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# **5-YEARS OF DIGITAL INNOVATION:** IMPACT REPORT

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Data Research, Innovation and Virtual Environments unit



# INTELLIGENT RESEARCH HOSPITAL

As Director of Innovation at Great Ormond Street Hospital (GOSH) I am proud that we are part of networks that span local and international organisations. We are all striving to improve the lives of patients and their carers, and the entire health system.

GOSH is one of the most digitally advanced hospitals in Europe. The implementation of our comprehensive electronic patient record paired with a state-of-the-art secure, trusted digital research environment sets us apart as an Intelligent Research Hospital. We are a go-to centre for innovation and we aim to leverage data and digital technologies to improve patient care and staff experience.

Innovation cannot happen in isolation and embracing new ideas can break down existing silos and uncover new ways of working. Established in 2018, the GOSH Data Research, Innovation and Virtual Environment (DRIVE) unit is a centre of engagement for innovation. We have collaborated with our staff and other NHS Trusts, academic institutes, and commercial organisations. I would like to thank our collaborators that have contributed their expertise, their ideas, and their time to take forward projects to improve health services for the future.

The DRIVE unit has had far reaching impacts for our staff, academic and industry collaborators. Our team has grown five-fold which highlights the demand for and significance of our work. Health leaders, commercial organisations and policymakers are recognising the importance of digital innovation to find new ways to understand complex health conditions and deliver better care.

#### As a part of GOSH, our patient-centred approach develops digital technologies that are fit for real-world benefit to children's health.

Digital technologies and data-led approaches can transform the care provided to patients, improve the experience for staff delivering care, and introduce efficiencies for the healthcare system. However, innovation is complex. Ideas may fail, they can challenge the status quo, or even be disruptive.

In this report we will reflect on our work so far. We will introduce just some of our inspirational collaborators at the DRIVE unit who have taken forward innovative ideas to transform the use of digital technologies in the health service.

**Professor Andrew Taylor** Director of Innovation





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# WHY IS **INNOVATION NEEDED?**

Our healthcare systems must leverage data and digital technologies to improve the outcomes for and experience of patients and their carers. This can also help to support healthcare staff.

The introduction of digital technologies to enable health services is a priority in the NHS Long Term Plan. Technology plays a central role in helping clinicians use the full range of their skills and reduce bureaucracy. It can stimulate research and enable service transformation. Digital technologies can also empower patients and carers to manage their health and care.

Several UK Government papers highlight the importance of NHS data and clinical infrastructure to the life sciences industry. Increased collaboration between the NHS, academia and industry is needed to maximise the benefits to patients and the healthcare ecosystem with investment in the sector.

For example, in 2022 the UK Government's Data Saves Lives strategy followed the 2020 National Data Strategy, with a focus on health and social care. It set out seven priority areas of action for the NHS to improve use of data to benefit individual patients, population level health, service planning and improvement, and research and innovation.

The DRIVE unit provides a one-stop-shop for expertise, advice and signposting that can turn new ideas into reality. The work of the DRIVE unit aligns with national ambitions, including developing technical infrastructure to harness the power of data in electronic patient records.

The unit has been cited as a leading exemplar within the NHS and attracted support from senior stakeholders across the NHS, academia, and industry. The Topol Review published in 2019 by Health Education England specifically endorsed this as a model for multi-disciplinary research data collaboration and rapid development and evaluation of new technology.

In 2023, our unit was highlighted as an exemplar for effective NHS data partnerships in guidance published by the NHS Transformation Directorate.

Since its establishment in 2018, the DRIVE unit has gone from strength to strength in its mission to advance the use of data and digital technologies for the benefit of patients and their families, healthcare staff and the healthcare system.

### The DRIVE unit provides a strategic way forward and aims to:

- Embrace new ideas to explore digital technologies that could improve patient outcomes and experience.
- Enhance digital connectivity to improve access to and embed the use of data at all points of care.
- Be the 'go-to' centre for paediatric innovation and foster collaborations between GOSH, industry and academic partners so children and young people can benefit at our hospital and beyond.

#### To achieve these aims our team has focused on:

- Embedding a culture of innovation through an Innovation Hub for ideas generation and proof-of-concept testing.
- Expanding GOSH's digital research capabilities to facilitate clinical and academic data innovation projects, including across multiple sites.
- Establishing a partnerships discovery team to expand our collaborations across sectors.



# INNOVATION **HUB: A CENTRE FOR ENGAGEMENT**

The DRIVE unit is well positioned to catalyse innovation with a dedicated hub that connects clinical and non-clinical experts with project support, data science and technology partners, and evaluation with patients and families.

Ideas from staff that have been taken through proof-ofconcept testing include an on-demand catering service to improve the experience for patients and families, a mobile application to support parents and families with the information they need in a health emergency, and an electronic calculator to find out the dose of medication required for a particular condition.

The team have also worked collaboratively with companies of various sizes across public, private and not-for-profit sectors. DRIVE is interested in collaborating with partners to share experience and skills, as we know that more can be achieved together.

Our staff have a wealth of knowledge and ideas on how to improve treatment and care, and the way the hospital works. We support them to make changes that can benefit patients and carers, and staff at GOSH and beyond.

Ideas@GOSH

### Ideas in numbers

Ideas@GOSH is a platform dedicated to problems and solutions, capturing the needs and ideas of our staff, patients and families. The suggestions are triaged by an inter-disciplinary group of hospital staff, breaking down silos and ensuring staff can get more holistic support.

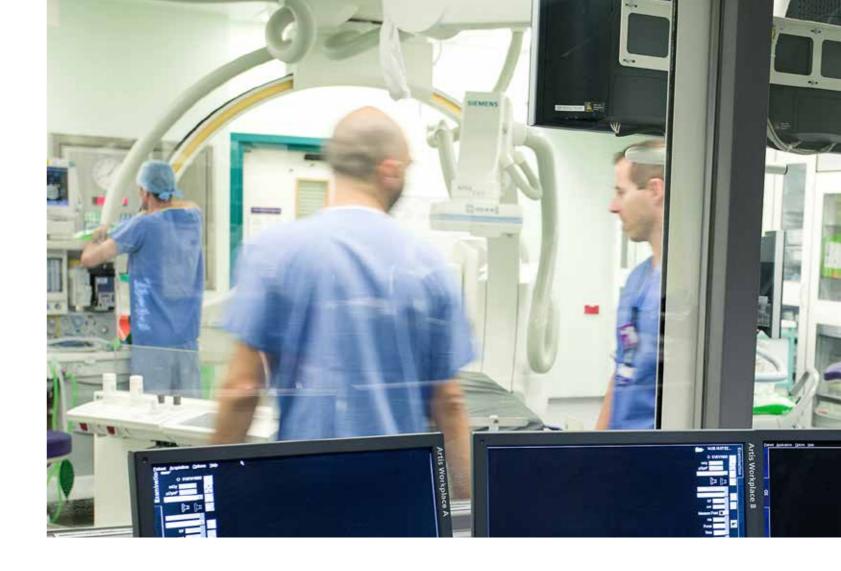
In the first 18 months since its launch in 2022, we have had over 110 ideas submitted including for software tools, virtual reality and data dashboards. This shows that the platform is vital to encourage a culture of innovation where peoples' ideas are valued and worked on collaboratively.

Over ideas submitted by staff

60% were referred to existing initiatives increasing collaboration and breaking down silos collaborative interactions with industry and academia

Over

were taken on as new projects, 10% were not taken forward



# Leading the way for data navigation

In collaboration with cardiology teams, GOSH DRIVE made a new information dashboard that collated and displayed vital data on patient outcomes in a rapid and accessible way. It is estimated to save approximately 10 hours of analyst time per week compared to the time it takes to manually curate the information. It can also improve support for patient care discussions by bringing more useful information together and presenting it all in one place.



Dr Cho Ng, Lead Consultant in GOSH's Cardiac Intensive Care Unit said:

"We had been struggling to find the

most efficient way to put together and understand the information we needed, so we worked alongside data scientists at DRIVE to create a new dashboard. This has made the information more accessible for our team within the trusted digital research environment."



Dr Lydia Briggs, Lead Data Scientist on the project said:

"I could sense check the app outputs thanks to the quick

replies and approachability of the cardiac department and analysts, which helped to progress the project. The clinical team are really pleased that the dashboard can help to advance care by enabling them to get the most out of health information that is routinely collected."



# **Collaborations and partnerships**

Working with the GOSH DRIVE unit means co-developing technologies in a real-world healthcare setting to create practical and scalable solutions. Since 2018, we have collaborated with academia and industry.

Our collaborators benefit from knowledge exchange with leaders in paediatric care, secure data access and proof-of-concept evaluation. The unit is also a dedicated space, close to GOSH that is modern and accessible. We have hosted events, workshops and meetings that have sparked new ideas and long-term collaborations.

For example, we were an early partner in the Industry Exchange Network (IXN) with University College London (UCL) Computer Science. The IXN brings together clinical and non-clinical healthcare staff, educators and students, and industry to design proof-ofconcept digital technologies. This takes a low risk and minimal cost approach in tackling challenges within the NHS. The IXN methodology was cited as best practice for attracting digital talent in the NHS in the 2019 Topol review.

Our unit has supported hundreds of students and over 60 projects with the IXN. The network has involved work with IBM, Microsoft, Intel and NTT data. We also hosted a hackathon which resulted in six abstracts published in the British Medical Journal Archives of Disease in Childhood. This demonstrates the novelty and high-quality of projects. UCLMotionInput is a touchless computing technology that started with this programme and is the largest project to date. The open software incorporates a huge range of physical movements, as well as speech, to control a computer. The software can promote hygiene in hospitals, and revolutionise computer use for those with mobility issues.

**Sheena Visram,** co-founder for UCLMotionInput and PhD student on the Clinical Informatics Research Programme said:

I want well-designed technologies to be used to deliver the best possible care and safety for patients. I believe we can create a more intelligent and technologically driven healthcare system through partnership between clinicians, industry, and academia.

Computer science for healthcare is exciting and advancing fast, and I'm encouraging clinicians along with the next generation of computer scientists to understand that.

> The unit has also partnered with Roche UK to harness the power of data by co-developing digital tools to uncover better ways to care for children and young people with rare and complex diseases. The five-year collaboration, a first of its kind, will develop the use of cutting-edge technologies, like artificial intelligence and machine learning, to enable better use of data that is routinely collected in treatment to improve care at GOSH and beyond. It also aims to develop a better understanding of how the NHS and pharmaceutical companies can work together.

**Alexandra Holland,** member of GOSH's Young Persons Advisory Group for research said:

With new diseases constantly evolving and gold standards for treatments changing, innovation is a process of continually driving forward to keep up. It's important for the NHS and industry to co-develop solutions so that data can most effectively improve hospitals and patient care.

**Professor Neil Sebire,** Chief Research Information Officer at GOSH DRIVE, said:

We are one of the most digitally advanced hospitals in Europe and have over 170 years of experience caring for children and young people with complex health conditions. This means we have a huge amount of experience and information that can help us to find new and better ways to diagnose and treat patients, and run our hospital. But we need new tools to harness the power of this data. Our partnership with Roche will help us do this by enhancing our data capabilities and infrastructure.

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Our collaboration with Roche has been recognised as an exemplar effective data partnership by the NHS Transformation Directorate in its 2023 guidance. The guidance sets out key concepts and principles for establishing data partnerships that will speed up innovations to benefit patients, and health and care systems.

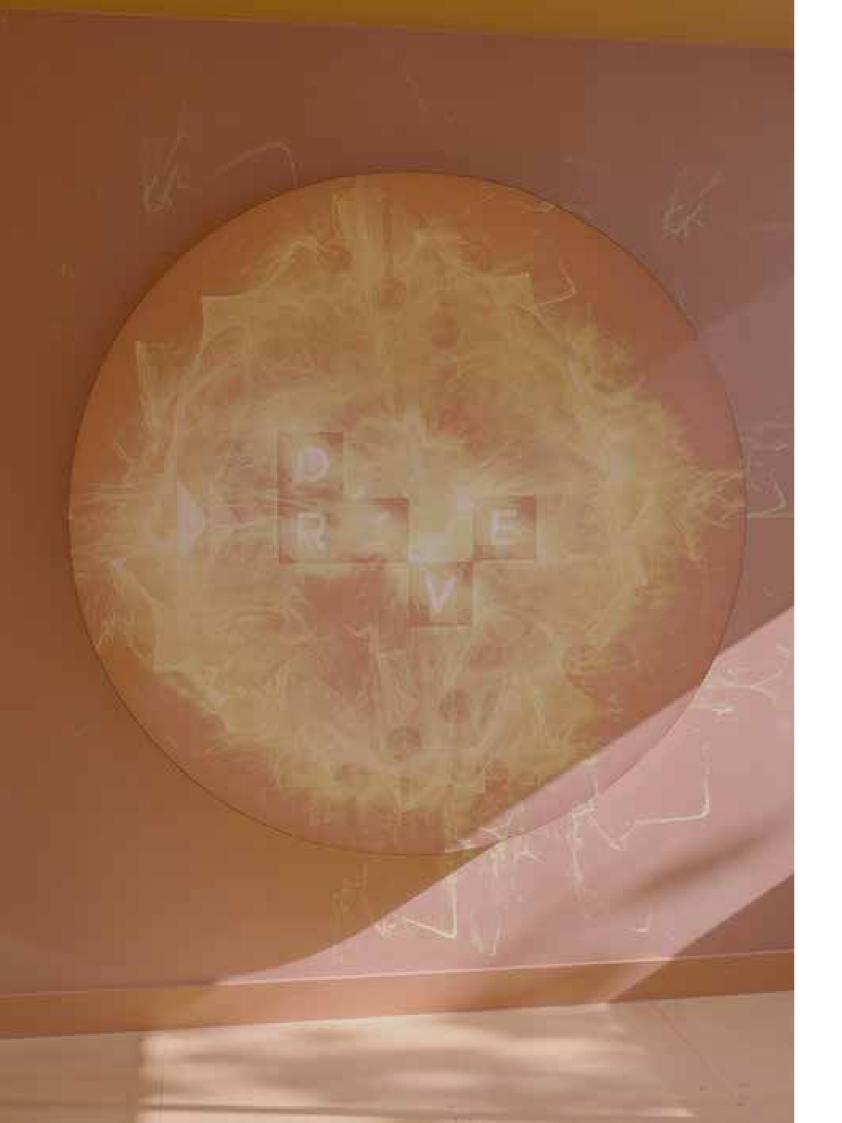
We value our collaborations across the UK and internationally. GOSH is an international centre of excellence in child healthcare and has been ranked in the top three specialist paediatric hospitals in the world. We contribute vast knowledge of paediatric healthcare, whilst we can learn from different healthcare ecosystems.

For example, we work with the Accelerate Redesign and Collaborate (ARC) Centre for Innovation at Sheba Medical Centre in Israel. Part of this collaboration involves a health technology start-up programme run from the ARC Centre. This focuses on supporting start-ups to develop, test and expand their reach.

#### **Professor Eyal Zimlichman,** Founder and Director of ARC said:

We're thrilled to be working with GOSH through the DRIVE unit. It's vital that we share knowledge about the very best technologies out there, and how our healthcare ecosystems can promote healthcare innovation to benefit child health, as well as scale innovation across hospitals to benefit more patients.

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# DIGITAL ENVIRONMENT: HARNESSING THE POWER OF DATA

Hundreds of thousands of data points are collected every day in routine patient care. At present only a small proportion of this information is used to inform a patient's diagnosis and treatment plans, or at scale to benefit future patients. As an Intelligent Research Hospital, GOSH is working to harness the power of data.

At the GOSH DRIVE unit data scientists support teams to leverage clinical and operational data using our secure, trusted Digital Research Environment (DRE). GOSH has also established a group to oversee the use of routine healthcare data for secondary purposes and provide assurance that projects meet data governance requirements. Launched in 2018, the world-leading DRE was established thanks to vital funding from GOSH Children's Charity.

GOSH's data lake extends over 20 years with over half a billion data items. Data continues to be added ever year. For example, GOSH clinicians, researchers and collaborators could explore data on over 100 thousand hospital admissions, 4.7 million treatments with medication and 5.9 million diagnoses, recorded between 2019 and 2023.

The DRE has supported over 300 projects as of 2023. These are complex data projects including onboarding of data, integration of data sets, collaborative digital workspaces for data processing and analytics, and building and deploying applications.

We are part of national and international collaborative projects across industry, academia, and health organisations. For example, we worked with the European Health Data Evidence Network (EHDEN) to set-up a paediatric focus group, and support data and digital projects for the European Children's Hospitals Organisation (ECHO), of which GOSH is a founding member.

"As the parent of a child that needed care on a paediatric intensive care unit and public member on research panels, I have been involved in discussions around the value, perceptions and ethics of data research projects.

"GOSH is a Data Controller of personal data that is collected to help provide and manage care of patients. It has obligations to keep this data secure and confidential. Therefore, to approve each project, I help the panel to consider things like whether data is sufficiently anonymised and if additional consent is needed from patients to use their data for the secondary purpose of research.

"It's important that parents' and patients' views are considered as this can improve the quality and impact of research. I am also a Senior Lecturer at the University of St Andrews in medical ethics and healthcare policy so I am interested in how better use of existing data can help innovation in the NHS. However, it doesn't matter what your knowledge of data science is as sharing your personal perspective is most valuable."

**Dr Morven Shearer**, parent research panel member





## Making every second count to improve critical care

Tracking, Trajectory and Triggering data, known as T3 data is a continuous data stream recorded about every 5 seconds. This includes vital signs such as heart rate and blood oxygen levels.

For the most seriously ill children on the Paediatric Intensive Care Unit (PICU), this data helps healthcare professionals monitor their condition and informs treatment decisions. This data can also improve our understanding of critical conditions and interventions that could help future patients.

Dr Samiran Ray, Consultant on PICU worked with the data science team to make this vast amount of data available in a useful format for future studies.

On the intensive care unit, we're always looking to predict the next step for a patient's treatment. One of my first projects using the DRE looked at whether we could curate T3 data and develop predictive models to support decision-making.

Often the first procedure for a child on PICU is breathing support with a ventilator. This is also often the last treatment to be stopped when they improve. Every day, clinicians like me face the decision of when to take a child off breathing support.

Together with researchers from the Turing Institute we built algorithms to support clinicians with this decision and identified challenges to doing this. We found that clinical experts are vital to find hidden meaning when data are missing. For example, when we are looking at data from ventilators, a clinician could tell us that a loss of some signals is caused by a patient being

disconnected from a ventilator temporarily to help them cough. Without a clinician the loss of signal might be misinterpreted.

Another memorable project looked at the use of low molecular weight heparin that helps to prevent blood clots forming, which can be a complication after children have been on PICU and need lots of drips or lines inserted into blood vessels. Although it is rare, sometimes children will need to have injections for up to 12 weeks, twice a day, and need many blood tests to check they are on the right dose. This can keep them in hospital for longer and be upsetting. We brought this data together to better understand how we can get the dose right sooner to reduce distressing blood tests in these children. This allowed us to change guidance for clinical teams.

Without support from the team at DRIVE, we would never have been able to access T3 data, which tracks

physiotherapist who works on the

Dr Emma Shkurka is a



Dr Samiran Ray, Consultant on PICU



cardiac intensive care unit (CICU). Respiratory physiotherapy is a popular treatment option for children on ventilators, however she noticed that more evidence was needed to further understand the safety and effectiveness of the treatment.

The data science team helped her to extract T3 data and develop a new method to study physiotherapy

on the CICU. Emma could find new and more accurate data on physiotherapy for children on ventilators as a greater number of children could participate in the study, the effect of multiple treatment sessions could be measured, and more clinical factors could be included. Her findings can inform clinical guidance for physiotherapists working with these patients, and this paves the way for future data science projects.

# Using common data standards to see the full picture

Data is at its most powerful when it is joined up. This is particularly important in paediatrics as often children have rare diseases, so it is only by joining up cohorts across the world that it is possible to spot patterns in symptoms, diagnosis and treatment outcomes.

Joining up data was extremely valuable during the COVID-19 pandemic when clinicians and researchers had to rapidly characterise the novel virus to find out how to diagnose and treat people. Especially complications in children which were rare events. This was when 4CE stepped in.

4CE is an international consortium for studies of the COVID-19 pandemic using electronic health record data. This is done in a safe and secure way, where patient data remain within hospital boundaries and only anonymised aggregate data and results are shared centrally for further analysis.

By using the DRE, we were able to extract and analyse the required GOSH patient data locally. The aggregate data from 27 hospitals across six countries were then joined and analysed together.

The study analysed over 27,000 laboratory values for 16 different tests which allowed identification of abnormalities that could help characterise severity and inform treatment of COVID-19 in children. The study identified complications associated with COVID-19 infection in children and young people so that clinicians could better plan for their care and inform families about possible outcomes.

Our work to join up paediatric data securely and effectively for research and innovation continues. We are mapping GOSH's electronic health record data to The Observational Medical Outcomes Partnership Common Data Model (OMOP) as a data partner in the EHDEN network. This project is in partnership with Aridhia, a company that provides computer software to enable safe, compliant collaboration for digital research.

So far, we have characterised over 7 million electronic health record data items to map to the OMOP model. We are currently automating the translation of our data to these standard categories

# **Combining data to understand** rare inflammatory diseases

"We lead a large UK-wide study, from across 17 NHS Trusts, to better understand the causes and best treatments for a rare inflammatory disease that damages the muscles precious long term data on many patients with juvenile dermatomyositis from across the UK.

secure data capture system for this study and trained all 17 study collaborators to use this system in REDCap. The REDCap, application allows us to capture data that is vital to this study but also automatically integrate other information already collected in the electronic patient possible as it would take far too long and be too costly to collect the data that we need.

"Now that we have the new secure data platform, many researchers can use it for their studies to uncover new treatments long into the future."

Professor Lucy Wedderburn, UCL Great Ormond Street



vital measures as part of everyday

care on intensive care units. We have

data from over 15,000 admissions at

GOSH over three years. We can now

securely examine this data to inform

even better diagnosis, treatment,

and care for patients in the most

critical conditions.

while ensuring accuracy through a quality assessment process. Structuring our rich data lake in this way will be revolutionary for paediatric research by enabling guicker, collaborative research so we can most effectively improve the lives of patients and families.

The use of common data models for research means that researchers and clinicians don't need to spend a lot of time and effort defining data specifications with collaborators and preparing data for each project. They can get started straight away using the data set which increases the speed at which they can get results to their questions.

At GOSH, we may only see a handful of patients with a rare condition so linking up with other centres of excellence in paediatric care can increase our pool of knowledge and the likelihood of making new findings in this under-served area.

Dr Natassa Spiridou, Head of the **GOSH Digital Research Environment** 

## **Trail blazers**

The potential for data to transform paediatric care has accelerated rapidly since 2018 when we introduced electronic patient records and our DRE. However, it is our trail blazing staff that have established GOSH as a pioneer in clinical data science by pursuing their innovative project ideas.

Cystic fibrosis (CF) is a genetic condition that mainly affects the lungs and digestive system. A build-up of mucus in the lungs can cause breathing problems and children with CF need to do many treatments every day to keep them well, including regular physical activity and airway clearance to clear excess mucus from the lungs. These treatments are time consuming and burdensome for children and families. Project Fizzyo wanted to see if there were ways to make these treatments easier and more fun to do. It also aimed to find out whether how often and how well these treatments were done at home would make a difference to clinical status.

Remote monitoring devices, such as activity trackers, and gamification of exercises using technology offer hope for improving physiotherapy, and Project Fizzyo is leveraging this to change physiotherapy for children with CF. We won the Ability.Net Digital Health Award in recognition of this work, as well as further funding from Rosetrees and Stoneygate Trusts, and the CF Trust to expand our research in CF. The GOSH DRIVE team were partners in developing our new digital health technology from day one. Use of the DRE infrastructure and the support of data science experts helped our team to gather the necessary data securely and efficiently for a clinical trial on airway clearance and physical activity. They also supported our team to work with Microsoft to develop computer games to encourage selfpractice of breathing exercises.

When the DRE launched in 2018, it felt like a miracle that data were pouring in, the likes of which we've never seen before. It was fantastic that we could now securely access data that measured and visualised every single breath, of every single airway clearance treatment, and every heartbeat and footstep that our participants took during the study to evaluate the impact on clinical outcome. This type of evidence from innovative technology can also allow healthcare professionals, like me, to be far more focused in the advice we give to patients.

Professor Eleanor Main, UCL GOS ICH





Dr Richard Issitt, UCL Institute of Cardiovascular Science

As a perfusionist my job is to keep a person alive by maintaining a patient's blood flow during heart transplant surgery. GOSH regularly treats children that need heart transplants, although this is very rare for children. It can be very difficult to find a matching donor heart with children waiting for many years. Unfortunately, while they wait, they will need to be spending lots of time in hospital and their condition may even be getting worse, which is very distressing. We simply need to get them hearts faster but we've always been constrained by locating a heart not just the right size, but the right blood type.

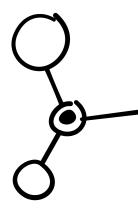
I was interested to see if we could remove the antibodies that give blood its 'type',



to allow a patient to have a heart that didn't match. I thought this could reduce waiting times by years.

By working with data scientists at DRIVE and within the DRE, I was able to track, for the first time, a huge number of measures that helped us develop our 'mismatch' heart transplant technique. This is now used across centres in Europe and the US.

Billions of data points are collected during operations that could provide valuable insights about the body and how we can improve heart transplants. Since my initial project on mismatched heart transplants, I have supported Masters and Doctoral students, for example to look at oxygen delivery through medical devices in the intensive care unit, which could lead to manufacturers improving their products.





# CLINICAL INFORMATICS RESEARCH: SPEARHEADING A NEW FIELD

The Clinical Informatics Research Programme (CIRP) is based at the DRIVE unit. Funded by GOSH Children's Charity it is the largest research programme of its kind. The programme builds vital skills and evidence for the application of data and computer science in healthcare. This is essential to support GOSH and its academic partners, including UCL, to lead cutting-edge digital innovation.

It offers the opportunity for data and computer scientists to work alongside clinical specialists and other hospital professionals to generate a portfolio of technology projects.

Academic projects supported by the CIRP have resulted in publication of over 150 academic papers and abstracts between 2019 and 2023. These have attracted interest from the BBC, the Times and Forbes.

The CIRP has supported and collaborated on 27 successful grant applications, leveraging further funding of approximately £10.5 million for clinical informatics and technology projects nationally from a range of funders. The programme has also built an impressive network of partners including higher education institutes across the UK and National Institute for Health and Care Research Biomedical Research Centres

## Filling in the gaps to improve medicines for children

Most medications prescribed for seriously ill children have not been tested in children through clinical trials therefore there is uncertainty about how they work.

By necessity, doctors must give these children medicines 'off-label' which means that the use falls outside of what has been approved by regulatory authorities. Data in electronic patient records can be used to fill in the gaps and better inform doctors about the use of 'off-label' medicines in children. This is exactly what **Professor Joe Standing** at UCL GOS ICH is doing.

"We conducted the largest ever study of posaconazole by using data from GOSH's electronic health records. Posaconazole is a medication that treats and prevents fungal infections in patients with compromised immune systems, for example children that need stem cell transplants. For this research we collated data on medicine dispensing and administration, and data on levels of posaconazole from blood tests. This allowed us to find the optimal dose for children under the age of 12, where previously there was no guidance for doctors.

When the DRE was introduced, it revolutionised the way we could study the use of medicines in children by automating data management processes. It reduced the chance of human error in data input and offered a more secure and collaborative way to do research. It allowed for standardisation of measures, for example all weights recorded using the same metric. This is particularly important for studying response to medicines as a key measure to determine dose is weight. The speed at which we can now extract data is incomparable. Tasks now take a matter of minutes which previously would have taken days or weeks."



Professor Standing's research has grown, and he now supervises around nine students, many of whom have been supported by the DRE in some way. **Emma Vestesson** is one of these students.

Speaking about her project, Emma said:

Antibiotics are life-saving medications that can treat and prevent disease. However, overuse of antibiotics can be harmful for patients and contribute to the rise in antibiotic resistant diseases which is a threat to public health world-wide. Antibiotic stewardship refers to how healthcare systems monitor the use of antimicrobials and data in electronic health records is vital to guiding these policies. I am studying how to tackle overuse of antibiotics to protect patients and the public.

The DRE facilitated secure access to anonymised data from GOSH about the prescription of antibiotic medications and I will use this to look for patterns in their use. This also means that I can build statistical models that could be used to predict what type of antibiotic could work best

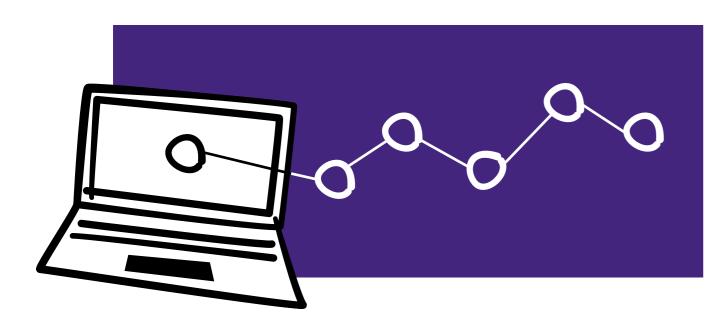
for a patient depending on the illness they have, and various other factors such as their age, or when they came to GOSH. By utilising data in electronic health records, we can provide better care by learning from previous similar



patients, and this can prevent the overuse of antibiotics by helping doctors to get the prescription right the first time.

During the COVID-19 pandemic I led a study that analysed data on antibiotic administration for patients at GOSH. I found that there was no evidence that antibiotic prescribing was significantly affected by the pandemic which provided helpful information around antimicrobial stewardship policies and responses to future pandemics.





### Supporting the skills needed in our future NHS

Since 2019, the CIRP has supported projects across a range of clinical areas including pharmacy, intensive care, imaging, cancer and operational hospital management. They have also looked at a range of technical areas within healthcare innovation including data science and imaging analysis, human-computer interaction, and virtual environments.

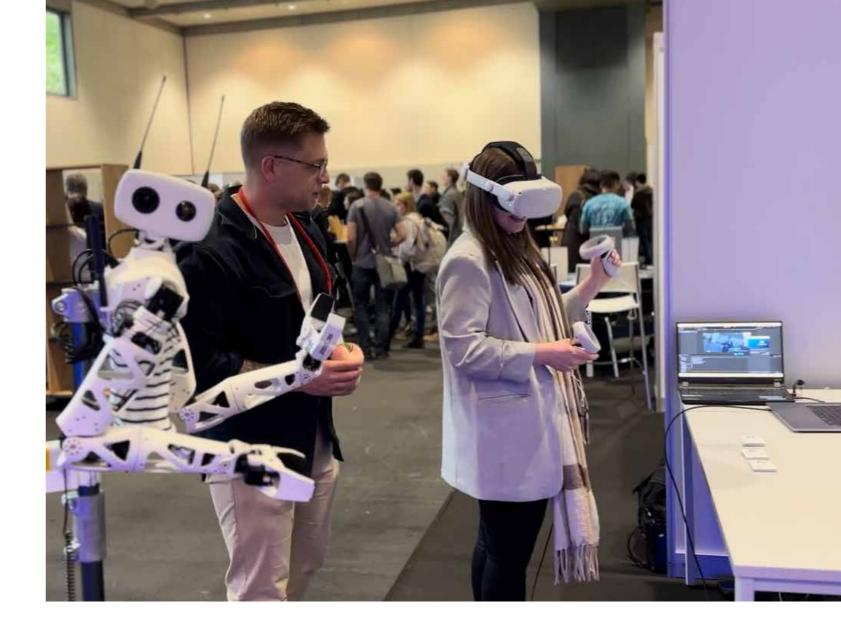
Our programme has high demands and has offered flexibility in opportunities to meet the needs of each person on the programme, from medical to computer science students, at Master's level to Professorships. This demonstrates the necessity of this programme at all levels, where resources can be rare.

### Tianxiao Wang, CIRP PhD student

I will use the data in electronic health records of cardiomyopathy patients to track their condition over time and build algorithms to find out how patients could be grouped based on the symptoms they have. Some of these patients have received ACE inhibitors a common treatment for heart problems. I will use an advanced computer technique to find out what may have happened to the patient had they not had this treatment. This is called counterfactual prediction. This model can be used to understand the treatment effects of ACE inhibitors depending on the sub-type of symptoms a patient may experience.

When starting this project, I needed to understand the day-to-day life of a patient with cardiomyopathy in hospital. It was crucial to have advice from clinical academics, who have insights on the experience at hospital paired with my knowledge of data science.





**Patrick Nurse**, NIHR Pre-doctoral Clinical and Practitioner Academic Fellow

I qualified five years ago as a nurse and secured my fellowship last year which gives me dedicated time to develop my

research skills. Using different research methods including interviews, scoping reviews and emerging data research techniques, I hope to understand nurses' experiences of using electronic patient record systems and how they impact decisions to examine how this technology is affecting patient safety and care. I will also seek to understand the experience of patients and families in relation to electronic medication administration.

I couldn't have secured this fellowship without DRIVE as I will be using the digital research infrastructure managed by the team. Professor Neil Sebire, Chief Research Information Officer on the DRIVE leadership team is my co-supervisor, and I can lean on the team's data science expertise, for example, in machine learning.

#### Mairi Therese Deighan, CIRP PhD student

I am a bioengineer interested in exploring the use of virtual reality (VR) in healthcare. VR has been used in hospitals around the world to improve patient care and train nurses and doctors. Using VR in hospitals is still very new in the UK and there is still a lot to understand about where VR is best suited and how it can be used most effectively. In my research, I am working directly with young people with cancer to design VR experiences that could be used in hospitals to improve teenage cancer care.

Without funding through CIRP I wouldn't be able to carry out this research. Being partnered with GOSH allows me to speak to healthcare professionals and understand the real-world context of VR in the NHS. From a series of workshops and interviews with young people being treated for cancer and healthcare professionals, I hope to write a VR action plan highlighting the steps that must be taken to bring this futuristic technology into everyday use in our hospitals.

# LESSON LEARNT

Established in 2018, GOSH DRIVE is a first of its kind unit, dedicated to innovation in the NHS. This was a key milestone for our ambition as an Intelligent Research Hospital. As a pioneer in innovation, it was expected that we would make mistakes and even experience failures. In sharing these, we want to support other health care organisations on their innovation journeys.

# Skills and training for digital innovation

Digital innovation projects that involve data and technologies are complex. Data and cyber security are of the upmost importance and all teams across GOSH are responsible for maintaining this. Our ICT, Information Governance, and Research and Development teams are particularly involved.

Our DRE platform provides secure technical infrastructure to enable project teams to manage and analyse data. Alongside the technical capability, we needed to develop appropriate governance processes to ensure that data were handled safely and according to data protection regulations and best practice. This required new skills and training and this work will continue as our technical capabilities continue to expand with new data types.

Accessing and analysing data at scale is a new frontier in healthcare. This means that our staff need to develop new understanding and skills to implement these types of projects, whether they be with staff internally, or in collaboration with other partners that can bring a wealth of capability. The DRIVE team worked hard to understand the governance landscape and other stakeholders so that we could bring together our existing processes and expertise. 

Stephen Mathew, Head of Innovation

# **Defining use** cases together

Developing a cutting-edge digital technology in isolation will not work. It is vital to consider the end user. Successful projects require engagement from technicians, clinicians, and operational teams. Involvement from the start and throughout can ensure a technology is appropriately design and implemented in the right place, at the right time.

Clinical input from across our services is invaluable when determining how digital technologies can benefit the diversity of patients that we see, ultimately improving their quality of care and experience. Involving representatives of the Allied team early on through attending demos or focus groups ensures varied viewpoints are considered which can shape projects and generate further enthusiasm, motivation, and engagement. This engagement and the flexibility with which it is done is vital, especially when clinical teams are juggling innovation projects alongside with their daily roles.

Ali Toft, Allied Health Professional Information Officer

# LOOKING AHEAD

The DRIVE unit has been pivotal in introducing innovation to the Trust. Our projects have supported staff to voice their ideas and find solutions, accelerated clinical data research, and demonstrated how the NHS can work with industry partners. We have also faced challenges with valuable learning that we will take into our future areas of work. Our areas of focus for the future include:

# The Clinical Intelligence Unit (CIU)

We will bring together and develop capabilities to leverage operational data. The CIU will partner with clinical teams to understand their needs and build digital tools that can support their roles.

We are also developing software that will be embedded in clinical care. For example, software that can automatically pull together evidence from millions of records to assist healthcare professionals in their decisions around care for a specific patient.

Dr Lola Solebo is a Consultant in Paediatric Ophthalmology at GOSH and post-graduate Epidemiologist at UCL GOS ICH. She has advised on how we can harness electronic patient data to improve eye care. She said:

"Steroid-induced glaucoma is the most serious complication of steroid eye drops to treat inflammatory eye disease. A digital tool could help clinicians understand the potential impact of a current dose to plan for future treatment.





If we know how many eye drops a patient has received and could then see the effects of this for previous children, could make better informed treatment plans."

## **Hospital without walls**

GOSH cares for children and young people with complex and rare conditions. They can be in hospital for weeks or months and may have to return frequently. Unfortunately, this can be difficult for families, and make it harder for children to attend school and keep in touch with friends.

The ability to monitor and care for more patients whilst they're at home can improve their experience, as well as reduce pressure on hospitals. This could also improve research by making it easier to take part and capturing different types of data at more regular intervals. For example, wearable devices could collect data in clinical trials to reduce the number of appointments for patients and provide even more valuable information on the treatment effects.



# **Artificial intelligence (AI)**

Al has potential to help patients, healthcare staff and the healthcare industry through better utilisation of medical and administrative data. However, there are barriers to developing Al in healthcare, for example the need for huge volumes of data to train models and a secure testing environment. We will develop our secure, trusted digital infrastructure to train and test Al tools for healthcare of the future, and work with clinicians, patients and families, and industry partners to identify suitable use cases.

"Clinicians spend too much time sifting through information that could be more efficiently processed and presented using AI tools. This would give them more time to do what they do best – provide patient facing care. But building and managing the deployment of AI is complex, both technically and for us humans to change the way we work. That's why it's important that we are bringing together all the necessary stakeholders, alongside meeting the technical requirements to do this."

**Dr Shankar Sridharan,** GOSH Chief Clinical Information Officer

# **Expanding collaborations**

Collaboration underpins innovation and we will expand our partnerships across industry going forward. This includes collaboration with life sciences and medical technology companies, from start-ups to multinationals.

We will also grow our collaboration networks with EHDEN paediatrics and ECHO to investigate research questions that are specific to children and operational improvements in paediatric hospitals.

### Research

CIRP alumni have gone on to secure further funding and investment in the field of clinical informatics and human-computer interaction. Furthermore, funding for the National Institute for Health and Care Research GOSH Biomedical Research Centre is supporting our first Applied Child Health Informatics theme to grow innovative data research and work with other academic and NHS organisations through a Paediatric Excellence Initiative.

In the next five years, we will bring together more innovators. We will exchange and combine our knowledge, ideas, and capabilities across professions and sectors, so that we can continue to build an Intelligent Research Hospital.

Children and young people have been brought up with technology. They are the key to co-creation and future success of technology in healthcare. We are excited by the work of the GOSH DRIVE unit that is exploring the potential for technologies, like artificial intelligence to improve care for children and young people, and support healthcare staff.



We hope the unique combination of researchers, clinicians, and young people brought together through the GOSH DRIVE unit means new technologies that are always human-centred, empathetic, and safe can be introduced to healthcare as well as being reviewed by children and young people in the future.

**Oceiah Annesley,** member of GOSH Young Persons Advisory Group for research Arcturis Advancing Insights



Hyland









A special thank you to collaborators and partners that have supported the DRIVE unit in the last five years.

This includes:	
Arcturis	Ocado Group
Aridhia	Roche
Hyland	YouTube
NTT Data	8foldGovernance

Founding partners:	
Aridhia	NTT Data
Arm	Microsoft
Barclays	Samsung

### And our clinical networks:

Accelerate Redesign	European Children's
and Collaborate (ARC)	Hospitals Organisation
Centre for Innovation at Sheba Medical	Future of Health
Centre	International Society
Alliance of Centres	for Pediatric
of AI in Medicine	Innovation (iSPI)

Children's Hospital Alliance

As well as our academic networks.

We look forward to continuing our work with you and building new relationships.



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