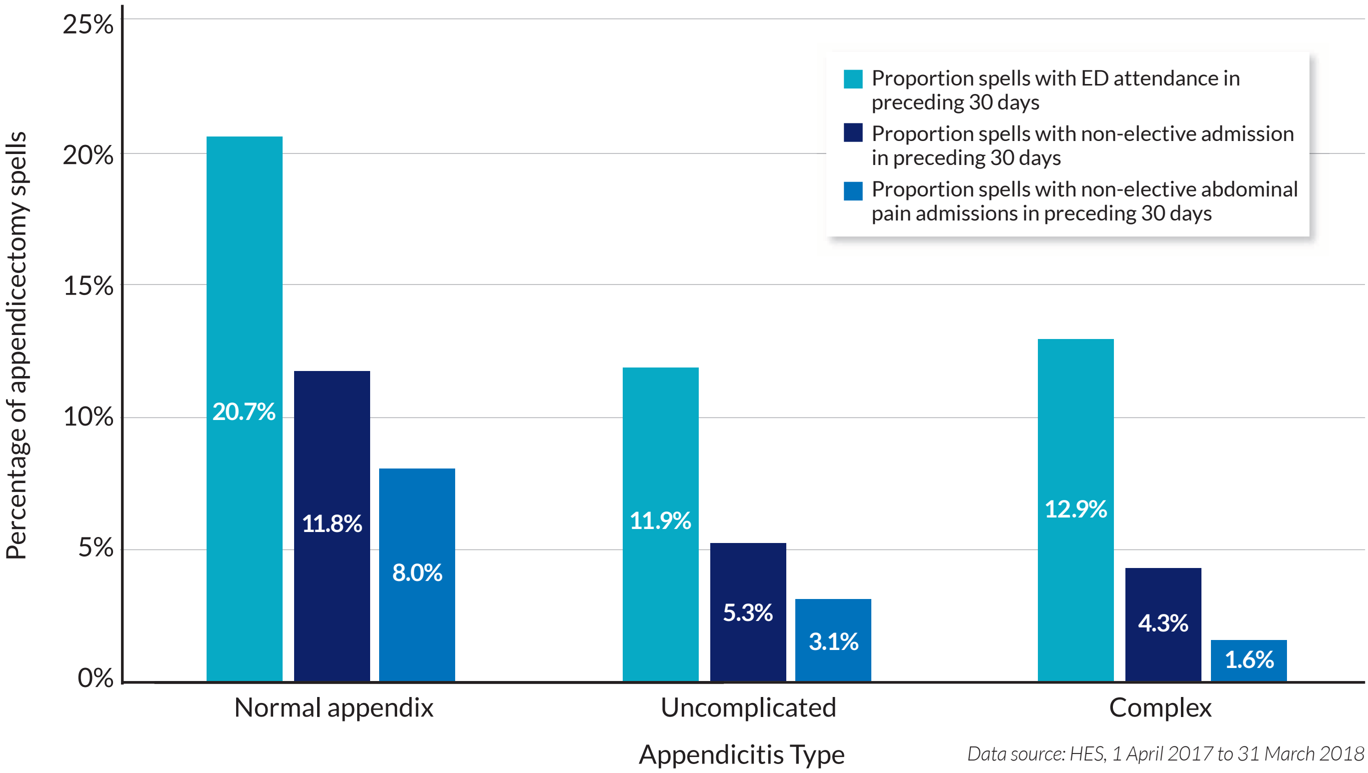
There are, however, data limitations in diagnosis that can hinder the decision-making process. Within the group of children who present with abdominal pain the following limitations can occur:

- data not shared between primary and secondary care providers;
- no data available on Emergency Department attendances;
- lack of data on variation in radiological investigations;
- the coding for diagnoses of abdominal pain is variable.

Admission to hospital for abdominal pain

Many children are seen or admitted to hospital in the month before they undergo appendicectomy (Figure 38).

Figure 38: Comparing the proportion of children who had normal, uncomplicated, and complex appendicectomy who had presented to ED or been admitted with or without a diagnosis of abdominal pain in the 30 days prior to appendicectomy



Data source: HES, 1 April 2017 to 31 March 2018

The proportion is highest in children who have a normal appendix removed: 24% had attended ED, of whom nearly half (11.8%) had previously been admitted to hospital.

Worryingly, 440 children (12.9%) who had complex appendicitis per year had been previously seen in ED and discharged without being diagnosed. (Between 2012/13 and 2016/17, there were at least 10 legal claims settled by NHS Litigation for delays in diagnosis or treatment of appendicitis at a cost of £390,000).[62]

This is because emergency departments do not consistently use a structured Abdominal Pain Pathway (APP) to stratify risk and guide investigation.

The Royal College of Emergency Medicine does have such a guideline,[63] but the guidance focuses on the emergency department aspect of care rather than the entire episode of hospital admission. For example, it does not include specific guidance on the roles of ultrasound or blood tests which are a key component in diagnostic aids for the diagnosis of appendicitis.

Variation in admission rates for abdominal pain

There is also a large variation in the volumes of children with abdominal pain being admitted to each hospital – between 25 and 650 per year (Figure 39).

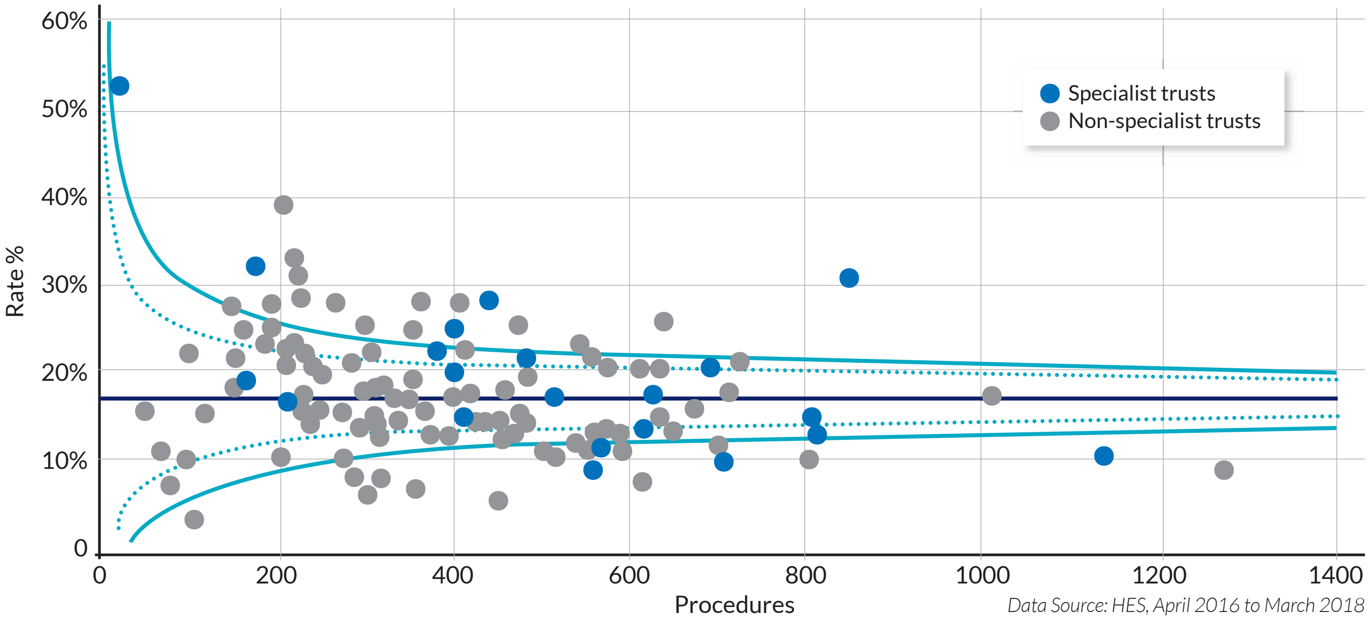
The data suggests significant variation between trusts in the threshold for admission of children with abdominal pain. Many admissions are likely to be avoidable if the right team and decision-making tools are in place.

A number of trusts use emergency decision units staffed by consultant paediatricians or paediatric advanced nurse practitioners working with surgical teams. We found that these worked well.

Variation in length of stay and discharge for abdominal pain

There is no difference in length of stay for abdominal pain between specialist and non-specialist trusts, but there are numerous trusts with a length of stay above the 99.8 centile (over 25% of children staying longer than one day) and a similar number of trusts below the 0.02 centile (fewer than 15% of children staying less than one day).

Figure 39: Percentage of children admitted with a primary diagnosis of abdominal pain who stay more than 24 hours



Data Source: HES, April 2016 to March 2018

The data also suggests significant variation between trusts in management of children with abdominal pain in the time taken to discharge.

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[62] *The statement draws on the NHS Resolution data used elsewhere in this report.*

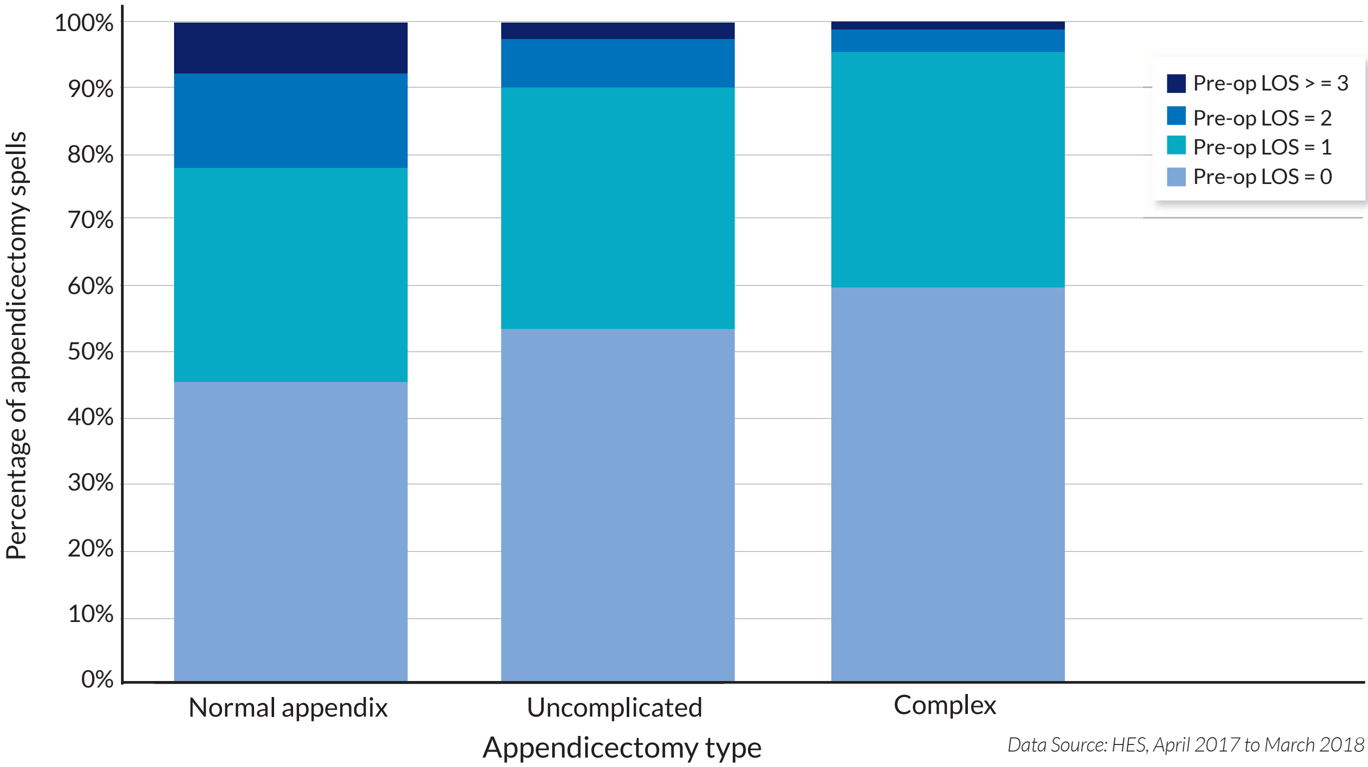
[63] *see Medicine RCEM (2013). Paediatric Acute Abdominal Pain Pathway.*

Pre-operative length of stay for children who undergo appendicectomy

There is variation in the pre-operative length of stay for children who undergo appendicectomy between those who are found to have simple appendicitis, complex appendicitis, and negative appendicectomy (Figure 40).

Typically, children who undergo negative appendicectomy have had a longer pre-operative length of stay. The longer pre-operative stay would appear to be an indication that the clinical team are unsure of the true diagnosis. When linked to the high rate of prior ED attendance (Figure 38) children with persistent non-specific abdominal pain are often recurrent attenders with a high rate of negative appendicectomy.

Figure 40: Preoperative length of stay (LoS, days) in children with normal (negative) appendicectomy, simple (uncomplicated) appendicitis, and complex appendicitis



Data Source: HES, April 2017 to March 2018

Access to diagnostics

Traditionally, appendicitis has been considered to require a clinical diagnosis. Today, the use of imaging, such as ultrasound and diagnostic laparoscopy, along with structured scoring systems and biomarkers, has been shown to reduce NAR and improve accuracy. [64, 65]

However, a current inequity in access to paediatric radiology contributes to variation in prompt and accurate diagnosis. This correlates to the comparison of the findings of two large snapshot studies[66, 67] for England and the Netherlands which points towards a link between patients with abdominal pain who receive perioperative imaging and NAR. Of patients in England 32.8% were imaged, where the NAR is 20.6%, compared to 99.5% of patients imaged in the Netherlands, where the NAR is 3.2%.

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[64] *Bachur, R.G., Hennelly, K., Callahan, M.J., Chen, C. and Monuteaux, M.C. (2012). Diagnostic Imaging and Negative Appendectomy Rates in Children: Effects of Age and Gender. PEDIATRICS, 129(5), pp.877–884*

[65] *de Castro, S.M.M., Geerdink, T.H., Macco, S., van Veen, R.N., Jensch, S. and Vrouenraets, B.C. (2018). Mandatory imaging in the work-up of children suspected of having appendicitis reduces the rate of unnecessary surgeries. Journal of Pediatric Surgery, 53(10), pp.2028–2031*

[66] *van Rossem, C.C., Bolmers, M.D.M., Schreinemacher, M.H.F., Bemelman, W.A., van Geloven, A.A.W., Pinkney, T.D. and Bhangu, A. (2016). Diagnosing acute appendicitis: surgery or imaging? Colorectal Disease, 18(12), pp.1129–1132*

[67] *Bhangu, A. et al, (2013). Multicentre observational study of performance variation in provision and outcome of emergency appendicectomy. British Journal of Surgery, 100(9), pp.1240–125*

Ultrasound

One study from a single hospital has found that adoption of universal ultrasound imaging in appendicitis could result in significant savings.[68] Ultrasound is the gold standard imaging tool for diagnosing appendicitis in children:

- it is cheaper than computed tomography (CT) and magnetic resonance imaging (MRI);
- it avoids the radiation dosage of CT;
- in experienced hands, it provides similar levels of diagnostic accuracy to CT and MRI.

However, many trusts have just one or two radiologists with experience in paediatric ultrasound which leads to inequity in access. This leads to variable out-of-hours and weekend availability and delays in diagnosis.

This is especially the case with appendicitis, since the peak time for children to present to emergency departments with abdominal pain is in the early evening. The result is that children often undergo surgery without preoperative imaging or are admitted pending ultrasound.

This gap in access could be addressed with either additional training in paediatric ultrasound for radiographers or surgeons themselves. Indeed, a possibility for improving access to imaging could be to train surgeons in performing ultrasounds to assess the appendix (a recent Australian study has demonstrated proof of concept).[69]

It is worth noting as well that the clinical standards for seven day services in the NHS, developed in 2013/14 and published by NHS England, which are now part of the standard NHS contract, call explicitly for seven day access to ultrasound in Diagnostics Standard 5.[70]

Diagnostic laparoscopy

Another type of imaging for diagnosis is diagnostic laparoscopy: the insertion of a small tube with a light source and a camera, into the abdomen or pelvis which relays images to a television monitor, for the purposes of diagnosis. It was the view of some trusts, specialist and non-specialist, that diagnostic laparoscopy was appropriate for children where there was diagnostic uncertainty. However, the case for this is unproven, particularly in children.[71]

In the presence of an inconclusive clinical picture and normal investigations, the best performing trusts were sending children home and arranging early review rather than performing diagnostic laparoscopy and appendicectomy.

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[68] *D'Souza, N., Marsden, M., Bottomley, S., Nagarajah, N., Scutt, F. and Toh, S. (2018). Cost-effectiveness of routine imaging of suspected appendicitis. Annals of The Royal College of Surgeons of England, [online] 100(1), pp.47–51*

[69] *Soundappan, S.S., Karpelowsky, J., Lam, A., Lam, L. and Cass, D. (2018). Diagnostic accuracy of surgeon performed ultrasound (SPU) for appendicitis in children. Journal of Pediatric Surgery, 53(10), pp.2023–2027*

[70] *NHS England (2017) Seven Day Services Clinical Standards https://www.england.nhs.uk/wp-content/uploads/2017/09/seven-day-service-clinical-standards-september-2017.pdf*

[71] *Maggio, A.Q., Reece-Smith, A.M., Tang, T.Y., Sadat, U. and Walsh, S.R. (2008). Early laparoscopy versus active observation in acute abdominal pain: Systematic review and meta-analysis. International Journal of Surgery, 6(5), pp.400–403*

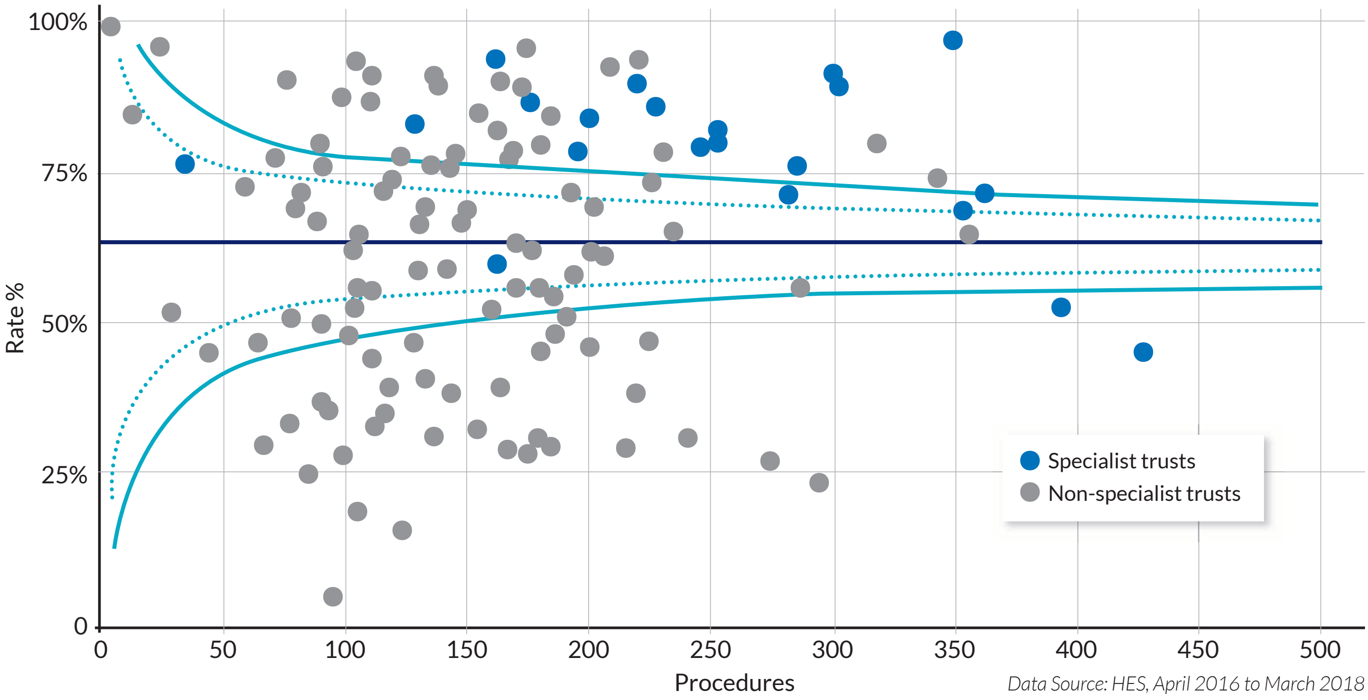
Surgery

Variability in laparoscopic appendicectomy

Of the two kinds of appendicectomy, laparoscopic appendicectomy (removing the appendix or part of the appendix via 'keyhole' surgery) has the advantages of reducing pain and scarring following surgery and has been shown to have outcomes that are equivalent to open appendicectomy.[72]

Overall, specialist trusts perform a higher proportion of laparoscopic appendicectomy than non-specialist trusts. This is despite specialist trusts dealing with higher proportions of children with complex appendicitis.

Figure 41: Percentage of laparoscopic appendicectomies by trust



Data Source: HES, April 2016 to March 2018

We were only able to meet with a very small number of general surgeons who did not have a specific interest in paediatric surgery to hear their views. However, reasons given for low rates of laparoscopic appendicectomy were:

- concerns about the suitability of equipment in place at trusts for performing laparoscopic surgery safely in children;
- lack of experience in paediatric laparoscopic appendicectomy.

Given that many non-specialist trusts can perform a high proportion of appendicectomies in adults laparoscopically, these reasons and the resulting variation in rates are not acceptable.

Delays in surgery for appendicitis

Most children undergoing appendicectomy have their operation within 24 hours of admission. Evidence suggests that in-hospital delays of 12 to 24 hours do not have an adverse effect on outcomes in children with appendicitis and that surgery after midnight should only rarely be performed.[73]

However, as shown, 10% of children with simple appendicitis and 5% of children with complex appendicitis waited more than 24 hours for surgery.

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[72] *Esposito, C., Calvo, A.I., Castagnetti, M., Alicchio, F., Suarez, C., Giurin, I. and Settimi, A. (2012). Open Versus Laparoscopic Appendectomy in the Pediatric Population: A Literature Review and Analysis of Complications. Journal of Laparoendoscopic & Advanced Surgical Techniques, 22(8), pp.834–839.*

[73] *Bhangu, A., Søreide, K., Di Saverio, S., Assarsson, J.H. and Drake, F.T. (2015). Acute appendicitis: modern understanding of pathogenesis, diagnosis, and management. The Lancet, [online] 386(10000), pp.1278–1287.*

Delayed diagnosis of appendicitis results in litigation costs to the NHS (see Litigation, page 120).

Some of this delay may reflect diagnostic uncertainty, but in our discussions with clinicians the reasons most commonly cited were:

- delays in being able to access diagnostic imaging;
- delays in access to emergency lists – especially in specialist trusts.

A suitable national target for appendicectomy would be that all children should receive appendicectomy within 12 hours of listing (see Recommendation 4, page 93).

Post-operative length of stay

There is good evidence that many children can be discharged within 24 hours of appendicectomy for simple appendicitis, or even on the same day.[74]

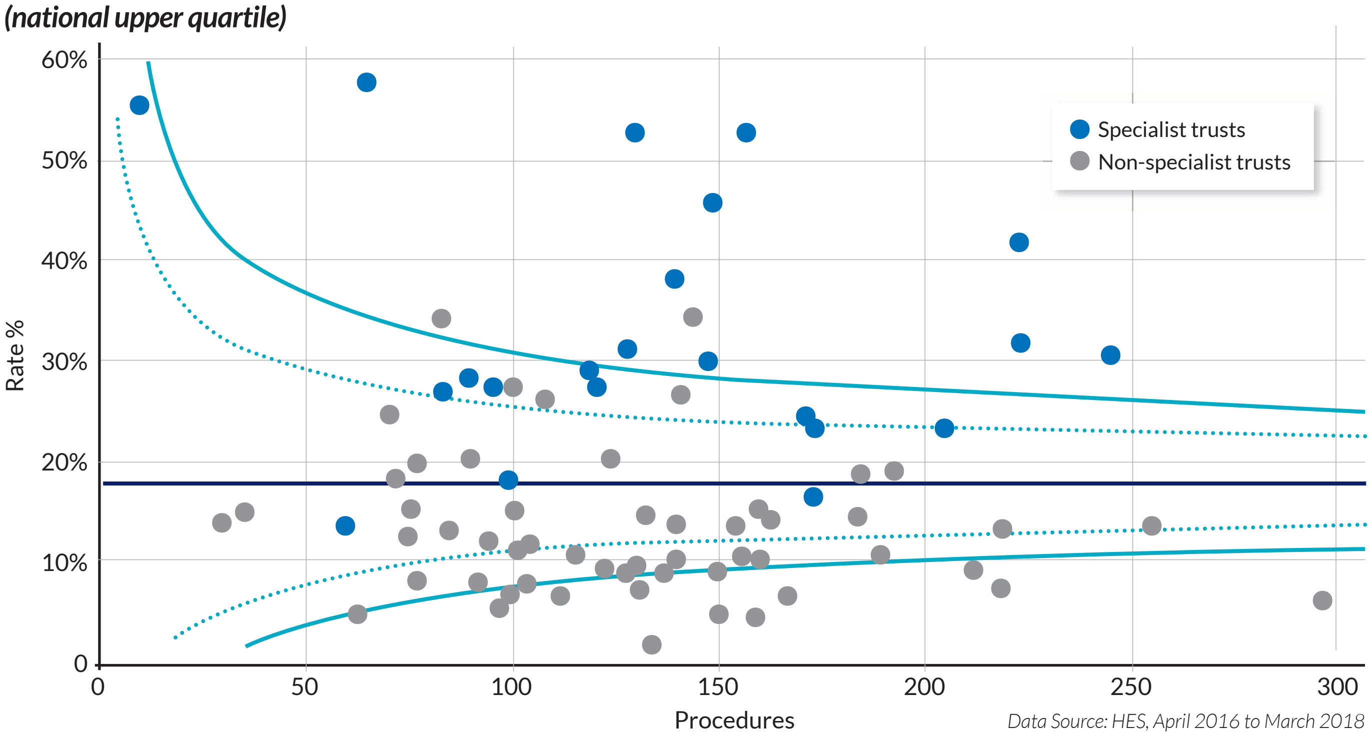
Children with complex appendicitis require a course of intravenous antibiotics following appendicectomy. GIRFT deep dive visits found considerable variation between surgeons in the duration of the course of intravenous antibiotics prescribed.

Often, there are no clear policies in place. In those trusts that do have a policy in place, the most common protocol is for children to receive intravenous antibiotics for five days post-operatively. There is growing evidence that the requirement for intravenous antibiotics can be reduced to three days providing the child is at normal temperature for at least 12 hours and is tolerating a normal oral diet.[75]

In more than 30% of specialist trusts post-operative length of stay for children with normal appendicitis exceeds three days (Figure 42a). It may be that the length of stay is determined by pre-operative factors, such as delays in access to emergency theatres. Trusts should determine the reasons why as a matter of urgency.

Figure 42b also shows that length of stay is significantly higher in children with complex appendicitis treated in specialist trusts. We have already seen that sicker children are treated at specialist trusts, and this is likely to be a significant factor in explaining these figures. However, specialist trusts should review their antibiotic regimen to align to recent evidence-based practice.

Figure 42a: Length of stay for children with non-complex appendicitis - percentage > three days (national upper quartile)



Data Source: HES, April 2016 to March 2018

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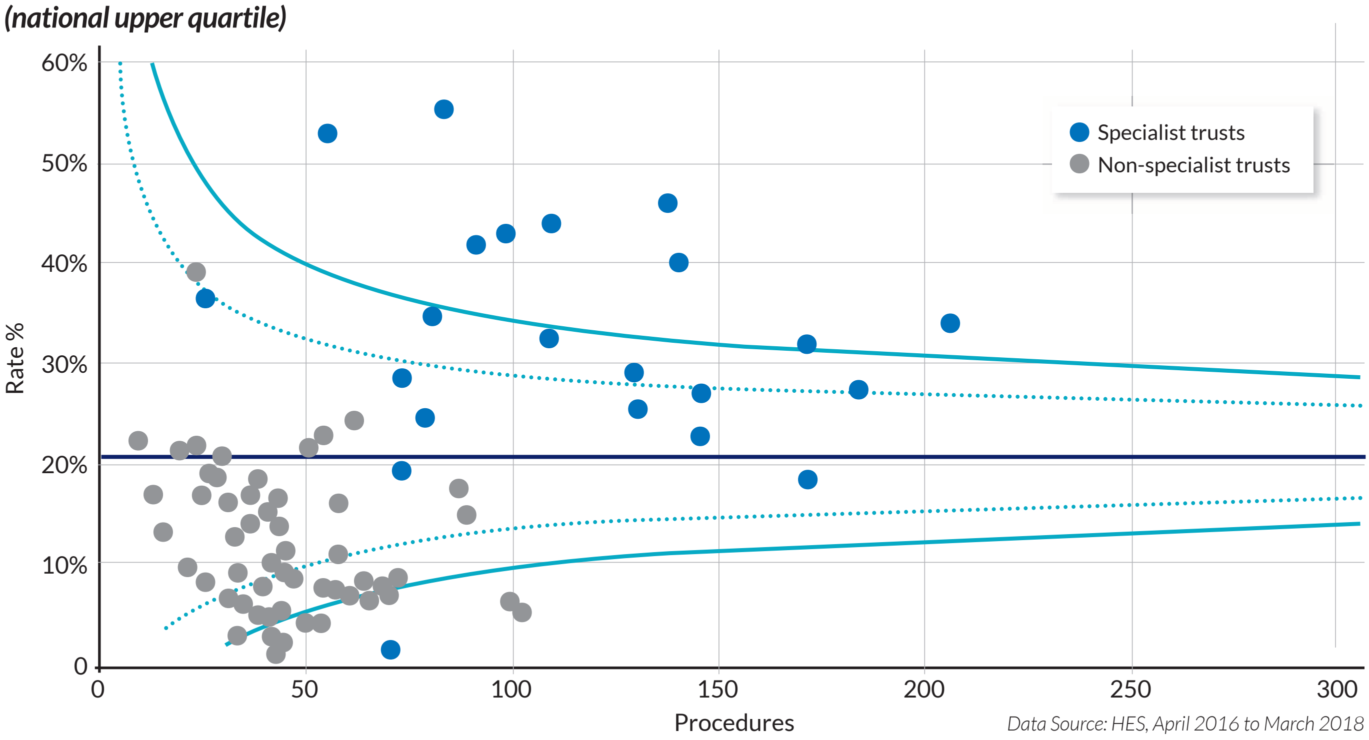
[74] Benedict, L.A., Sujka, J., Sobrino, J., Aguayo, P., St. Peter, S.D. and Oyetunji, T.A. (2018). Same-Day Discharge for Nonperforated Appendicitis in Children: An Updated Institutional Protocol. Journal of Surgical Research, 232, pp.346–350

[75] Lansdale, N., Fryer, S., Stockdale, M., Bancroft, J., Orr, J., Corbett, H. and Kenny, S. (2019). Prospective evaluation of a clinical response directed pathway for complicated appendicitis. Journal of Pediatric Surgery, 54(2), pp.272–275.

Figure 42b: Length of stay for children with complex (peritonitis or abscess) appendicitis - percentage > six days (national upper quartile)



Data Source: HES, April 2016 to March 2018

Conclusions

Appendicitis is one of the most common general surgical emergencies, but we found a high degree of unwarranted variation, including a north-south difference in the incidence of complex appendicitis, which needs further examination, and 10% of children undergoing appendicectomy having a normal appendix removed.

Access to diagnostic ultrasound would help ensure all children receive the right, timely and necessary surgery. Improvements should be made to ensure there is access to seven-day imaging. In addition, children should be cared for within defined care pathways to reduce the variation in care, improve outcomes and shorten lengths of stay.

2. Testicular torsion

Testicular torsion occurs when a testicle twists on its axis, cutting off the blood supply. When this happens, the testicle will die within around six hours unless the blood flow can be restored by emergency surgery to untwist it.

Boys typically present with acute (sudden) scrotal pain and tenderness. Unfortunately, many boys present late and the testis is doomed.[76]

Treatment

Not all boys with acute scrotal pain have a torsion, but, unless there is a definite alternative diagnosis, all boys presenting with these symptoms and signs need emergency surgery (within an hour of presentation in hospital).

There are two possible treatment routes, depending on the state of the testicle at the time of surgery:

- **orchidopexy** – if the testicle can be saved, both testicles are fixed to prevent recurrent torsion
- **orchidectomy** – if the affected testicle is considered irretrievable, it is surgically removed.

Unfortunately, many boys present late and the testis will not survive. Testicular torsion represents a challenge for hospitals in terms of capability and delays in surgery as a result of transfers. Delayed or missed diagnosis of testicular torsion is also a cause of litigation.

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[76] *MacDonald, C., Kronfli, R., Carachi, R. and O'Toole, S. (2018). A systematic review and meta-analysis revealing realistic outcomes following paediatric torsion of testes. Journal of Pediatric Urology, 14(6), pp.503–50*

Capability and responsibility

Scrotal exploration is a very simple surgical procedure and does not require advanced training.

We understand The Royal College of Surgeons (RCS), British Association of Urological Surgeons (BAUS), and medical indemnity providers support adult surgeons engaged in occasional paediatric practice to perform acute scrotal exploration and do not support surgeons who refuse to perform scrotal exploration.

Both the general surgical and urology curricula mandate proficiency in this procedure for award of the Certificate of Completion of Training (CCT).

Despite these points, many urological surgeons feel this procedure lies so far outside their normal surgical practice that they are not willing or capable of performing it. There is a contrary view in general surgery that this procedure is a urological rather than general surgical procedure, and that the urologists should perform it.

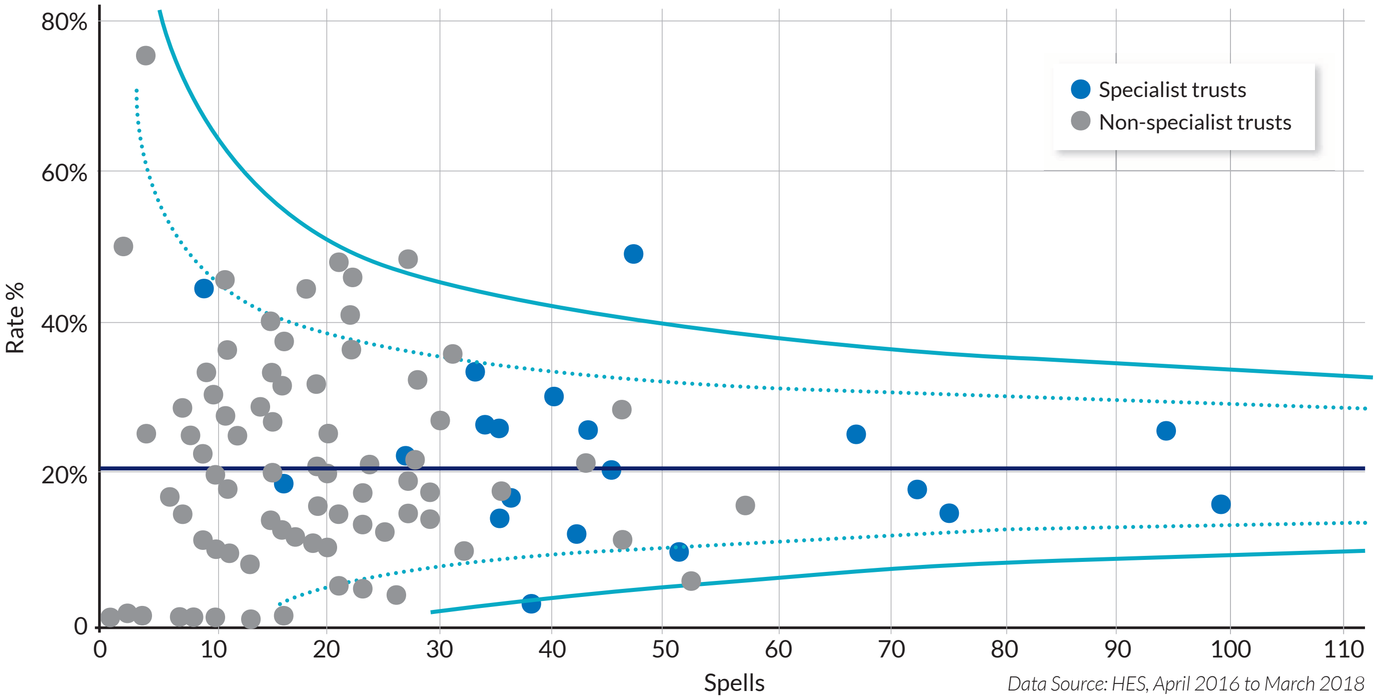
This is problematic for several trusts, even when they have robust measures in place. The main concerns centred on confusion over who should be performing the surgery. We heard of many cases where, as a result of surgeons refusing to perform surgery, boys had to be transferred to specialist trusts for their surgery. Clearer trust policy, and adherence to this policy, would help improve this.

Variation in outcomes

We looked at the rates of orchidectomy in boys (Figure 43). This offered us the best available picture of rates of testicular loss but will under-estimate the actual rate since some testicles that are fixed will not survive and will atrophy. There is no way to currently assess the true testicular atrophy rate. This has been estimated to be as high as 60%.(53)

The overall orchidectomy rate was 20%, with a range of 0-50%. This rate is at the lower end of the range reported by systematic review.(53)

Figure 43: Orchidectomy rates by trust



Data Source: HES, April 2016 to March 2018

Transfers and delays in surgery

The six-hour time window from the onset of symptoms and time to presentation in hospital means any transfers increases the risk of testicular loss.

We found that in some specialist trusts, one in four boys had been transferred from another trust although the overall average transfer rate was much lower at one in ten (Figure 44). This variation suggests that many but not all trusts have an acceptable policy of managing boys requiring scrotal exploration.

One reason for transfer is refusal of the surgical or anaesthetic team to perform the procedure.

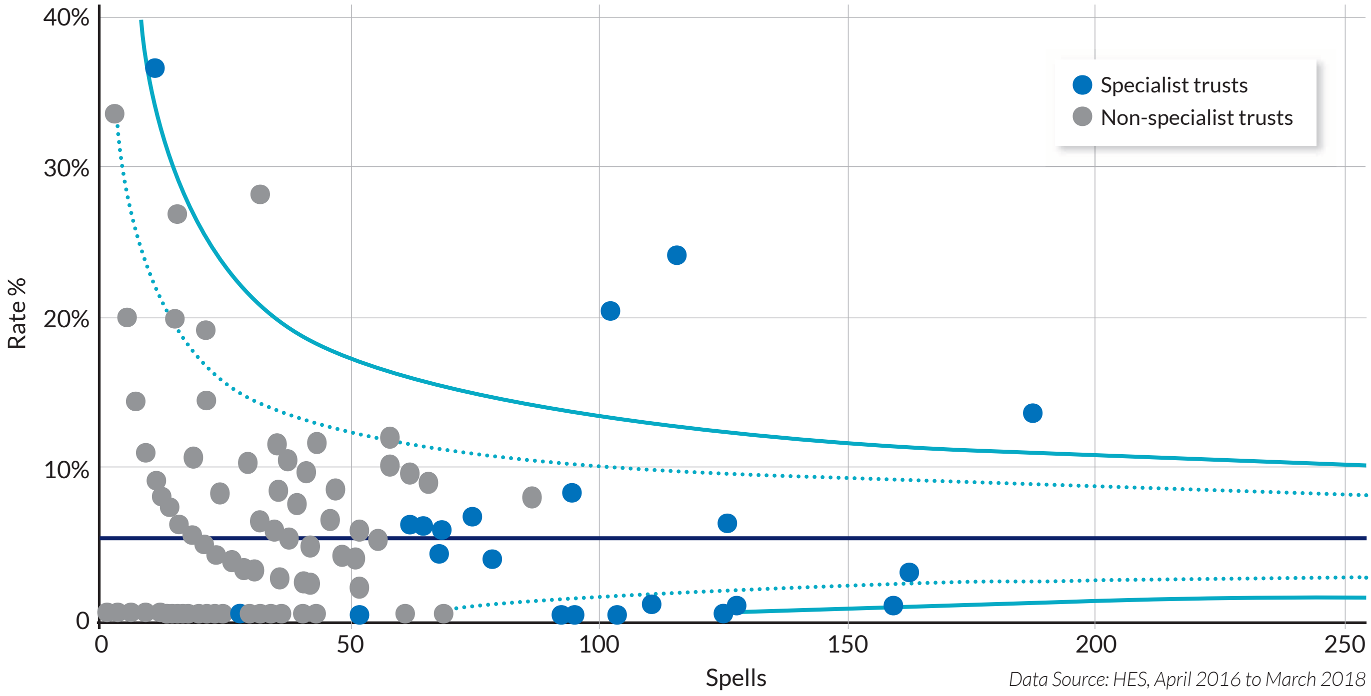
Other issues were caused by amalgamation of hospitals into larger trusts, particularly where acute services are now spread over two sites. It is not unusual for a paediatric emergency department to be on one site while emergency theatres are on another site. Although within-trust transfers are likely to be less problematic than transfers from trust to trust, any transfer inevitably increases the time from presentation to surgery.

Trusts were well aware of these and related issues due to fragmentation of acute services. They frequently cited the need for capital funds to redevelop NHS estate in order to provide joined-up, connected services (see Environment of Care, page 111). In addition, it seemed that trust medical directors ultimately felt unable to mandate that surgeons perform this procedure.

Sometimes this meant that no robust policy was in place. This led to out of hours' discussions between non-specialist and specialist trusts that ultimately led to further delays.

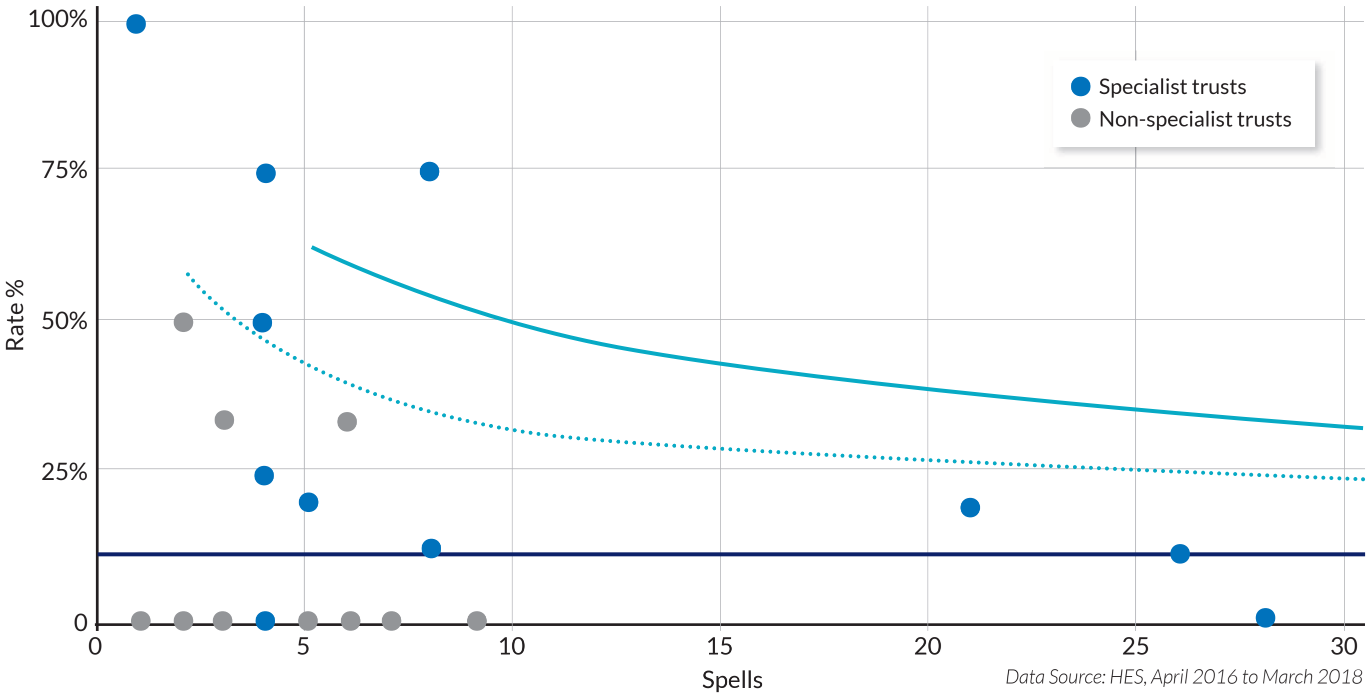
Boys under the age of two were often transferred to specialist trusts for treatment (Figure 45). This will usually be for anaesthetic reasons and constitutes acceptable practice.

Figure 44: Boys with a diagnosis of testicular torsion who were transferred in from another trust



Data Source: HES, April 2016 to March 2018

Figure 45: Boys under the age of two with a diagnosis of testicular torsion who were transferred in from another trust



Data Source: HES, April 2016 to March 2018

Although trusts were aware that transferring boys with testicular torsion was an issue, almost all trusts had no robust audit arrangements, and clinicians and managers were not aware of outcomes.

Variation in guidelines on transfers

In many areas, specialist trusts have agreed guidelines with adjacent non-specialist trusts as to which boys should be transferred. The guidelines vary significantly from trust to trust.

Other trusts have no such agreements in place, which clearly represents an ongoing risk.

In 2018 NHS England published guidance on the management of paediatric torsion[77] which sets out the requirements for transfers.

Workforce guidelines

Adult general surgeons and urologists need to work together to work out the best system. In trusts without middle grade urological cover, the best solution is for general surgical trainees to undertake the scrotal exploration with consultant urological oversight.

Age guidelines

There is no national consensus on the age limit of boys that non-specialist trusts should treat or transfer due to age-related anaesthetic concerns.

Based on our discussions with clinicians from 89 trusts, we believe the threshold should match that set in the anaesthetic Certificate of Completion of Training (CCT). This would mean all acute trusts that admit children should be able to offer emergency scrotal exploration in boys over the age of two. This age may be lower in trusts with an enhanced paediatric anaesthetic capability.

Trusts should ensure that their anaesthetic and surgical teams have the capability to do this and provide additional training where required. This issue should be considered as part of consultant appraisal.

Any boys who have to be transferred despite this guidance should be reported via trust critical incident reporting system.

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[77] *NHS England (2018) Commissioning guide: Management of Paediatric Torsion https://www.england.nhs.uk/mids-east/wp-content/uploads/sites/7/2018/03/torsion-commissioning-guide.pdf*

Challenges in analysing the data

Analysing the clinical impact of the issues affecting care for testicular torsion proved challenging:

- We were not able to use emergency department (ED) coding to track the journey of boys presenting with acute scrotal pain because the coding in a significant number of trusts was not robust enough.
- We were only able to use HES data for boys with a diagnosis of testicular torsion. This does not offer a full picture of how many boys require emergency scrotal exploration.
- Current data constraints meant we were unable to ascertain the time from onset of pain to presentation in ED (since many boys present outside of the six-hour time window), or the time from arrival in ED to surgery.
- We looked at outcome by what procedure had been performed. The testicle was generally either fixed or removed. A significant number of boys had been diagnosed with torsion who did not undergo surgery. This was almost certainly boys with scrotal pain mis-coded as having torsion. Despite this issue, around half of specialist trusts admitted boys transferred from other trusts. Some of these were boys under the age of two years, which almost certainly was an appropriate anaesthetic decision.

The current data gap makes it impossible to establish a detailed picture of the magnitude of problems in providing care for boys with acute scrotal pain who require surgical exploration.

Ideally, this data should be incorporated into routine data collection. Litigation data showed that between 2012/13 and 2016/17 at least four claims were settled for delays in diagnosis and/or treatment for boys with testicular torsion costing the NHS £201,000.

Conclusions

Testicular torsion is a time-critical surgical emergency. We found that too many boys are being transferred for surgery, leading to unacceptable delays and increasing the risk of testicular loss. Scrotal exploration for suspected testicular torsion is a straightforward procedure which all general and urological surgeons can perform. We found wide variation in the age at which surgeons and anaesthetists were prepared to treat boys with this condition and no evidence to support this variation. We recommend that all non-specialist providers should put systems in place to reduce the delays of emergency scrotal explorations.

Recommendation	Actions	Timescale
4. Improve the care of children requiring emergency paediatric surgery for appendicitis and testicular torsion.	**a** NHS England and NHS Improvement, Royal College of Surgeons (RCS), Royal College of Paediatrics and Child Health (RCPCH), Royal College of Anaesthetists (RCA) and Royal College of Radiologists (RCR) to produce a model appendicectomy pathway which includes: • ED to diagnosis (ultrasound, assessment decision units) • preoperative care • surgery • postoperative care	Within 12 months of publication Within 18 months of publication
	b Trusts and Operational Delivery Networks to reduce the incidence of negative (normal) and complex appendicectomy rate by employing shared care between paediatricians and surgeons and adopting the appendicectomy model.	As per their plan
	c GIRFT and Public Health England to investigate regional variation in the rates of complex appendicitis.	Within nine months of publication
	d Operational Delivery Networks to review capacity as necessary to ensure that all boys with suspected testicular torsion are assessed promptly and treated close to home to reduce the incidence of testicular loss.	

Variation in practice: elective

In this section, focusing on elective surgery, we summarise five specific conditions and procedures in which we found variation in practice during our GIRFT visits. These are:

1. Umbilical herniotomy
2. Hydrocele
3. Hypospadias surgery
4. Circumcision
5. Orchidopexy for the undescended testis

1. Umbilical herniotomy

An umbilical hernia appears as a painless lump in or near the navel (belly button). They are congenital and arise due to a defect in the abdominal wall. Umbilical hernias are very common in infants and young children, particularly in babies born prematurely. They can be a source of great concern to parents who worry that strangulation (when the blood supply to the herniated tissue is cut off, causing infection in the bloodstream) may occur.

In fact, although they can appear very large, the vast majority of hernias regress with time and surgical problems during childhood are extremely rare. In many cases, the umbilical hernia goes back in and the muscles reseal before the child's first birthday. Prospective studies suggest that over 90% of umbilical hernias will close by the age of four and that closure can even occur in late childhood.[78, 79] Since most hernias heal themselves, there is no case for repair in children less than four years of age.

Treatment

Umbilical herniotomy involves division of the hernial sac and repair of the abdominal wall defect, usually with sutures.

The reasons for carrying out umbilical herniotomy are primarily cosmetic. In some cases, repair is carried out in young children who require peritoneal dialysis and even then, not all children require repair.

Risks of surgery include injury to underlying bowel, infection, subcutaneous collections (fluid collecting beneath tissue) and recurrence.

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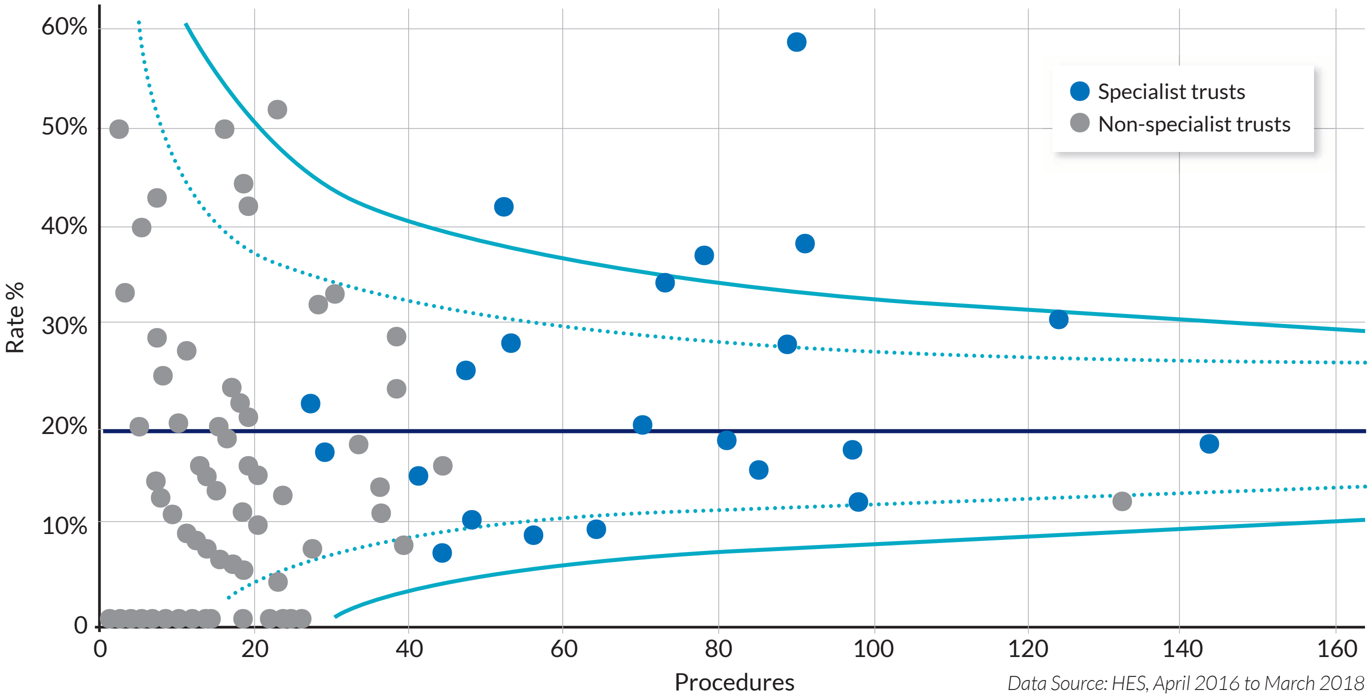
[78] *Zens, T., Nichol, P.F., Cartmill, R. and Kohler, J.E. (2017). Management of asymptomatic pediatric umbilical hernias: a systematic review. Journal of Pediatric Surgery, 52(11), pp.1723–1731.*

[79] *Heifetz et al. (1963). Observations on the disappearance of umbilical hernia in infancy and childhood, Surgical Gynaecology and Obstetrics, 116:369-473*

Rates of herniotomy

Given the evidence that most umbilical hernias will close naturally by the age of four, the rate of umbilical herniotomy in children under three should be very low. However, one in five children who undergo umbilical herniotomy are under three. Both specialist and non-specialist trusts perform umbilical herniotomies in this very young age group (Figure 46).

Figure 46: Proportion of children under three years of age undergoing umbilical herniotomy



Data Source: HES, April 2016 to March 2018

Laparoscopic inguinal herniotomy

A small number of umbilical herniotomies are carried out during laparoscopic inguinal herniotomy (about 70% of all hernias are inguinal hernias which occur in the groin) because the camera is typically inserted through the umbilicus. This reason does not explain the numbers of umbilical herniotomy in this young age group.

Size of hernia

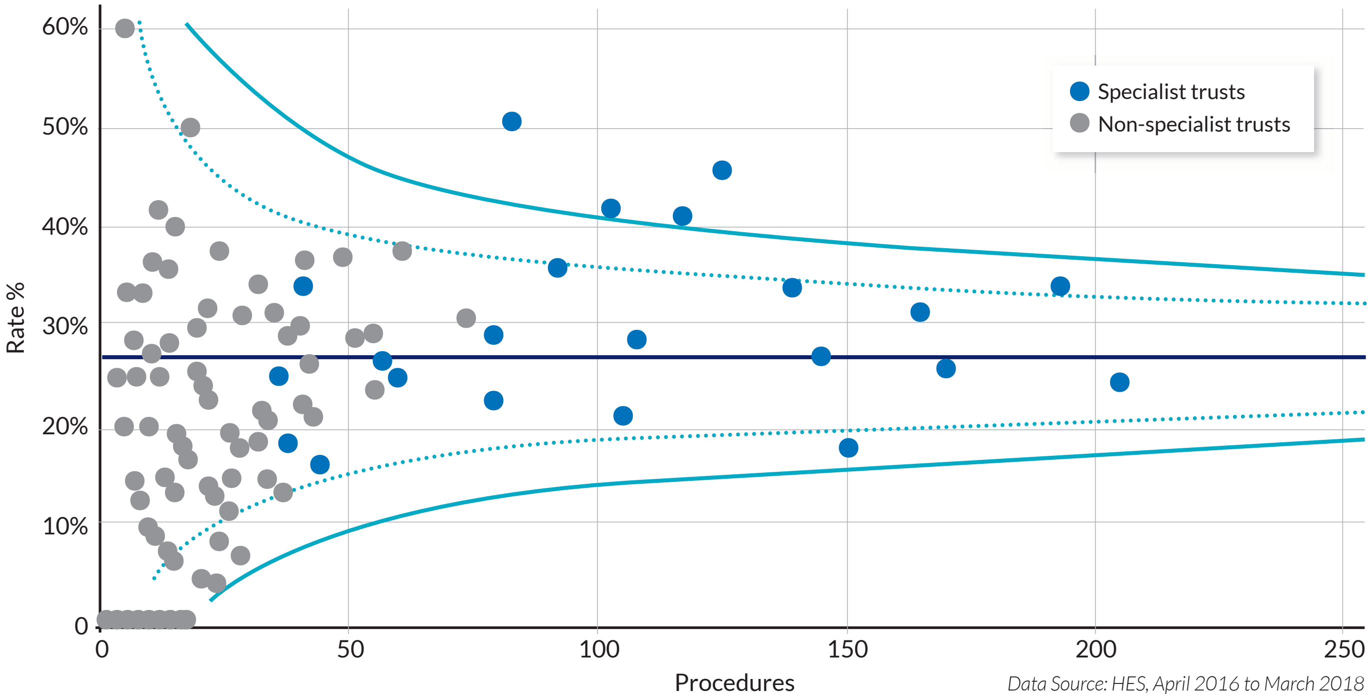
One of the reasons given for early repair was the large size of umbilical hernias in some Afro-Caribbean children. Although large hernias are less likely to close, there is no evidence that large hernias in Afro-Caribbean children are more likely to develop complications, meaning there is no indication for early repair.

If umbilical herniotomy surgery was not unnecessarily performed in children < three years of age, 222 children each year would be spared surgery.

2. Hydrocele

Hydrocele is a common condition in young boys where fluid collects around the testicle. Most cases will self-resolve in the first few years of life. For this reason, most UK paediatric surgeons would concur that surgery is rarely required in the first three years of life. Figure 47 shows that over one in four boys are having a repair under the age of three years. Hydroceles will resolve in over 96% of young boys over one year of age after one year of follow-up.[80]

Figure 47: Proportion of children under three years of age undergoing repair of hydrocele



Data Source: HES, April 2016 to March 2018

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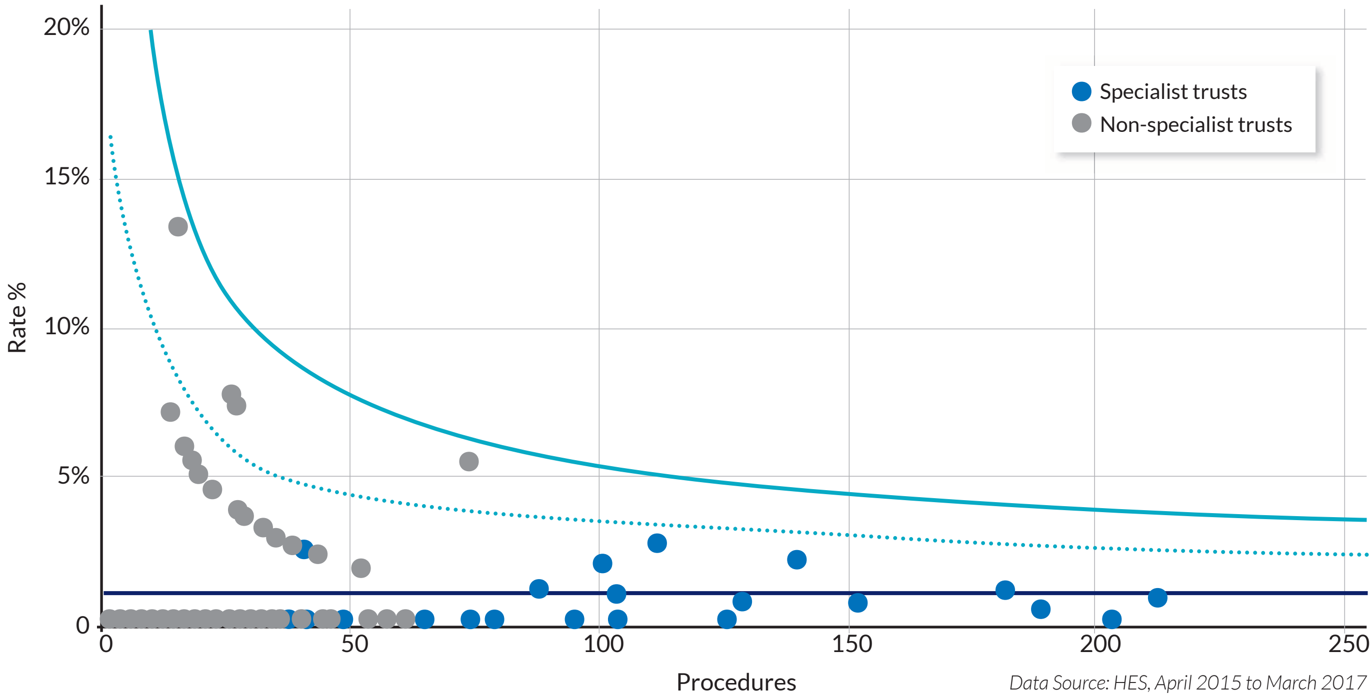
[80] *cer-Demir, T., Ekenci, B.Y., Özer, D., Turanoğlu, M.A., Haberal, K.C., Bilgin, E.B. and Hiçsönmez, A. (2018). Natural History and Conservative Treatment Outcomes for Hydroceles: A Retrospective Review of One Center's Experience. Urology, 112, pp.155–160.*

Hydrocele repair is a straightforward procedure in trained hands. Figure 48 shows the reoperation rate for hydrocele after one year. Several provider trusts breach the 95% upper confidence limit for reoperation rates, which should be < 1 %. This means there are some trusts with reoperation rates that are too high.

If hydrocele surgery was no longer carried out in boys under two years of age, around 220 unnecessary operations would be avoided each year.

Figure 48: Proportion of children under three years of age undergoing repair of hydrocele



Data Source: HES, April 2015 to March 2017

3. Hypospadias surgery

Hypospadias is a congenital disorder where the urinary opening is not at the usual location on the head of the penis. It is the second most common birth abnormality of the male reproductive system, affecting about one in every 250 males at birth.

Hypospadias is complex reconstructive surgery. It is not emergency surgery and parents need to make careful choices about the pros and cons of reconstruction. There is evidence that half of parents whose son has had hypospadias surgery have to some degree regretted their decision.[81]

Caseload volumes

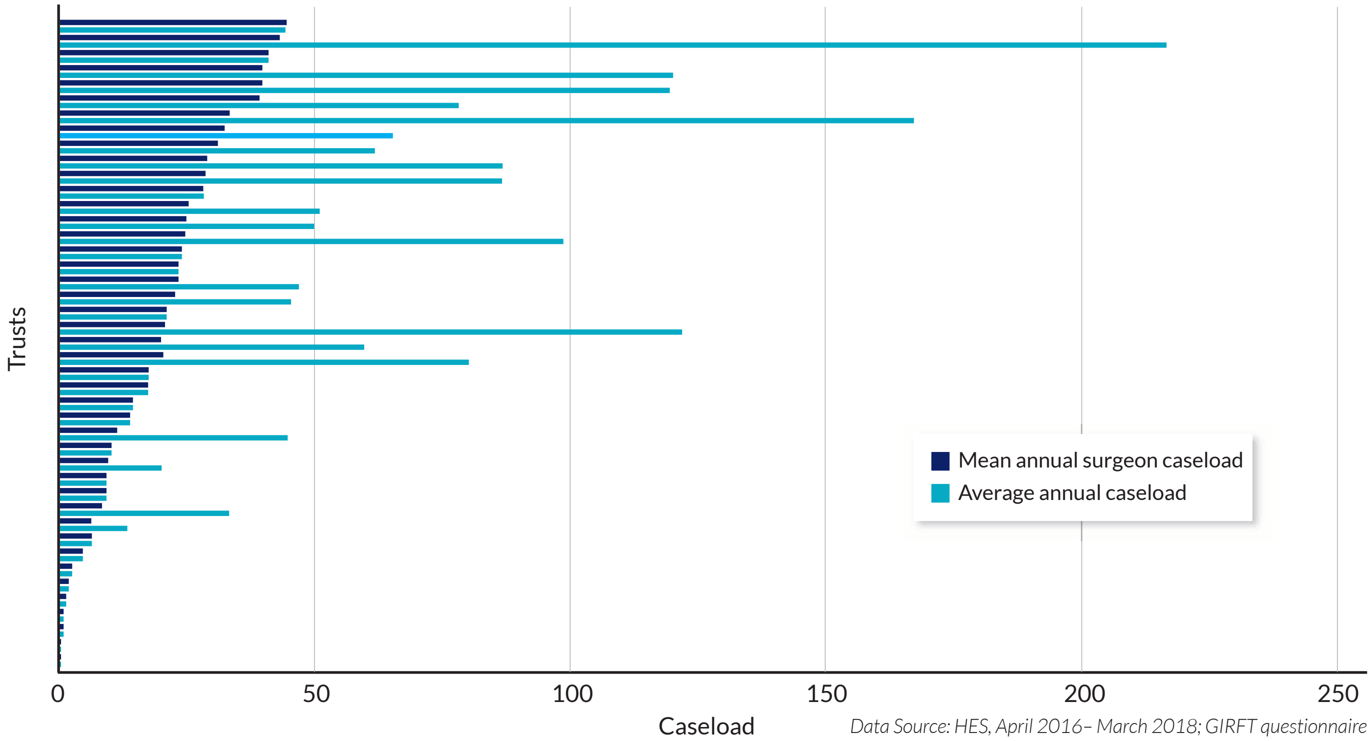
We reviewed current caseload volumes. Approximately 2,000 boys undergo surgery in England each year. Surgery currently takes place in 46 trusts, some of which are specialist and some non-specialist. Where surgeons travel out from the hub to perform surgery, we added those cases to the hub and surgeon volumes.

Variation by trust and surgeon

There is huge variation in caseload volumes by trust: from 0.5 cases per year to 216 cases per year (Figure 49). In addition 73% of operations took place in just 15 trusts.

In many low-volume trusts, surgery is usually performed by one surgeon. This means that, apart from in the very low-volume trusts, annual volumes per surgeon match those seen in specialist trusts (Figure 49). In fact, in some specialist trusts, it could be argued that too many surgeons perform hypospadias repair, diluting index caseload per surgeon. That said, the lone surgeon has no peer group for support and governance and may struggle to incorporate new techniques into their practice.

Figure 49: Annual average caseload of hypospadias surgery by trust and surgeon



Data Source: HES, April 2016– March 2018; GIRFT questionnaire

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[81] *Lorenzo, A.J., Braga, L.H.P., Zlateska, B., Leslie, B., Farhat, W.A., Bägli, D.J. and Pippi Salle, J.L. (2012). Analysis of Decisional Conflict Among Parents Who Consent to Hypospadias Repair: Single Institution Prospective Study of 100 Couples. Journal of Urology, 188(2), pp.571–575.*

Establishing minimum annual caseload volumes

The positive volume-outcome relationship was not apparent in the two-year data we analysed, but becomes apparent in larger numbers of boys over a longer time period. For every ten extra cases a trust performs, the reoperation rate drops by one percent.

We are recommending that trusts continually assess whether surgeons are performing enough hypospadias repairs to be able to maintain performance.

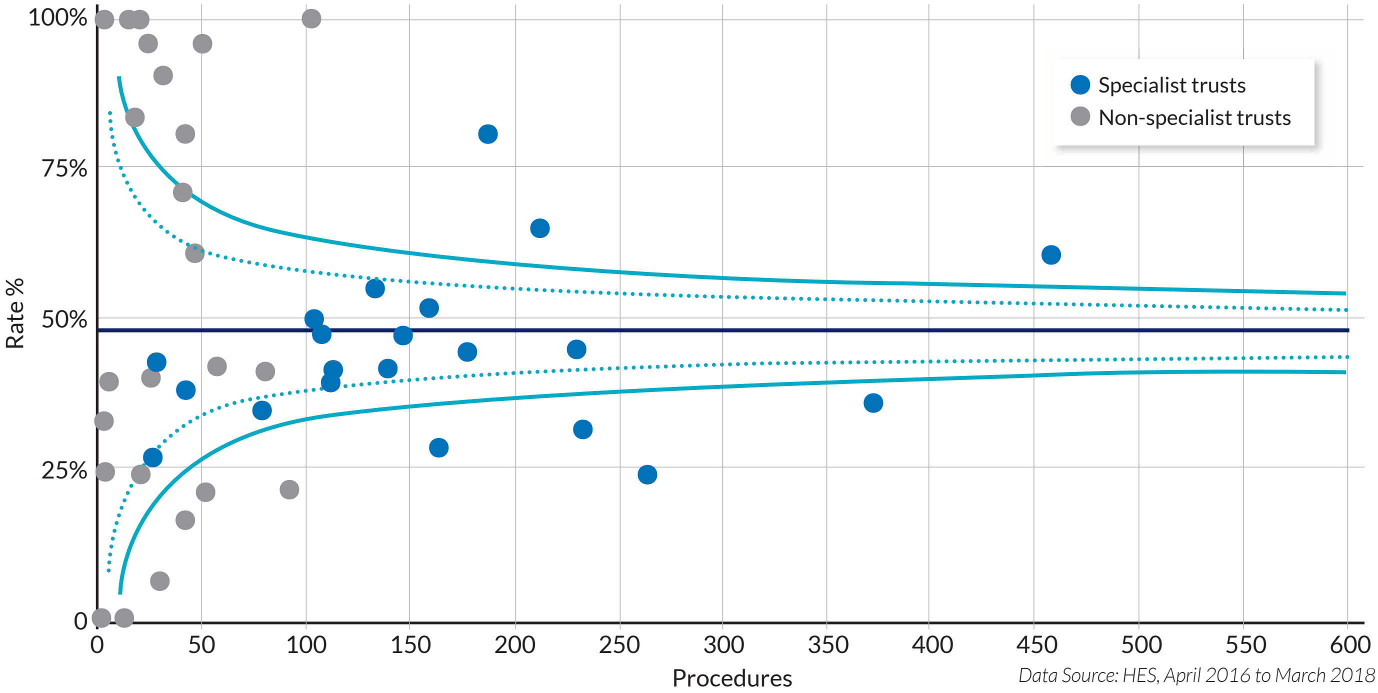
Age at the time of surgery

Hypospadias surgery can be performed at any age. There is a lack of evidence as to the optimum age at which surgery should be undertaken but most surgeons and the American Academy of Paediatrics recommend either repair before the age of two years or when boys are old enough to give their own consent for the repair.[82]

We found that the age at which boys undergo surgery is highly variable (Figure 50) with up to 100% of repairs being performed outside the consensus age range in some lower volume trusts. In other trusts, 75% of repairs were performed within the recommended age range. The reasons for this were variable:

- Established practice: some surgeons had been trained to perform hypospadias at three years of age. Although surgery is feasible, three-year-olds are potentially old enough to remember surgery and also more likely to interfere with their dressings.
- List pressures: some surgeons stated that their capacity was exceeded by demand which led to slippage in the age at which surgery was performed.

Figure 50: Percentage of children less than 12 months and greater than 24 months of age at time of hypospadias repair



Data Source: HES, April 2016 to March 2018

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[82] *Timing of elective surgery on the genitalia of male children with particular reference to the risks, benefits, and psychological effects of surgery and anesthesia. American Academy of Pediatrics. (1996). Pediatrics, [online] 97(4), pp.590–594*

Outcomes/ unwarranted variation

We found variation for hypospadias surgery for:

- Number of cases seen as day cases;
- Use of multiple stage of hypospadias repair;
- Emergency readmittance;
- Reoperation rates.

Day surgery

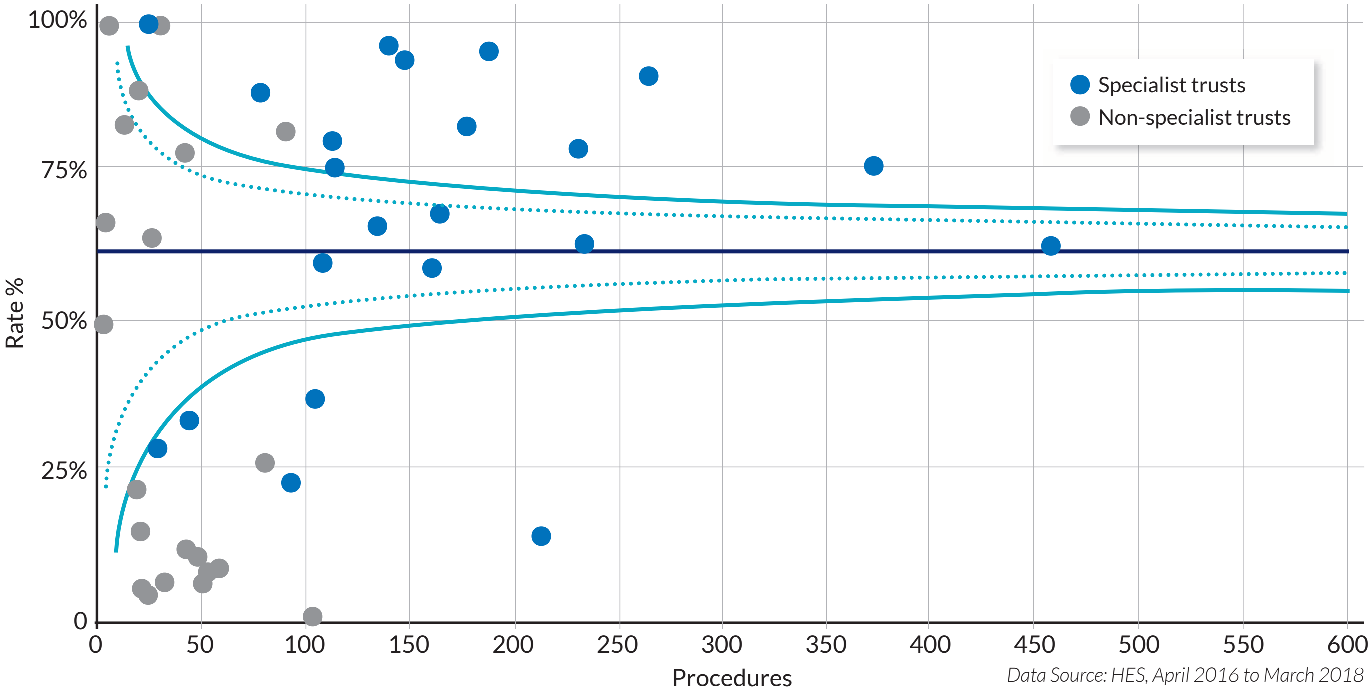
Surgical practice is constantly evolving: 20 years ago, boys were routinely kept in hospital for up to a week following hypospadias surgery. Since then, the evidence base supports performing this surgery as a day case procedure. However, we found that some trusts have not adopted day surgery.

There is substantial variation in the day case rates for hypospadias surgery (Figure 51).

Trusts with low day case rates for hypospadias surgery cited reasons such as reducing complications, the geographic distance from boys' homes, and concerns over social circumstances as reasons for treating boys on an inpatient basis.

The data does not support the assertion that day case surgery increases complications. We found that high day case rates for hypospadias surgery are not associated with increased reoperation rates. Numerous trusts with high day case rates achieve low reoperation rates. For example, the trust with the lowest hypospadias reoperation rate has a day case rate of over 80%.

Figure 51: Day case rates for hypospadias surgery (length of stay = 0)



Data Source: HES, April 2016 to March 2018

Use of multiple-stage hypospadias repair

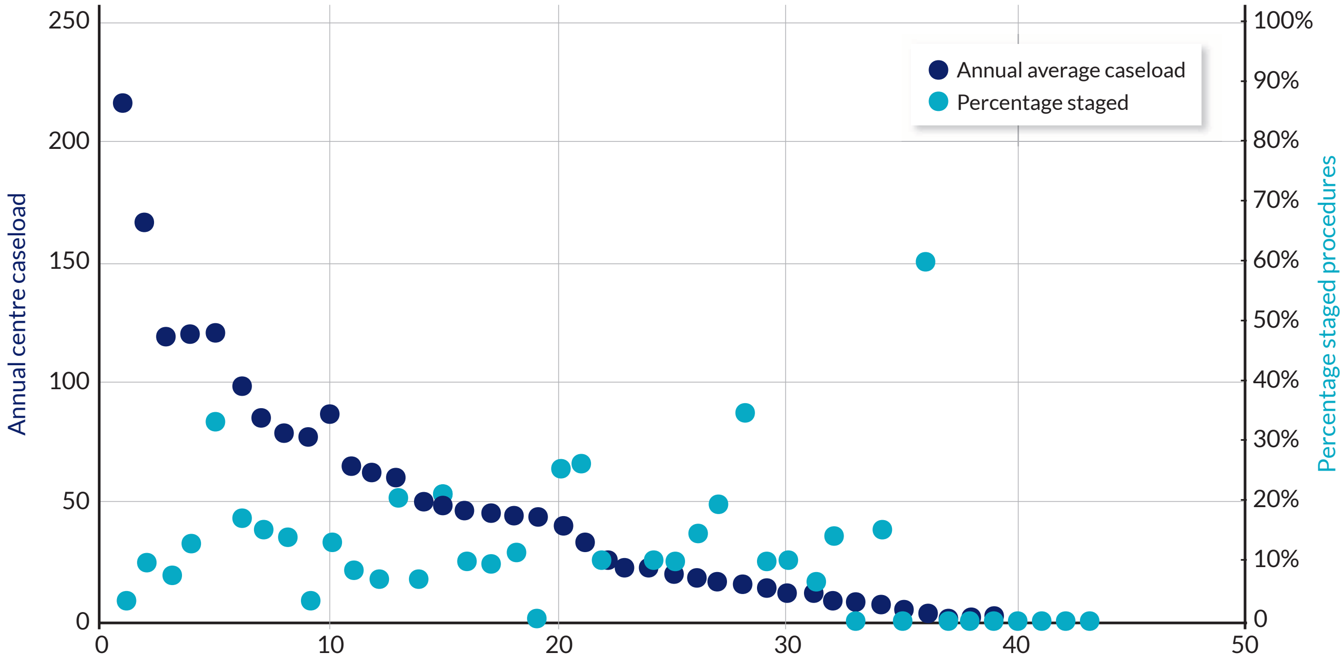
There is a choice of procedures for carrying out hypospadias repair. Some of these take place over multiple stages, requiring more than one operation. Multiple-stage surgery is indicated in more severe forms of hypospadias repair. However, there is clear evidence that milder forms of hypospadias can be repaired in a single stage.

Clearly, multiple-stage surgery imposes a greater burden on boys and their families than single-stage repair. It also takes up more theatre time and other resources.

Given this, it was surprising to find significant variation in the use of multiple-stage repairs between trusts: from 0-60% (Figure 52). This was unrelated to trust volume or casemix (severity of hypospadias).

Outlier trusts should review their use of multiple-stage repairs. Reducing the percentage of staged repairs to less than 10% (that achieved by the best quartile of trusts) would result in 580 less unnecessary operations in boys each year.

Figure 52: Scatter plot showing average annual trust caseload and the percentage of staged hypospadias procedures performed



Data Source: HES, April 2016 to March 2018

Emergency readmittance following hypospadias surgery

There is wide variation in the number of boys readmitted as an emergency following hypospadias surgery (this excluded dressing removal). On average one in ten boys are readmitted as an emergency following hypospadias repair. Some trusts can keep emergency readmissions below 3%, while the rate exceeded 30% in one trust (Figure 53).

From discussions with clinicians during deep dive visits, it became clear that several measures can be taken that will contribute to successful post-operative care.

Before surgery:

- parents are given clear explanations and clear written information forms;
- children and parents meet specialist urology nurses and play therapists.

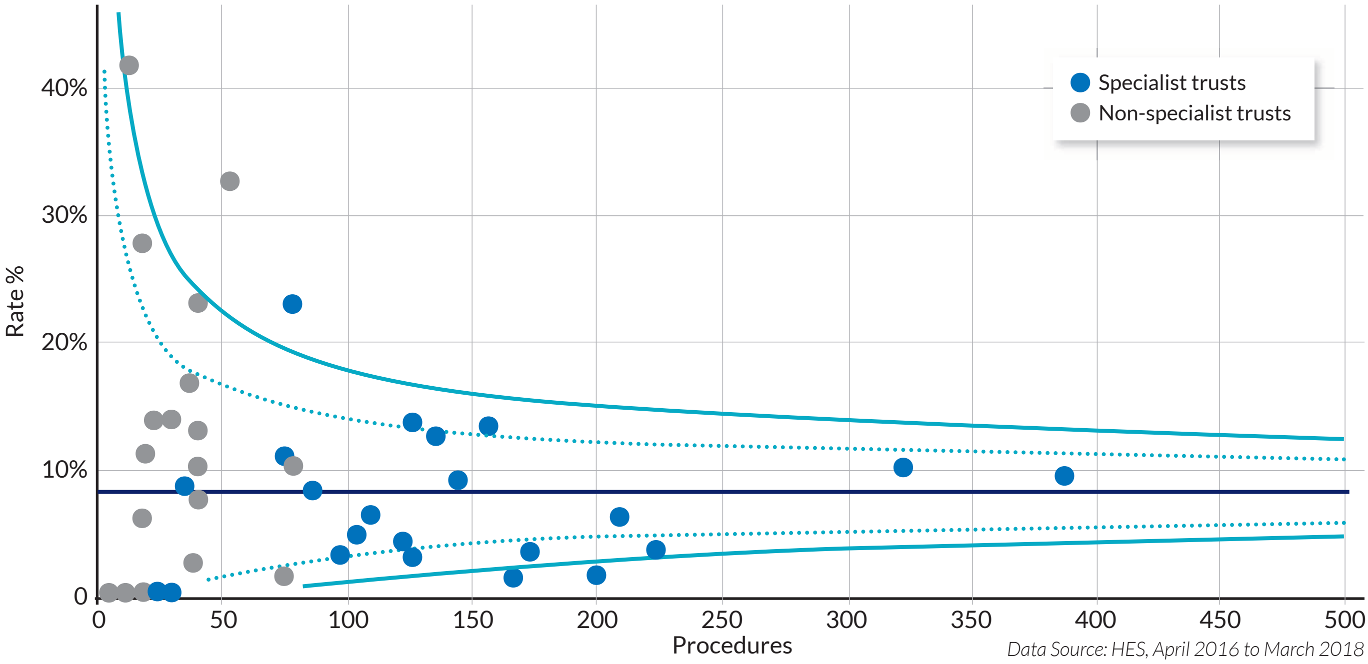
These are followed up on the day of surgery with:

- further parental education and support;
- clear, take-away advice on how to deal with common problems and concerns;
- clear signposting on who to contact for further guidance.

Each of these measures lead to fewer parents needing to bring their sons to emergency department and avoid unplanned admissions.

This was further supported by the ability of larger trusts to field a comprehensive and experienced nursing, anaesthetic, and surgical team.

Figure 53: All cause emergency readmissions following hypospadias surgery



Data Source: HES, April 2016 to March 2018

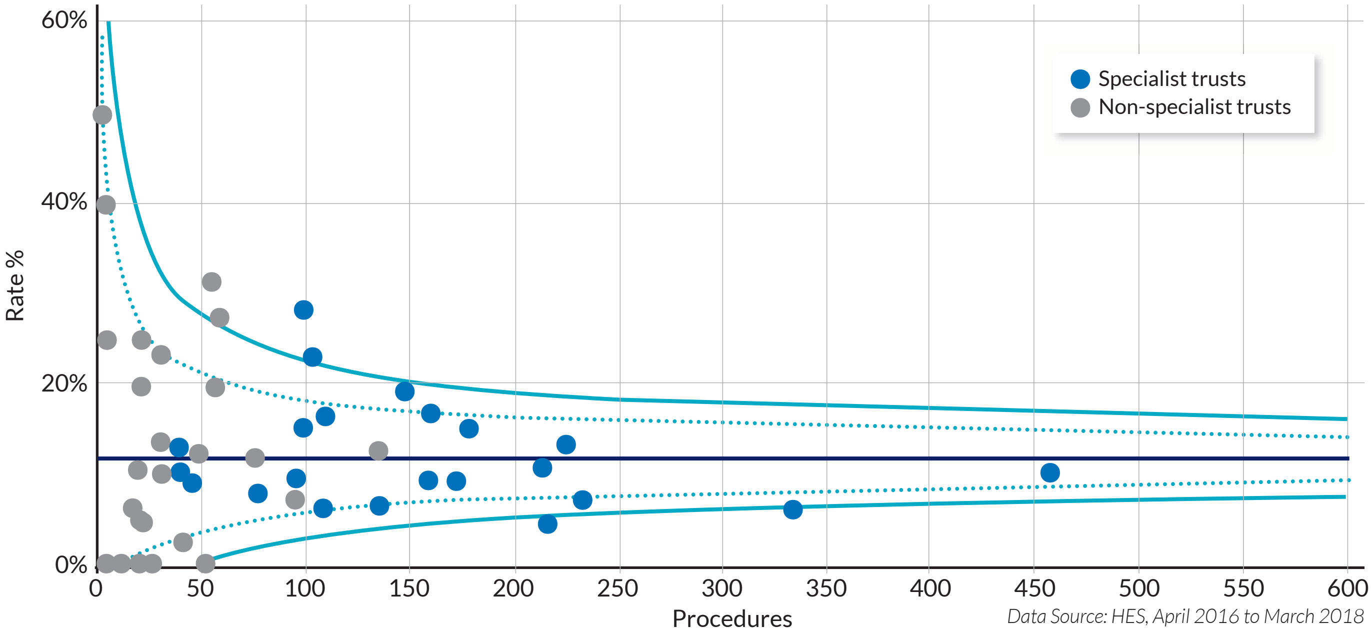
Reoperation rates following hypospadias surgery

The overall reoperation rate for hypospadias in the two years following surgery in England was 12% (this is similar to a recent Australian study).[83] However, rates varied considerably between trusts, with some above and others below the 99.8th centile (Figure 54). To note, reoperation within two years underestimates the true reoperation rate, as over 20% of reoperations are after two years.(15)

The best-performing trust had a reoperation rate of 5%.

If the reoperation rate was less than 7% in all trusts, around 60 boys per year would be spared having to undergo a reoperation.

Figure 54: Reoperation rate after two years following primary hypospadias repair



Data Source: HES, April 2016 to March 2018

Improving outcomes through coding

Since 2014, the British Association of Paediatric Surgeons (BAPS) has funded an online registry of all hypospadias repairs in the UK – the National Outcome Audit of Hypospadias (NOAH). This allows recording of operative findings and detail to supplement HES data. In addition, parents are asked to sign consent for mobile phone-based feedback to benchmark parental satisfaction over the decision they have made (for their son to undergo surgery). It is disappointing that only 30% of all hypospadias repairs are included in the registry and that some of the largest centres in the country do not contribute. Outcomes could be improved by increasing the richness of data available to surgeons to allow them to judge their outcomes with their peer group.

In addition, ICD-10 allows coding for four degrees of severity of hypospadias. We found that in significant number of providers, the code 'hypospadias - other' was being commonly used. This precludes accurate analysis of casemix.

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[83] *Schneuer, F.J., Holland, A.J.A., Pereira, G., Bower, C. and Nassar, N. (2015). Prevalence, repairs and complications of hypospadias: an Australian population-based study. Archives of Disease in Childhood, 100(11), pp.1038–1043.*

4. Circumcision

Each year, 9,500 circumcisions are performed on boys under 16 years of age for medical reasons. This means that by their 16th birthday, 2.6% of boys will have undergone a circumcision for medical reasons. The evidence base indicates that less than 1.5% of boys need circumcision by their 16th birthday. This would suggest that at least 4000 unnecessary circumcisions are performed on boys each year, resulting in unnecessary pain and stress, as well as costing the NHS £5 million annually.

Circumcision is the surgical removal of the foreskin. It is performed as a day case and requires a general anaesthetic. While circumcision may be undertaken for religious, cultural, or medical reasons, our focus here is purely on the medical indications for circumcision.

The diagnostic code most often used is phimosis – a condition where the foreskin is too tight to be pulled back over the head of the penis. Phimosis is normal in babies and young children as the foreskin and glans of the penis are initially fused.

High volumes and variation

The percentage of boys with full retraction of the foreskin increases with age (Table 9). Since 99% of boys have full retraction by age 17, that leaves only 1 in 100 requiring circumcision for phimosis by their 17th birthday.

Table 9: Foreskin retraction by age

Age	Percentage of boys with full retraction of foreskin
1	10%
10	50%
17	99%

Data Source: [84, 85. 86]

Given this, we would expect rates of circumcision to be very low in boys under the age of five. Overall, 17.5 % of circumcisions are in boys aged under age five years, and the picture is similar in both specialist and non-specialist trusts. In some trusts as many as 50% of boys are under the age of five at the time of their procedure. Though some boys under five will have circumcision because of congenital abnormalities of the foreskin, this number is relatively small (hypospadias is excluded from the figures) (Figure 56).

Some of the trusts with the highest numbers of circumcisions are not large volume trusts for other conditions such as inguinal herniotomies. This would also suggest unwarranted circumcision.

It is important to note that young boys, especially those under age five years, are unable to give informed consent or assent. It is therefore especially important that surgeons and parents consider the evidence base and consider less radical options when making the irreversible decision to perform circumcision.

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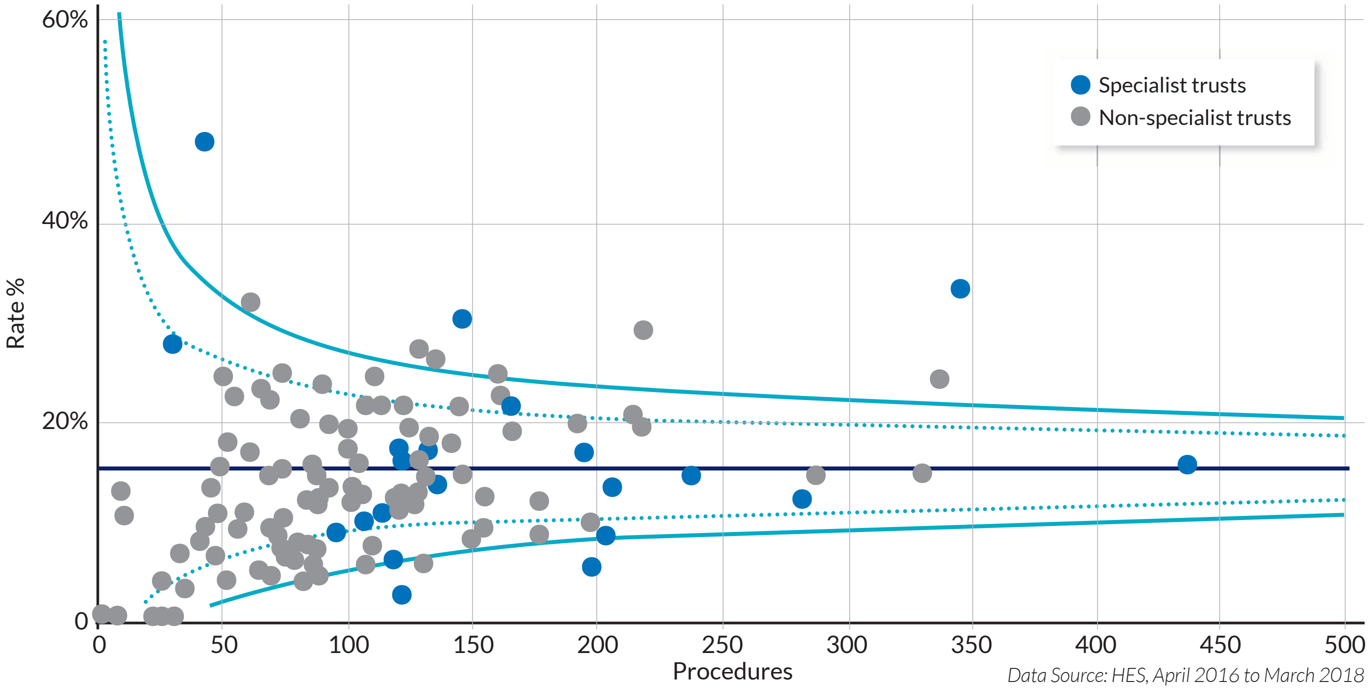
[84] *Kayaba, H., Tamura, H., Kitajima, S., Fujiwara, Y., Kato, T. and Kato, T. (1996). Analysis of Shape and Retractability of the Prepuce in 603 Japanese Boys. The Journal of Urology, 156(5), pp.1813–1815.*

[85] *Oster, J. (1968). Further fate of the foreskin. Incidence of preputial adhesions, phimosis, and smegma among Danish schoolboys. Archives of Disease in Childhood, 43(228), pp.200–203*

[86] *Spilsbury, K., Semmens, J.B., Holman, C.D.J. and Wisniewski, Z.S. (2003). Circumcision for phimosis and other medical indications in Western Australian boys. Medical Journal of Australia, 178(4), pp.155–158*

Figure 56: Rate of therapeutic circumcision in boys under five, by trust



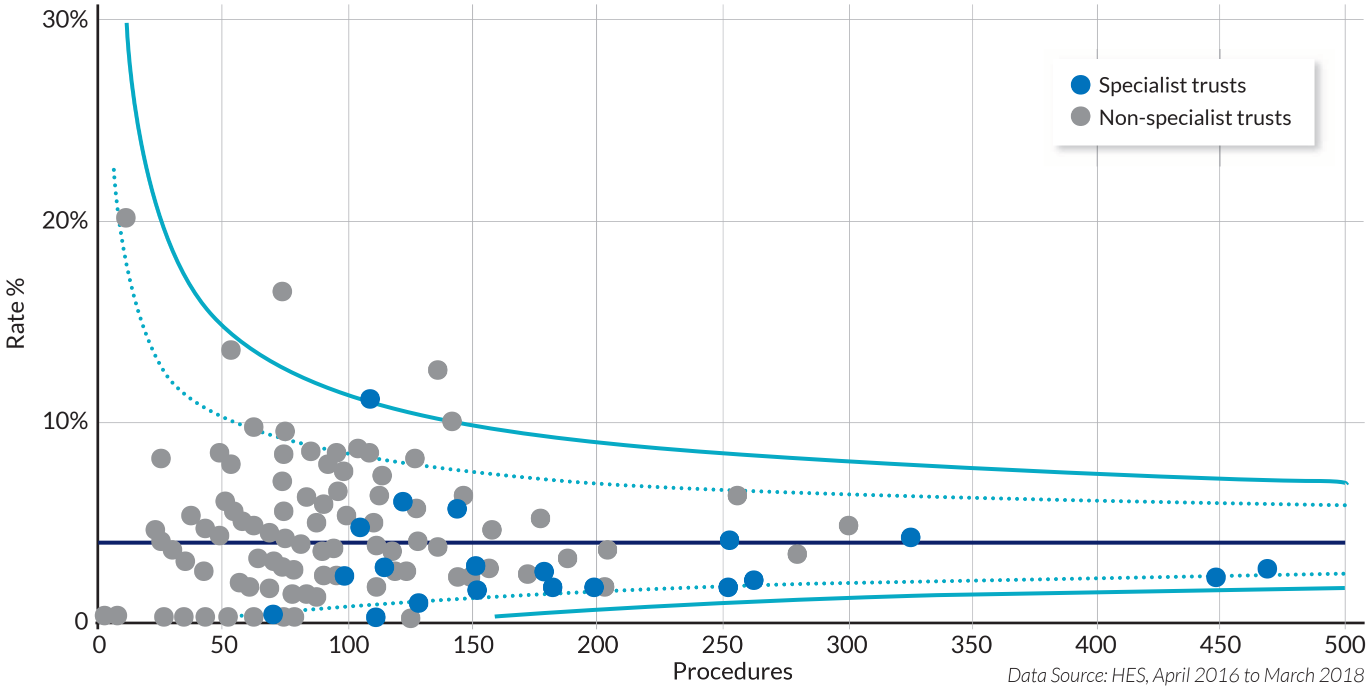
Data Source: HES, April 2016 to March 2018

Readmission after circumcision

There is wide variation in readmission rates after circumcision. Some trusts are achieving rates of 0%, while in others the rate exceeds 15% (Figure 57).

If the readmission rate in all trusts matched the rate in the upper quartile of best performing trusts (1.5%), 677 readmissions would be avoided.

Figure 57: All cause readmission rate within 30 days of discharge following circumcision



Data Source: HES, April 2016 to March 2018

When it may be appropriate to have a medical circumcision

Circumcision is appropriate in some cases. For example, to reduce the risk of urinary tract infection in boys with congenital malformations that predispose them to urinary tract infection.[87] It is also an option for boys with congenital abnormalities of the foreskin although it may be preferable to reconstruct the foreskin.

Circumcision is also one of the treatment options for balanitis xerotica obliterans[88] but even this can be effectively treated by preputioplasty.[89] Balanitis xerotica obliterans is rare in boys under the age of five years.

Circumcision may also be appropriate treatment for boys with phimosis as they approach adolescence, although other treatments such as topical steroids and preputioplasty can conserve the foreskin.

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[87] *Singh-Grewal, D. (2005). Circumcision for the prevention of urinary tract infection in boys: a systematic review of randomised trials and observational studies. Archives of Disease in Childhood, [online] 90(8), pp.853–958.*

[88] *Balanitis xerotica obliterans: a chronic, often progressive disease, which can lead to phimosis and urethral stenosis*

[89] *Wilkinson DJ, Lansdale N, Everitt LH, Marven SS, Walker J, Shawis RN, et al. Foreskin preputioplasty and intralesional triamcinolone: a valid alternative to circumcision for balanitis xerotica obliterans. J Pediatr Surg. 2012;47(4):756-9.*

5. Orchidopexy for undescended testis

Orchidopexy is a relatively non-complex treatment to bring undescended testis from the groin or abdomen to the scrotum.

Variation in day case rates

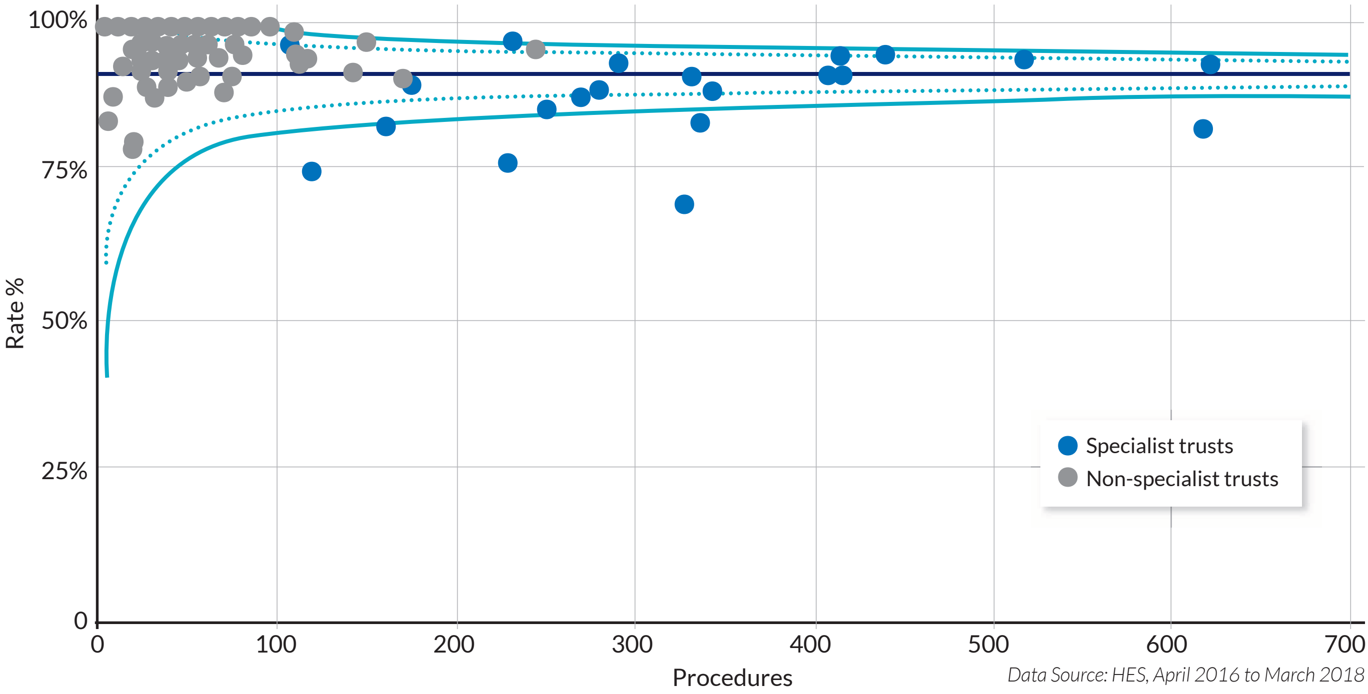
Up to 20-30% of orchidopexies are performed laparoscopically (using keyhole surgery), but this is not an indication to keep boys in as inpatients. Some boys will have concurrent medical conditions that mandate overnight stay for safe post-operative monitoring, but these cases are in a minority.

There is significant variation in the use of day case for orchidopexy (Figure 58). The trust with the lowest day case rate had a rate of just 63%. In that trust alone, over 50 boys per year stay in an inpatient bed for no reason, costing over £40,000 per annum.

Many specialist trusts treating high volumes of boys achieve day case rates of >90%.

There is no consistent link between rates of laparoscopic orchidopexy and day case rates, although the trust with the lowest day case rate had the highest (>30%) laparoscopy rate. Laparoscopic orchidopexy can be safely performed as a day case procedure.

Figure 58: Day case rates for orchidopexy



Data Source: HES, April 2016 to March 2018

Conclusions

We need to improve the way we decide which children require surgery for common conditions Across conditions, children are undergoing unnecessary surgery – up to 4,000 boys annually undergo unnecessary circumcision as a result of a lack of evidence base and training in alternative treatments. We see a similar situation in both hydrocele and umbilical herniotomy, where conditions usually resolve over time.

NHE England and NHS Improvement are running an evidence-based interventions (EBI) programme which aims to prevent avoidable harm to patients, to avoid unnecessary operations, and to free up clinical time by only offering interventions on the NHS that are evidence-based and appropriate. This programme has contributed to reducing unwarranted variation and in its first phase included surgical interventions including tonsillectomy and grommets. The programme is currently in its next phase, which is considering additional paediatric surgery interventions. This programme may support the reduction of unnecessary surgery taking place for medically indicated circumcisions, umbilical herniotomy and hypospadias surgery. More detail on the programme is available on the EBI website[3].

For procedures/conditions such as orchidopexy for undescended testis there is also scope for increasing the scope of day case surgery and reviewing or establishing new or amended clinical guidance (recommendation 3).

Furthermore, as previously discussed, there is an opportunity to reduce unnecessary follow-ups following day case surgery (recommendation 6).

Recommendation	Actions	Timescale
5. Reduce unnecessary surgical procedures through Operational Delivery Networks by applying evidence-based surgical decision-making.	**a** Trusts and Operational Delivery Networks to continually review and improve surgical decision making, based on the priorities outlined in box A. (below)	Ongoing
	b GIRFT and NHS England and NHS Improvement to consider paediatric procedures for inclusion in the Evidence Based Interventions Programme.	Within nine months of publication

Box A	
Medical circumcision	i. Less than 10% of medical circumcisions should be in boys under five years of age ii. Increase awareness of alternative to medical circumcision
Hydrocele	i. No hydrocele repairs in boys under Three years of age (most spontaneously resolve by this age)
Umbilical herniotomy	i. No umbilical herniotomies in children under three years (most spontaneously resolve by this age)
Hypospadias surgery	i. Reduced staging of surgery meaning less pain and disruption for children and their families

Recommendation	Actions	Timescale
6. Provide patients with a clinic review if necessary, after routine low risk procedures, without requiring routine out-patient follow-up appointments.	**a** Trusts and Operational Delivery Networks to review existing practice against this goal, and change processes as necessary, for the following procedures: circumcision, inguinal or umbilical herniotomy.	Within nine months of publication

Measuring clinical outcome data

The importance of national benchmark data both as a research and assurance tool cannot be overstated. Benchmark data offers a set of data against which an organisation can measure and compare its outcomes overtime with peer organisations and use the findings to inform decision making.

Although Hospital Episode Statistics (HES) data is extremely useful in measuring caseload and certain outcomes, it is limited by not necessarily being able to measure most relevant outcomes. To fill this gap, national registries have been established. It was found, however, that levels of participation in these registries varies greatly and this is also the case when demonstrating participation in national registries as a revalidation requirement for clinicians involved in paediatric surgery.

Multiple reasons were given for non-participation: a recurring theme was that participation in national registries is not a mandatory requirement of commissioners.

Examples of registries include the National Outcome Audit of Hypospadias (NOAH), and the British Association of Paediatric Surgeons Congenital Anomaly Surveillance System (BAPS-CASS).

National Outcome Audit of Hypospadias (NOAH)

Current participation in the British Association of Paediatric Surgeons (BAPS) sponsored NOAH is low. Only around a third of all hypospadias cases are being registered and some of the largest and most prestigious trusts in the country do not participate. Current issues with the database include:

- funding – the registry is currently funded by BAPS members;
- non-membership of BAPS is a barrier to use – non-BAPS members are not allowed to enter data without becoming BAPS members at their own expense, and many choose not to do this;
- participation is not mandatory.

The database has the potential to offer:

- a much richer picture of outcome reporting;
- increased detail about the anatomy of the hypospadias and surgery performed;
- parent-reported outcomes;
- links to NHS numbers for long-term tracking.

British Association of Paediatric Surgeons Congenital Anomaly Surveillance System (BAPS-CASS)

BAPS-CASS is a rolling programme to register data in neonatal surgical index cases. It has run for the last 13 years as a collaboration between BAPS and the National Perinatal Epidemiology Unit (NPEU) in Oxford. The data collected means the UK is one of few countries that has been able to publish near population-level outcome data for paediatric surgery.

The programme allowed GIRFT to compare its trust-level data with HES data in order to assess the proportion of cases being submitted to the programme. It was found that, although most trusts are committed to collecting and submitting data, several did not engage in the programme. The registry requires manual data entry which was difficult for several small volume trusts who struggled to find the administrative resource to ensure data quality and register it.

To date, the impact of the programme has been limited, as:

- feedback data is not provided to trusts and clinicians in real-time;
- none of the data has been used to inform commissioning of children's specialist surgery.

Core outcome sets

In recent years, considerable work has gone into establishing core outcome sets (COS) designed to enable patients, parents and clinicians to define meaningful outcomes. One example is, the COMET (Core Outcome Measures in Effectiveness Trials) initiative.

Core outcomes are already available for several neonatal and paediatric surgical conditions. These can be used to generate strong long-term outcome data to assist in research and innovation as well as providing quality assurance to parents, patients, commissioners, networks, trusts and commissioners. Building future databases to incorporate core outcomes should be a long-term strategic objective in all clinical specialties.

The National Clinical Improvement Programme

GIRFT has developed the National Clinical Improvement Programme (NCIP) under the leadership of Sir Norman Williams. The programme has created a secure online portal that presents outcomes data for both team and individual consultant-level activity. The portal is currently being trialled by a number of NHS trusts. It links to information about a clinician's practice and presents data from metrics across a number of surgical specialties. The aim is to drive scrutiny of patient outcomes and enable consultants to identify improvements to their clinical practice..

Specialty specific content (including paediatric surgery) has been co-developed by leading clinicians in surgical specialty associations. Although the main data source is Hospital Episode Statistics (HES), GIRFT is working with NHS Digital to extract data from hospital theatre databases. In addition, it is anticipated that National Registry data will be linked to NCIP in the future. As well as providing feedback to individual clinicians and teams, NCIP also has the potential to be the data source for Operational Delivery Networks in paediatric surgery and for key performance metrics to be measured.

Conclusions

Exploiting innovations in health data analytics by using the National Clinical Improvement Programme will help monitor outcomes at clinician, provider, network and national level. The surgical specialty associations, together with Royal Colleges and NHS England and NHS Improvement, should work to develop linked data sets via the electronic patient records that permit measurement of meaningful outcomes for children undergoing surgery, particularly by using Core Outcome Sets.

Recommendation	Actions	Timescale
7. Drive improvements in patient outcomes by strengthening how clinical data is collected, shared and analysed. This includes exploiting innovations in health data analytics by using the National Clinical Improvement Programme to monitor outcomes at clinician, provider, network and national level.	**a** GIRFT and specialist societies to review existing paediatric general and urology surgery registries and audits. Review to include understanding the gaps and barriers (eg; participation) and where data collected from HES can support monitoring of outcomes.	Ongoing
	b GIRFT, specialist societies and NHS England and NHS Improvement to develop a plan based on action a, which includes how NCIP can support in developing data tools in paediatric surgery and linking with existing data sources to drive improvements in outcomes.	Ongoing
	c Updated guidance to be sent to trusts and ODNs to support participation and advise on how the tools can enable continuous improvement.	Ongoing

For any child, a positive and safe healthcare experience can have a life-long positive impact. This is recognised in several key standards and guidelines:

- the Royal College of Surgeons' (RCS) standards for children's surgery[90] require that children should be treated in an environment that is:
  - safe;
  - suitably staffed and equipped;
  - child and family-friendly.
- the Department of Health's Estates and Facilities guidelines for the design of day surgery facilities are consistent with the standards set by the Children's Surgical Forum.[91]

Current variation

Where possible we visited day case units, inpatient wards and operating theatres to assess patient journeys, and the efficiency of patient flow against the RCS standards.

We found huge variation in the environment of care across paediatric services.

Many older hospitals simply predate the RCS standards and have not been brought up to date. Even in recently built hospitals, the standards have not always been followed.

We have highlighted the following key areas which have an impact on patient experience and productivity:

- child-specific areas;
- the route from ward to theatre;
- transfer between sites.

Child-specific areas

Child-specific areas of importance in the delivery of care are:

- preoperative assessment areas;
- theatres;
- recovery areas.

There is currently a wide variation in approach. In some trusts, children can spend their preoperative time in play and assessment areas. As well as meaning children do not encounter post-operative children in recovery, this avoids taking up bed space and improves flow.

We found some examples of best practice, where theatres are decorated to be child-friendly and recovery areas are bright and attractive. Unfortunately, this was not the case at many trusts.

We found several trusts that run mixed adult and child clinics. This can have a negative impact on children's experience and create potential safeguarding risks.

Photo courtesy of Birmingham Children's Hospital

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[90] *Children's Surgical Forum, RCS (2015) Standards for non-specialist emergency surgical care of children https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/standards-for-non-specialist-emergency-surgical-care-of-children/*

[91] *Department of Health Estates and Facilities Division (2007) HBN 10-02 Surgery: Day Surgery Facilities. https://www.gov.uk/government/publications/day-surgery-facilities-buildings-guidance*

The route from ward to theatre

We found many examples where the children's day case ward is located a long distance from the operating theatre. Children are being taken through corridors crowded with equipment and instrument trays into the industrial environment of the theatre with little or no thought given to making the experience child-friendly. In the worst cases, journeys involve taking several lifts, crossing roads and going outdoors from building to building. The effects of such long journeys not only adversely impacts the experience of the child and their family, they also play a significant role in poor list productivity, leading to an impact on costs.

Photo courtesy of Alder Hey Children's Hospital

A further issue is that over the last 30 years there has been a huge expansion in the amount of hardware required in operating theatres. Inadequate storage space means that corridors get used as a storage area for hardware and surgical trays. This is unacceptable and increases the risk of tampering, theft and breaches of sterilisation, as well as potentially affecting the route from the ward to theatre.

Transfer between sites

In the last decade several hospitals have merged, forming larger trusts. Many trusts now have services split across multiple sites, which can mean that children who arrive at emergency departments must be transferred to another site to undergo emergency surgery. This incurs significant delays, resulting in poor experience and outcomes, as well as increasing the costs of care.

Causes of variation

During our deep dive visits, we probed trusts to find out what factors were restricting their ability to implement an improved environment of care.

The following key themes emerged:

- competing priorities;
- funding and investment.

Competing priorities

Children's surgery often falls behind other competing priorities. Co-location of medical and surgical day care services often leads to competing interests for beds. In non-specialist trusts, children's surgery typically involves different trust units; usually the surgical division and women's and children's division.

We found several examples of trusts which had been forced to use day surgery facilities, such as beds, and ward space, to cope with demand for care of older people. This meant that theatre facilities and staff were not being used for surgery, impacting significantly on costs and productivity.

Despite fluctuation in capacity and demand in day case wards across a week, we found that theatre leadership teams were often reluctant to tackle timetabling to smooth and address these issues. This often seemed to be due to a reluctance to change surgical and anaesthetic job plans.

Funding and investment

The drift of non-complex general paediatric surgical cases from non-specialist to specialist trusts means some non-specialist trusts now believe their case numbers are insufficient to merit investing in paediatric infrastructure. This is particularly marked in low-volume trusts, where it is common for children to be seen in mixed adult/children settings and to be treated on a mixed adult/children operating list.

In almost all cases, trust leaders were aware of these issues and that they affected all services, not just children's, but the capital funds for transformation were not available.

It is worth noting that not all improvements require capital funding. Several trusts have tackled the problems outlined above by undertaking a fundamental timetable redesign and scheduling all children's surgery to take place simultaneously in a day surgery unit.

Conclusions

The environment of care is an important aspect of wellbeing for children and families, at a time when stress and discomfort are already high. We found that many trusts, as a result of inadequate capital funding and workforce, and other competing priorities, were unable to make the environment of care in paediatric surgery suitable for children.

It is therefore a concern that in some trusts we visited the environment of care for children was not child-friendly, with some children staying in mixed adult/child wards or travelling long distances to theatre. This can lead to a frightening and upsetting experience for children and also can lead to safeguarding concerns. We recommend trusts take steps to improve the environment of care for children and young people undergoing surgery and that the environment meets the standards outlined in RCS Standards for Children's Surgery with consideration to preoperative assessments, journey to the theatre and recovery areas.

Recommendation	Actions	Timescale
8. Take steps to improve the environment of care for children and young people undergoing surgery.	**a** Trusts and Operational Delivery Networks to review facilities compared to expectations for child-friendly environments as described or referenced in health building notes and RCS standards for children's surgery consider business case for any improvements apparent, and implement as appropriate.	Within 12 months of publication

Photo courtesy of Sheffield Children's NHS Foundation Trust

Measuring patient experience

Often when a child has surgery it's the first time they have been in a hospital. Adverse experiences have the potential to cause lifelong problems such as needle phobia. It is therefore vital to listen to child and family experiences, both directly from patients or through patient groups and charities, in order to improve care and care delivery.

Currently, very limited data is collected that would enable any review of patient perception of care at hospital-level to inform service transformation. We looked at two sources of patient experience data:

- NHS Friends and Family Test (FTT);
- Care Quality Commission's Children and Young People's Inpatient and Day Case Survey.

NHS Friends and Family Test (FFT)

The NHS Friends and Family Test (FFT) is designed to give people the opportunity to provide quick and easy anonymous feedback about their experience of NHS services. Although overall response rates are low, it is one of the few global measures of how patients view the quality of their care. National reporting, however, does not provide a breakdown for children's inpatient services.

NHS England and NHS Improvement has recently reviewed the FFT and as a result has included a new question: 'Overall, how was your experience of our service', with a response scale that has tested well with children and young people.[92] NHS England and NHS Improvement is supporting providers in ensuring their feedback forms are child friendly and have a collection of resources available to support providers to improve the collection of feedback from children and young people. There is variation however between providers in how they implement FFT.

CQC's Children and Young People's Inpatient and Day Case Survey

The Care Quality Commission's (CQC) 2016 'Children and young people's inpatient and day case survey'[93] provides a comprehensive trust-level report. However, the report is not published regularly, which reduces its usefulness in monitoring and improving performance.

The report does not offer an overall summary measure of satisfaction, making it difficult to assess overall trust performance.

NICE guidelines: Babies, children and young people's experience of healthcare – in development

NICE is currently developing guidelines on babies, children and young people's experience of health care. The guideline's scope has identified current practice as:

"Many NHS providers of healthcare services for children currently carry out user surveys directly with children as well as with their parents or carers. Some run user groups to obtain feedback from children and young people and their parents or carers, with a view to improving the provision of services and the experience of healthcare.

Whilst there are some examples of good practice and initiatives to improve children and young people's experience of healthcare, such as those contained in the Patient Experience Network report of 2016[94], there is variation in practice across the country".

NICE therefore aims to help reduce this variation in practice by publishing guidance which focuses on children and young people's experience of health care. It is expected to be published in 2021.

Conclusions

The method of collecting patient experience data is lacking for paediatric surgery. There is no specific method of collection of children's experience of paediatric surgery services specifically, and in existing data collection methods there is no clear, tailored way of collecting feedback from children. Existing sources of patient experience data are also not updated regularly. This makes it difficult to see trust level and national level experiences of children and families using inpatient services.

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[92] *NHS England & NHS Improvement (2019) Using the FFT to improve patient experience guidance https://www.england.nhs.uk/wp-content/uploads/2019/09/using-the-fft-to-improve-patient-experience-guidance-v2.pdf*

[93] *see www.nhssurveys.org/surveys/1113*

[94] *Blunt, L and Evans, R (January 2016) Improving Patient Experience for Children and Young People -2015, http://patientexperiencenetwork.org/wp-content/uploads/2015/11/PEN-Improving-PE-for-Children-Young-People-Executive-Summary-2016-FINAL.pdf*

Recommendation	Actions	Timescale
9. Improve how we gather and respond to the experience of children and their families / carers while in hospital.	**a** Review what mechanisms (including Friends & Families Test and CQC Children and Young Person's Inpatient and Day Case Survey), are available to enable the capturing of children, young people's, and their families/carers' experiences.	Within six months of publication
	b Based on action A, liaise with NICE, NHS England and NHS Improvement, ODNs and trusts to produce and implement a plan to enable the improvement in how we gain and use children's and their families' experience of care at hospital-level.	Within 12 months of publication

Photo courtesy of Alder Hey Children's Hospital

Leadership

During visits we found that many clinicians could clearly see where improvements in quality and productivity were needed but the communication links between clinicians and management to enable the realisation of these improvements were lacking.

It was apparent through discussions in the non-specialist trusts where leadership recognised the importance of treating children in a safe, child-friendly environment. They often had good communication and feedback links between ward and board. However, we often heard trust leadership were under pressure and issues around paediatric surgery were eclipsed by competing priorities, for example, in trusts overwhelmed by older patients with complex medical and social needs.

Governance

The Children's Surgical Forum's Standards for Children's Surgery[95] requires trust executive management and senior staff to commit to providing a high-quality children's surgical service, with a multidisciplinary children's surgery committee reporting to each trust's executive board.

We found, during the visits, representation at trust board level is essential for ensuring effective service provision from 'ward to board'. Therefore, we were concerned to find that:

- 17 out of 67 non-specialist trusts lacked a designated children's lead at board level;
- 8 out of 67 non-specialist trusts lacked a children's nursing lead at board level.

However, even when there was trust representation, we found that many staff members were unaware who their representatives were.

We did find some examples of good practice. For example, non-specialist trusts that had an effective lead clinician for children's surgery and that held regular children's surgery committee meetings.

Therefore, developing stronger clinical leadership and responsive relationships between management/board and clinicians is essential to help enable improvements to the care children receive.

Recommendation	Actions	Timescale
10. Ensure the children's voice is heard in hospitals by implementing ward to board representation of children's services, and by trusts active participation in Operational Delivery Networks.	**a** Trusts to review their governance arrangements compared to the goals described by RCS Children's Surgical Forum, consider any possible improvements and implement as appropriate, sharing experiences in doing so with GIRFT. Operational Delivery Networks should also share experiences across trusts in the network.	Within six months of publication
	b GIRFT and NHS England and NHS Improvement to consider any further policy development based on action A.	Within six months of publication

Product and technology procurement costs

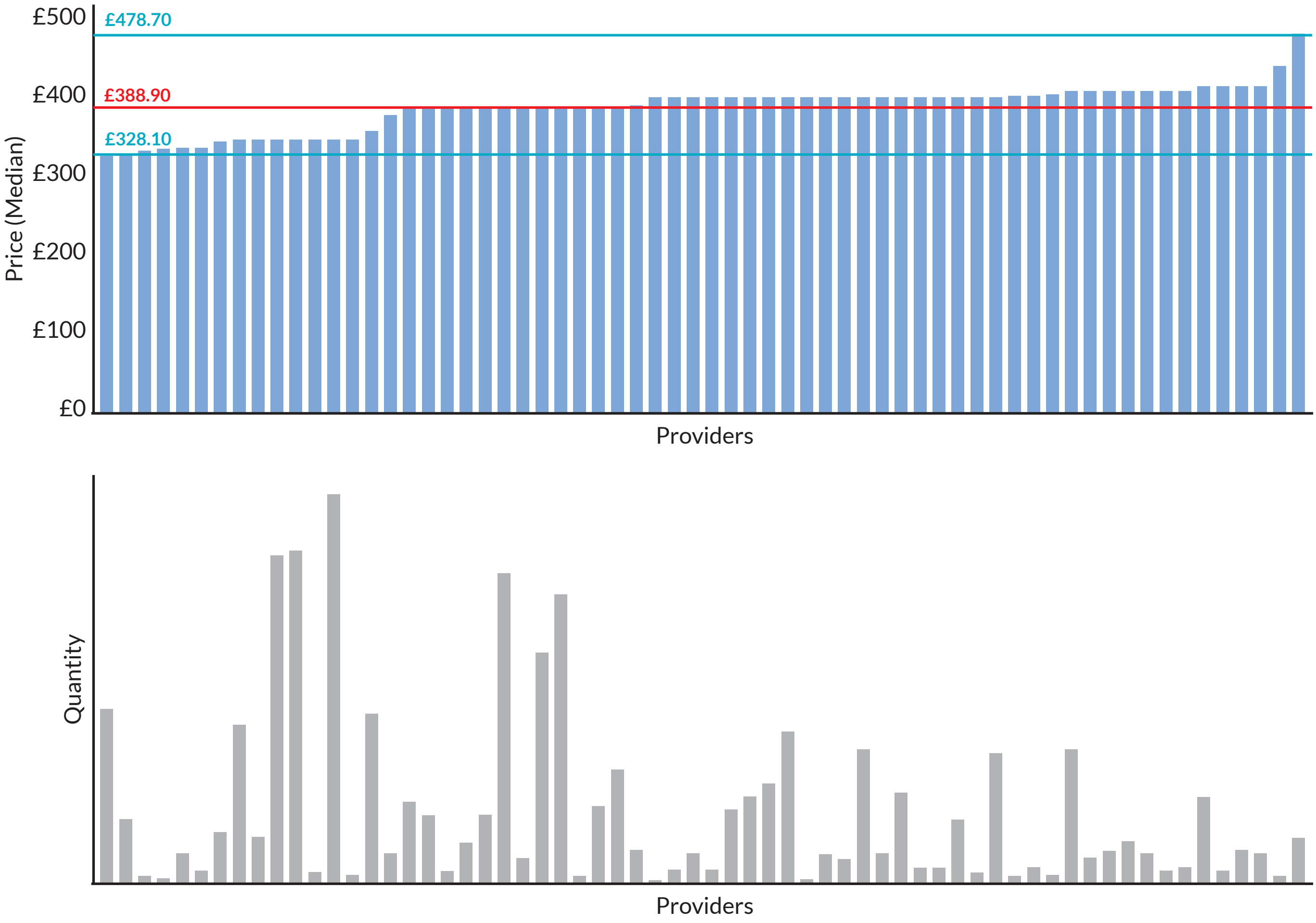
In 2016 NHS Improvement mandated all trusts to submit their monthly purchase order data to a central database – the Spend Comparison Service (SCS). This is the first time a single national dataset of procurement information has been established for the NHS.

For the last 18 months the GIRFT programme has been analysing this data to better understand the variation in products and brands used and prices paid across NHS trusts. This analysis has identified unwarranted variation in products and brands used and prices paid across NHS trusts for various specialities.

Unwarranted variation between prices paid in paediatric surgery

We looked at 33 typical products used by paediatric surgery departments across the NHS and found unwarranted variation in prices paid for the same product from the same supplier. As an example of product price variation, we looked at the prices paid for the same laparoscopic sealer and divider instrument from one supplier. Figure 59 clearly demonstrates the variation in prices being paid by each trust, in the selected sample, with no correlation to volumes purchased.

Figure 59: Product price variation for a laparoscopic sealer and divider instrument (1 supplier; 1 brand)



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[95] Royal College of Surgeons of England (2013) Standards for Children's Surgery, available via: https://www.rcseng.ac.uk/standards-and-research/standards-and-guidance/service-standards/childrens-surgery/standards-of-care/

Looking across the 33 products if all NHS trusts were able to achieve the lowest price paid across the country, then the NHS could save nearly £4.3m (10%) on the national spend of £42m per annum.

This does not take into account the even greater savings that could be achieved by switching suppliers and brands, but more work is needed to define equivalency and to validate them. However, to note, many of the products we looked at are also used in other specialties so potential savings are not specific to paediatric surgery.

Reducing unwarranted variation and improving value for money

GIRFT has established a programme to help root out unwarranted variation, improve the evidence-base to enable better decision-making, accelerate adoption of new proven technologies, and improve overall value for money by reducing supply chain costs.

The GIRFT Clinical Technology Optimisation programme has been working with GIRFT clinical leads to examine the data and evidence that support products. In some cases, national Clinical Technology Advisory Panels (CTAPs) have been established with leading clinicians from the specialty to address safety, efficacy, innovation and value – with the objective of providing better information to clinicians and procurement professionals across the NHS.

GIRFT has also been working with the new NHS operating model for NHS procurement, including the new Category Towers, to develop plans for helping trusts and clinicians to address variation and improve value for money.

To understand whether different brands have clinical impacts, NHS England and NHS Improvement is launching 'Scan4Safety'[96] in which individual products can be traced to individuals. We are looking at the feasibility of creating links between NCIP and Scan4Safety to identify efficacy of different brands and, perhaps most importantly, allow tracking of new implants or procedures across the NHS.

Recommendation	Actions	Timescale
11. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	**a** GIRFT to use sources of procurement data, such as SCS and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	Ongoing
	b GIRFT to identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	Ongoing
	c Trusts, STPs and GIRFT to use Category Towers to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	Ongoing

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[96] *https://www.scan4safety.nhs.uk/*

Litigation

We examined the impact and causes of litigation in paediatric surgery with a view to reducing the cost of litigation and improving patient care.

Giving providers and clinical staff the opportunity to learn from best practice, claims, complaints, severe untoward incidents (SUIs)/severe incidents (SI)/patient safety incidents (PSI) and inquests will help improve patient care and reduce the frequency of incidents. In turn, this will lead to reduced costs, both in terms of litigation itself and of managing complications related to incidents.

Clinical negligence claims in paediatric surgery

NHS Resolution data shows that clinical negligence claims in paediatric surgery were estimated to cost between £10.3m and £21.4m per year in the five years from 2012/13 to 2016/17.

About the data

We included only claims directly coded to paediatric surgery in our data set.

We recognise that in hospitals without a paediatric surgery service some of the procedures which could be the subject of these claims would be carried out by other surgical specialties. In order to focus on the specialist service of paediatric surgery these claims have not been included in this data set but have been instead included in our review of the operating surgeon's specialty.

Variation in average litigation costs

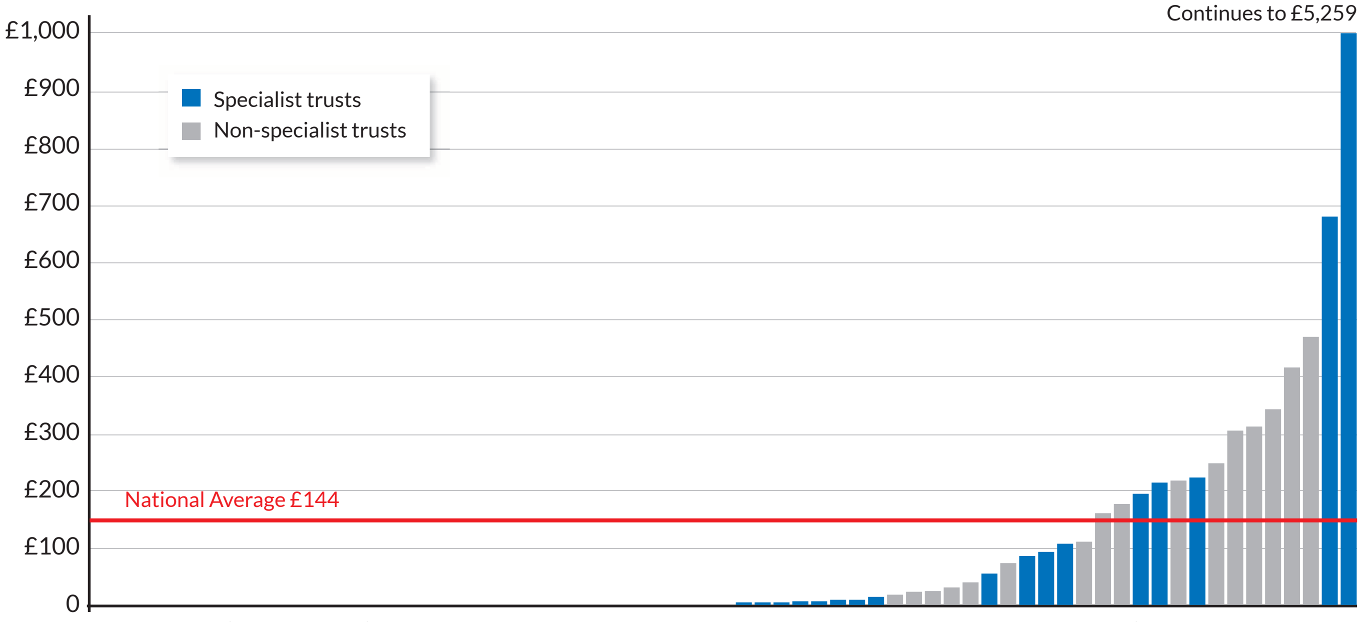
The estimated average cost of litigation per paediatric surgical admission is £144 (Figure 60).

There is huge variation between trusts: the best performer achieves an average litigation cost of £0 per paediatric surgery admission over five years. At the other end of the scale, one provider generates an average of £5,259 in litigation costs per admission in the same period. The extent of variation in paediatrics is due in part to younger patients tending to receive a higher level of damages. This reflects the greater estimated impact of negligence on a younger patient's future life plus the longer period that damages will need to cover.

Thirty-four of the non-specialist trusts had no claims against them in the five-year period we looked at.

Trusts with higher volumes of surgical cases are at higher risk of litigation. However, if a low activity provider has even one claim against them, their litigation costs can quickly become very costly, affecting their litigation burden and their benchmarked position. This is the case for the two trusts with the greatest litigation cost per admission.

Figure 60: Estimated litigation costs for paediatric surgery per admission by trust



Denominator includes day case, elective and emergency admission for paediatric surgery, paediatric urology, paediatric gastrointestinal surgery and paediatric ENT.

Data Source: NHS Resolution 2012/13 to 2016/17

Claims trends and causes

There is no clear trend in either volume or estimated costs of claims over the five-year period we looked at.

The volume of claims does not necessarily correlate with the estimated costs. One claim was estimated at £10.6m while there were 14 claims of over £1m. These figures show how individual claims can have a dramatic effect on the national cost of litigation in this specialty each year.

Table 10: Volume and cost of medical negligence claims against paediatric surgery notified to NHS Resolution 2012/13 to 2016/17

Year	No. of claims	% change in Claims No.	Total costs (£m) (including estimated and reserve values)	% change in Total costs
2012/13	39	-	£10.3m	-
2013/14	31	-20.51	£21.4m	106.92
2014/15	42	35.48	£15.0m	-29.68
2015/16	38	-9.52	£17.6m	17.16
2016/17	39	2.63	£13.7m	-22.46
Total	189	-	£78.0m	-

Source data: NHS Resolution 2012/13 to 2016/17

Table 11: Most common causes of medical negligence claims against paediatric general and urology surgery – 2012/13 to 2016/17

Cause	Number of claims	Percentage of claims
Judgement/timing	79	41.8%
Unsatisfactory outcome to surgery	54	28.57%
Interpretation of results/clinical picture	47	24.87%
Retained foreign object post-operation	8	4.23%
Inadequate nursing care	7	3.7%

Data source: NHS Resolution 2012/13 to 2016/17

We looked in further detail at the causes for claims, in an effort to understand how to reduce them.

Informed consent

There were six claims directly identified as relating to informed consent. However, the impact of lack of informed consent is more significant because it also played a role in many of claims which were attributed to 'unsatisfactory outcome of surgery'.

Many of these claims are clearly avoidable through an adequate consenting process in which an informed parent/guardian and child is involved in shared decision making.

Never events

Never events are incidents that require investigation under the Serious Incident framework. These events include ‘retained foreign object post-operation’, 'wrong site surgery' and 'wrong implant/prosthesis'. They represent system failure and are patient safety issues that can be eradicated by more diligent organisation and closer adherence to tools, including the World Health Organisation checklist.

Retained foreign object post-operation

It is concerning that ‘foreign body left in situ’ resulted in eight claims.

The Revised Never Events Policy and Framework established in 2012 recognises ‘foreign body left in situ’ and ‘retained instrument post-operation’ in one never event category: ‘retained foreign object post-operation’. This event includes retention of any items (such as swabs, needles, instruments and guide wires) . The risk of retention of such items could be mitigated by a fundamental formal counting/checking process at the start of a procedure and before completion.

Reducing claims

Given the potential impact and costs of claims in paediatrics, it is doubly important that every effort is made to learn from claims. This will help the specialty improve the safety and quality of patient care and reduce the costs of litigation, in turn ensuring that resources are not unnecessarily diverted from frontline care. Most importantly, it means more patients will receive the right care first time, with fewer failed or ineffective treatments, shorter lengths of stay, and fewer care packages needed for patients suffering complications.

Several of the most common causes of claims are avoidable. Issues of poor judgement and timing, as well as errors related to interpretation of results/clinical picture, often relate to inexperience and poor decision-making that could be addressed through training.

Improving record keeping

There is some evidence that claims cannot be defended effectively because providers do not have the necessary documentary evidence. Collecting and keeping this evidence would improve the ability to prove that processes have been followed correctly and that patient’s interests have been considered.

Sharing details of litigation

During our deep dive visits, it became clear that many providers had little knowledge of the claims against them. This included some providers with high litigation costs per admission as well as those at the low end.

Sharing knowledge of claims would help providers learn lessons that would inform future practice. Discussion of settled claims at departmental morbidity and mortality meetings is one way in which trusts can ensure that actions are taken to minimise the risk of recurrence of the same problems.

Further work is needed at a local and national level to analyse claims in order to improve patient care.

Conclusions

Litigation costs in children’s surgery vary widely between trusts. Litigation in children’s surgery can be particularly costly, because of the long-lasting impact of mistakes on children and families. Better data collection, sharing of litigation cost data, and sharing of details of claims are important steps to ensure trusts learn from such experiences, and improve care, as well as reduce costs.

Recommendation	Actions	Timescale
12. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT litigation data pack.	For immediate action.
	b Clinicians and trust management to discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS Resolution of any claims which are not coded correctly to the appropriate specialty via *CNST.Helpline@resolution.nhs.uk*.	Upon completion of 12a.
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trusts panel firm should be able to provide support.	Upon completion of 12b.
	d Claims should be triangulated with learning themes from complaints, inquests and serious untoward incidents (SUI) serious incidents (SI)/ patient safety incidents (PSI) and where a claim has not already been reviewed as SUI/SI/PSI we would recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all frontline clinical staff in a structured format at departmental/directorate meetings (including multidisciplinary team meetings, morbidity and mortality meetings where appropriate).	Upon completion of 12c.
	e Where trusts are outside the top quartile of trusts for litigation costs per activity GIRFT we will be asking national clinical leads and regional hub directors to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trusts examples of good practice where it would be of benefit.	For continual action throughout GIRFT programme.

Activity opportunities and notional financial opportunities

This report sets out a series of ways to improve the delivery of paediatric surgery using the existing resources available to the specialty.

Potential benefits

Improvements to the patient experience would be seen in shorter stays and fewer repeat visits. This also benefits providers, reducing the costs of common procedures and pathways and freeing up resource for other purposes.

While the impact in some areas is hard to measure, in others there is a clear tangible benefit.

Notional financial opportunity

The notional financial opportunity could be between £11.3m and £19.4m. This opportunity is in addition to the potential cost savings in procurement.

These figures provide a financial value for a wide range of efficiency opportunities, which may not be cash-releasing.

The figures are based on a selection of metrics (Table 12) and provide an indication of what may be possible. The metrics do not represent a comprehensive set of all opportunities discussed in the report.

Further opportunities

The opportunity values shown are for illustration only. Individual providers and clinicians should assess their own services to determine the unwarranted variation that exists and the associated opportunity. Their assessment will help them to prioritise the service changes that they wish to deliver.

Individual providers may also have other opportunities that are not included here.

Table 12: Activity opportunities and notional financial opportunities

Improvement *(opportunities are per annum)*	**National mean average or better**			**Top quartile* or better**		
	Target	**Activity opportunity**	**Gross notional financial opportunity**	**Target**	**Activity opportunity**	**Gross notional financial opportunity**
Reduce the number of operations in babies with necrotising enterocolitis by 50% *Activity source: NNRD 2012-13*	50% reduction	106 procedures	£1.1m	50% reduction	106 procedures	£1.1m
Perform a higher percentage of surgery as day case procedures *Activity source: HES 2017-18*	Specialist Trusts 79% Non-Specialist Trusts - 94%	1,405 bed days	£0.9m	Specialist Trusts 87% Non-Specialist Trusts 98%	4,124 bed days	£2.7m
Increase proportion of procedures carried out on day of admission *Activity source: HES 2017-18*	85%	370 bed days	£0.2m	95%	1,087 bed days	£0.7m

Table 12: Activity opportunities and notional financial opportunities (continued)

Improvement *(opportunities are per annum)*	**National mean average or better**			**Top quartile* or better**		
	Target	**Activity opportunity**	**Gross notional financial opportunity**	**Target**	**Activity opportunity**	**Gross notional financial opportunity**
Reduce length of stay in hospital for certain procedures *Activity source: HES 2016-18 (appendicectomy)*	Anti-reflux surgery - 6 days Pyeloplasty - 2.5 days Nephrectomy (non-malignant) - 2.6 days Nephrectomy (malignant) - 7.4 days Simple Appendicectomy - 2.5 days Complex Appendicectomy - 4.5 days	6,728 bed days	£2.9m	Anti-reflux surgery - 5 days Pyeloplasty - 2 days Nephrectomy (non-malignant) - 2 days Nephrecomy (malignant) - 5 days Appendicectomy - 2.4 days	14,402 bed days	£6.2m
Reduce the number of operations where the procedure is not carried out and has to be rebooked *Activity source: HES 2017-18*	4%	591 procedures	£0.3m	2%	1,497 procedures	£0.8m
Reduce the negative appendicectomy rate *Activity source: HES 2017-18*	10%	264 procedures	£0.9m	4.4%	585 procedures	£2.0m
Reduce the proportion of Hirschsprung's disease patients having a formation of colostomy procedure *Activity source: BAPS-CASS audit 2010-2012*	36%	16 procedures	£0.1m	27%	28 procedures	£0.1m
Reduce the number of elective umbilical hernia repairs in children under 3 years in line with current research *Activity source: HES 2016-18*	Reduce by 75%	222 procedures	£0.4m	Reduce by 75%	222 procedures	£0.4m
Reduce the hydrocele surgery in children under 2 years in line with current research *Activity source: HES 2016-18*	Reduce by 80%	249 procedures	£0.5m	Reduce by 80%	249 procedures	£0.5m

Table 12: Activity opportunities and notional financial opportunities (continued)

Improvement *(opportunities are per annum)*	**National mean average or better**			**Top quartile* or better**		
	Target	**Activity opportunity**	**Gross notional financial opportunity**	**Target**	**Activity opportunity**	**Gross notional financial opportunity**
Reduce the proportion of hypospadias repairs performed in 2 stages *Activity source: HES 2016-18*	22%	221 procedures	£0.3m	10%	566 procedures	£0.8m
Reduce circumcision rate to <1.5% in under 16s *Activity source: HES 2016-18*	1.5%	1,810 procedures	£2.6m	1.5%	1,810 procedures	£2.6m
Reduce 30 day emergency readmission rates for certain procedures *Activity source: HES 2016-18*	Circumcision - 4% Pyeloplasty - 11%	173 admissions	£0.1m	Circumcision - 1.5% Pyeloplasty - 8%	417 admissions	£0.3m
Reduce the number of 1 year re-operation rates in certain procedures ***2 year re-operation rate** *Activity source: HES 2016-18*	Inguinal herniotomy - 1% Hypospadias* - 12% Hydrocele - 1% Orchidopexy - 3% Pyeloplasty - 9%	213 procedures	£0.3m	Inguinal herniotomy - 0.5% Hypospadias* - 7% Hydrocele - 0.5% Orchidopexy - 1.7% Pyeloplasty - 6%	452 procedures	£0.7m
Significantly reduce outpatient follow ups for circumcision and inguinal hernia *Activity source: BAPS-CASS audit 2010-2012*	Circumcision - zero follow ups except for certain complications Inguinal hernia - stop follow ups except for pre-term babies or < 30 day gestational age	2,292 outpatient appointments	£0.4m	Circumcision - zero follow ups except for certain complications Inguinal hernia - stop follow ups except for pre-term babies or < 30 day gestational age	2,292 outpatient appointments	£0.4m
Total			**£11.3m**			**£19.4m**

Data source: HES (savings calculated compared to baseline of 2019-20)

About the GIRFT programme

Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS.

Funded by the Department of Health and Social Care and jointly overseen by the Royal National Orthopaedic Hospital NHS Trust and NHS England and NHS Improvement, it combines wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after the pilot programme, it delivered an estimated £30m-£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model is now being applied in 41 different areas of clinical practice. It consists of four key strands:

- a broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors;
- a series of discussions between clinical specialists and individual hospital trusts, which are based on the data – providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area of practice, in the context of the national picture. This then enables the trust to understand where it is performing well and what it could do better – drawing on the input of senior clinicians;
- a national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for NHS-wide improvement; and
- an implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

GIRFT and other improvement initiatives

GIRFT is part of an aligned set of workstreams within the NHS Improvement Directorate. It is the delivery vehicle for one of several recommendations made by Lord Carter in his February 2016 review of operational efficiency in acute trusts across England.

As well as support from the Department of Health and Social Care and NHS England and NHS Improvement, it has the backing of the Royal Colleges and professional associations.

GIRFT has a significant and growing presence on the Model Hospital portal, with its data-rich approach providing the evidence for hospitals to benchmark against expected standards of service and efficiency. The programme also works with a number of wider NHS programmes and initiatives which are seeking to improve standards while delivering savings and efficiencies, such as NHS RightCare, sustainability and transformation partnerships (STPs), and Integrated Care Systems (ICS).

Implementation

GIRFT has developed a comprehensive implementation programme designed to help trusts and their local partners to address the issues raised in trust data packs and the national specialty reports to improve quality. GIRFT regional hubs provide support at a local level with clinical and project delivery leads able to visit trusts and local stakeholders in each region on a regular basis. They advise on how to reflect the national recommendations into local practice and support efforts to deliver any trust specific recommendations emerging from the GIRFT visits. These teams also help to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice.

Through all its efforts, local or national, the GIRFT programme strives to embody the 'shoulder to shoulder' ethos that has become GIRFT's hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

Glossary

Abbreviations

Societies and other organisations

AUGIS - Association of Upper Gastrointestinal Surgeons.

BAPM - British Association of Perinatal Medicine.

BATRAS - The British Association of Plastic, Reconstructive and Aesthetic Surgeons.

BAUS - British Association of Urological Surgeons.

CQC - Care Quality Commission.

HQIP – Healthcare Quality Improvement Partnership - Medical Royal Colleges, the Royal College of Nursing and National Voices. *www.hqip.org.uk*

NICE - Improving health and social care through evidence-based guidance. *www.nice.org*

RCR – Royal College of Radiologists.

RCS – Royal College of Surgeons.

Other abbreviations

Clinical commissioning groups (CCGs) - These were created following the Health and Social Care Act in 2012, and replaced Primary Care Trusts on 1 April 2013. CCGs are clinically led statutory NHS bodies responsible for the planning and commissioning of healthcare services for their local area.

EGS data - Emergency General Surgery data.

HES - Hospital Episode Statistics - submitted to allow hospitals to be paid for the care they deliver. The aim is to collect a detailed record for each 'episode' of admitted patient care delivered in England, either by NHS hospitals or delivered in the independent sector but commissioned by the NHS.

PROMs – patient recorded outcome measures.

Other terms

Anastomosis - a connection made surgically between adjacent blood vessels, parts of the intestine, or other channels of the body. In this case it is between the two separated parts of the oesophagus.

Casemix - the type or mix of patients, categorised by a variety of measures, including: demographics, disease type and severity, and the diagnostic or therapeutic procedures performed.

Co-morbidities - conditions co-occurring with a primary disease or disorder.

Day of surgery admission - Admission to hospital on the same day that surgery takes place.

Deprivation index - Deprivation indices are a measure of the level of deprivation in an area.

Elective surgery - Surgery that is scheduled (planned) rather than an emergency.

Emergency surgery – surgery that is not pre-scheduled.

ICD-10 - International Classification of Disease is a system of medical coding created by the World Health Organisation (WHO) for documenting diagnoses, diseases, signs and symptoms and social circumstances. Itis a statistical classification that is used by health care providers and national and regional organisations to report/summarise an episode of care. It is mandated nationally for use across the NHS and the UK government has a commitment to report UK diagnostic statistics to WHO using ICD-10.

Image guided intervention – diagnostic and treatment activities that make use of technology that provides images of inside the body, e.g. MRI scans, radiography, with the aim of delivering more targeted care.

Imaging – the process of creating images of inside the body for diagnostic or treatment purposes.

Index admission - admission with a principal diagnosis of a specified condition.

Integrated care systems - Advanced local partnerships taking shared responsibility to improve the health and care system for their local population. *www.england.nhs.uk/integratedcare/integrated-care-systems*

Interventional radiology – a range of techniques that use radiological images to diagnose and treat diseases in a minimally invasive way.

Laparoscopy – type of surgical procedure that allows a surgeon to access the inside of the abdomen (tummy) and pelvis without having to make large incisions in the skin. This procedure is also known as keyhole surgery or minimally invasive surgery.

Length of stay - This is a term to describe the duration of a single episode of hospitalisation.

Necrosis - the death of most or all of the cells in an organ or tissue due to disease, injury, or failure of the blood supply.

Non-elective - Emergency admission and treatment/surgery that is not pre-scheduled.

Oncology - The branch of medicine concerned with the prevention, diagnosis, and treatment of cancer.

Oesophageal atresia - a congenital condition (birth defect) that affects the alimentary tract. It causes the oesophagus to end in a blind-ended pouch rather than connecting normally to the stomach. Babies often present after birth with shortness of breath and choking during feeds.

Pathway - An agreed set of evidence-based practices and interventions for a specific patient group.

Patient Level Information and Costing Systems (PLICS) - A system of collecting and deriving costs at the patient level.

Reference costs - are the average unit cost to the NHS of providing defined services to NHS patients in England in a given financial year. They show how NHS providers spend money to provide healthcare to patients. NHS providers submit reference costs annually.

Stoma - during surgery to divert the flow of faeces and/or urine.

Stricture - an abnormal narrowing of a channel in the body.

Surgical assessment unit - A model of care for patient who have a confirmed or probable surgical condition are assessed and diagnosed by a consultant in the relevant surgical discipline.

Swenson procedure - in the Swenson procedure, all layers of the bowel lacking ganglion (nerve cells) are removed from 1cm above the dentate line (the line demarcating the anus). Bowel containing nerve cells is 'pulled-through' and anastomosed (joined) at this level.

Tertiary unit - A hospital that provides specialised consultative healthcare (as opposed to a primary or secondary healthcare provider).

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Simon Kenny

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Appendix 1

Table 13: Specialist trusts hosting nationally commissioned highly specialised surgical services

Trust	Nationally commissioned service
Great Ormond Street NHS Foundation Trust	Bladder exstrophy Complex tracheal disease Congenital hyperinsulinism Paediatric intestinal pseudo-obstructive disorders
Central Manchester University Hospitals NHS Foundation Trust	Bladder exstrophy Congenital hyperinsulinism
Birmingham Children's Hospital NHS Foundation Trust	Liver transplantation Small bowel transplantation Specialist paediatric liver disease
King's College Hospital NHS Foundation Trust	Liver transplantation Small bowel transplantation Specialist paediatric liver disease
Leeds Teaching Hospitals NHS Trust	Liver transplantation Specialist paediatric liver disease
Imperial College Healthcare NHS Trust	Reconstructive surgery service for adolescents with congenital malformation of the female genital tract

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