



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

Roche

Harnessing the power of data and AI to drive personalised healthcare at Great Ormond Street Hospital and beyond

A playbook for health industry-NHS collaboration



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Executive Summary

We know that precision medicine, using targeted treatments, is a key goal for patient care. But how do we get there? The answer lies in the expert use of data. Linking genetic and phenotypic data using clinical and data science, and engineering expertise, offers the potential to build an ecosystem that could dramatically enhance patient outcomes.

One way data use can be optimised is through increased collaboration between healthcare organisations and the pharmaceutical industry. But with this come several challenges. For example, how in reality does this work? How do you overcome the important ethical and regulatory considerations required to engender trust to achieve the desired benefits? What safeguards need to be in place for the processing of routinely collected NHS data? And how can this data be made accessible and useable to help future patients while maintaining privacy? So called 'real world data' is complex, often incomplete, not necessarily in a usable format, and not linked to the individual patient or their condition - a far cry from clinical trial data.

Finding ways for the NHS and industry to work together to use the huge amounts of patient data that are generated, in an ethical,

effective and secure way, could greatly impact clinical care, improve the working lives of clinical teams, and ensure that the NHS, in combination with industry, supports the development of novel treatments that deliver targeted care in a sustainable way.

The NHS organisation Great Ormond Street Hospital for Children ([GOSH](#)) and the pharmaceutical company Roche Products Limited ([Roche UK](#)) are working to do just this. Our [long-term partnership](#) has been established to harness the power of data and artificial intelligence to co-develop digital tools aimed at identifying better ways to care for children and young people with rare and complex diseases.

We're incredibly proud of our collaboration to date, which has already been used in an [NHS England Guide To Effective NHS Data Partnerships](#) as an example of a successful NHS data partnership that offers positive patient, healthcare system and societal impact. Detailed learnings and recommendations from the first two years of the partnership have also been published as a peer-reviewed article in the Royal College of Physicians [Future Healthcare Journal](#).



Dr Rebecca Pope (she/her),
UK Digital & Data Science
Innovation Lead, Roche



Professor Andrew Taylor,
Director of Innovation,
GOSH



Professor Neil Sebire,
Chief Research
Information Officer,
GOSH

Who is this playbook for?

In this playbook we outline our experiences of the start of our partnership journey; what has gone well and what hasn't, and how we have worked in partnership to harness the best from two very different cultures across the NHS and industry. We provide candid and constructive reflections on real-world issues, barriers and

potential mitigations, moving from strategy to sustainable impact, all of which can be scalable across the NHS and beyond.

We hope this will be a useful guide for other healthcare organisations interested in working towards the future of health using healthcare data.

ABOUT THE PARTNERSHIP

In December 2021, Roche UK and GOSH established a formal collaboration with the goal of moving closer towards personalised healthcare for children through the better use of data that is routinely collected in treatment.

GOSH is an international centre of excellence in child healthcare, recognised as one of the most digitally mature Hospitals in Europe and leads the NHS North Thames Genomic Medicine Service, one of seven in England. GOSH's first-of-its-kind Data, Research, Innovation and Virtual Environments Unit (GOSH DRIVE) was established as a centre of engagement for innovation and aims to become a leading informatics centre. As a global pioneer in personalised healthcare, Roche UK believes that better patient care can be achieved through collaborative working with the NHS.

The partnership is jointly addressing practical data engineering and analysis issues, using cutting-edge technologies like artificial intelligence (AI) to improve care at GOSH and beyond. By enabling the automated analysis of anonymised information (such as genomic data, images and text), tools and clinical workflows can be developed to enhance clinical decision-making at scale across the NHS, with the ultimate goal of ensuring patients get the best possible care at each step of their journey, built on learnings from every patient that has been treated before.

Roche UK is providing funding and their staff to work closely with GOSH DRIVE. All projects undertaken within the partnership are conducted within GOSH's secure digital research infrastructure and no patient data is shared between the organisations or outside of GOSH. All intellectual property rights (IPRs) is owned by GOSH. The partnership is supported by a project steering group made up of representatives from GOSH and Roche UK, and is expected to last for five years.



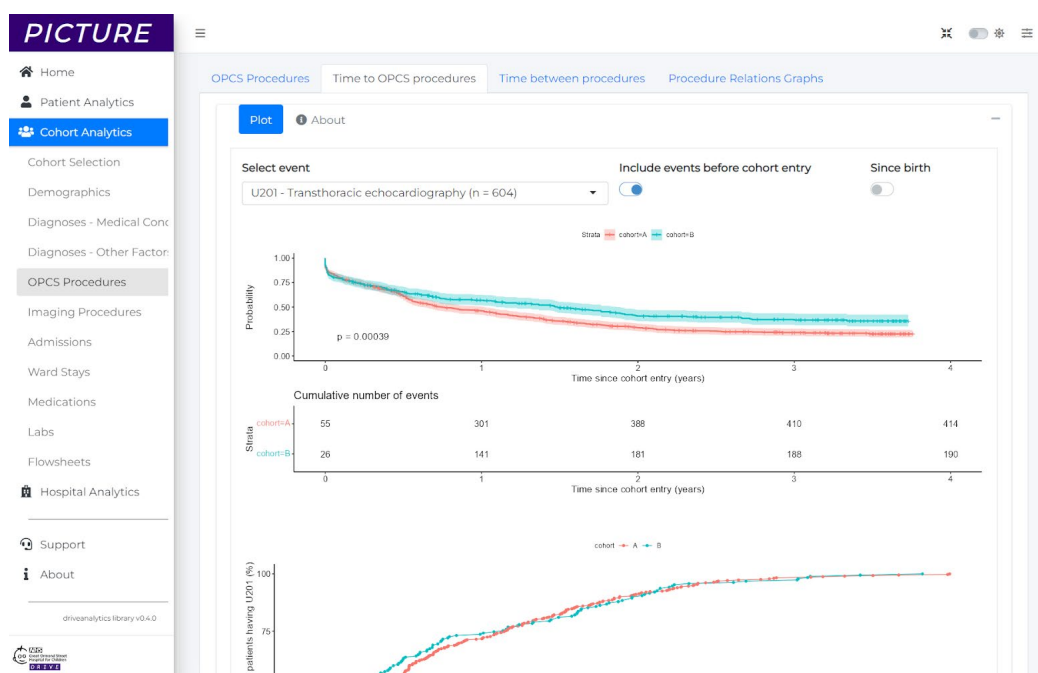
Partnership objectives

Over the first two years of the partnership, GOSH and Roche UK have worked collaboratively with the objective of:

- Establishing a **Clinical Insights Unit (CIU)**, to partner with clinical and operational teams to understand their needs, identify inefficiencies and build digital tools that can support their roles
- Improving clinical decision support (CDS) and research capability through data
- Improving research data using digital tools and applications such as AI and natural language processing (NLP)
- Using real world data to improve paediatric personalised healthcare
- Improving clinical and research insights through data from sensors, devices and wearables

What we have achieved so far

- Partnership created: legal terms established and agreed, processes worked through, commercial and intellectual property agreements agreed, staff contractual arrangements established, 7 workstreams established
- Governance structure created to ensure compliance: Data Partnership Committee established
- Patient engagement through the Trust Council of Governors and patient advisory groups
- Staff engagement and appointment of 10 clinical innovation officers
- NLP pipeline built, redefining how free text data can be accessed and used (see page 11)
- A way to represent structured genomic data in a standard format, shared with NHS England who are incorporating this into ongoing national genomic data standards
- Scalable tool called PICTURE (see image below) developed for rapid and reproducible research using real world Electronic Patient Record (EPR) data
- CIU established to focus on scalable and reproducible analysis of non-identifiable real world EPR data to improve hospital operational efficiency with clear operational and productivity gains for financial sustainability





OUR LEARNINGS AND RECOMMENDATIONS

GOVERNANCE FRAMEWORK FOR OUR PARTNERSHIP

The Association of British Pharmaceutical Association (ABPI) is the trade body for UK pharmaceutical companies. The ABPI has produced routes to cross-sector working to create conditions where cross-sector collaboration can flourish. Based on the 2021/22 ABPI Code of Practice, the route chosen for the GOSH-Roche partnership was to establish a 'Collaborative Working Agreement'.



Working within the requirements of the ABPI's Code of Practice is a relatively new approach for our organisation and we weren't familiar with the regulatory requirements and considerations.

There have been some important learnings while establishing the partnership but we've worked hard together to ensure everyone has a clear understanding of what's needed to ensure we're compliant and, most importantly, why. It's an ongoing learning process as we develop more outputs from our partnership but we have established trust and clear lines of communication to help us resolve any challenges.

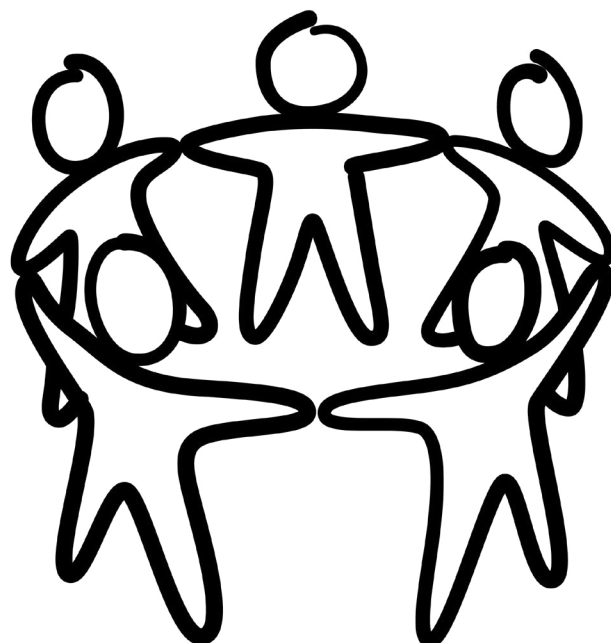


Stephen Mathew,
Head of Innovation,
GOSH

Recommendations:

Collaborative Working requires any outputs of the collaboration align with the ABPI Code of Practice and Roche UK's broader regulatory commitments.

- During early scoping discussions ensure the NHS partner understands the approval mechanisms and builds in sufficient time for compliance review and approval
- Ensure a shared standard operating procedure (SOP) and materials tracker that outlines each partner's responsibilities that is jointly maintained and monitored by project managers from each partner and overseen by the Steering Committee



COMMERCIAL ARRANGEMENTS



In a collaboration that involves the use of data, public trust is essential. From the start, we have been transparent about the details of the partnership and how we have ensured patient data remains safe and secure.



Dr Alexandros Zenonos,
Personalised Healthcare Digital
Solutions Lead, Roche

Both partners followed strict data protection principles and put in place key documents.

A Collaboration Agreement

- Sets out the overall aims of the project and each parties' overall roles and responsibilities, and broad parameters for data protection

Intellectual Property

- Agreed that Intellectual Property Rights (IPRs) will be solely owned by GOSH (save for those related only to Roche UK), emphasising that promoting benefit, rather than seeking competitive advantage, was the driver for collaboration

Honorary Contracts for Roche UK employees

- Provides additional technical and organisational measures for data access and makes Roche staff accountable for acting in accordance with existing GOSH policies, procedures and clinical governance frameworks
- Under direct supervision of GOSH employees and within the secure GOSH digital infrastructure, the honorary contracts allow certain Roche collaborators to work on projects using anonymised patient data

Service level agreement (SLA)

- Manages arrangements under which Roche UK staff are based at GOSH, clarifies the terms of the Honorary GOSH contracts and the status of Roche UK staff members, and ensures pre-employment checks are consistent with NHS checking standards

Data agreement

- Means by which safeguards are ensured sets the default position that Roche UK process data as a data processor

Data protection impact assessment (DPIA)

- A detailed explanation of the layers of protection being put in place to ensure data are shared safely and compliantly



While we haven't encountered any challenges in terms of the commercial arrangements of our partnership, it's clear that a potential barrier could be NHS access to appropriate legal advisors, both in terms of the monetary investment and the level of sophistication needed when dealing with complex data sharing issues.

Dr Rebecca Pope, (she/her)

UK Digital & Data Science Innovation Lead,
Roche



Recommendations:

- A national-level, single appraisal process – facilitated by NHS England – should be established for the negotiation of data partnership agreements (DPAs) between industry and the NHS
- Anonymised (non-identifiable) data (defined according to ICO guidance) should be used for industry-NHS partnerships, wherever possible
- Establishment of a Data Partnership Committee, that includes the Data Protection Officer and Caldicott Guardian (responsible for protecting the confidentiality of people's health and care information and making sure it is used properly)
- Computer code and tooling developed from NHS data should be shared under open licences for scientific review and re-use across the sector. This bolsters public trust and ensures that the use of NHS data that fuels data-driven technological innovation is fair and equitable. This also supports the calls for open coding in the NHS



Infrastructure

Our partnership is aiming to develop analytical digital tools and algorithms and move them into real world clinical practice. Digital infrastructure in the NHS is limited and when setting out to develop an infrastructure that could support these ambitions at GOSH, Roche had not anticipated the number of challenges we would encounter. While overcoming operational challenges, upskilling and a cultural change were also needed at the Trust to develop a digital infrastructure that could support our analytical and AI builds at scale.

Shiren Patel,
Head of Innovation Technology and Data Research, GOSH

Recommendations:

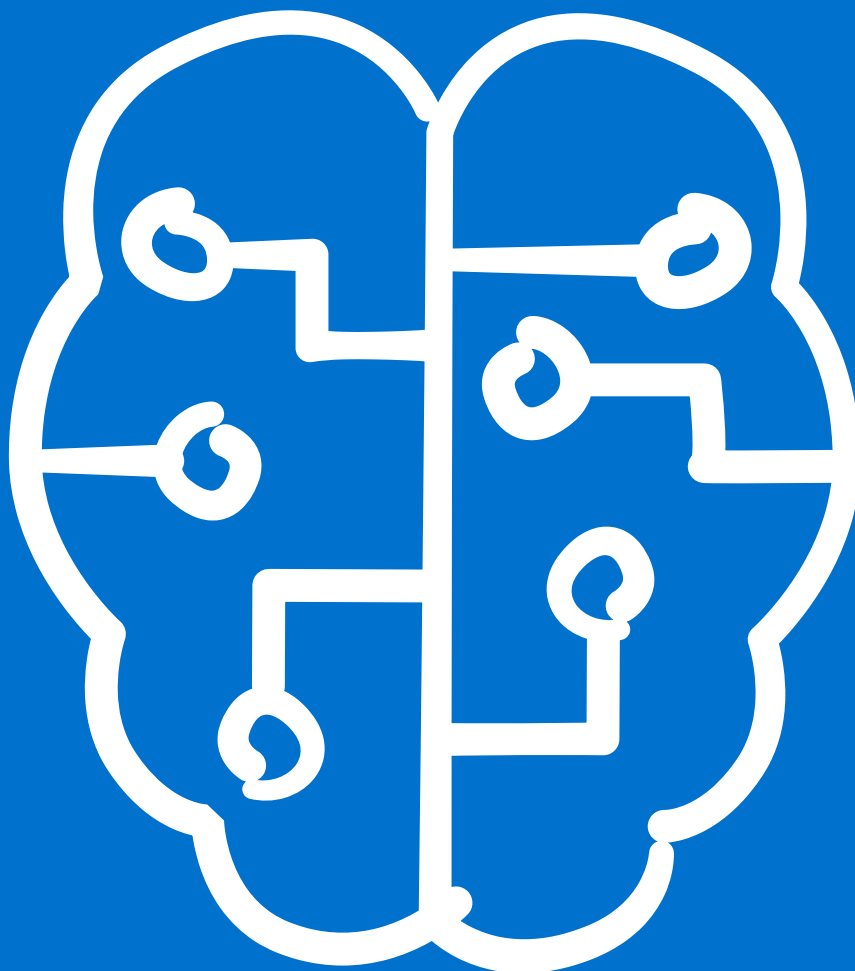
- Technical ICT lead: the steering committee agreed to fund a technical ICT lead to catalyse the required changes and work with stakeholders across GOSH's ICT team
 - o This role has continued to be essential as the ICT and infrastructure (cloud) requirements to deploy algorithmic tools are quite different to previous NHS ICT requirements and team activities
- Consider the ICT staff resource availability and skill sets, and the technical infrastructure needed
- Despite useful cloud guidance frameworks, ICT teams from across the NHS will need significant support and resourcing to implement a 'Cloud First' approach



USING STATE-OF-THE-ART AI TO UNLOCK VITAL INFORMATION FROM PDF REPORTS

Clinical data is almost universally stored as a PDF. This is useful for the treating clinician but does not support secondary use and analysis. Extracting this data is incredibly time-consuming, meaning vital information that could guide clinical decision making may be lost.

In order to support secondary use and analysis of this data, the GOSH-Roche partnership has developed a [Natural Language Processing \(NLP\) pipeline](#) that can extract relevant structured information from PDF and convert it into a standardised format that enables further analysis. This work will support improved prediction, prevention, diagnosis and precision medicine at scale using information that has not previously been available.





The NLP pipeline runs within GRID (GOSH Research Intelligence Development), a secure digital space. Using GRID, we have been able to unlock 10 years of cardiology data from PDFs in just a few hours, a process that would have previously taken several months to complete manually.



Shiren Patel,
Head of Innovation Technology
and Data Research, GOSH



Genomic medicine has the potential to offer a greater understanding of how our genetic makeup impacts on our health and to change the way disease is managed and treated. Using the NLP pipeline we have developed the Genomic Information Finder (GIF) which can extract information from genomic reports. GIF unlocks multiple new possibilities for improved hospital operations and research.



Dr Pavithra Rajendran,
NLP Technical Lead, GOSH



The GIF code is now available as open source on GitHub

CLINICAL ENGAGEMENT FOR INNOVATION



Clinical engagement is key for successful innovation and development in healthcare. By direct and early engagement with GOSH clinical staff who are involved in patient care, we aimed to drive forward and embed innovation, development and sustainable engagement to create solutions that are effective, safe and improve the outcomes of patient care.



Dr William Bryant,
Senior Data Scientist and Clinical Insights Unit Lead, GOSH

GOSH already had a clinical Chief Research Information Officer (CRIO) and clinical Director of Innovation, who were directly involved with establishing the collaboration. However, once established, specific projects required additional subject matter specific clinical engagement from particular clinical teams to succeed.



Healthcare staff across all professions in the hospital were keen to participate, but people are already stretched and finding time for additional activities is hard. Traditional 'research', which many of us are familiar with, has high engagement levels; the challenge we face is how to use our teams' time and skills in novel activities like innovation and developing relationships with external partners.

Dr Rossa Brugha,
Deputy Chief Research Information Officer, GOSH



Recommendations:

- We established a deputy CRIO and panel of clinical information representatives to act as liaison between the informatics and data analytics team and the clinical services to identify and prioritise projects and provide practical input
- Central innovation project management process established to capture, triage and plan project actions
- Ongoing communication and engagement programme for awareness of innovation across the organisation

PROJECT MANAGEMENT AND WAYS OF WORKING



// In this partnership we have built up trust and overcome challenges to work as 'one team'. It is very important to create a good strong team working environment where everyone is comfortable to speak freely and raise issues. We want to make sure everyone is heard, and we hear from all perspectives.

Victoria Stevens,
Partnership Project Manager, GOSH



// It is important that everyone is working towards the same goal and is clear on what needs to be done. The whole team needed to be comfortable discussing blockers, especially when initial decisions about the rationale for work-streams were made by senior management and executive teams but were perhaps unclear to the wider team.

Nicholas James,
Partnership Project Manager, GOSH

Recommendations:

- Clear briefings for the wider team on how workstreams would aid the existing goals and vision of GOSH DRIVE, with clarification of roles and responsibilities across the team
- Regular team calls, open and honest feedback sessions, ways-of-working operational framework, impact retrospectives and planning discussions

// Roche UK is familiar with agile working but this approach is challenging when the team includes two distinct organisations that don't share infrastructure or resource planning.

Dr Alexandros Zenonos,
Personalised Healthcare Digital Solutions Lead, Roche

Actions:

- Quickly initiated project management tooling and equipped relevant Roche UK team members with GOSH laptops
- Dedicated project managers from each organisation to manage the lifecycle of our partnership, including setting up project management software where deliverables are managed, and blockers have a clear route of escalation
- Regular impact retrospectives and agile delivery to facilitate a culture of collaboration and communication to overcome conflicting priorities and organisational cultural barriers
- Early engagement with ICT on project management tooling set up and maintenance

CONCLUSION

Despite some challenges, we have made fantastic progress.

- ✓ Built a scalable analytics platform 'PICTURE' which is allowing rapid and reproducible research using real world data
- ✓ Developed reproducible NLP pipelines which can rapidly and securely unlock information from thousands of PDF reports, saving months of expert NHS staff time
- ✓ Open-sourced code for our Genomic Information Finder (GIF) via GitHub to be used by the wider system
- ✓ Established a Clinical Insights Unit which has delivered 9 advanced analytics projects at GOSH in its first year; providing insights to improve data-driven decision making throughout the hospital and identifying millions of pounds of projected financial benefit
- ✓ Created a team of clinical and operational Innovation Officers at GOSH with protected time for engagement
- ✓ Delivered over 20 presentations on the partnership to external audiences
- ✓ Presented outputs of the partnership at high impact AI conferences
- ✓ Published 12 peer reviewed academic articles
- ✓ Been recognised in NHS England Guide To Effective NHS Data Partnerships as an example of a successful NHS data partnership that offers positive patient, system and societal impact
- ✓ Supported the growth of a data engineering team and pipeline to facilitate safe and reproducible use of deidentified data for research and innovation

We are incredibly proud of all that we've achieved so far. But this is just the start. Over the coming years, we intend to develop our tools further into clinical practice and deployment with the aim of improving the care at GOSH and beyond.